

**EMBODIMENT, ALTERED PERCEPTION
AND COMFORT AFTER STROKE**

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A thesis submitted in partial fulfilment of the requirements
of the University of the West of England, Bristol
for the degree of Doctor of Philosophy

Faculty of Health and Applied Sciences,
University of the West of England, Bristol

February 2019

Abstract

After stroke, changes to body perception are common. However, little is known about what these disturbed perceptions feel like to the stroke survivor. This programme of work used embodiment theory to explore stroke survivors' experiences of altered body perception and whether these perceptions were uncomfortable from a holistic perspective. It explored whether participants indicated a need for clinical interventions and the feasibility of using assessment tools to collate information about the body.

A range of methodologies were used. A scoping review of the literature identified 28 studies exploring first-person accounts of altered body perception. Stroke survivors described the body across conditions as strange and unfamiliar; reflecting a changed awareness and means of relating to the body. Concurrently, a phenomenological study was conducted. A purposive sample of 16 stroke survivors able to communicate verbally, at least six-months post-stroke and experiencing motor and sensory impairments, were selected. Semi-structured interviews were conducted and analysed using interpretative phenomenological analysis. Participants described uncomfortable altered perceptions. The body did not exist, was hindered by strange perceptions and uncontrollable. The body was isolated, but participants were hopeful for improvement. Altered perceptions were difficult to comprehend and describe.

From this, a feasibility and acceptability study explored the use of three assessment tools to communicate the altered body. Ten participants, including a proportion with communication problems, were purposively selected. Participants wanted to communicate the experience of altered body perception and discomfort to health professionals and their preferred visual tools to achieve this.

Stroke causes a complex sense of physical and psychosocial disembodiment, which is uncomfortable and of concern to survivors. Embodiment research

suggests these domains may interact with one another. Clinical recognition and support to communicate altered body perception and discomfort from a holistic perspective may elucidate the multimodal experience of altered perceptions and foster new approaches for rehabilitation.

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iii. Glossary of terms

- The individual who experienced stroke was described using the three terms below:

Stroke survivor – *when discussing an individual who is living with the effects of stroke in the community*

Patient – *when discussing a stroke survivor in terms of a clinical relationship*

Participant – *when discussing a stroke survivor who has participated in primary research*

It is acknowledged that it is never optimal to refer to someone in terms of the health condition they have experienced and that referring to them in condition-specific terms can be perceived as disempowering and can denote passivity or imbalance in power dynamics. However, using some 'object' terms were necessary to ensure clarity of meaning within this work. Research into cancer suggested that the majority of participants identified with the terms 'survivor' and 'patient', as such these terms were adopted throughout (Park, Zlateva and Blank, 2009).

Activities-of-daily-living (ADLs) - the basic actions which constitute caring independently for one's own body, such as eating, mobility and personal care (Mlinac and Feng, 2016)

Acute phase - the initial phase after stroke which lasts for about two weeks from stroke onset (Kiran, 2012)

Altered body perception - a perceptual experience arising from a neurological cause, which disturbs the representation of the neural body scheme, which in turn disturbs perceptual function (amongst other things), resulting in both physical and psychosocial problems (Rubio and van Deusen, 1995)

Aphasia - a cognitive impairment affecting processing and production of language, affecting 21-38% of stroke survivors (Berthier, 2005)

Apraxia - *see ideomotor apraxia*

Body - the means through which the world is perceived, navigated and experienced

Bodily - pertaining to the body

Body consciousness - a term used to refer to cognitions towards the body (Miller and Murphy, 1981).

Body image - a theoretical construct which relates to the beliefs and attitudes towards one's own body, comprised of perceptual experience, conceptual understanding and emotional attitude towards the body (Gallagher and Zahavi, 2008)

Body representation - how the external structure of the body is mapped and interpreted internally

Body schema - the unconscious, internal representation of the body which operates within the perceptual field and is maintained by visual, somatosensory and proprioceptive feedback (Klinke, Thorsteinsson and Jónsdóttir, 2014; Gallagher, 1986; Lotze and Moseley, 2007)

Cartesian dualism - a philosophy put forwards by Descartes that the mind and body are two separate entities. The body is rooted in the physical or material world which is controlled by the mind or consciousness (Descartes, 2008)

Chronic phase - the period 6 months post stroke until symptoms resolve (Kiran, 2012)

Cognitive function - in stroke literature this usually refers to all aspects of attention, concentration, memory, perception, decision making amongst other things and can affect many areas of functioning

Comfort - a term which highlights the absence of physical and psychosocial contributors which cause discomfort, used as a marker of acceptable care in nursing practice (Kolcaba and Kolcaba, 1991)

Conscious awareness - to have attention or awareness brought to focus on the body due to problematic body processes e.g. a sense of body unfamiliarity can bring conscious awareness to the body

Contralateral - relating to the side of the body in which the stroke deficit is exhibited (the opposite side to which the brain lesion occurred)

Conscious - to be aware of the body or environment

Corporeal - relating to a person's body

Embodiment - “*the experience of the bodily senses and of having a body*” (Eccleston, 2016, p1)

Emotional lability - uncontrollable crying or laughing after stroke which is not in proportion with external stimuli. Up to half of stroke survivors can be affected (Tang et al., 2009)

'External' body perception - a term derived from this thesis referring to changes in perception of the external or visually observable body parts such as limbs or the way the body is navigated in space

Extrapersonal - the area of space beyond the peripersonal space, which the body has to move to get to (Nijboer et al., 2014)

Function - a measure of physical and motor recovery, often used interchangeably with the ability to engage in activities-of-daily-living

Hemiplegia/ paresis - full or partial paralysis down the contralateral side of the body

Holistic - a perspective towards the individual which values the 'whole' person, including: physical, environmental, emotional and social factors, personal histories, beliefs, attitudes and relational aspects of interaction (Gardner, 2014). The term is broader than a biopsychosocial conception of the patient, which potentially takes a compartmentalised perspective to illness and does not explicitly reflect on the multidimensional, cumulative and experiential aspects of the lived experience (Kolcaba and Steiner, 2000); Solli and Barbosa da Silva, 2012). The term is commonly used in the nursing literature and is congruent with the perspective towards patient comfort adopted in this thesis (Kolcaba and Steiner, 2000).

Ideomotor apraxia - a condition in which the patient struggles to move or orientate the body to imitate movements, move objects or use tools correctly (Wheaton and Hallett, 2007)

Intentional action - *see intentionality*

'Internal' body perception - a term derived from this thesis referring to changes to perception of the 'internal body' - which cannot be visually perceived - such as bladder or swallow dysfunction

Intentionality - the unconscious motivation to enact body movements e.g. unconsciously moving an arm to scratch an itch (Gallagher, 2005)

Kinaesthetic phantom - the perception of a moving limb which is actually static (Antoniello et al., 2010)

Neglect - used as an umbrella term to describe inattention towards the body (personal neglect) or environment (extrapersonal neglect) on the contralateral side (Chen-Sea, 2001). Motor neglect refers to the "*underutilisation of the affected limb compared to the healthy one... despite normal muscle strength*" (Sampanis and Riddoch, 2013, p1)

Nocioceptive pain - pain which occurs as a result of damage or potential damage to tissue (Nicholson, 2006)

Neuropathic pain - pain which occurs as a result of disturbances in the central nervous system (Nicholson, 2006)

'Object' body - a disembodied perspective towards the body which can occur during illness, in which the body is considered separate from the individual's identity and can be considered as *other* (Gadow, 1980)

Perception - the experience of body and environmental stimuli through the senses or sensory input (can occur consciously or unconsciously)

Peripersonal - the area of space within arms-reach surrounding the body, which includes objects and environmental stimuli located close by (Nijboer et al., 2014)

Positionality - developing awareness about the researcher's ideas, attitudes and beliefs to reflect on how their position may affect the research process (Clancy, 2013)

Postural phantom - the perception that the hemiplegic limb is not in the place that it is perceived to be (Antoniello et al., 2010)

Pusher Syndrome - a condition in which patients push their bodies towards their affected side which can result in loss of balance. Patients perceive the body to be upright when it is visually off-centre (Karnath and Broetz 2003)

Self - attitudes and beliefs about oneself (Baumeister, 1990)

Sense of agency - *see intentionality*

Sense of body ownership - a perception that the parts of the body belong to the individual (Gallagher, 2005)

Senses - referring to perception of stimuli through a 'sense organ' e.g. vision, hearing, smell, taste

Somatosensory or sensory - sensations arising from the body (e.g. touch, proprioception, pressure, pain, temperature). Not used to reflect the 'senses' (vision, hearing, smell, taste, balance)

Spatial inattention - *see neglect*

Sub-acute phase - approximately up to 6 months after stroke (Kiran, 2012)

Unconscious - to be unaware of the body or environment

Verticality - altered perception of the visual vertical (Yelnick et al., 2002)

Whole-body - pertaining to research which reflects on body changes after stroke in terms of the whole-body experience as opposed to focussing on one body area or condition

iv. Acknowledgements

First and foremost, I would like to express my utter gratitude and admiration to my three supervisors: Dr Mary Cramp, Dr Ailie Turton and Dr Stuart McClean.

When starting this PhD adventure I had no idea what to expect, I was in awe of academics and could not foresee myself filling those shoes. Yet through unwavering support and constant opportunities highlighted to me by my supervisors I am astounded to finally find myself here at the end of three years. My supervisors have always been approachable, calm, optimistic and supportive – walking me through milestones at absolutely the right moments in my progression. I can't believe what you have made possible for me. Thank you.

I would also like to thank other important colleagues who have supported me on the way. Dr Tim Moss, thank you for listening so patiently to my endless campaign to optimise the PhD existence. We made things happen! Thanks to the Centre for Appearance Research team for advising me on how best to navigate this tricky cross-disciplinary topic and sharing your coffee morning cake. And special thanks to Dr Jenny Barke – without your thoughtful email informing me of this PhD opportunity I never would have undertaken this eventful journey.

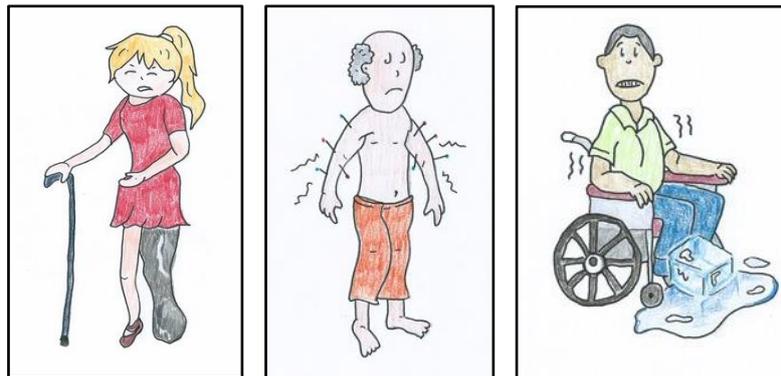
Special thanks to the stroke service who provided endless support and opportunities for me when conducting the studies and disseminating my findings. I am sorry that confidentiality means I cannot name you here and give you all the credit you deserve. Keep on your fabulous work, as the study participants kept telling me, you really do change lives. Thank you to the participants and PPI members who made this work possible. My eyes have been opened to your experience in ways I didn't think possible. You have made this personally rewarding, by shaping the way I see the world and everyone in it. You have also made it tremendously enjoyable, particularly the PPI group lunches in which we always covered so much more than the research topic.

To my Blue Lodge colleagues and the Shut up and write group. As someone not particularly suited to long periods of solitary working, you were my sanity. I cannot thank you enough for the distractions, feedback and laughs; Leah for making me stick to my Pomodoros, and Sarah, you are an absolute wonder for surviving the editing process, I will definitely return the favour.

And finally, to my non-work friends and family. Without you this would not have been possible. Thank you for all the ad-hoc babysitting and words of encouragement. Dad, the king of grammar, this thesis would make much less sense without your revisions. Mum, the offers of open-ended babysitting, always with a smile has taken a ton of parental guilt off my shoulders. To Milo, I'm sorry I have had to be such a busy-bee over the last few years. You have managed my parental outsourcing like a true champion, never moaning once. At last 'the book' is finished, now let's go have some fun.

"Even in this day and age of new neuroimaging technologies, data analysis methods and virtual reality settings, patients and their stories remain the most precious avenue to discover more about our sense of bodily awareness and ownership... let patients speak by themselves, describe their bodily feelings in their own words"

(Dieguez and Lopez, 2017, p205)



Original drawings of the experience of common altered body perceptions by Claire Angell (stroke survivor)

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Chapter 1: Background and thesis overview

1.1 Chapter introduction

This chapter introduces the concept of 'altered body perception' after stroke and provides a rationale for exploring this in terms of patient experience. It highlights a gap in the literature documenting experiential accounts of this phenomenon and describes how listening to subjective experiences could deepen understanding of body perception processes and better understand patient needs. It introduces key terms and concepts and introduces a way of accessing patient experiences through the novel and holistic construct of comfort. The research aims and objectives are described, followed by an outline of the thesis construction.

1.2 Introducing stroke

Stroke is defined by the World Health Organisation as a disruption of blood flow to the brain which results in damage to brain tissue (WHO¹, 2018). Approximately 110,000 strokes occur in England each year leading to around one in four fatalities (National Audit Office, 2010). Stroke is the leading cause of severe and complex disability in the UK (Adamson, Beswick and Ebrahim, 2004). Stroke incidence is rising, with projections showing a 34% increase across the EU in the next 20 years, at a total cost of €45 billion (Stevens et al., 2017). In the UK, stroke impact in terms of treatment and loss of productivity has been shown to cost £8.9 billion per annum (Saka, McGuire and Wolfe, 2009). Much of the burden of stroke care falls to family and friends and is a significant hidden cost impacting the lives, employment and opportunities of both carers and stroke survivors (Dewey et al., 2002). As such, ensuring stroke rehabilitation is timely and effective is a key concern to both individuals and policy makers.

Stroke can cause a multitude of consequences, affecting the way the physical body is perceived, experienced and used. Common changes experienced in the first three months include upper and lower limb weakness which affects 77% and 72% respectively; lower

limb sensory deficit affecting 30%; visual neglect, 20%; visual deficit, 26% and urinary incontinence affecting 48% (Lawrence et al., 2001). Muscle weakness is one of the most commonly experienced consequences and a major contributor to disability (Canning et al., 2004). A study collating the self-reported experiences of 1,424 stroke survivors, found 80% reported having a physical disability and 39% stated that the physical effects of stroke were most difficult to deal with (Stroke Association, 2016). These effects can continue in the long term. A large study of UK stroke survivors found that significant numbers experienced ongoing bodily issues one to five years post-stroke (McKevitt et al., 2011). These were related to mobility, falls, pain, fatigue, vision and continence, as well as a reduction in social participation, work and income. Body changes such as weakness, pain and fatigue alongside changes to memory, speech and personality led to around 50% of participants self-reporting mild to severe levels of disability five years after stroke (Pallesen, Pederson and Holst, 2014). These body changes can also reduce functional independence. A longitudinal study examining survivors of ischaemic stroke, found that one third were functionally dependent at hospital discharge and 8% after three years (De Campos et al., 2017).

In clinical practice body impairments after stroke are often considered by how much they impact independent performance of daily activities (Duffy et al., 2013; Rubio and van Deusen, 1995). For example, alongside motor impairment, changes to sensory and cortical processes affect the ability to balance and navigate the environment and impact the ability to engage in independent activities – more so than changes to factors that are not body focused such as language and memory (Mercier et al., 2001). Similarly, shoulder pain, has been related to reduced functional independence (Nickel et al., 2017). Severity of spatial inattention (commonly referred to as neglect) was shown in 184 patients, to be related to sensory and motor impairment and increased dependency in activities-of-daily-living, specifically the ability to engage in self-care (Nijboer et al., 2013). Deficits in tactile sensation and proprioception were related to reduced independence in personal care, mobility and day-to-day activities and led to increased length of hospital stay, though this association requires further exploration (Carey, Lamp and Turville, 2016; Sommerfeld and von Arbin, 2004; Tyson et al., 2008).

Body changes after stroke are also related to psychological wellbeing. Post-stroke depression has been independently associated with reduced functional independence in both the acute and chronic phases of stroke recovery (Kang et al., 2018; Ramasubbu et al., 1998). Post-stroke depression may also reduce participation and efficiency of engagement in rehabilitation (Gillen et al., 2001; Sinyor et al., 1986). Another study in which the relationship between psychological disorders and functional outcomes in 592 participants were explored, found that 21% of this sample exhibited symptoms of a potentially diagnosable psychological disorder at stroke onset (West et al., 2010). This figure reduced to 12% over the course of 52 weeks, yet those who had ongoing psychological symptoms, experienced poorer outcomes in physical activities such as personal care and mobility. As such, understanding how changes to the body after stroke affect the individual both physically and psychologically is important to encourage independence and reduce the burden of care.

1.3 Body perception

The concept of body perception encompasses the entire experience of the 'lived body', a phenomenological construct which construes the body as the "*vehicle for being in the world*" (Merleau-Ponty, 2001, p82). The 'lived body' sees the physiological bodily experience as inextricably linked to the environment and individual intention to engage with the world (Gallagher and Zahavi, 2008; Merleau-Ponty, 2001). Stroke disrupts this lived experience. It can cause changes to body perception such as altered physical sensations in an affected body part, changes to the way that body part is able to function within the environment, alongside changes to the physical and psychosocial processing of the lived experience (Rubio and Van Deusen, 1995). Body perception occurs as a result of a cohesive integration of information from multimodal bodily and environmental systems, such as visual, olfactory, auditory, tactile, proprioceptive, visceral and vestibular inputs (Azañón et al., 2016; Dieguez and Lopez, 2017). In lay terms the concept of body perception reflects how the body is perceived, felt, used and understood. It captures the way the body and brain represent the sense of the body, which is defined by Berlucchi and Aglioti (1997) as:

“a mental construct that comprises the sense impressions, perceptions and ideas, about the dynamic organisation of one’s own body and its relation to that of other bodies, [which] is variously termed the body schema, body image and corporeal awareness” (p560).

Body perception is not only a physiological construct. Psychological processing of body changes may be closely linked to how the body is perceived and understood. Baier and Kanarh (2008) found in a sample of 12 acute stroke patients with disturbed awareness of their motor deficit in hemiparesis, that 92% exhibited a sense that their limb did not belong to them and 25% expressed negative emotions towards their affected limb. This echoed the findings of qualitative stroke studies which describe how perception of the self can be significantly affected by living with a body experiencing altered tactile sensation, pain and motor disturbance (Ellis-Hill, Payne and Ward, 2000; Kitzmüller, Häggerström and Asplund, 2013; Kvigne and Kirkevold, 2003). Such experiences can lead to objectification of the body because it becomes perceived as strange, confusing, unreliable or unfamiliar, leading to a conceptual separation between the body and self (Ellis-Hill, Payne and Ward, 2000). It is unclear how these psychosocial experiences impact on body schema and rehabilitation, as they require further research.

1.3.1 Body schema, intentional action and body image

The terms body schema and body image have been used in varying ways throughout the literature, often interchangeably, to denote different bodily experiences. However, more recently, consistent definitions of the terms have evolved and there is considerable agreement as to what constitutes body schema and the recognition of body representation through action (De Vignemont, 2010).

Body schema can be described as the unconscious, internal representation of the body which operates within the perceptual field and is maintained by visual, somatosensory and proprioceptive feedback (Klinke, Thorsteinsson and Jónsdóttir, 2014; Gallagher, 1986; Lotze and Moseley, 2007). Body schema processes are comprised of automatically coded, unconscious, sensorimotor and proprioceptive information which are key in

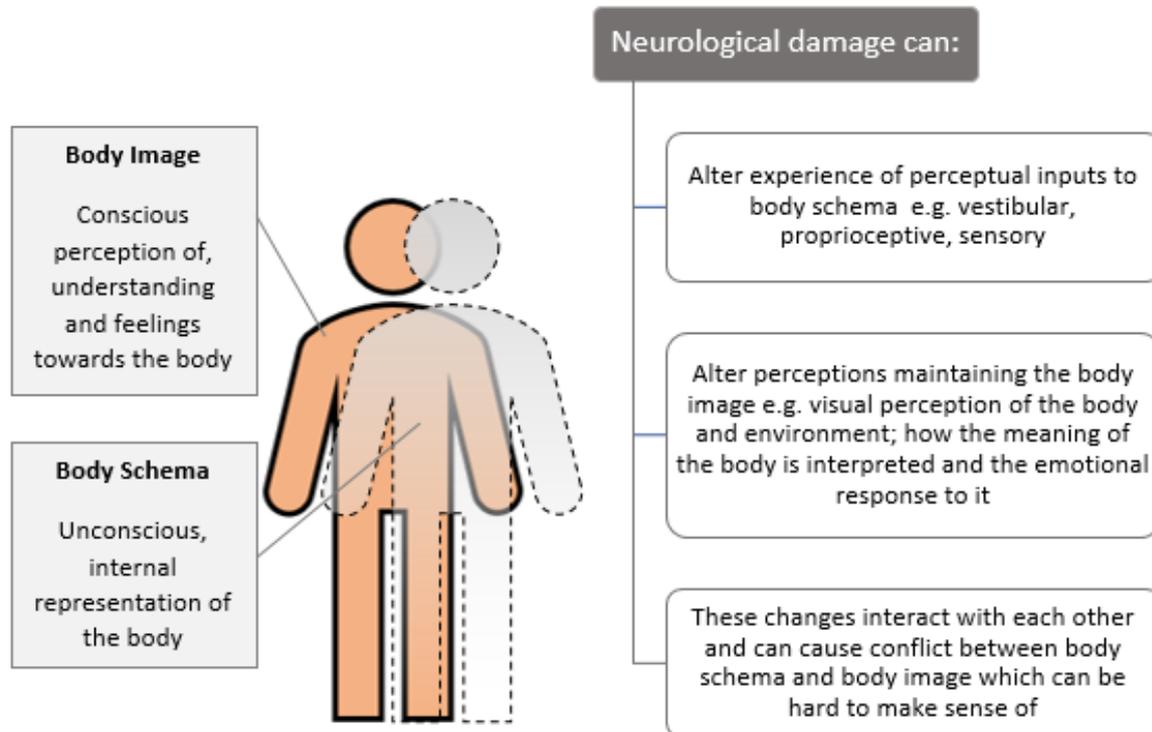
maintaining bodily movement, action and awareness (Gallagher and Zahavi, 2008). Yet they are not automatic processes, but rather shaped by the unconscious *“intentional experience or goal-directed behaviour of the subject”* (Gallagher, 2005, p26). Body schema conditions pertain directly to the unconscious sense of bodily self. These include conditions affecting altered perceptions of size and scale of the body and sense of body ownership such as perceptions of lost or duplicated limbs or forgotten body areas as seen in personal neglect (Dieguez and Lopez, 2017).

The body schema is responsive to the wants and needs of the individual who is motivated to act within a constantly stimulating and changing environment. This unconscious motivation to enact body movements has been referred to as body ‘intentionality’, ‘intentional action’ or a ‘sense of agency’ – and will be referred to as ‘intentional action’ from hereon (Merleau-Ponty, 2001; Gallagher, 2005). This construct is closely related to the ‘sense of body ownership’ in which the individual conceives their body or action as relating to their sense of self, a sense which is frequently disrupted post-stroke (Gallagher, 2005).

Body image as a theoretical construct relates to the beliefs and attitudes towards one’s own body and is comprised of perceptual experience, conceptual understanding and emotional responses (Gallagher and Zahavi, 2008). These attitudes and beliefs are affected by multifarious factors such as cultural or interpersonal factors, alongside perceptual bodily information. These facets are conscious, reflective and observed particularly when individuals’ ability to relate to the body becomes disrupted (Klinke, Thorsteinsson and Jónsdóttir, 2014). They might involve using conscious attention to direct limb movement or to adjust experiences of pain or pleasure, yet they are driven by unconscious, perceptual information coded into the body schema (Gallagher and Zahavi, 2008). Body schema and body image as two perceptual systems are not distinct, but closely related and interact on one another in complex ways to inform the sense of body perception (Gallagher, 2005; See Figure 1). Gallagher (2005) highlights the experience of unilateral personal neglect after stroke as empirical evidence of body schema and body image as distinct concepts. He describes how the sense of being unable to perceive the

left side of the body in personal neglect, despite intact motor and sensory function, exemplifies an undamaged body schema and a disrupted body image.

Figure 1. The relationship between body image and body schema



1.3.2 Body perception terms

The multimodal approach to body representation and the constructs of body image and body schema are well established. As such, this thesis conceptualises body perception as an umbrella term, encompassing both the body schema and the body image (Gallagher, 1986; Klinke, Thorsteinsson and Jónsdóttir, 2014). To maintain consistency the term 'altered body perception' will be adopted to refer to the experience of changed perceptual experiences after stroke. This term broadly aligns with that of Rubio and Van Deusen (1995), who define the term 'perceptual and body image dysfunction' in stroke. This dysfunction is described as arising from a neurological cause, which disturbs the representation of the neural body schema, which in turn disturbs perceptual function

(amongst other things), resulting in both physical and psychosocial problems. Conceptually, this term is appropriate because it encapsulates a broad understanding of post-stroke changes, reflecting neural, perceptual, physical, environmental and psychosocial experiences, which are likely to be described in experiential accounts post-stroke. In this thesis the term 'dysfunction' has been replaced with 'altered', to avoid any negative connotations associated with this label on patient experience.

1.4 What is known about altered body perception changes after stroke?

The stroke literature has documented an extensive array of changes in which individuals' perception of their body may become disrupted. To provide an overview, the characteristics of some of these conditions are described below (Table 1). This summary demonstrates the plethora of ways in which body perception, body areas and functions can be impacted by stroke and gives an idea of the many terms used to refer to these varying experiences. The majority of research examines these experiences using 'objective' data collection methods. The advantage of describing these experiences via 'subjective' data collection methods is discussed further in Sections 1.5 and 1.6.

Table 1. An outline of post-stroke conditions in which altered body perception may occur

	Body perception change	Description
CHANGES TO PERCEPTION OF BODY AWARENESS	Neglect or inattention (other terms: unilateral; visual; visuospatial; personal; motor neglect; hemi inattention)	A common condition which impacts awareness of personal and extrapersonal space on the contralateral side (not due to motor or sensory impairments), making patients unable to process bodily or environmental information on that side. Reports of incidence vary (Bowen, McKenna and Tallis, 1999). In a study of 349 patients up to four weeks post-stroke, 23% had visuo-spatial neglect and 8% personal neglect, both of which were related to level of disability (Appelros et al., 2002). It is less clear how these difficulties persist in chronic stages of stroke recovery.
	Anosognosia	When patients demonstrate underestimation or lack of awareness of a deficit, such as limb paralysis in hemiplegia (Orfei et al., 2007). Anosognosia often co-occurs with neglect. Incidence varies widely, from 7-77% depending on diagnostic tools used and time since stroke onset (Orfei et al., 2007). There is little data reporting how this condition progresses in the chronic stage.
	Asomatognosia and Somatoparaphrenia (or limb misidentification)	In asomatognosia, patients do not recognise the body as their own and deny ownership of a limb. In somatoparaphrenia, this loss of bodily recognition is taken a step further and limbs may be given a different identity such as believing they belong to a nurse (Feinberg and Venneri, 2014). Incidence of combined conditions alters rapidly as time post-stroke progresses, with 61% reporting limb misidentification at onset, reducing to 15% after one week (Antoniello and Gottesman, 2017).
	Phantom limb sensations	A perception of limbs being in different locations to where they visually appear or the perception of movement in static limbs. These perceptions were identified in 54% of 50 participants up to 2 years after ischaemic or haemorrhagic stroke (Antoniello et al., 2010).
	Alien hand syndrome	A rare condition in which the limb is perceived as being controlled by an external force (Kikkert et al., 2006)
	Supernumerary phantom limb	A rare condition in which patients have a belief that they have additional limbs (Yoo et al., 2011).
	Allochiria	A rare condition in which patients mislocate their body areas in response to sensory or non-sensory stimuli (e.g. reporting pain in the right knee whilst pointing at the left), which often co-occurs with neglect (Venneri et al., 2012).
CHANGES TO PERCEPTION OF SENSATION	Somatosensory perception e.g. tactile perception, proprioception, allodynia	Changes to sensation occur frequently after stroke. In a study of 70 patients evaluated at stroke onset and 2, 4 and 6 months after, 7-53% experienced altered tactile sensations, 31-89% experienced difficulty recognising objects and 34-64% experienced altered sense of proprioception (Connell, Lincoln and Radford, 2008). Another study of 51 patients showed 47% experienced changes to touch discrimination and 49% changes to sense of limb position in the contralateral hand (Carey and Matyas, 2011).
	Pain e.g. shoulder pain, tension headaches, spasticity, central post-stroke pain – including allodynia, hyperalgesia	Chronic pain conditions occur frequently after stroke and include central post-stroke pain, shoulder pain, pain from spasticity and headache (Klit, Finnerup and Jensen, 2009). Widar et al. (2002) classified pain conditions in 43 participants, 2 years post-stroke, highlighting that 15 had central post-stroke pain (neuropathic pain); 18 nociocptive pain and 10 tension-type headache. Shoulder pain is particularly common in the first-year post-stroke affecting nearly 30% of stroke survivors due to multimodal changes affecting biomechanical factors, changes to muscle tone and neuropathic processes (Adey-Wakeling et al., 2015).

Body perception change	Description
Hemiplegia, hemiparesis, muscle weakness, spasticity (often reported in terms of motor function)	Impairments in upper and lower limb movement are suggested to affect 77% and 72% of stroke survivors respectively in the first three months post-stroke (Lawrence et al, 2001). Factors associated with motor function impairment are complex, but one study of 95 patients in the first 3 months post-stroke, found body perception changes such as hemiparesis (67-81%) and muscle spasticity or stiffness (19-21%) were likely to contribute (Sommerfeld et al., 2004).
Balance	Tyson et al. (2006) found in a study of 75 people post-stroke, that 83% exhibited balance impairment in the first four weeks. Poor balance was associated with muscle weakness and somatosensory impairment. It may also be related to changes to vision and processing conditions such as neglect (Park, 2016).
Movement processing conditions e.g. Apraxia also termed dyspraxia	Ideomotor apraxia is a disturbance of the performance of deliberate learned movements. In a sample of 50 patients residing in a rehabilitation centre on average 85 days post-stroke, ideomotor apraxia was identified in 54% of those with right hemiplegia and 25% of those with left hemiplegia (Kaya et al., 2006).
Fatigue	A condition in which the body may feel depleted or effortful, alongside mental changes affecting motivation or concentration (Worthington et al., 2017). A systematic review, found that rates of fatigue post-stroke were experienced in 39-72% of individuals (Colle et al., 2006). Drummond et al. (2017) found 43% of individuals (n=268) 4-6 weeks post-stroke identified fatigue, which was associated with lower mood, pre-stroke fatigue and poorer mobility.
Urinary incontinence	Changes in bladder sensation and muscle use can result in urine leakage and altered perception that the bladder is full. It affects 40-60% of stroke survivors at stroke onset, reducing to 15% at one-year post-stroke (Thomas et al., 2009; Woodward, 2014).
Dysarthria	A condition in which muscle weakness and uncoordination affects the ability to produce speech. It is reported to affect 70% of individuals at stroke onset, reducing to 27% after 3 months and was associated with increased levels of disability (Ali, Lyden and Brady, 2015).
Dysphagia	Problems with swallowing are common and change over time post-stroke. Smithard et al. (1997) found that out of 121 patients, 51% had problems swallowing at stroke onset, which reduced to 27% after 7 days and 8% at 6 months, though 3% developed swallowing problems by this time point.
Perceptual 'sense organs' e.g. ocular; auditory; gustatory; olfactory processes	Visual effects are common after stroke. A study of 323 patients with suspected visual problems, 68% exhibited eye movement problems; 49% visual field loss and 27% low vision (Rowe et al., 2008). Hearing disorders after stroke are also common and can affect how the individual is able to process and navigate their body within their environment (Bamiou, 2015). Changes to taste and smell are less widely acknowledged but can impact individuals' ability to perceive their body and environment. Wehling et al. (2015) found one-year post-stroke 28% of participants exhibited reduced olfactory function and 15% lost this function. Green, McGregor and King (2008) highlight the impact of altered gustatory processes describing how changed perception of taste may result in altering one's diet in potentially negative ways.

BODY CHANGES AFFECTING MUSCLES OR MOVEMENT

CHANGES TO SENSE PERCEPTION

1.5 Stroke management and altered body perception

Current stroke assessment and rehabilitation is driven by a functional, outcome-focused approach (Salter et al., 2005). This approach is built on the International Classification of Functioning, Disability and Health framework (ICF) developed by the World Health Organisation (WHO², 2018). The ICF evaluates body changes in illness in broad terms, including a physical component (function, impairment, activity and participation) alongside contextual, environmental and personal factors. This framework is considered to provide a biopsychosocial approach to the individual as it integrates medical and social models of functioning and disability. Theories such as Cartesian dualism which underpin the ICF perceive the individual as objectively measurable and separated in terms of mind, body and environment (Solli and Barbosa da Silva, 2012). However, philosophically this is problematic as the individual remains conceptually segmented (Solli and Barbosa da Silva, 2012). This is compounded as the ICF relies on a third-person viewpoint of body experience which ignores subjective accounts of illness (Solli and Barbosa da Silva, 2018). As such, conditions such as impaired limb movement are considered and treated in terms of observable functional impairment, which overlooks the potential multiple causative influences for such a restriction (Wade, 2006). Psychological changes such as depression or anxiety, tend to be evaluated independently from body changes making it difficult to understand how these factors interact with one another (Zigmond and Snaith, 1983). Missing a subjective dimension within the ICF means clinicians do not fully understand how the holistic experience of disability affects functional and contextual domains; or how individuals cope with the incomprehensibility of these impacts whilst retaining a sense of empowerment and autonomy (Taule and Raheim, 2014; Ueda and Okawa, 2003).

Altered body perception after stroke as a holistic concept, is not routinely screened in current clinical practice. Instead, aspects of body perception and function are assessed such as impoverished spatial attention (Plummer, Morris and Dunai, 2003); somatosensory impairment (Doyle et al., 2010); muscle spasticity changes (Cheung et al., 2015); or central post-stroke pain (Klit, Finnerup and Jensen, 2009). These changes are evaluated in the hospital setting, at a minimum on admission and discharge (NICE¹, 2018).

Problematically, tools measuring the extent of perceptual changes are often inadequate and inconsistently used, meaning there is little consensus about the incidence and impact of these body changes (Bowen et al., 2011; Edmans and Lincoln, 1987; Kessner, Bingel and Thomalla, 2016). For example, when assessing complex conditions such as unilateral neglect, assessments are often ineffective in distinguishing between personal and motor neglect (Plummer, Morris and Dunai, 2001). Likewise, assessment of fatigue usually relies on quantitative measures such as the Fatigue severity scale, which reflects the experience in simplified terms ignoring the effect on bodily and psychological domains (Lerdal et al., 2009). Yet, detecting nuanced body changes after stroke is important as they impact outcomes and have a huge effect on the individuals' ability to relate to themselves and their environment (Demeyere et al., 2016; Klinke et al., 2015; see Table 1).

In stroke assessment, it may be that the only way to capture the necessary information to illuminate complex disorders of conscious experience, is through collating first-person, subjective data (Dieguez and Lopez, 2017). For example, perceptual disorders after stroke encompass difficulties in processing, organising and interpreting sensory information, sometimes resulting in an inability to perform activities (Teasell et al., 2003; Rubio and Van Deusen, 1995). These deficits by their very nature are complex; overlap with sensory processing and cognitive disorders and may affect *“any or all of the sensory modalities”*, making it difficult to draw conceptual boundaries around conditions (Bowen et al., 2011, p5). They are difficult to assess and fully comprehend, particularly in terms of short-form, one-off, third-person assessment. Research into apraxia after stroke demonstrating disruption in participants 'intention' to engage in activity, highlighted the need for contextualised subjective descriptions of complex neurological experiences to allow patient voices to direct rehabilitation (Arntzen and Elstad, 2013). Utilising first-person accounts can illuminate how individuals become aware of sensory bodily experiences, allowing the physical, lived, felt experience to reveal a deeper understanding of the perceptual system (Eccleston, 2016). This could aid clinical understanding of body representation mechanisms and patient experiences.

1.5.1 Altered body perception in other conditions. A model for stroke?

Accounts of body experience have not yet been used to good effect in the clinical stroke environment but have been used to improve practice and develop interventions in other conditions. Complex Regional Pain Syndrome (CRPS) is a chronic pain condition in which individuals often experience pain to touch, altered temperature or disrupted movement and function. CRPS can occur as a result of stroke or from other causes such as trauma to limbs. It has been considered an *“exaggerated response to a traumatic lesion or nerve damage”* in which central representation of the body becomes disturbed (Lewis and McCabe, 2010; Pertoldi and Di Benedetto, 2005, p283). Body perception in CRPS has been defined as:

“the process of how we perceive our bodies, [which] involves complex interactions between proprioceptive, vestibular, somatosensory and visual inputs interrelating with motor systems” (Lewis and Schweinhardt, 2012, p1321).

In more accessible language it has been described as: *“the individual’s perceived alteration of their CRPS affected body part while regarding the remainder of their body as normal”* (Lewis and McCabe, 2010, p62). Lewis et al. (2007) found patients with CRPS experienced a complex array of somatosensory and psychological states. They reported feelings of hostility and disassociation from the body; inconsistency between what is observed and physically perceived; altered sense of the body image; changes to awareness and the level of attention given to affected body areas. This demonstrated a complex physical and psychosocial impact of altered body perception on the individual. Their findings were supported by research into altered body perception in other chronic pain conditions, such as back pain (Moseley, 2008¹); neck pain (Lauche et al., 2012); amputee phantom limb pain, rheumatoid arthritis and fibromyalgia (McCabe et al., 2009).

A CRPS assessment tool has since been devised which explores subjective ratings of perception of the affected limb in terms of sense of body ownership, level of attentional focus and emotional response (Lewis and McCabe, 2010). This holistic perspective can provide useful information about body representation which has proved helpful for

directing treatment approaches. Similar approaches are being employed in research exploring arthritis (Nishigami et al., 2017); anorexia (Urgesi et al., 2012) and lower back pain (Wand et al., 2014).

Commonalities between stroke and chronic pain conditions have been considered in the literature. Moseley, Alberto and Spence (2009) found similarities between CRPS and inattention after stroke. Participants with CRPS were exposed to tactile stimuli when their hands were parallel and then crossed over the midline. Participants responded more to stimuli located in their 'less-affected' side regardless of which limb was placed there, indicating that deficits in tactile processing were more related to the space in which the body is positioned rather than the body itself. Acerra, Souvlis and Moseley (2008) highlighted commonalities in neuroimaging and clinical presentation between CRPS, stroke and phantom limb pain and suggested transferability of treatments such as mirror visual feedback, motor imagery, sensory discrimination training and constraint induced movement therapy which may all aid cortical reorganisation. Use of mirror visual feedback in rehabilitation has been shown to be effective in improving motor and sensory function in both stroke and in CRPS - the rationale being that observing a healthy limb in place of the affected limb, provides visual input which can override impaired perceptual input and provide a normalised perception (Cacchio et al., 2009; Hartman and Altschuler, 2016; McCabe et al., 2003). Similarities in understanding of the mechanisms between conditions and body representation constructs, suggest that it may be useful to draw on this conceptual overlap to further understanding in research and improve the patient experience of living with altered body perception after stroke.

1.6 First-person accounts of altered body perception after stroke

Accounts of living with body changes after stroke suggest these are a significant experience which may impact activities, safety and the ability to mobilise the body. Doolittle (1991), who captured the early experiences of lacunar stroke found that patients described stroke as *"a bodily event. The arm and leg weakness was the stroke"* (p236). She stated that, *"It is imperative to know what it means to the person to*

experience weakness and paralysis and how personal meanings and practical activity are disrupted" (Doolittle, 1991, p238).

Several studies have used qualitative interviewing to reflect the stroke survivor experience within specific conditions. The first case-series capturing first-person experiences of sensory impairment after stroke described discomforting and painful sensations such as *"boiling water being poured down the left arm"* and *"as if a log of wood were hanging from [the shoulder]"* (Head and Holmes 1911, p224). More recently, qualitative exploration of upper limb somatosensory impairment found participants described altered perceptions such as numbness, tingling, burning, heaviness, altered sensitivity to touch and temperature and described limbs as *"dead"*, *"gone"*, or *"cut off"* (Carlsson, Gard and Brogårdh, 2017; Doyle, Bennett and Dudgeon, 2014, p996). Stroke survivors experiencing neglect have described a sense of bodily strangeness, peculiarity and uncertainty as they experienced their bodies and surroundings (Klinke et al., 2015). Antonello et al. (2010) found that in a sample of 50 stroke survivors over half experienced phantom limb sensations such as perceptions that their limb was not in its actual place or was perceived to be moving in a way that was not 'real', which conflicted with their visual perceptions. In 2014, Turton et al. conducted a pilot study amongst a sample of 11 survivors to explore the concept of altered body perception after stroke and its impact on day-to-day activities. Through clinical assessment, a questionnaire about body perception and the use of a digital visual tool they found that most participants had altered perceptions of their limb size; weight; temperature or awareness of their body, which impacted their safety, mobility and activities (Turton et al., 2014).

Several studies have also focused on the psychological experience of living with altered body perceptions after stroke. Pallesen (2014, p235) noted that living with an unreliable and *"forcibly present"* body long-term, led some participants to feel worried about their increased vulnerability. They described feeling weary over the new level of effort required to engage the body and felt they had fewer friends and an altered sense of identity and self. Ellis-Hill, Payne and Ward (2000) reflected this changed identity as a sense that the body and self became separated after stroke, the perplexing, conscious and unreliable body was a source of frustration which the mind attempted to bring under

control. The limited research available suggests that these body changes are likely to affect the relationship the individual has with their body, as the body becomes altered and the perceptual experience feels strange. The effects of these changes on individual psychosocial experience is poorly understood. However, due to the diversity of post-stroke body changes and the variety of ways these can impact on activity, participation and identity, understanding individual experiences and tailoring rehabilitation is key.

1.7 ‘Embodying’ body perception

Like the concept of body perception, the idea of embodiment sees the body as the centre of human experience. It conceives the body as a perceptual filter which informs our understanding and interpretation of the world around us. Embodiment is “*the identification of an abstract idea with a physical entity*” (MacLachlan, 2004, p2) or, “*the experience of the bodily senses and of having a body*” (Eccleston, 2016, p1). It aligns with the phenomenological literature which has sought to explore the bodily and lived experience in substantial depth (Merleau-Ponty, 2001; Leder, 1990). It embeds cognition in physiological perception, seeing cognition as *situated* and inexorably linked with movement and action, bridging the dualistic notion of the body-mind put forward in Cartesian dualism (Eccleston, 2016; MacLachlan, 2004). Embodiment brings together complex psychological and physiological constructs such as physical sensation, bodily awareness, consciousness, movement, sense of body ownership, the idea of the self and motivation to act. It is hinged on key principles of body schema and body image and conscious or unconsciously directed movement of the body, which determine how intentional action or agency is experienced. Embodiment theory states that the sense of self is based in the body and is comprised of the sense of body ownership and the ability to engage the body in agency (Imaizumi, Asai and Koyama, 2016). This broad conception of embodiment inherently incorporates the experience of emotional and social self and the expression of this through language and gesture (MacLachlan, 2004).

Understanding of body perception through multimodal systems of body representation is inherently holistic and cannot ignore patient perspectives and attitudes towards their

bodies. For example, impairment of somatosensory function can be experienced in a multitude of ways affecting multimodal areas of perception, such as deficits in tactile processing, an inability to recognise objects or the ability to perceive the body as one's own (Van Stralen, Zandvoort and Dijkerman, 2011). Theories of embodied cognition draw on these understandings of body representation and support the idea that our physical sensory experience is fundamental in shaping our cognitive understandings and perceptions (Eccleston, 2016). In this model, understanding patient perspectives and bodily experiences is key to uncovering a deeper insight into changes to body representation; through this 'lens' patient experience becomes fundamental to clinical understanding.

Currently there is little consensus as to which are the most effective strategies for rehabilitating sensory and perceptual problems after stroke and as such patients report that rehabilitation for sensory problems is often focused on compensatory as opposed to remedial strategies (Bowen et al., 2013; Doyle et al., 2014; Schabrun and Hillier, 2009). An embodied approach may help to illuminate these processes and deepen understanding. It can explore the different ways the body is represented in illnesses like stroke and explore mechanisms which compensate for deficits – for example the use of visual input to mitigate for impaired somatosensory information (Klinke, Thorsteinsson and Jónsdóttir, 2014). Antoniello et al. (2010, p1119) highlight the advantage of collating first-person accounts of phantom limb sensations to elucidate such mechanisms, emphasising how through *“providing a window into the seldom visited world of altered body image after stroke, our results have broad implications for understanding the process of pathological corporeal awareness”*. The application of embodiment theory in stroke rehabilitation is therefore useful as it can provide a new, holistic, transdisciplinary approach (Martínez-Pernía and Ceric, 2011).

Øberg, Normann and Gallagher (2015) highlight the benefit for physiotherapists of conceptualising the body in terms of multimodal systems of body representation, to aid clinical understanding and direct effective rehabilitation strategies. They suggest both patient and therapist need to engage in an embodied interaction in which

communication is through words, gestures and physical interaction. The advantage of this model is that it can incorporate the:

“concepts of the body schema, body image, sense of ownership and sense of agency... help in the differentiation/interpretation/understanding of signs and symptoms, bodily expressions and verbal communication and thereby support intervention” (p246).

These approaches perceive the patient in embodied terms, seeing the individual as a physical, environmentally-situated, participatory agent. Normann, Fikke and Øberg (2015) argue for the clinical application of these phenomenological principles and embodiment theory to somatosensory impairment in the upper limb. They suggest that through perceiving the body and self as unified, the therapist can reintegrate the disembodied paretic limb. They discuss how using touch, visual input, goal-orientated action and verbal prompts which adopt personalised language about the limb, can aid sense of body ownership and intention to use the limb.

1.8 Can comfort theory be used to explore body experience?

In order to amplify patient-voice in the clinical environment, explore the impact of altered body perception changes on the individual and identify issues which are pertinent to the stroke survivor, it is necessary to identify a holistic construct to describe body experience. ‘Comfort’ is a broadly defined term, frequently used in nursing to denote *“acceptable standards of care”* (Kolcaba and Kolcaba, 1991, p1301). Kolcaba and Kolcaba (1991) identified four meanings of the term comfort in current language, which reflect different experiential states: relief from discomfort, a state of ease or contentment, relief from pain and a source of pleasure. Comfort can be experienced as both a mental and physical construct, for example the anticipation of the relief of physical discomfort can provide a sense of mental comfort (Kolcaba and Kolcaba, 1991). Patient accounts of comfort support the breadth of this construct. Patients have used the term to refer to physical experiences such as the alleviation of bodily discomfort or making the body comfortable in the physical environment, and psychological experiences such as feeling

independent and worthwhile or in reference to relationships with professionals, friends and family (Hamilton, 1989). The holistic nature of the term is supported in other studies showing patients prioritise social, cultural and environmental factors alongside physical contributors to discomfort (Kolcaba and Wilson, 2002; Hamilton, 1989; Yousefi et al., 2009).

Comfort is frequently used as an outcome in nursing to ensure patients remain free from bodily and psychological 'discomforts' such as pain, distress, nausea or worry (Kolcaba and Wilson, 2002; Wilson and Kolcaba, 2004). Discomfort is a key marker which may limit certain activities and by reducing discomfort caused by pain, individuals may be better able to achieve functional outcomes (Pasero and McCaffery, 2004). Improving outcomes by alleviating discomfort may also reduce associated health-related costs (Kolcaba and Wilson, 2002). Whilst there is little consensus over what discomfort feels like to patients, they highlight that it is of primary concern to them and it may be a fundamental factor which can improve patient outcomes (Kolcaba and Wilson, 2002; Rogeau et al. 2014). It is a broad, multidimensional and holistic construct which is easily understood by patients and clinicians due to its common use in language, which may make it a useful construct to explore embodied experiences after stroke (Kolcaba and Kolcaba, 1991).

Rogeau et al. (2014) developed a pilot scale to identify sources of discomfort after stroke. It rated physical changes such as motor impairment, unsteadiness, fatigue, vision, bladder, digestive problems and pain alongside communication problems and mood disorders. Findings showed 62 patients in the first six weeks post-stroke experienced multiple sources of discomfort and rated motor impairment, fatigue, stiffness, pain, unsteadiness, depression and anxiety as the most uncomfortable factors. Comfort was suggested to be an important factor contributing to quality of life and was associated with stroke severity and dependence on care. It is worth noting whilst the questions presented in this study were refined following patient feedback, they were designed by neurologists in line with the ICF framework – meaning patients were unable to freely contribute to building of the questionnaire and could not openly comment on what it was about an activity that caused the discomfort (WHO², 2018). However, this study provided

useful evidence that comfort is a patient-friendly construct which is important to the patient and can reflect physical and psychological changes.

When discomfort is alluded to in the stroke literature, it reflects a broad range of experiences of bodily change. Kitzmüller, Häggerström and Asplund (2013) talk about living the 'discomforting body' after stroke when referring to changes such as spasticity and decreased muscle function leading to pain, or paresis leading to falls. The perception of a limb being in the wrong place has been reported to cause discomfort when sleeping (Antoniello et al., 2010). Pallesen (2014, p236) used the term "*new bodily discomfort*" to denote unusual body changes such as foot ulcers resulting from the use of a leg brace and epilepsy. Stroke survivors described the perception of not being able to move the affected arm; the sense of the arm moving on its own and having to look for the hand in neglect as discomforting (Klinke et al., 2015).

To focus clinical attention on contributors to discomfort, Kolcaba (1991) devised a holistic definition of comfort delineated into three tiers: 'ease', 'relief' and 'renewal'. 'Ease' referred to a state of calm; 'relief' referred to the alleviation of discomfort and 'renewal' (later termed 'transcendence') referred to a sense of strength and invigoration which can enable the individual to rise-up beyond their experience of discomfort. This led to the development of the 'taxonomic structure of comfort' to examine these three tiers within four contextual areas: the physical, psychospiritual, environmental and sociocultural (Kolcaba, 1991). Considering comfort in a holistic framework elucidates the complexity of the term and its myriad of influencing factors. It highlights that the experience of comfort is dynamic and fluid and how the cumulative interrelated elements that contribute to the experience of comfort may be larger than the sum of its parts (Kolcaba and Wilson, 2002).

The holistic construct of discomfort is congruent with the premise of embodiment theory – that the 'lived experience' is multimodal and holistic - and in line with the way patients relate to and describe their bodies. Comfort theory could be a useful construct to explore the holistic effects of altered body perception after stroke, which could contribute to the embodiment and body perception literature. To achieve the widest understanding of

comfort and discomfort experienced in altered body perception after stroke, this project will borrow from Kolcaba's (1991) holistic perspective of comfort.

1.9 Summary and rationale

After stroke, body perception changes are often complex and problematic, affecting physical experience, function and psychosocial perspectives towards the self. Yet these bodily consequences are frequently left untreated and stroke survivors living with chronic effects of disability must cope with these long-term effects independently (Andrew et al., 2014). The observer-perspective of body perception changes has been utilised in stroke assessment and widely described in the literature. However, the first-person, subjective experience of these changes is rarely reflected leading to a gap in clinical understanding. As Faircloth et al. (2005, p929) summarised: "*[stroke] seems to be documented as an event that leads directly to a phenomenon (the recovery) but is overlooked as a bodily occurrence*".

Body perception literature in which multimodal theories of body representation are utilised, highlight how exploring the bodily experience from both objective and subjective standpoints can advance theoretical thinking and clinical understanding. However, current assessment and exploration of perceptual changes after stroke are not well designed to access the patient-voice. Embodied perspectives and comfort theory could provide a holistic framework to discuss body perception changes after stroke. Currently it is not known how stroke survivors conceptualise and describe their changed body and whether living with these body changes is uncomfortable or requires intervention. It is not known what it is like living with multiple altered body perceptions, how these changes evolve over time and how to most effectively direct rehabilitation efforts to improve individuals' outcomes. Utilising the subjective accounts of the altered body could determine which issues are problematic for patients and how to best direct rehabilitation efforts. This could address the ongoing agendas of both patients and clinicians who must live with and manage chronic body changes after stroke.

1.9.1 Research aims and objectives

The overriding aims and objectives of this programme of work are outlined below and are described in more detail within each relevant chapter.

Aim:

The overall aim of this programme of work is to research stroke patients' perceptual experiences of their bodies and explore whether these perceptions are comfortable.

Research questions:

1. How are patient experiences of altered body perception after stroke described in the literature?
2. What experiences of altered body perception do stroke survivors describe and how does this affect their experiences of comfort?
3. Do stroke survivors want to use assessment tools to communicate their experiences of altered body perception after stroke?

Objectives:

1. Conduct a scoping review to ascertain current knowledge and understanding of what changes to body perception experiences patients report after stroke (revealed by exploratory or experimental research) in a variety of disciplines to:
 - Explore how experiential accounts of 'altered body perception' add to understanding of the concept
 - Explore similarities between these experiential accounts of 'altered body perception'
 - See whether patients describe issues that require intervention
 - Highlight gaps in the literature regarding clinical understanding of this phenomenon
2. Conduct a qualitative study to understand the experience of altered body perception post-stroke and how this affects patient experiences of comfort by:

- Exploring patients' descriptions of the discomfort associated with experiences of altered body perception; viewing discomfort from a holistic perspective
 - Exploring whether participants feel altered body perception or associated discomfort is a problem that would benefit from additional recognition or support. Ascertain if they have had their altered body perception clinically assessed; accessed any clinical support or found a beneficial intervention themselves
 - Collate and integrate these findings with that of the literature review to inform the next phase of work
3. Conduct a qualitative study to explore whether stroke survivors want to communicate their altered body perceptions and discomfort to health professionals and the feasibility and acceptability of using assessment tools to support this process, in order to:
- Explore individual need to communicate their experiences of altered body perceptions and discomfort
 - Explore the relevance and acceptability of a selection of diverse assessment tools for capturing the experience of altered body perceptions and comfort from the perspective of a person living with stroke
 - Explore the use of these assessment tools in a group of people with aphasia

1.9.2 Patient and Public Involvement

In line with current NHS strategy to improve patient consultation in health care decisions (Department of Health, 2012), development of the research questions and the qualitative studies within this programme of work have been informed by a Patient and Public Involvement (PPI) group at all stages. The group contained three members who experienced altered body perceptions, one of whom had additional communication needs. The group discussed the concept of altered body perception, relating it to their

own experiences of the condition and they concurred that it is an issue which is pertinent to the experience of life after stroke. PPI contribution to the primary research studies are detailed in Sections 3.9.1 and 5.7.1.1.

1.9.3 Thesis construction

This thesis is comprised of seven chapters, describing the three studies conducted during this programme of work. The introductory chapter outlines the field, the gaps in the literature and provides a rationale for conducting further research in this area. It introduces key concepts and terms and highlights the structure of the programme of work. This is followed in Chapter 2 by a scoping review of the literature which serves to identify experiential accounts of altered body perception after stroke. This scoping review was conducted concurrently alongside a phenomenological study which explored the experiences of altered body perception after stroke and provides the introduction and context for this study. The method used in the phenomenological study is outlined in Chapter 3 and the analysis and discussion are contained in Chapter 4. Following the completion of these studies a further acceptability and feasibility study was conducted, exploring the use of assessment tools to communicate altered body perception and comfort after stroke. The method of this study is described in Chapter 5 and the analysis and discussion in Chapter 6. Chapter 7 contains an overview of the work conducted, discussion of the implications for patients and practitioners and key recommendations for future research and practice.

Chapter 2: Exploring experiential accounts of 'altered body perception' after stroke: A scoping review

2.1 Chapter introduction

This chapter builds on the premise that researchers and clinicians look at altered body perception issues from an observer standpoint, meaning it is likely that the literature around patient experiences of 'altered body perception' after stroke is limited. Whilst clinical boundaries to define perceptual changes post-stroke are helpful to categorise experiences, they may also limit exploration of similarities between experiences and it is not known whether there is overlap between these experiences when viewed from a patient perspective. This scoping review provides an exploration of the literature to ascertain patient experiences of altered body perceptions after stroke, to explore similarities between accounts and pinpoint gaps in the literature.

2.2 Rationale for choosing a scoping review

The literature in which perceptual changes after stroke are explored is diverse. It reflects changes occurring in multiple perceptual domains, which may be experienced in any body area. The field is confused by a myriad of differing terminology which serves to make the subject matter appear disparate and unclearly demarcated. For example, stroke literature captures experiences in which perception of the body is lost or confused, under terms such as 'phantom limb sensation' (Antoniello et al., 2010); 'neglect' (Tham, Borrell and Gustavsson, 2000); 'sensory impairment' (Doyle, Bennett and Dudgeon, 2014); or 'anosognosia' (Chatterjee and Mennemeier, 1996). Whilst terminology is useful for diagnostic and rehabilitative purposes, it is unlikely that the terms reflect the patient experience of living with these conditions. Being able to collectively explore the lived experience of the altered body is important to patients, researchers and clinicians (Antoniello et al., 2010; Baier and Karnath, 2008; Connell, McMahon and Adams, 2014).

As noted in Complex Regional Pain Syndrome, researchers found it useful to view body perception changes holistically and group them under the concept of 'body perception disturbance', enabling them to explore how these interrelated facets are informed by body image and body schema (Lewis et al., 2007; Lewis and McCabe, 2010, Section 1.3).

The disparate nature of the literature and terminology used to denote experiences of altered body perception, suggest the search was best suited to a scoping review methodology, as opposed to a systematic review. A systematic review is appropriate when there is a clearly formulated research question and the literature can be appraised on quality and categorised by methodology (Khan et al., 2003). Whereas a scoping review is preferred when it is necessary to explore and examine emerging evidence and map the existing literature in an area to give an idea of its scope, boundaries and limitations (The Joanna Briggs Institute [JBI], 2015). As such, a scoping review does not critically appraise the literature, but uses the literature to demarcate the current state of the field (JBI, 2015). Importantly, this approach is designed to reduce bias, as it takes a comprehensive and systematically rigorous overview of all relevant literature through a bounded inclusion process. Scoping reviews differ from narrative reviews which, though often comprehensive, do not provide the same level of rigour and inclusive search techniques (Green, Johnson and Adams, 2006). Scoping reviews are useful for illuminating concepts, determining the suitability of undertaking a systematic review, or whether to review a research area in terms of a specific methodology (Levac, Colquhoun and O'Brien, 2010).

Scoping reviews are a relatively new, yet increasingly popular method for conducting systematic and comprehensive literature searches. Guidelines for how to conduct reviews are still developing. The primary scoping review protocol was developed by Arksey and O'Malley (2005) and was refined by Levac, Colquhoun and O'Brien (2010). From these frameworks, further methodological clarity was provided by The Joanna Briggs Institute (JBI, 2015). The latter is the most comprehensive protocol, comprising of extensive guidance for all stages of the review process and as such was adopted for this review.

2.3 Defining the research question

As discussed in the introduction chapter, the term ‘altered body perception’ captures a wide variety of experiences and is not yet commonly used to describe the perceptual changes to the body which occur after stroke. When planning this review, it was not clear what type of literature should be searched for, precisely which conditions and experiences should be reflected by the term, or what terms in the literature were used to define perceptual body experiences. Initial reading around the topic into areas such as embodiment supported the idea of conceptualising the topic as broadly and holistically as possible (Eccleston, 2016; Gallagher, 2005). It became clear that the clinical literature was segregated based on medical constructs, designed to make subject areas more manageable to approach. However, qualitative literature exploring participant accounts contradicted these dichotomies and presented ‘altered body perception’ as a holistic term (e.g. Ellis-Hill, Payne and Ward, 2000). In order to bridge this conceptual divide, the research question and search terms were devised to capture the broadest array of literature available. However, one parameter was included to create boundaries and retain focus within the review: to ensure the literature reflected participant accounts of the experience of bodily perceptual changes, as opposed to the impact of those changes, such as psychosocial or functional consequences.

In scoping review methodology, it is legitimate to set parameters on the research question once the breadth of the field has been ascertained to ensure that the review does not become limited in scope (Arksey and O’Malley, 2005). As such the scoping review research question evolved in a two-stage process which refined its scope and identified a manageable quantity of literature. The initial question: “What kind of changes to body experience occur after stroke?” resulted in the identification of 12,222 published records (Section 2.4). To focus the search within the identified literature, the research question was revised (Section 2.3.1) and the selection criteria updated (Table 2).

2.3.1 Aims and objectives:

The revised aim of the scoping review was to ascertain current knowledge and understanding of what changes to body perception experiences patients report after stroke (revealed by exploratory or experimental research) in a variety of disciplines to:

- Explore how experiential accounts of ‘altered body perception’ add to understanding of the concept.
- Explore similarities between these experiential accounts of ‘altered body perception’.
- See whether patients describe issues that require intervention.
- Highlight gaps in the literature regarding clinical understanding of this phenomenon.

2.3.2 Iterative process between the scoping review and qualitative study

Due to a lack of clarity around which literature would fall under the term ‘altered body perception’, the scoping review was conducted concurrently to the qualitative research study exploring body perception and comfort after stroke (Chapter 3). The two pieces of research iteratively informed each other as they developed.

During the initial formation of the concept of ‘altered body perception’, it was considered likely that the term would reflect the experiences of altered sensation, perception and awareness of the body. These experiences inherently related to the ‘outer body’ – meaning the body which is experienced and navigated within space - for example pain in the arm, or the lack of awareness of body parts typified in neglect or anosognosia. However, it became clear through data from the qualitative study that participants equally considered changes to ‘internal’ body perception such as bladder dysfunction, sexual dysfunction and dysphagia as important when considering their post-stroke bodily experiences. They also referred to altered experiences relating to their ‘means of perception’, describing changes to visual impairment (hemianopia); the ability to process

and order information evident in conditions such as apraxia; and fatigue (which was construed by participants as both a bodily and cognitive issue).

Participants also described their experiences in terms of loss of movement or inability to perform activities because this was when perceptions such as muscle weakness or perceptual loss became apparent. However, changes to body awareness in the experimental literature are usually evaluated when the body is static using cognitive tests such as the Behavioural Inattention Test (Wilson, Cockburn and Halligan, 1987). To reflect perceptual changes in movement, the scoping review search criteria was widened to include experiential data capturing the moving body. Thus literature relating to 'internal' and 'external' body perceptions and the moving and static body were considered and the search terms and concepts of the review were refined whilst retaining a focus on patient experience. This iterative process reflected the exploratory nature of redefining this perceptual experience through a new perspective.

2.3.3 Searching for similar scoping reviews

A preliminary search was conducted to ascertain whether any existing scoping reviews had been completed. Searches were conducted in AMED, CINAHL PLUS, COCHRANE (CDSR), MEDLINE, PSYCHINFO and GOOGLE SCHOLAR using the terms 'scoping review', 'stroke', 'body perception' (Appendix A.1). The only related scoping review returned was by Kessner, Bingel and Thomalla (2016) which grouped studies exploring somatosensory deficit after stroke to provide an overview of assessment, prevalence and interventions. No other scoping reviews which explored the phenomenon of 'altered body perception' as described in this thesis, or related concepts were identified.

2.4 Search strategy

JBI (2015) suggest conducting a large and comprehensive three-step search of published and unpublished literature, in which terms are identified and initial searches conducted. This is followed by hand-searching and snowballing of results. The development of the

selection criteria is described after this three-step process, because it was derived from the iterative search method (Section 2.4.4).

2.4.1 Step 1: Initial limited searches

Firstly, a small primary search utilising at least two databases was conducted, to gather key terms through looking at the titles, abstracts and associated keywords used to categorise relevant literature. These ‘mini searches’ were conducted in four databases: AMED, CINAHL PLUS, MEDLINE, PSYCHINFO (Appendix A.1). This identified the most used and appropriate terms to describe ‘altered body perception’ after stroke, along with their synonyms. Key terms were identified and honed through discussion with the supervisory team. Terms were systematically split into four categories (stroke, altered, body and perception) to facilitate the search (Appendix A.2).

Due to the broad nature of the subject and the varying discourse in different disciplines, general terms were included such as “feel”, “sense”, “ownership”, “experience” and “embodiment”. This broadened the search from purely physiological or neurological approaches to the topic and avoided omitting studies through subject specific rhetoric. This approach led to a large volume of literature being returned. Arksey and O’Malley (2005) suggest that this is an unavoidable part of the scoping review process. They recommend using an openly iterative approach in which decisions are made as the process unfolds and the researchers have more insight into the breadth of the field and volume of literature. They recommend transparency in reporting to aid replicability and mitigate the iterative process.

2.4.2 Step 2: Systematic searches

2.4.2.1 Searching published databases

Secondly, a comprehensive and systematic search of all relevant databases using all appropriate identified terms was conducted initially in April 2016 and re-run in February

2018. Eleven published literature databases were searched: AMED, ASSIA, BNI, CINAHL PLUS, COCHRANE (CDSR), EMBASE, MEDLINE, IBSS, PsychINFO, SAGE and Web of Science (Appendix A.1). These databases were identified as relevant to the literature search through consultation with a librarian and the supervisory team. These databases were purposely chosen to span several disciplines to ensure they captured variances in how the phenomenon of 'altered body perception' was represented. Terms were joined with a maximum of three words between the categories 'altered' and 'perception'; and 'perception' and 'body', to ensure that the studies returned were as relevant as possible (Appendix A.3).

2.4.2.2 *Searching the grey literature*

A grey literature search ran concurrently to the searches of the published literature, utilising the databases detailed in Appendix A.1. However, the majority of the databases were unable to process the search required. Once it was apparent that there was sufficient published literature available to get a 'scope' of the phenomenon, the grey literature searches were omitted from the process.

2.4.3 Step 3: Additional searches

In the third phase, the reference lists of the selected studies were searched to identify or 'snowball' any other relevant studies. This process was conducted and 10 studies were identified. Additionally, a further 20 studies were identified during the process of searching for titles useful for other parts of this thesis. It was not necessary to contact authors of the studies regarding further publications because of the high volume of literature available to review.

2.4.4 The search process: iteratively updated selection criteria and extraction of results

In line with JBI (2015) protocol for scoping reviews, the PICO (Population, Intervention, Comparison, Outcome) framework used in systematic reviews was not applied to the research question. Instead the question was framed around the concept, participants and context. The concept was to identify any literature on somatosensory or perceptual body experiences (including visual perceptual disturbances) which occur due to stroke.

Participants included adults over 18, any time post-stroke who experienced stroke from any cause. The context was not restricted by setting, perspective (observer or patient), results, date of publication, study quality, source type or discipline. The criteria were devised iteratively in four phases and are tabulated below (Table 2).

Table 2. Process of developing selection criteria

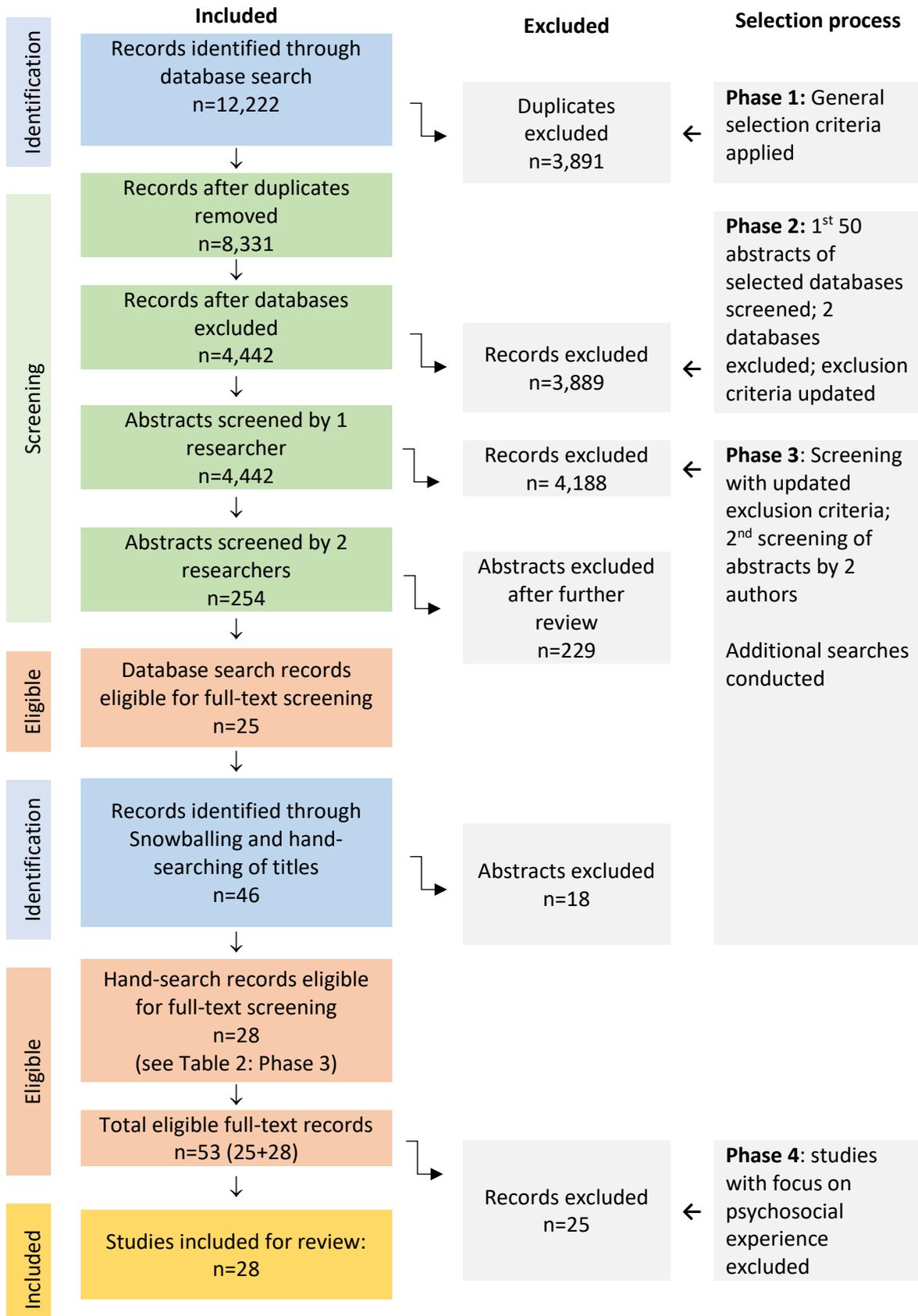
	Description of the iterative development of selection criteria and extraction of results
Phase 1	<ul style="list-style-type: none"> ▪ The initial selection criteria relating to the 'Concept, participants and context' criteria were applied. Studies related to children or animals, focused on other conditions or not solely about stroke, non-scientific literature and research not in English, were excluded. ▪ 12,222 records being identified and stored in referencing software Refworks. ▪ 3,891 duplicates were removed using an automatic Refworks function, followed by a title screening for further duplicates, resulting in 8,331 unique records.
Phase 2	<ul style="list-style-type: none"> ▪ The goal of the second phase was to refine the research question. ▪ Two researchers (HS and AT) screened the first 50 titles and abstracts from six selected databases to explore the literature obtained. Two databases contained less than 50 abstracts, therefore 260 were screened in total (Appendix A.4). The consensus rate for inclusion between the two researchers was 97%, adding rigour to the process and meeting JBI (2015) protocol suggesting that two authors are involved in screening. Due to the high consensus rate, one author (HS) screened the remaining titles and abstracts independently but consulted the supervisory team when unsure. ▪ In line with the research aim, the research question was refined to relate to first-person experiences of altered body perceptions (Section 2.3.1) and only studies containing direct accounts of patient experience (such as interview, survey, writing, drawing or verbal affirmation of experiences) were included. ▪ Studies reflecting experiences of interventions or participant experiences of 'unnatural' settings (e.g. experimental conditions) which might affect their description of altered body perceptions were excluded. ▪ Records reflecting reports, conference posters or proceedings, were excluded. ▪ Databases BNI and CDSR were identified as not yielding any relevant titles and included numerous studies not related to stroke, so were excluded (n=3,889). This left 4,442 records for consideration.
Phase 3	<ul style="list-style-type: none"> ▪ Titles and abstracts of these 4,442 records were screened by one author (HS) in line with the updated exclusion criteria. ▪ 127 case studies were identified and excluded as they were likely to be based on 'observed' data from clinicians which did not reflect the first-person experience of altered body perception, resulting in 4,315 records. ▪ During the screening process, excluded literature was categorised into relevant areas exploring altered body perception, such as 'assessment', 'mechanisms', 'interventions', 'holistic effects' and 'terms' to inform thinking and discussion around pertinent areas for the thesis as a whole. ▪ 127 records were identified for inclusion and were categorised into survey (n=102) and qualitative research (n=25) studies. ▪ The abstracts of the 102 survey studies were screened by two authors (HS and AT) of these 99 were excluded, predominantly because it was not explicitly stated in the abstract that they contained first-person data. The 25 qualitative abstracts were reviewed and three were excluded (two were not journal articles and one was a duplicate). Following the exclusion of the survey and qualitative studies, 25 studies remained. ▪ Snowballing and hand-searching of these titles, led to the identification of a further potential 46 records. After screening the abstracts, 18 were excluded (two were not solely about stroke; nine were not focused on altered body perception; three were not in English; two did not contain first-person experience; one was an intervention study; one was grey literature), leaving 28 records remaining. When combined with the previously identified 25 studies, this provided 53 studies to evaluate.

Phase 4	<ul style="list-style-type: none"> ▪ The full text of all 53 studies was explored in NVivo 11 (QSR International, 2016). Data relating to first-person experience of ‘altered body perception’ were identified and coded. Ancillary study information was charted in Excel to determine which studies met the selection criteria and related to the key concepts identified in the research question (Appendix A.5). ▪ All 53 studies contained first-person data (or author summarised first-person data) on ‘altered body perceptions’, however they varied in the degree to which they focused on the bodily experience. Some studies provided an in-depth description and reflection on participants’ bodily experiences, whereas other studies provided a more cursory reflection on the bodily experience focussing instead on a psychosocial interpretation of the experience. Studies without a significant bodily focus were excluded. This resulted in 25 studies being excluded, the reasons for which are described further in Appendix A.6. Overall 28 studies were identified for review and the rationale for their inclusion is in Appendix A.7.
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2.4.5 Charting the findings

JBİ (2015) suggest that the review findings are charted to provide a descriptive summary of the selected studies which were then grouped under conceptual ideas. As such, the literature is not synthesised or thematically analysed, but classified within a thematic framework. Clarification of this process was confirmed directly with the JBİ institute (Appendix A.8). This is in line with other scoping review analytic processes which advise conceptual mapping of ideas (Arksey and O’Mally, 2005; Levac, Colquhoun and O’Brien, 2010). As advised by JBİ (2015) the literature was not critically appraised, as at this early stage of scoping the field it is advisable to retain all literature to get a full picture of current research and gaps. The results were descriptively summarised (Section 2.5.1), grouped in terms of body perception change (Table 3) and then explored for commonalities through a thematic framework (Section 2.5.2 and Appendix A.9).

Figure 2. Prisma flow diagram

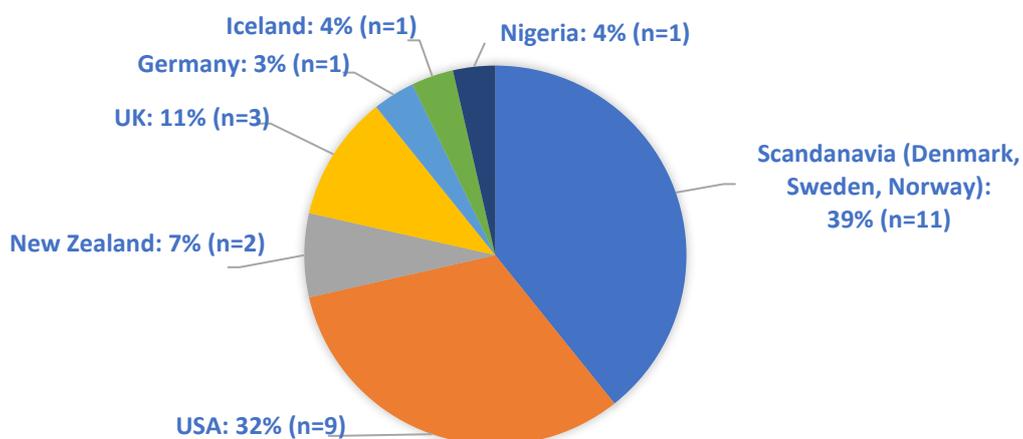


2.5 Analysis

2.5.1 Descriptive summaries

The title and authors of the 28 studies selected for inclusion in the review are detailed in Table 3 and the ancillary information in Appendix A.5. Studies were conducted in the UK and internationally (Figure 3). Nine studies focused on the time-period less than six months post-stroke; 12 studies between stroke onset and two years; and six explored participants from stroke onset to more than 2 years post-stroke. Five of these studies used quantitative survey methods; 20 used qualitative interview-based methods; two used case-study style reports; and one used mixed-methods. Three of the five studies used quantitative methods to capture experiences of pain and utilised pain assessments, visual analogue scales and clinical examinations (Bashir et al., 2017; Jönsson et al., 2006; Widar et al., 2002); the two studies on body awareness conditions (phantom sensations and anosognosia) used structured questionnaires alongside MRI scans (Antoniello et al., 2010, Baier and Karnath, 2008). Of the qualitative studies, six utilised phenomenology; 11 used 'qualitative methods' combined with varying analytical approaches; one used ethnography; one a life-narrative approach and one used grounded theory.

Figure 3. Pie-chart showing geographic spread of included studies



Studies were grouped into a variety of post-stroke bodily experiences: six on body awareness (including anosognosia, phantom limb sensations and neglect); three on somatosensory impairment; four were focused on pain; two on conditions in which there is disrupted movement or coordination of movement such as apraxia; three on balance and mobility; one on fatigue and nine on holistic or embodied accounts of body perception experiences (Table 3).

Table 3. Final 28 selected studies

Awareness of the body
<ul style="list-style-type: none"> • Antonietto et al. (2010). Phantom limb after stroke: an underreported phenomenon. • Baier and Karnath (2008). Tight link between our sense of limb ownership and self-awareness of actions. • Chatterjee and Mennemeier (1996). Anosognosia for hemiplegia: patient retrospections. • Ellis and Small (1994). Denial of eye closure in acute stroke. • Klinka et al. (2015). "Getting the Left Right" the experience of hemispatial neglect after stroke. • Tham, Borell and Gustavsson (2000). The discovery of disability: a phenomenological study of unilateral neglect.
Sensory impairment
<ul style="list-style-type: none"> • Carlsson, Gard and Brogårdh (2017). Upper-limb sensory impairments after stroke: self-reported experiences of daily life and rehabilitation. • Connell, McMahon and Adams (2014). Stroke survivors' experiences of somatosensory impairment after stroke: an interpretative phenomenological analysis. • Doyle, Bennett and Dudgeon (2014). Upper limb post-stroke sensory impairments: the survivor's experience.
Pain
<ul style="list-style-type: none"> • Bashir et al. (2017). Central post-stroke pain: its profile among stroke survivors in Kano, Nigeria. • Jönsson et al. (2006). Prevalence and intensity of pain after stroke: a population-based study focusing on patients' perspectives. • Widar, Ek and Ahlström (2004). Coping with long-term pain after a stroke. • Widar et al. (2002). Long-term pain conditions after a stroke.
Coordination and movement processing
<ul style="list-style-type: none"> • Arntzen and Elstad (2013). The bodily experience of apraxia in everyday activities: A phenomenological study. • Blijlevens, Hocking and Paddy (2009). Rehabilitation of adults with dyspraxia: health professionals learning from patients.
Balance and mobility
<ul style="list-style-type: none"> • Da Silva et al. (2014). Falling, balance confidence and fear of falling after chronic stroke • Gorst et al. (2016). Foot and ankle impairments affect balance and mobility in stroke (FAIMIS): the views and experiences of people with stroke. • Schmid and Rittman (2007). Fear of falling: an emerging issue after stroke.
Fatigue
<ul style="list-style-type: none"> • Kirkevold et al. (2012). Fatigue after stroke: manifestations and strategies.
Altered perceptions as a holistic or embodied experience
<ul style="list-style-type: none"> • Doolittle (1991). Clinical ethnography of lacunar stroke: implications for acute care. • Eilertsen, Kirkevold and Bjørk (2010). Recovering from a stroke: a longitudinal, qualitative study of older Norwegian women. • Ellis-Hill, Payne and Ward (2000). Self-body split: issues of identity in physical recovery following stroke. • Faircloth et al. (2004). Disrupted bodies: experiencing the newly limited body in stroke. • Faircloth et al. (2005). Constructing the stroke: sudden-onset narratives of the stroke survivor. • Kitzmüller, Häggström and Asplund (2013). Living an unfamiliar body: the significance of the long-term influence of bodily changes on the perception of self after stroke. • Kvigne and Kirkevold (2003). Living with bodily strangeness: womens' experiences of their changing and unpredictable body following a stroke. • Taule and Raheim (2014). Life changed existentially: a qualitative study of experiences at 6-8 months after mild stroke. • Timothy, Graham and Levack (2016). Transitions in the embodied experience after stroke: grounded theory study.

2.5.2 Analytical themes

From this initial mapping, the studies were explored for commonalities through a process of reading the studies and identifying terms and topics of focus which occurred in multiple instances. Two thematic constructs were identified, namely: 'The body as strange and unfamiliar' and 'Becoming conscious of the body' (Appendix A.9 includes the rationale for forming these constructs). The latter theme was comprised of two areas: 'Noticing the body during movement' and 'Talking to the body'. These themes did not constitute a full thematic analysis but instead reflected commonalities between participant accounts of different perceptual experiences. The two constructs related closely to the objectives of the review as they ascertained current knowledge of what changes patients report about altered body perception and explored similarities between experiential accounts.

2.5.2.1 *The body is strange and unfamiliar*

The body was described as feeling strange and unfamiliar across many studies which encompassed all categories of body experiences identified during the charting process (Section 2.4.5). Perceptions of unfamiliarity were often discussed in terms of disturbed sense of body ownership, wherein the affected parts were no longer perceived as part of the bodily whole. Through looking at commonalities between patient accounts of body changes post-stroke, the overlap between experiences became quite striking.

In accounts of neglect, participants described the body as surreal and strange as participants expressed a sense that affected limbs did not belong to them and found them difficult to locate (Klinke et al., 2015; Tham, Borrell and Gustavsson, 2000). In participants' reflections on the experience of anosognosia in hemiplegia, limbs were attributed to other people and felt like they did not belong to the body (Baier and Karnath, 2008). Similarly, those describing phantom sensations emphasised how they were unable to find their limbs (Antoniello et al., 2010). These phantom experiences were

also described by Doolittle (1991), in which participants described 'losing' their limbs at night.

Participants often expressed perceptions that limbs were moving when they were not. These experiences were evident across five out of six of the studies focused on bodily awareness issues of neglect, anosognosia and phantom sensations (Antoniello et al., 2010; Baier and Karnath, 2008; Chatterjee and Mennemeier, 1996; Klinke et al., 2015; Tham, Borrell and Gustavsson, 2000). Antoniello et al. (2010) described these phenomena in more detail, terming the perception that the hemiplegic limb is not in the place where it is perceived to be as a 'postural phantom' and the perception of a moving limb as a 'kinaesthetic phantom'. They highlighted that 22 out of 27 of their participants described postural phantoms as worse at night, when there was no visual input and similarly, how the perception of kinaesthetic phantoms stopped when contradicted by visual information.

The body was defined as similarly disconcerting in accounts of holistic or embodied experiences, in which participants termed the body as strange, unfamiliar, alienating, unreal, half, numb, gone or like somebody else (Eilersten et al., 2010; Ellis-Hill, Payne and Ward, 2000; Faircloth et al., 2005; Kitzmüller, Häggerström and Asplund, 2013; Kvigne and Kirkevold, 2003; Taule and Raheim, 2014; Timothy, Graham and Levack, 2016). The apraxic body was described as peculiar or odd and participants described having to search for a limb and then displayed uncertainty about how to use the body (Arntzen and Elstad, 2013). Individuals experiencing sensory impairment described affected limbs as asleep, dead, anaesthetised, cut off and not part of the body (Carlsson, Gard and Brogårdh, 2017; Connell, McMahon and Adams, 2014; Doyle, Bennett and Dudgeon, 2014). In descriptions of loss of sensation, spasticity, weakness and pain affecting balance and mobility, participants described the foot as not feeling 'right' and feeling like it no longer belonged to the body (Gorst et al., 2016).

Due to the quantitative (and therefore less subjectively descriptive) nature of three of the four studies describing pain, it was difficult to identify whether participants experienced the painful body as being strange and unfamiliar. In the qualitative accounts, participants

described perceptions of numbness and, in the case of nociceptive pain, expressed a desire to “*get rid of the arm*” suggesting an impact on the perception of bodily wholeness (Widar, Ek and Ahlström, 2004, p219). Previous research by Widar et al. (2002) described in more detail the pain characteristics and demographics of these same participants, highlighting that 29 out of 43 individuals experienced hemiplegia and other perceptual changes such as allodynia and thermal changes. However, due to the research focus on pain there was little exploration of these other perceptual experiences which may be associated with the experience of bodily strangeness. Pain was also described as fatiguing (Taule and Raheim, 2014; Widar et al., 2002; Widar, Ek and Ahlström, 2004). In accounts of fatigue, participants used phrases of feeling ‘over-medicated’ to describe the feeling of bodily tiredness or ‘in low gear’ to denote feelings of mental fatigue (Kirkevold et al., 2012). Whilst these terms reflect a change in the bodily experience, it is not known if this difference is reflecting a similar sense of bodily alienation captured in the previous accounts due to the slight variation in terminology and the lack of literature in this area.

2.5.2.2 *Becoming conscious of the body*

2.5.2.2.1 Noticing the body during movement

Moments in which participants became aware of their altered body perceptions through attempting to engage in activity or movement were described frequently across selected studies. The body often failed to respond adequately and felt for many, out of control, unresponsive, unpredictable or slow. Participants described the process of attempting intentional actions (an embodied desire to act, which is not consciously reflected on) but were unable to execute these movements.

Chatterjee and Mennemeier (1996) found in retrospective participant accounts of anosognosia for hemiplegia, that awareness of weakness emerged over time and had to be discovered by attempting to engage in activities. Participants described being unaware of their altered perceptions when not engaging the body and the body was static. No other research endeavoured to describe the emergence of awareness of anosognosia, but rather captured the clinical characteristics (Baier and Karnath, 2008). However, this

type of reengagement with the body through movement was described in accounts of neglect. Tham, Borrell and Gustavsson (2000) and Klinke et al. (2015) both highlighted the process of perceiving the body post-stroke, emphasising how this is a convoluted process of noticing limitations and bringing conscious attention to mitigate for lost perception. In Tham, Borrell and Gustavsson (2000), participants described having to fail in tasks which involved perceiving the left side of space before they could start asking themselves 'why' they couldn't do it, and then to adopt strategies to mitigate the problem.

In sensory impairment, participants noticed difficulties of judging where the limb was in space or attuning how much grip pressure to apply to objects while attempting to engage in and execute activities (Carlsson, Gard and Brogårdh, 2017; Doyle, Bennett and Dudgeon, 2014). Connell, McMahon and Adams (2014) noted how participants often described the impact of altered sensory perception through memorable experiences. For example, one individual expressed not feeling burns on his hand after someone tipped coffee on him. They highlighted the difficulty of verbally conveying a sense of perceptual loss and how useful it is to employ a familiar example which may provide a conceptual anchor for both the interviewee and their audience.

In action or movement processing disorders, the perception of the body as strange and unfamiliar became evident to participants when the body would not respond as required and the body became alien to itself and its environment (Arntzen and Elstad, 2013; Blijlevens, Hocking and Paddy, 2009). Faircloth et al. (2005) captured the lack of bodily response as a primary indicator for some that a stroke was occurring, which then triggered participants to question what was wrong with their bodies. In Gorst et al. (2016), Da Silva et al. (2014) and Schmid and Rittman (2007) the focus was primarily on participants engaging in mobility, therefore altered body perceptions such as weakness and unresponsive body parts were described in terms of not being able to move or control the body. Studies adopting a holistic or embodied perspective to participant accounts, repeatedly described the body as out of control, unpredictable and unreliable which contributed to the perception of bodily alienation (Doolittle, 1991; Eilersten et al., 2010; Ellis-Hill, Payne and Ward, 2000; Faircloth et al., 2004; Kvigne and Kirkevold, 2003).

In many perceptual changes (apraxia, sensory impairment, neglect and embodied experiences) participants maintained a sense that they could achieve activities, despite being unable to perform intentional movements (Blijlevens, Hocking and Paddy, 2009; Carlsson, Gard and Brogårdh, 2017; Faircloth et al., 2004; Klinke et al., 2015; Kvigne and Kirkevold, 2003; Tham, Borrell and Gustavsson, 2000). Kvigne and Kirkevold (2003, p1304) described an example of this:

“she unconsciously used her paralyzed arm as before the stroke, with the result that the flower vase was thrown to the floor... they forgot that their body had changed and lost its function and, for example, ‘started to walk and fell down’”.

Cognitive awareness of the sense of the body whilst engaged in activity, was a complex and incongruous experience and varied, in some cases, depending on the meaning attributed to the movement. In apraxia, Arntzen and Elstad (2013) highlighted how at times participants struggled to attribute actions to body parts, unsure whether they had achieved something or someone else had, showing uncertainty in body ownership. This uncertainty towards the body was emphasised in neglect as participants repeatedly forgot their left hand but still appeared preoccupied with taking care of it: *“Even though I do not feel my hand, it is still in here [points to his head] when I think about it”* (Klinke et al., 2015, p1631). The sense of body ownership evolved during recovery of neglect, whilst feelings of bodily strangeness remained:

“the 4 participants now primarily believed that their left legs belonged to them. The feelings of alienation toward the left arm remained during the whole discovery process; however, the women described how they slowly got used to the left arm” (Tham, Borrell and Gustavsson, 2000, p402).

Participants then relied on an *“intuitive feeling”* (p403) wherein they employed cognitive strategies to overcome their perceptual limitations to engage in activity. Context and meaning of activities were shown in neglect to support bodily reintegration with the environment. Participants attended more easily to meaningful stimuli, such as caring for a

baby or hazards, suggesting an unconscious component to re-orientating the body to its environment (Klinke et al., 2015; Tham et al, 2000).

In some studies, it was not the patients' attempts to regain movement and function which drew conscious attention to the body but vice versa, as the altered perceptions impacted movement. Participants described how heaviness in the body inhibited movement (Eilersten et al., 2010; Timothy, Graham and Levack, 2016) or pain became worsened as participants attempted or refrained from activity (Bashir et al., 2017; Widar, Ek and Ahlström, 2004). Across four of the body perception categories devised for charting the studies, bodily slowness was mentioned: in holistic accounts of altered perceptions (Kitzmüller et al., 2013; Kvigne and Kirkevold, 2003; Taule and Raheim, 2014); in sensory impairment (Doyle, Bennett and Dudgeon, 2014); in coordination and movement processing (Arntzen and Elstad, 2013) and in body awareness (Blijlevens, Hocking and Paddy, 2009).

2.5.2.2.2 Talking to the body

In the majority of studies across the post-stroke conditions, participants referred to stroke affected body parts in objectified, third person language. This verbalisation of bodily alienation was closely linked with the sense of bodily strangeness and unfamiliarity. For example in neglect, body parts were described as feeling like objects and termed in the third person (Blijlevens, Hocking and Paddy, 2009; Tham, Borrell and Gustavsson, 2000). Doolittle (1991) highlighted how post-stroke participants *"lost a sense of bodily wholeness and their full attention turned to the new object at their side"* (p237). Experiences of perceptual loss, which might be assumed to mute bodily awareness, instead made the body salient and conscious through the loss of intentional action. Participants became *"trapped in an object like body"* (Ellis-Hill, Payne and Ward, 2000, p729). This entrapment forced, an internal communicative act between mind and body which was termed by one researcher as *"body talk'... The mind is telling the body – which does not listen – what to do"* (Faircloth et al., 2004, p75; Faircloth et al., 2005).

In many body perception changes, objectification and conscious awareness of the body were useful tools, enabling individuals to cognitively direct movement and regain some bodily control. In apraxia, participants referred to keeping body parts under surveillance and directing them to achieve activities (Arntzen and Elstad, 2013; Blijlevens, Hocking and Paddy, 2009). Accounts of the female experience of life after stroke, conceptualised this as the 'non-spontaneous body', which was an "*expression of a body that was no longer able to do different things without consciously thinking about how to do it*" (Kvigne and Kirkevold, 2003, p1299). Similar accounts of loss of automatic bodily responses were found in sensory impairment (Doyle, Bennett and Dudgeon, 2014). In neglect, participants described how failure in activities, while upsetting, was also useful to increase awareness of bodily limitations (Klinke et al., 2015; Tham, Borrell and Gustavsson, 2000). One participant described the benefit of bodily objectification in this process:

"I often try to explain to myself that something is wrong by imagining that my body is like the body of inseparable Siamese twins – accordingly, when I move, I simultaneously need to pay attention to my twin – we are part of the same body even though we are different... I find it helpful to imagine or even emphasise that I need to remember my twin by saying it out loud" (Klinke et al., 2015, p1630).

Talking to the body demonstrated participants' attempts to make intentional action conscious and to generate response from the 'object' body. The nature of this dialogue was at times bidirectional. In accounts of fatigue, one participant described this as the body talking back to the mind: "*it feels like my body says that "now I can't anymore"*" (Kirkevold et al., 2012, p667). In accounts of apraxia, Blijlevens, Hocking and Paddy (2009) highlighted how participants who struggled to access the correct information to instruct the body, had to wait for that information to surface in its own time, or had to spend a long time prior to activities thinking them through.

2.5.2.3 What do patients want help with?

Patients were not explicitly asked what they wanted support with in any of the selected studies. However, strategies to manage the altered body or recommendations for improving rehabilitation and outcomes were discussed in many studies. Accounts which focused on sensory impairment and balance and mobility highlighted how little attention was paid to rehabilitating sensory issues post-stroke, due to the professional focus on recovery of motor function. Participants perceived that sensory impairment had a significant impact on life and was important to them, but they received minimal intervention to improve sensory perception (Carlsson, Gard and Brogårdh, 2017; Doyle, Bennett and Dudgeon, 2014; Connell, McMahon and Adams, 2014; Gorst et al., 2016).

Problems for patients in verbalising body perception changes were highlighted in several instances. In neglect, the authors highlighted that the condition was problematic for patients to reflect on and suggested that patients were hesitant to try to communicate their experiences to professionals due to a lack of vocabulary to express their experiences and for fear of being perceived as mentally unstable if reporting bizarre perceptions (Antoniello et al., 2010; Klinker et al., 2015). In sensory impairment, a lack of vocabulary to articulate experiences was evidenced through participants' difficulty describing conflicting experiences (such as numbness but also being able to feel) and a reliance on using examples of past activities to demonstrate an ongoing experience of a sensory perceptual change (Connell, McMahon and Adams, 2014).

The way in which professionals communicate about perceptual changes was also mentioned by several authors as an important area for development. Schmid and Rittman (2007) described communication as a major factor affecting the development of fear of falling and suggested patients needed better communication from professionals to lessen embarrassment when talking about this issue, alongside more strategies to manage physical weakness which can affect safety when mobilising. Kirkevold et al. (2012) suggested that to manage post-stroke fatigue, patients needed to be better supported by professionals to understand their new normalcy and help them manage their experiences. Widar, Ek and Ahlström (2004) recommended improved

communication to ensure understanding of pain and pain management. Accounts of conditions affecting movement processing did not reflect on communication but did recommend prompt diagnosis due to the pervasive impact these changes have on patients' lives (Arntzen and Elstad, 2013; Carlsson, Gard and Brogårdh, 2017).

Faircloth et al. (2004) did not give any recommendations about patient needs but did point to readdressing the medical conceptualisation of the 'mind over matter' dichotomy which underpins stroke rehabilitation. They suggested that patients have an ongoing dialogue with their bodies in which they talk to their bodies and their bodies talk back, which had a holistic impact on the development of their new post-stroke self. Timothy, Graham and Levack (2016, p1572) furthered this notion suggesting that patients need to be "*experts of their own bodies*" through 'body listening' and awareness. This could be supported by health professionals who could facilitate patients connecting with their bodies at a cognitive and emotional level. Likewise, studies in which a 'whole-person' perspective were taken stressed the importance of considering rehabilitation in terms of the individual by focussing on personal and social factors as well as physical milestones (Doolittle, 1991; Kvigne and Kirkevold, 2003; Taule and Raheim, 2014).

2.6 Discussion

This scoping review looked at the stroke literature capturing first-person information about body perception changes post-stroke, to ascertain what changes patients described and how experiential accounts elucidated the phenomenon. It aimed to identify similarities and differences within these accounts; to determine whether participants described requiring intervention and highlighted areas for further research. The identified literature encompassed a broad spectrum of perceptual changes and its variety provided an insightful overview of post-stroke bodily changes. However, it did not provide the whole picture of the post-stroke experience. For example, no studies were identified which explored patient experiences of 'internal' body perception changes post-stroke, such as bladder problems; sexual dysfunction; changes to vision or hearing; dysphagia; dysarthria; or the experience of balance issues such as altered perception of

verticality or Pusher syndrome. Despite this, there were numerous similarities in patient accounts across the literature considering the diversity of research topics examined, suggesting that the themes identified were relevant to the patient experience of altered body perception.

2.6.1 Exploring first-person accounts to elucidate the phenomenon

Exploring commonalities across quantitative and qualitative findings helped to elucidate the phenomenon of altered body perception. Movement and sense of body ownership were identified as important factors which highlighted individual experience of perceptual changes. For example, difficulty getting the body to respond to intentional action and recognising body parts as their own were evident in accounts of sensory impairment of the upper arm (Carlsson, Gard and Brogårdh, 2017; Doyle, Bennett and Dudgeon, 2014); when exploring factors impacting balance and mobility in the foot and ankle (Gorst et al., 2016); in neglect (Klinke et al., 2015); anosognosia (Chatterjee and Mennemeier, 1996) and apraxia (Arntzen and Elstad, 2013). Findings which explored neglect and anosognosia, showed similarities as body ownership abnormalities of kinaesthetic and postural phantom sensations were articulated in both. Body ownership issues were present again in discussion of apraxia, as participants were unsure if they or others had completed actions (Arntzen and Elstad, 2013). These commonalities formed a bridge between studies focusing on these diverse conditions.

The relationship between body ownership and sense of control over bodily actions, has been explored experimentally through employing the rubber hand illusion. This task explores the extent to which a participant can integrate a rubber hand into their sense of body schema, elucidating the role of multimodal tactile, proprioceptive and visual inputs to creating a sense of body ownership (Botvinick and Cohen, 1998). Using this illusion, Kalckert and Ehrsson (2012) demonstrated that a sense of bodily movement and control was linked to a stronger sense of body ownership. In a similar rubber hand illusion task in stroke patients, Burin et al. (2015) found that the illusion was perceived more strongly in hemiplegic limbs (which had intact sensory and proprioceptive processes). They suggested that a lack of movement in hemiplegic limbs may inhibit body ownership due to progressive reduction in feedback. Further to this, Burin et al. (2017) again used the rubber hand task to test individuals' sense of agency that the body will respond as required, asking participants to rate their belief that observed movements occurred as a result of their intended action. They suggested that an individual's belief and sense of body ownership was related to whether the limb moved in the way the participant

expected it to and that observing movement is one way to increase belief that actions can be attributed to individual sense of agency. These experiments suggested that the relationship between: sense of body ownership; bodily movement and individual will to achieve intentional actions are related, but the relationship is complex and not yet fully understood.

Many accounts described the relationship between the body and self. They suggested that the dialogue between the two and the objectification of the post-stroke body, were key facets contributing to the perception of the body as unfamiliar and impaired body ownership. Disruption of intentional movement was hinged on the perception of the body as 'other'. As Kitzmüller, Häggerström and Asplund (2013) pointed out *"we do not have any consciousness of our bodies as intentional objects as we are our bodies"* (p26). As intentional movements can no longer be enacted, this impacts the embodied perception of the self as an acting and participatory agent in the world. The authors suggested that professional input needs to be directed towards bringing the shattered components of the body and self into alignment. Practically, this means regrouping the physical perceptions of limb dis-ownership, lost perception and bodily disorder, whilst also considering the holistic impact of other altered perceptions such as pain and fatigue which disrupt individuals' ability to engage in the world (Kitzmüller, Häggerström and Asplund, 2013).

Exploring patient accounts of altered body perceptions provided insight into the experience of perceptual change after stroke both within specific perceptual experiences and between them. Several authors demonstrated how patient accounts alongside clinical data such as neuropsychological testing and MRI, elucidated mechanisms of altered perceptions in conditions such as anosognosia (Baier and Karnath, 2008; Chatterjee and Mennemeier, 1996; Ellis and Small, 1994). For example, Chatterjee and Mennemeier (1996) demonstrated that by understanding more about how patients become aware of their limb weakness, that theories of psychological denial or cognitive impairment as reasons for anosognosia were unlikely. They offered an alternative explanation: that the experience was more likely linked to internally-generated intentions, which the patient could become aware of over time during self-initiated or

externally directed movements. Similarly, through analysing patients' survey responses of perception of limb ownership alongside MRI and clinical data, it was shown that sense of limb ownership and awareness of limb movement are likely to occur in the same neural structure (Baier and Karnath, 2008). As such, utilising first-person patient accounts of their bodily experiences post-stroke shed light on understanding of causative mechanisms for perceptual changes post-stroke.

Viewing patient accounts of a specific post-stroke issue from a purely qualitative angle was also insightful in terms of mapping the impact of altered perceptions and identifying factors for rehabilitation. Through capturing patient descriptions of altered perception of sensation, pain, muscle strength and tone, Gorst et al. (2016) explored common features of impaired balance and mobility, thereby demonstrating the link between these altered perceptions, their impact on motor recovery and the importance of considering sensory impairment during rehabilitation. This highlighted the advantage of perceiving these body perception issues collectively and how accessing patient experiences can facilitate this.

The holistic nature of participants' accounts of 'whole-body' experiences post-stroke provided yet another angle to view altered perceptions. Timothy, Graham and Levack (2016) captured the embodied experience of early-stage stroke survivors and highlighted aspects such as the body being perceived as strange, which was associated with sensory loss, lack of bodily control and a changed sense of body ownership. They drew attention to the sense of effort and concentration associated with the new, demanding body as factors which increased the sense of distance between the body and self. One advantage of capturing bodily experiences without focussing on a specific post-stroke condition, is that perceptual change is described in patient-terms and reflects embodied experience of altered perceptions. For example, Timothy, Graham and Levack (2016) described disturbed body ownership in terms of a psychological perception of a loss of freedom. They argued that participants displayed a more cohesive body-self when they regained a sense of physical movement and a psychological sense of freedom. This perspective neatly illuminated the interplay between the holistic factors which contribute to the complexity of post-stroke impairments.

Similarly, the experience of bodily perceptual changes was linked to the perception of the sense of self in other studies in which a holistic perspective was adopted. In Kitzmüller, Häggerström and Asplund (2013, p25) one participant described difficulty orientating the self to objects and personalised the experience by saying *“I don’t perceive as quickly as before, maybe I’m not the same person as before”*. Psychological factors were shown to influence altered perception in neglect, as instances in which ‘meaningful’ stimuli such as hearing or holding a baby could encourage participants to attend to the affected side (Klinke et al., 2015; Tham, Borrell and Gustavsson, 2000). These findings add to the construction of the sense of body ownership, as the body is perceived through movement, action and intentions, which are closely linked to psychological perceptions of the body.

Psychological, social and environmental factors contribute to a ‘whole’ physical and psychological self, so identifying contextual factors which can aid and motivate rehabilitation efforts could prove useful (Klinke et al., 2015). For example, Lucas and Vuilleumier (2008) showed that neglect patients could, in a visual search task, more easily identify emotionally salient faces (with happy or fearful expressions) and colourful faces compared to non-expressive or black and white faces, on their contralateral side. The benefit of using meaningful and individualised stimuli to improve attention to the body, self and environment may prove useful to rehabilitation, but requires further research.

2.6.2 What are the gaps in the literature?

Researching patient experiences such as hemiplegia, numbness (sensory impairment), anosognosia, mobility and balance impairments and neglect together brought up commonalities in terms of how patients experience altered body ownership (in both physical and psychosocial terms) post-stroke. Whilst research effectively described the changed relationship between the body and self, it was not clear whether abstracting the hemiplegic or unperceived body was a useful process for stroke survivors and whether it affected sense of body ownership and reintegration of the body into the body schema. Evaluating multiple perceptual changes in parallel drew attention to the many aspects affecting individuals’ sense of the body. It became evident that little is known about how

patients use physiological and psychological body objectification as a means to cope with their altered perceptions. These convoluted processes require further research. This could elaborate physiological mechanisms for how the individual experiences the bodily sense of altered perception; how they become aware of it; how they draw conscious attention to the body; how bodily objectification interacts with this and the dialogue between body and mind is developed; and how bodily awareness evolves over time. These processes appear at first glance a useful, non-linear process to relearn the body post-stroke. However, it is not known if they may be an inhibitor to reintegrating the post-stroke body into the body schema. As such further research is required to determine what techniques patients use to 'reanimate' the 'object' body and which parts of this process are the most effective to aid rehabilitation.

Only six studies reflected the experiences of altered body awareness over two years post stroke, as most accounts were focused on the early stages. This focus on early recovery was particularly evident in the accounts of anosognosia which captured experiences in the acute phase (Baier and Karnath, 2008; Chatterjee and Mennemeier, 1996; Ellis and Small, 1994). As anosognosia is believed to be a temporary condition, little has been reported on the long-term experiences of living with the condition (Cocchini, Beschin and Della Sala, 2002). In the early stages post-stroke, participants are less likely to have conducted independent activities to 'relearn' how to relate to their new post-stroke bodies and realise the extent of their altered perceptions, which may be key factors in the experience of anosognosia (Chatterjee and Mennemeier, 1996). Only Antoniello et al. (2010) considered body awareness issues in the longer-term and highlighted ongoing abnormalities in attributing limbs to others and 'losing' limbs when visual input was absent. Considering their similarities, it would be interesting to explore similarities between anosognosia, neglect and phantom perceptions in the chronic stage, once a patient has time to orientate to their new, stroke-impaired body and new surroundings. In line with this, no experiential literature about the awareness of movement (kinaesthesia) post-stroke was identified for inclusion in this review. Having more idea about how patients perceive body movement after stroke would also help elucidate issues highlighted in the body awareness literature.

None of the literature selected for this review explicitly asked patients what they wanted professional support or intervention for. Instead the authors surmised from their interpretation of the data, the clinical problems and solutions which would improve the issues described. Studies reflecting the use of quantitative methods and those with a case-series design did not attempt to reflect on clinical applicability of their findings as this was not their aim. Whilst there have been broad suggestions about how research should evolve to meet patient needs (Pollock et al., 2014), it is clear that each individual's stroke experience is unique and it would be useful to know more about how patients' needs match clinical priorities. For example, patients with sensory impairment highlighted their need for sensory reintegration, which they felt was not met due to a clinical focus on mobility and compensatory strategies (Connell, McMahon and Adams, 2014; Doyle, Bennett and Dudgeon, 2014). This clinical focus may limit the potential for motor recovery and sensory reintegration to be rehabilitated simultaneously which could perhaps achieve greater motor improvement (Bolognini, Russo and Edwards, 2016).

2.6.3 Limitations

2.6.3.1 Searches and terms

There were some practical limitations accruing literature for this review. Search functions on several databases were limited; some were not able to refine the search to just title and abstract, or English only criteria. As a result, it is likely that some extraneous studies were included in the studies returned. In line with the comprehensive nature of scoping reviews, it was felt that it was important to retain all titles and hand-search these to avoid missing any useful titles which may be excluded if the search was re-run with more limited terms. However, the volume of published literature included made the search process time-heavy and formed the basis of the decision to exclude the grey literature search – a potentially fruitful data source which may further elucidate the experience.

Due to the undefined and evolving nature of the term 'altered body perception' the search terms identified were as broad and comprehensive as possible, in line with

scoping review methodology (JBI, 2015). However, as the term ‘altered body perception’ evolved iteratively throughout the process of the scoping review and the qualitative study (Chapter 3), participants highlighted that the term should reflect both ‘internal and external’ experiences in which the body is perceived as altered. Whilst it is likely that the comprehensive search criteria would have picked up studies relating to these areas, it is possible that the search may have benefited from adding in more specific terms relating to less obvious body areas affected by stroke: for example, bladder, dizziness, swallow (dysphagia), vision and sexual function.

Several studies related to sleep disturbances such as Restless Leg Syndrome and sleep apnea appeared frequently in the search literature, however they were discounted as they did not contain first-person accounts of these experiences (Woo et al., 2017). These body experiences queried the importance of consciousness at the time of the perceived disturbance and whether reflection on the experience after the event or the impact of the altered perception on sleep is sufficient to warrant inclusion under term ‘altered body perception’. If conditions of perceptual loss are included such as neglect, then it seems intuitive that other body changes which have consequences on the bodily experience, for example in terms of lost sleep, should be included in this broad definition.

2.6.3.2 Exclusion criteria

The exclusion criteria were applied as broadly as possible to ensure the inclusion of as many studies as possible. Areas of ambiguity were resolved through discussion between co-researchers. This potentially impacts the replicability of this review. However, due to the evolving nature of the concept of ‘altered body perception’ this was perceived as an unavoidable part of the process. For example, Tham, Borrell and Gustavsson (2000) included application of an Occupational Therapy intervention which was not reflected on in the study. Technically, because this study reflected the experience of a 16-week Occupational Therapy intervention, it could have been excluded. However, following discussion, the study was included on the grounds that it reflected participant experience of neglect as opposed to their involvement with the intervention. Likewise, some studies such as those utilising structured survey response and visual analogue scales, provided

more limited detail on patient experience. These findings were useful to illuminate characteristics of experiences and their mechanisms, but they contained less volume of patient experience information than other methods such as patient interviews. However, it was considered beneficial to include this information to get a true scope of the literature, whilst exploring which data were most useful to describe experiences.

Care was taken to select studies which focused on altered body perceptions in stroke survivors. However, an unavoidable ambiguity was identified in Jönsson et al. (2006). In this study, 297 stroke survivors' pain experiences were described but of these 38-40% of participants experienced pain *prior* to their stroke. Problematically this meant it was difficult to solely relate experiences in this study to the specific experience of post-stroke pain. Despite this, the study was retained and explored in the review. This was a pragmatic decision, reflecting the likelihood that much stroke pain literature will share this issue. To omit this literature would not reflect the true scope of the patient experience of altered body perception after stroke. It highlighted a common issue faced by health professionals who must deal with altered perceptions resulting from multiple origins in clinical practice, whilst trying to apply research findings describing 'singular conditions' and ignoring the comorbidity of body changes.

Every effort was made to ensure a rigorous inclusion process based on studies containing first-person accounts of bodily perceptual changes after stroke. Yet it is acknowledged that due to the diversity of data presented and undefined nature of the term 'altered body perception', that this process entailed some subjective reasoning which may not be easily replicable. To mitigate for this the process is detailed as transparently as possible and the excluded studies are detailed in Appendix A.6.

2.6.4 Reflection on the method

The non-prescriptive and inclusive approach is a great strength of this method, which allows the literature from a wide variety of disciplines to be used to inductively influence concepts and ideas. Within this review this approach was advantageous, because at the outset it was unknown how the term 'altered body perception' would evolve during the

search and analysis phases. It facilitated a broad and thorough understanding of the literature and current 'lenses' through which this phenomenon is perceived. Through allowing the research question and selection criteria to evolve in response to the literature search it was possible to identify novel areas to focus on. However, it is acknowledged that a scoping review may be considered a less robust approach because a full critical appraisal of the literature is not undertaken (JBI, 2015). The strength of this approach is its inclusivity of all study designs. Nevertheless, it is a time-heavy approach, so should not be undertaken without appropriate resources.

2.6.4.1 Reflection on the inclusion of diverse methodologies

A range of study designs were incorporated into this review which were beneficial to elucidating different aspects of the phenomenon of 'altered body perception'. Whilst a scoping review does not need to critically appraise the quality of literature, it is useful to reflect on the scope of the different methodologies included when reflecting on the research question. Quantitative, survey methodology and case-series designs tended to focus on prevalence of conditions and identifying causative mechanisms of experience, whereas qualitative interview methods were more focused on capturing patient experiences and their descriptions of frequently experienced phenomenon to inform rehabilitation and interventions. Typical quantitative and qualitative methodological constraints applied to study designs and they were executed with varying quality. For example, in the majority of the pain literature survey response questionnaires were used, meaning the nature of the questions captured the breadth rather than depth of individual experiences (Bashir et al., 2017; Jönsson et al., 2006). In other conditions the direct style of questioning could be construed to elicit leading responses (Antoniello et al., 2010; Ellis and Small, 1994).

The strengths of using quantitative methods were that they often referred to the mechanisms which underpinned participant descriptions of experiences. For example, Baier and Karnath's (2008) exploration of anosognosia for hemiplegia, utilised structured questions alongside clinical examinations and MRI or CT scanning, using patient reference to limb ownership and awareness of limb movement to explore anatomical brain

structures. Whilst the studies adopting case-series or quantitative designs were insightful in terms of mechanisms, they also highlighted the lack of qualitative research about the experiences of pain and experiences of body awareness conditions such as phantom sensations or anosognosia post-stroke.

Qualitative methods were executed with varying success, often depending on the congruence in methodological choices or how clearly the methods were described. Faircloth et al. (2004; 2005) conducted a secondary analysis of large amounts of qualitative interview data, however the methodology was not clearly reported, making the findings difficult to review critically. Many study designs were simply described as qualitative, without any further description about which methodology was adopted (Blijlevens, Hocking and Paddy, 2009; Doyle, Bennett and Dudgeon, 2014; Taule and Raheim, 2014; Widar et al., 2002); or were incongruent and adopted a general 'qualitative' method and a style of analysis intended for a different method such as interpretive phenomenological analysis or grounded theory (Connell, McMahon and Adams, 2014; Kirkevold et al., 2012). Yet many studies were reported transparently, were rigorously conducted and of good quality (Arntzen and Elstad, 2013; Carlsson, Gard and Brogårdh, 2017; Doolittle, 1991; Ellis-Hill, Payne and Ward, 2000; Gorst et al., 2016; Kitzmüller, Häggerström and Asplund, 2013; Timothy, Graham and Levack, 2016).

At times, research questions restricted by a focus on a very specific perceptual change felt fragmented in relation to the term 'altered body perception', as it was clear participants would have been experiencing a broader range of perceptual issues than those being examined. For example, in Widar et al. (2002) and Widar, Ek and Ahlström (2004) studies about pain experience, participants were described as experiencing hemiplegia, yet the focus on pain meant data on the wider experience of having paresis in affected limbs was not examined. Research questions with a more broad focus on a 'condition' such as on sensory impairment or anosognosia, or with a focus on a specific bodily area such as the upper limb, were able to reflect in more depth about the experience of the 'altered body perception' discussed. However, these findings rarely reflected on the comorbidity of post-stroke experiences. On the other hand, research questions which focused on the broad, holistic nature of the altered body were useful in

elucidating an embodied angle to the experience but they were not able to provide the depth of the bodily experience of altered perception evident in the previous studies. As such looking at these studies together provided a new insight as they illuminated different aspects of the same phenomenon.

2.7 Conclusion

This review has demonstrated commonalities between first-person accounts of diverse experiences of altered body perception. It has demonstrated the value of viewing these conditions from the patient-perspective to provide focus on the body perception changes experienced, as opposed to only discussing it terms of functional or psychosocial impact. This was reflected as many authors highlighted the need for a more integrated and holistic approach to rehabilitation. These findings provided evidence for the development of an umbrella concept of 'altered body perception' in the stroke literature which could enable patients and clinicians to talk about and treat body changes in collective and mutually understood terms, which keep bodily perceptual changes at their core. Patient-clinician communication was highlighted as problematic when considering altered body perceptions, as patients were at times unable to express their body changes to professionals. This emphasised the lack of language to reflect body changes and the contentious experience of relating bizarre and unusual experiences. It was also evident that very little was known about patients' priorities in terms of the treatment of altered body perception and further research is therefore vital to ensure clinical and patient goals and communication are aligned.

A key commonality between conditions was the interaction between intentional action, movement and body ownership. In this, the body which did not move or respond as desired, was closely tied to individuals' intention to act. In parallel, the body which became perceived as strange, was not perceived as part of the bodily or psychological self and was distanced and objectified. The process of creating a dialogue between the body and mind to achieve action made the body conscious, furthering the objectification and dis-ownership of the body. The lack of body ownership at a physiological level interacted

with the sense of psychological distance from the body, which manifested theoretically, in a worsened sense of 'self'. This highlighted an important gap in the literature: that little is known about how patients reflect on these complex changes between the physical and psychological self.

Chapter 3: Methodology: A phenomenological study exploring experiences of altered body perception after stroke

3.1 Chapter introduction

The introduction and scoping review chapters highlighted that it is common to experience changes to how the body is perceived after stroke. However, the literature around what altered body perceptions feel like to the patient, is limited. This chapter presents the methodology of a study to explore the patient experience of altered body perceptions after stroke.

3.2 Aims and objectives

The aims of this qualitative were to understand the experience of altered body perception post-stroke and how this affects patient experiences of comfort by:

- Exploring patients' descriptions of the discomfort associated with experiences of altered body perception; viewing discomfort from a holistic perspective
- Exploring whether participants feel altered body perception or associated discomfort is a problem that would benefit from additional recognition or support. Ascertain if they have had their altered body perception clinically assessed; accessed any clinical support or found a beneficial intervention themselves
- Collate and integrate these findings with that of the literature review to inform the next phase of work

3.3 Epistemological perspective

This is a qualitative phenomenological study of the experiences of how the body feels after stroke and how these experiences affect comfort. Phenomenology is uniquely placed to facilitate understanding about lived experience and as such, is well-suited to address the research questions and objectives of this study. Phenomenology seeks to examine individuals' conscious, perceptual and embodied experiences, to uncover the essence of the phenomenon in question (Starks and Trinidad, 2007; Creswell, 2006). It is through accessing rich and complex descriptions of the phenomenon being explored that it can capture embodied and experiential meanings from participants (Finlay, 2009).

The value of studying human conscious experience is widely acknowledged. However, critics argue that accessing this knowledge through the 'lens' of first-person, subjective experience may make classical phenomenology - based on prominent philosophical approaches by Husserl (1859-1938), Heidegger (1889-1976) or Merleau-Ponty (1908-1961) - less rigorous than 'objective' scientific methods rooted in the external world (Dennett, 2003; Zahavi, 2007). However, as highlighted by Gallagher and Zahavi (2008), when researching the human mind, it is impossible to omit data which captures the embodied experience of consciousness, which is inherently subjective. There is no other way to access the lived experience of the human body other than through participant accounts. Phenomenology embraces the tension between 'objective' science and constructed and subjective knowledge. The challenge is to conduct good quality phenomenological studies that can describe experiences with sufficient detail, transparency and reflection to pull apart the strands of subjectivity which inevitably permeate the method.

3.3.1 An interpretive phenomenological approach

Analysis for this study was inspired by an interpretive phenomenological approach which looks at individual experiences in depth, then explores commonalities between cases (Smith and Osborn, 1999). These were presented as shared themes. Interpretive phenomenology is based on the work of Martin Heidegger. This approach branched from that of his mentor

and predecessor Edmund Husserl who proposed a more descriptive phenomenological methodology based on his pursuit to describe 'what we know'. For Husserl, collective phenomenological descriptions represented an objective reality. This reality could be recounted more objectively if the influence of the researcher was bracketed out and removed (Reiners, 2012). Based in the hermeneutic tradition, Heidegger however, sought to describe and interpret the experience of 'being'. He was more interested in "*interpreting and describing human experience*" (Reiners, 2012, p2). He rejected the concept that it was possible to generate objectivity through bracketing as he believed all descriptions are observed and recounted through the interpretive 'lens' of the observer. He argued that we each have a unique way of understanding ourselves and how we relate to the world, of which we may not be aware. Interpretation was therefore vital as it could illuminate aspects about a phenomenon of which the participant may be unaware and therefore unable to describe. Heidegger's philosophical standpoint sees the mind and body as inextricably linked and situated in its environmental context. This construct is congruent with embodiment theory.

An interpretive rather than descriptive phenomenological approach was chosen for this study. It involves looking beyond participants' conscious descriptions of living in an altered body, through interpreting their language, context and 'ways of being' to explore the experiences of which they may not be consciously aware. The embodied experience of living with altered body perceptions after stroke is a complex phenomenon, mired by competing demands made of the individual's consciousness. The individual may feel altered physical sensations such as pain, the feeling of a changed body shape, or an unresponsive body. Altered sensations may be experienced in multiple body parts simultaneously and may change daily. These body changes may cause a complex range of emotions and impact the ability to self-care, complete daily activities or leave the house. Psychologically, individuals may be focused on different stages of their stroke journey: the trauma of the stroke, their current problems or how they will manage their future. For a stroke survivor, many of these issues may be dealt with subconsciously as they manage their day-to-day lives. To fully convey the complexity of their lived experience through description may be impossible. Additionally, there may not be the language or the shared understanding to describe their perceptions (Connell, McMahon and Adams, 2014). Interpretation is therefore a useful tool

to get a further glimpse into the lived world of the stroke survivor. The skill of the researcher can highlight meanings that the individual may be unable to reflect on, yet which may be conveyed through their context or language.

My position on subjectivity falls in line with Heidegger, in that I believe it is impossible to remove the researcher from the scientific method. The researcher's perspective is inextricably entangled with that of the research process, yet many of these issues can be mitigated by reflecting on one's role and 'positionality' as a researcher. Criticisms of the method are that researchers' interpretation of accounts may lead toward inaccurate representation of data (Dennett, 2003). Yet interpretation inaccuracies can be mitigated through transparent reporting using quotes anchored in the data. Others highlight that small sample sizes mean findings are not generalisable, yet small sample sizes can yield more in-depth analysis of the phenomenon (Smith, Flowers and Larkin, 2009). Despite these limitations, I feel that there is an important place for the phenomenological method as there is so much to be gained from really listening to and interpreting participant experiences of a complex phenomenon. It is a creative method which generates in-depth and insightful data from a truly holistic perspective.

3.3.2 Merleau-Ponty and embodiment

Whilst Heidegger wrote about the experience of being, he did not focus extensively on the experience of embodiment. This became the focus of his successor Merleau-Ponty (Merleau-Ponty, 2001), whose theory will be used to guide this study. Merleau-Ponty (2001) argued that the body was the primary means through which we perceive and understand the world. He looked beyond the division between subjectivity (consciousness) and objectivity (the 'object' or real world) and suggested the experience of the lived body blurred these boundaries. For him, the body was something between subject and object, in that it could be both perceived and observed (Carmen, 1999). He suggested that there is no dualist distinction between body and mind and proposed "*a third category beyond the merely physiological and the psychological*" (Gallagher and Zahavi, 2008), p135). For example, suggesting that "*thought and sensation as such occur only against a background of perceptual activity that we always already understand in bodily terms, by engaging in it*"

(Carmen, 1999), p206). Through this phenomenological embodied perspective, Merleau-Ponty (2001) was able to explore more about consciousness, physiology and psychology. His reflections on the experience of consciousness as perceived through the body, delivered rich insights into bodily mechanisms and means of perception.

For Merleau-Ponty (2001), the self, the body and the world could only be understood through embodied experience and were inextricably linked concepts. The experience of perception was grounded in a lived world; it was contextual and perceived through the body. *“I am conscious of the world through the medium of my body”* (Merleau-Ponty, 2001, p82). Merleau-Ponty (2001) considered the concept of the ‘lifeworld’ as intersubjective and emphasised that individuals experience the world, its meaning and others through the lived body. Exploring the experience of recovery in stroke survivors with neglect, Tham, Borrell and Gustavsson (2000), highlighted the importance of the ‘lifeworld’ in phenomenology, noting how it is through critical examination of the interaction between the body and the subjective ‘lifeworld’ that we seek to describe the essence of phenomena. Though the phenomenologist will never be able to tangibly understand the experience of the ‘other’, understanding their relationship with their ‘lifeworld’ and studying them within their own context provides another piece of the puzzle (Clancy, 2013).

Merleau-Ponty (2001) also redefined the concept of ‘intentionality’ from that of his predecessors. He argued that the body has a physiological ‘need’ for mobility which often operates outside of conscious awareness.

“In the normal person every event related to movement or sense of touch causes consciousness to put up a host of intentions which run from the body as the centre of a potential action either towards the body itself or towards the object” (Merleau-Ponty, 2001, p125).

Mobility and our response to the world are embodied. He argued that without the mobility of the body, one could not understand the world. Leder (1990) concurred, articulating how the body though at times absent from consciousness, is inextricably linked to movement to

enable us to perceive both our own bodies and the world around us stating: “*Perception is itself a motor activity*” (Leder, 1990, p17).

Concepts such as the physiological nature of embodied perception, the ‘lifeworld’ and ‘intentionality’ are relevant concepts within this study (Merleau-Ponty, 2001). In stroke, the body as a means for perceiving, engaging with and understanding the world is considerably altered. The body is no longer a dynamic medium to interact with the world, as the body’s ‘need’ for mobility has been impacted and it has become uncooperative and difficult to manage. The body may be forgotten when absent, is forced into conscious awareness through altered perceptions, sensations and mobility. Through considering the body’s physiology as a unit of perception for both physical perception and the experience of being and self, one can move beyond the reductionist conception of stroke as being predominantly about functional loss. Similarly, through looking at embodied perception as the means with which we engage with others and the world, the impact of the stroke-related loss of this perception on an individual’s ‘lifeworld’ gathers greater significance. It encourages the researcher to perceive the physiological consequence of stroke in a broader and more holistic light.

Merleau-Ponty (2001) grounded his reflections in real perceptual experiences of the lived body, using patient descriptions of anosognosia, allochiria and apraxia to develop his theories, thereby making his reflections directly applicable to the experience of life after stroke. As such, more recent researchers continue to draw on the relevance of Merleau-Ponty’s (2001) concepts to explore the experience of stroke and develop our understanding (Normann, Fikke and Øberg, 2015; Arntzen and Elstad, 2013; Arntzen, Hamran and Borg, 2015; Tham, Borell and Gustavsson, 2000). It is clear Merleau-Ponty’s (2001) theories facilitate a truly embodied phenomenological perspective, they capture ‘lifeworld’ context and are applicable to an interpretive approach. They are clinically orientated and are still used in person-centred stroke research today (Arntzen and Elstad, 2013; Klinke et al., 2015).

3.4 Methods

3.4.1 Ethics

Ethical approval was granted by the University of the West of England Research Ethics Committee on 21st March 2016 (REF No: HAS/16/03/114) and an amendment to the original ethics form was approved on 13th December 2016 (Appendix B.1).

3.5 Selecting the sample

Smith and Osborn (2007) highlight the ambiguity inherent in determining a number of cases to explore in phenomenological studies and suggest that cases must remain of a manageable size to facilitate in-depth analysis and to maintain the richness of individual accounts. This study aimed to recruit 15 to 20 participants to shine a light on the phenomenon of altered body perception and comfort, whilst providing a detailed, rich and holistic account of experience. Congruent with this methodology, a purposive sampling strategy was utilised to identify participants relevant to the phenomenon being studied (Smith, Flowers and Larkin, 2009). The advantage of this approach was that it provided access to the most information rich cases for exploration (Emmel, 2013).

3.5.1 Selection criteria

Included participants had to have experienced cerebral ischemic or haemorrhagic stroke and be experiencing motor, sensory, proprioceptive or attentional issues as a result. Research shows that these types of changes are likely to produce changes to how individuals perceive and experience their bodies after stroke (Doyle, Bennett and Dudgeon, 2014; Gandevia, 1982; Tham, Borell and Gustavsson, 2000). The selection criteria were guided by a sample frame which is detailed in Section 3.5.1.1.

Only participants who were at least six-months post-stroke were included, as stroke symptoms are likely to have stabilised somewhat after this point (Jørgensen et al., 1995).

Through interviewing those with stable stroke symptoms, it was hoped to capture the residual, longer-term experiences people live with after stroke. This time frame also gave individuals a gap between the stroke event and participating in interview, wherein they could reflect on the changes they had experienced and consider what issues were impacting comfort in their day-to-day lives. Included participants were over 18 years and were not limited by demographic characteristics.

Participants who had experienced Transient Ischaemic Attack, spinal stroke, any condition affecting their neurological or nervous system other than stroke, or any other condition which caused altered body perceptions, were excluded. This allowed descriptions of altered body perceptions to be attributable primarily to stroke. In practice this meant that individuals experiencing conditions such as fibromyalgia, Complex Regional Pain Syndrome (not related to stroke), diabetic neuropathy, or rheumatoid arthritis amongst other conditions, were excluded. Less 'significant' conditions such as osteoarthritis, lower back pain or localised injury, which individuals could distinguish as being non-stroke related, were subject to discussion amongst the research team and considered for inclusion. Due to stroke occurring with increasing age, it was unrealistic to expect participants to only experience stroke-related changes in their experience of their bodies. The management of this issue is discussed further within Chapter 4, Section 4.3.5.1.

Participants with significant communication problems which severely compromised their verbal communication, were excluded. This was due to the exploratory aim of this study, which would have been limited by including participants unable to take part in verbal interview. However, to aid the inclusion of those with mild speech problems in stroke research, individuals with aphasia who were able to communicate verbally were included and time was taken to ensure their communication needs were met. Participants with significant cognitive impairment such as problems with memory or comprehension which affected their ability to make decisions, were excluded from the study. This was because it was considered unethical to work with those unable to give full informed consent.

3.5.1.1 Sample frame

Purposive sampling in this study was guided by a sample frame, to ensure a variety of perspectives were collated. Key characteristics included were age, gender, ethnicity, time since stroke onset and ‘level’ of independence which was adapted from the Modified Rankin Scale (Rankin, 1957; see Table 4). This approach facilitated in-depth exploration of the phenomenon, whilst also looking at distinctions which may vary the experience across cases, thereby capturing the complexity of events which make up the experience of altered body perception after stroke (Emmel, 2013). Through diversifying ‘lifeworld’ factors such as demography or experience of stroke recovery, it was possible to explore in more detail differences between accounts. However, it is worth noting that within IPA there is ambiguity around being able to achieve in-depth analysis, whilst exploring broader sample sizes, using more diverse groups. Smith, Flowers and Larkin (2009) discuss this tension and suggest that sample diversity should be governed by the specificity of the phenomenon of interest and the time-scale and depth of the study. Therefore, potential concerns about being able to analyse the data in sufficient depth were ameliorated by the specificity of the focus on altered body perception and comfort, coupled with the broad 18-month timescale of this study.

Table 4. Sample frame characteristics

Characteristic	Group
Age	<ul style="list-style-type: none"> • 18-44 • 45-74 • 75+
Gender	<ul style="list-style-type: none"> • Male • Female
Ethnicity	<ul style="list-style-type: none"> • White • Mixed / multiple ethnic groups • Asian / Asian British • Black / African / Caribbean / Black British • Other ethnic groups • Prefer not to say
Time since stroke	<ul style="list-style-type: none"> • 6 months - 2years • 2 years +
‘Level’ of independence, adapted from Modified Rankin Scale (Rankin, 1957)	<ul style="list-style-type: none"> • Level 1: No disability to slight disability. Able to look after their own affairs without assistance, may be unable to carry out all previous activities. • Level 2: Moderate to severe disability. Requires help in some or many activities. May or may not be able to walk independently.

Demographic variables were a useful means to diversify perspective of life after stroke. Age was included, because 75% of strokes occur in people over 65 years and these individuals are likely to experience poorer functional recovery than younger survivors (Kotila et al., 1984; Royal College of Physicians, 2016). Whereas younger stroke survivors may experience stigma as their life experiences diverge from that of their peers (Stone, 2005). Gender was included, as women are likely to experience higher levels of disability post-stroke and worsened mental health (Roquer, Rodríguez Campello and Gomis, 2003; Mazure et al., 2014). Ethnicity was included, as being from a minority ethnicity has been associated with poorer clinical outcomes and linked to alternative perceptions of illness and disability when compared to a Westernised medical model of health (Ellis et al., 2014; Stewart et al., 1999; Sanderson, Calnan and Kumar, 2015).

Time since stroke onset was an important variable to include, as ongoing time post-stroke is associated with reducing functional and motor outcomes, increased psychological distress and reduced health related quality of life (HRQoL) (Godwin et al., 2013; Huang et al., 2014; Jørgensen et al., 1995; Meyer et al., 2015). Finally, 'level' of independence was included as dependency in activities-of-daily-living and ongoing motor dysfunction is associated with reduced quality of life three-years after stroke (Choi-Kwon et al., 2006). This category was adapted from the Modified Rankin Scale (Rankin, 1957; Van Swieten et al., 1988). This scale assesses functional outcome after stroke and was reduced from six-points into the two 'levels' of independence in Table 4. Individuals were ascribed to these categories at the discretion of the author. For example, if participants discussed needing carer support, they were allocated to 'Level 2' as they were unable to conduct activities independently.

3.6 Recruitment strategy

3.6.1 Recruitment procedure

Participants were selected iteratively to meet the requirements of the sample frame between March and October 2016. Participants were predominantly recruited from a community stroke charity in the South West of the UK. Two stroke cafés, two stroke physiotherapy groups and a stroke activity group, attended by approximately 86 stroke

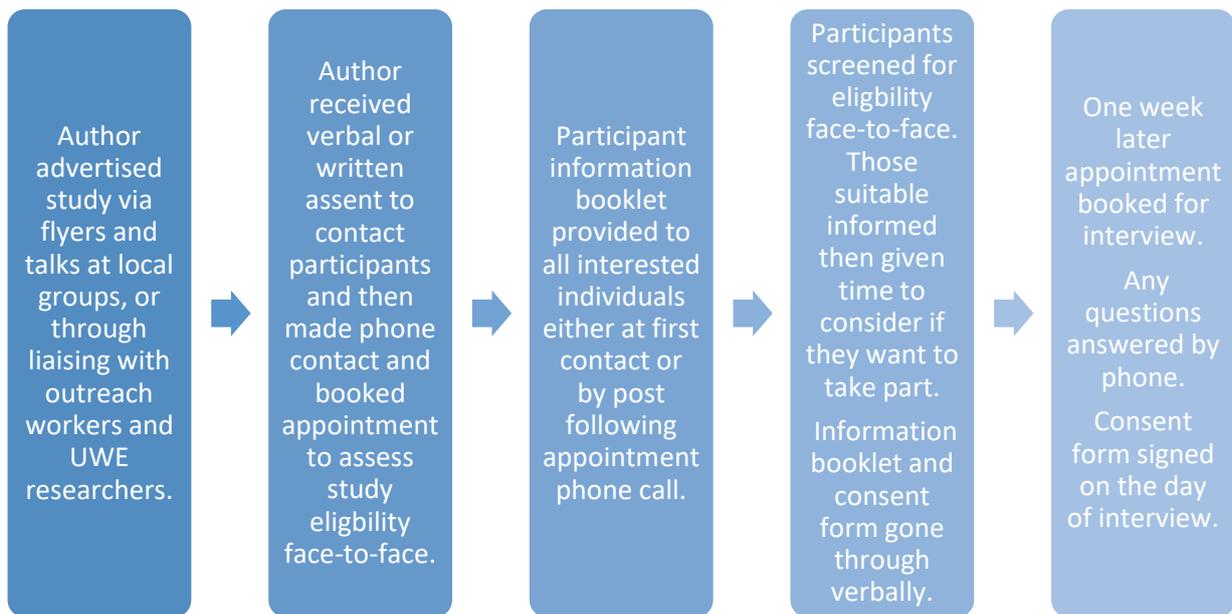
survivors and carers, were approached. Charity outreach workers who conducted home visits with stroke survivors, were contacted and given advice on how to share this study's details and gain permission to contact those interested. Three stroke researchers at the University of the West of England identified and approached stroke survivors working on other research projects and gained assent for them to be contacted. Lastly, a local charity working with Black, Asian and Minority Ethnic (BAME) people was approached to encourage participation of those from a wider cultural demographic (Table 5).

Table 5. Recruitment locations

Source of recruitment	Number of participants
Charity physiotherapy group	6
Stroke Cafés	6
Stroke activity group	1
Outreach services referral	1
BAME charity	1
Other researchers	1

The study was promoted via a flyer (Appendix B.3) and a participant information booklet (Appendix B.4; UWE¹, 2015). Resources were adapted to be inclusive of those experiencing aphasia, reading, visual or cognitive difficulties (NIHR CRN, 2014; Palmer and Patterson, 2011; Brady, Fredrick and Williams, 2012). The information sharing process leading from gaining participants' assent-to-contact to providing consent to take part in interview is outlined below (Figure 1). Further detail about the assent form and process is included in Appendix B.5. The consent form was based on the UK Data Archive (2017) template and is included along with the consent process in Appendix B.6. Information was presented as transparently as possible to ensure understanding from the participant. This ensured valid consent was obtained and participation was autonomous and un-coerced (Comstock, 2013; Corrigan et al. 2009).

Figure 1. Information sharing process leading to consent

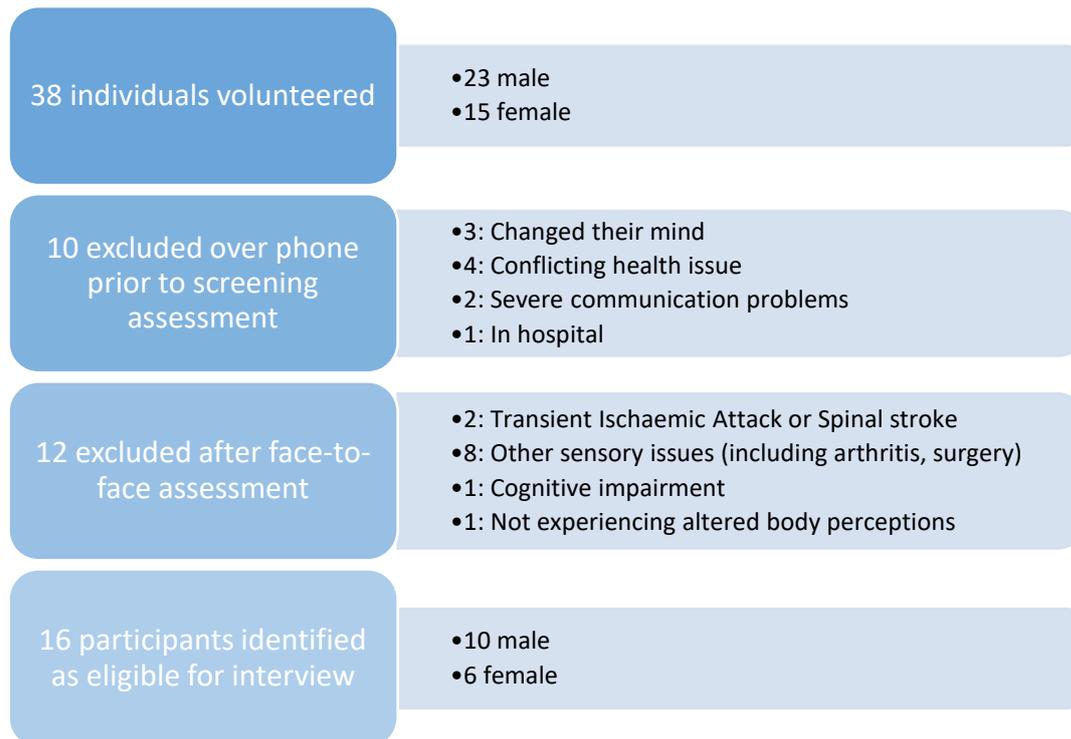


3.6.2 Eligibility screening process

Overall, 38 participants volunteered to take part in the study. The selection process is figuratively outlined below (Figure 2). Sixteen participants were eligible to take part which was a sufficient number to explore the phenomenon of interest in sufficient depth. Participant characteristics, medical history and description of altered body perceptions were captured through participant perspective and not validated by medical reports – an approach congruent with the phenomenological method.

The eligibility screening process was conducted as an informal face-to-face conversation usually in individuals’ homes and was guided by the eligibility questions (Appendix B.2). The PPI group emphasised that volunteers should not perceive ineligibility to take part as another experience of failure – a feeling they stated was common in stroke rehabilitation. Care and sensitivity were used when describing the reasons to participants who were not suitable or not required to take part, to ensure they didn’t personalise any of these issues. If an individual raised an issue which made them ineligible for the study when booking the screening appointment, they were gently informed at this point to avoid wasting their time.

Figure 2. Eligibility screening of volunteers for interview

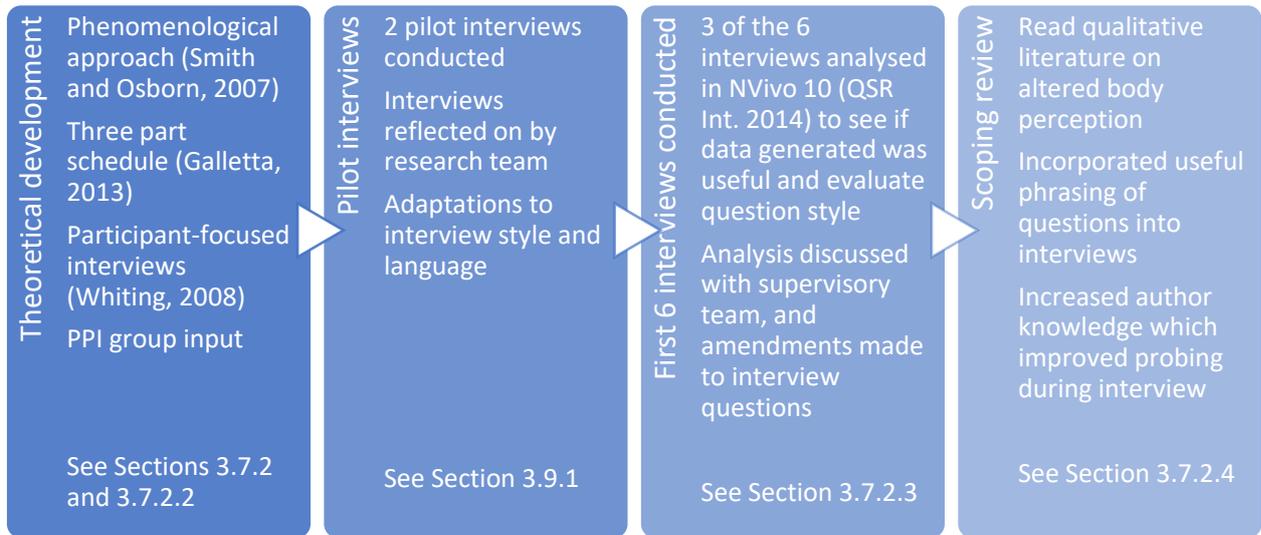


3.7 Data collection

3.7.1 Developing the interview schedule

The interview schedule was developed iteratively through a multi-faceted process summarised in Figure 3 and outlined in more detail in the following sections. This approach is congruent with a phenomenological approach which suggests that the question list should not be prescriptive and should be responsive to the needs of the participant (Smith and Osborn, 2007).

Figure 3. Factors influencing development of interview schedule



To ensure the interview schedule captured the required information and was sensitive to the needs of the participant, the author conducted two pilot interviews with members of the PPI group. Participant feedback of the interview process alongside the audio-recorded interviews were reflected on by the research team. The use of questions and interview technique were evaluated and amended. It was noted that a more muted and naïve response from the interviewer facilitated a better flow of information from the participant. The interview schedule was amended from a compartmentalised focus on individual body changes and the physical, emotional, social impact of each change, to a more fluid and flexible approach. This was because participants tended to talk about body and psychosocial issues in an interconnected way, rather than in terms of cause and impact.

3.7.2 The interview schedule

3.7.2.1 Language and flow

The language and flow of the interview was informed by an interpretive phenomenological approach which advises using a flexible and semi-structured interview schedule to facilitate a conversation between the researcher and participant (Smith and Osborn, 2007), to facilitate participant-driven data (Milne and Oberle, 2005). This allows the researcher to

develop rapport, to be responsive to the participant's previous answer and probe areas of interest. In this approach the researcher tries to enter the 'lifeworld' of the participant and the conversation is often guided by the participant.

Nunokoosing (2005) highlight that there is no interview which will get the 'true' story from a participant about their experience, as stories vary with retelling and as individuals reinterpret them. The interview is a space to collect stories from participants which may lead to new avenues of thought. Participants may have versions of stories they are used to telling and have aspects they want to remain private and it is the skill of a good interviewer to build a relationship to allow them to tell their story in an insightful and reflective way. Therefore, interview data is collaboratively co-constructed. A phenomenological approach highlights the need for data to be participant driven and reflects on the role of the researcher within this process.

Congruent with Smith and Osborn (2007) open-questions were utilised at the beginning of the interview and to introduce new topics which were then 'funnelled' into more specific areas through probing. This enabled participants to direct and explore the content of their answers. As topics were drawn to a close the researcher gave a brief summary of the participant's response to ensure common meaning was understood and there were no further areas that needed clarification (McConnell-Henry, Chapman and Francis, 2011). Specific clarification was sought when participants discussed ambiguous terms such as discomfort, pain or loss of sensation to ensure they described their experience fully and a common meaning was understood.

During interview minimal interruptions were used. Engagement and rapport were maintained through positive body language, eye contact and brief verbal engagement such as 'mmm' and 'uh-huh'. In qualitative research the interviewer must become comfortable with silence, so as not to disrupt and attempt to structure the participant's narrative (Milne and Oberle, 2005). Participants' own language was reflected back to them, to demonstrate engagement with their story, strengthen rapport and ensure common understanding. The language used in the interview was concise and simple to enable participants with any

comprehension difficulties to understand the meaning. The language and nature of the questions were discussed and agreed by the PPI group prior to interview.

The research team discussed the terminology used to describe altered body perceptions to ensure that the terms had common meaning, were easily understood and not too medicalised. For example, the term 'sensation' may be interpreted as referring to a skin surface changes and may not be interpreted as referring to a sense that a body part doesn't exist; the term 'discomfort' may not encapsulate a sensation of pain; the term 'feelings' may encourage a description of emotions rather than body changes. Due to this potential miscommunication, participants were asked broadly about their body changes after stroke and participants' own terms were used thereafter to describe changes.

3.7.2.2 Interview structure

The interview was broadly split into three parts (Galletta, 2013) and tailored to a participant focused interview framework (Whiting, 2008). The initial segment was used to introduce the interview, build rapport, reduce apprehension and understand broad issues about the participant's context and other aspects of their stroke. Contextualising questions provided description of the participants' 'lifeworld' (Bevan, 2014). This section gave context and meaning to participants' accounts of changes to bodily awareness, somatosensory experience and the impact on their holistic experience of comfort (Appendix B.7). The language in this section focused on the present to reduce historic accounts of stroke experiences and concentrate on participants' current needs. For example, the question "*How have you felt since your stroke*" evolved to "*How has your stroke affected you*", which was influenced by the phrasing of questions in the scoping review literature (Doolittle, 1991). The 'less-affected' side of the body was discussed, to give participants a benchmark when reflecting in later discussion about the 'more affected' side.

The middle segment of the interview involved more focused questions about the experiences of altered body perceptions, how comfortable these were, health professional input and engagement with treatments and rehabilitation (Sections 2 to 5, Appendix B.7). Complex embodied experiences were disentangled. These in-depth questions were saved

until the middle section, to allow time to build trust and rapport meaning participants were less likely to feel vulnerable and give fuller answers (Galletta, 2013; Bevan, 2014).

Phrasing of questions differed between interviews to encourage comprehension and engagement from the participant. For example, some participants were unable to comprehend the question asking: *“What does your body look like in your ‘mind’s eye’?”* and this was often rephrased as: *“If you were to imagine a picture of your body, not through what it looks like but what it feels like, what would that picture look like?”* Care was taken when phrasing questions about the impact of altered perceptions on sensitive topics such as intimate relationships or community and culture. Cues were taken from the participant about how to address these questions appropriately.

The final interview section asked about overall impact of the body changes and which changes participants would like treated (Section 6, Appendix B.7). This section was designed to gauge which sensations were most troubling to the participant and which they would most like intervention for. This was to give an indication as to the severity of their symptoms and to see whether there was similarity between the issues they wanted treated which might indicate a direction for clinical interventions. This section was designed to move focus from the past and present, towards the future. This was intended to give participants a sense that the interview was drawing to a close and enable them to move on from any difficult or challenging narratives they had been discussing, reflect on their situation and clarify any previous responses.

3.7.2.3 Initial phase of six interviews

After the first six interviews the quality of the data emerging from the interviews alongside the reflexive notes were analysed in NVivo 10 (QSR International, 2014), to determine whether the questions were generating data relevant to the research aims and objectives and ensure participants were understanding the concepts being discussed. This process confirmed that the interview questions were appropriate and generating useful information. It highlighted the advantage of clarifying specific body changes – for example by asking *“are you experiencing any pain”*. The research team discussed whether it was leading to ask

about certain sensations directly and resolved that if the question was about a common and broadly understood perception such as pain, then it was legitimate to ask about this directly and it would not be construed as a leading question. As a result, in the latter ten interviews changes such as pain and temperature change were asked about explicitly, to ensure a common understanding.

3.7.2.4 *The scoping review*

The scoping review was conducted concurrently. The identified literature informed the interview process by improving the interviewer's knowledge on the subject of altered body perceptions and identifying similar interview schedules to learn from. This enabled more focused probing around specific issues. For example, a broader understanding of post-stroke pain (Widar, Ek and Ahlström, 2004) enabled the interviewer to probe in more detail when participants described headaches – detail which may not have had as much focus previously as it is a less commonly discussed stroke symptom.

3.7.3 *Interview setting*

Smith and Osborn (2007) highlight the importance of interviewing participants within an environment that feels familiar, in which they feel comfortable. Within this study all participants chose to conduct the interview within their own home. This was beneficial as it enabled the interviewer to see and step into a component of the participant's 'lifeworld'. Often this was reflected in the interview content, as participants could refer directly to the objects and areas in their homes wherein they experienced their altered body. Participants also chose the time of the interview. Many chose morning interviews to mitigate for any stroke symptoms they may be experiencing, such as fatigue which often worsened during the day. It was made clear to participants that they could have breaks and were under no obligation to answer any questions they didn't feel comfortable with.

Interviews lasted from 33 to 106 minutes and the mean interview length was 75 minutes. Two participants appeared to tire during the interview process and symptoms of their

aphasia increased. They were offered a break and the interviews were shortened as a result. Two participants outlined their need for clear and simple questioning to enable them to understand and respond to the questions. Three participants had to end the interview at a certain time due to other commitments.

3.8 Data Analysis

3.8.1 Participants

Sixteen participants were eligible to take part in the study. The frequency of participant characteristics related to the sample frame are detailed below in Table 6. The time since stroke-onset ranged from eight months to 22 years. The average was five years since stroke onset, though half the participants were less than two years since stroke onset. There were six female and 10 male participants. Ages ranged from 39 to 79 years, the average age was 59 years. Four participants were under 55 years; 11 participants were between 55 and 75 years and one participant was over 75 years. Fifteen participants identified as White British and spoke English and one participant was Indian and did not speak English. Fourteen participants' independence was classified by the interviewer as 'Level 1'. This meant they were 'slightly' disabled and experienced varying levels of hemiplegia and difficulty walking, however they were able to 'get by' independently. Two participants were classified as 'Level 2', meaning they were 'moderately' disabled, required assistance in many activities and were unable to get by independently. One participant used a wheelchair. Five participants experienced mild aphasia and exhibited some slurring of speech or word finding difficulty, however they were all able to express themselves verbally. The participant who did not speak English was interviewed via an interpreter.

Table 6. Summary of frequencies of participant characteristics within sample frame criterion

Age and Gender	Ethnicity	Time since stroke: 6 months -2 years	Time since stroke: 2 years+	Independence: level 1*	Independence: level 2*	Total participants: 16
Male 18-55	1 x WB ^o	1	--	1	--	1
Female 18-55	2 x WB ^o 1 x AI ^o	1	2	2	1	3
Male 55-75	8 x WB ^o	5	3	8	--	8
Female 55-75	3 x WB ^o	--	3	3	--	3
Male 75+	1 x WB ^o	1	--	--	1	1
Female 75+	--	--	--	--	--	0

WB^o: White British; AI^o: Asian/ Indian

*Independence - Level 1: No disability to slight disability. Able to look after their own affairs without assistance, may be unable to carry out all previous activities. Level 2: Moderate to severe disability. Requires help in some or many activities. May or may not be able to walk independently

Participants represented each diversifying factor of the sample frame. The sample frame ensured diverse demographic characteristics were represented, increasing the theoretical transferability of the findings than would be possible in a more demographically similar group (Pringle et al., 2011). Within this sample, the ethnicity of participants was representative of the regional population (Office of National Statistics, 2011). Gender was representative of the worldwide picture of stroke prevalence (Appelros, Stegmayr and Terént, 2009). However, the sample had a lower age range and level of dependency after stroke than represented nationally or worldwide (Stroke Association, 2017). The time since stroke onset was split evenly between the two groups which categorised individuals as less than, or more than two years post-stroke (for further discussion see Appendix B.8).

Table 7. Individual participant characteristics

Participant Number and pseudonym	Gender	Age	Ethnicity*	Time since onset	Independence Level ^o : 1 or 2	Side of body affected most	Context
1: Toby	Male	46	WB	19 months	1	Left	Lives with partner and 2 children, employed full time, attends many hobbies and activities
2: Johan	Male	66	WB	11 months	1	Left	Lives with partner, children left home, forced to retire by stroke, ad-hoc work, attends community activities
3: Alistair	Male	72	WB	11 months	1	Left	Lives with partner, children left home, retired, engaged with Church, attends many hobbies and activities
4: Becky	Female	58	WB	9 years	1	Right	Lives alone, volunteers, engaged with Church, attends stroke group activities
5: Michelle	Female	49	WB	4 years	1	Right	Lives with partner and 1 child, volunteers, attends some community activities
6: Tim	Male	65	WB	8 months	1	Right	Lives with partner, forced to retire by stroke, attends many community activities
7: Stuart	Male	60	WB	20 months	1	Right	Lives with partner, forced to retire by stroke, attends many community activities
8: Daniel	Male	79	WB	11 months	2	Left	Lives with partner and 1 adult child, retired, no social life – feels isolated
9: Dave	Male	65	WB	18 months	1	Left	Lives with partner, forced to retire, attends some community activities
10: Amal	Female	54	AI	8 years	2	Left	Lives alone, doesn't speak English, no social life – feels isolated
11: Marc	Male	64	WB	2 years	1	Left	Lives with partner, children left home, retired, attends some community activities
12: Sarah	Female	56	WB	23 years	1	Right	Lives with 1 adult child, volunteers, attends many community activities
13: Joel	Male	64	WB	2 years	1	Left	Lives with partner, attends community activities
14: Leah	Female	51	WB	21 years	1	Right	Lives with partner, children left home, volunteers, attends stroke group activities
15: Tom	Male	56	WB	10 years	1	Left	Lives with father, attends stroke group activities
16: Lou	Female	39	WB	17 months	1	Right	Lives with partner and 2 young children, struggling to return to work, attends many community activities

*WB: White British; AI: Asian/ Indian

^oIndependence - Level 1: No disability to slight disability. Able to look after their own affairs without assistance, may be unable to carry out all previous activities. Level 2: Moderate to severe disability. Requires help in some or many activities. May or may not be able to walk independently.

3.8.2 The analytic process

The analytic approach undertaken in this study was a thematically presented Interpretive Phenomenological Analysis (IPA) which was broadly in line with that described in Smith, Osborn and Jarman (1999) and Smith, Flowers and Larkin (2009). Smith, Osborn and Jarman (1999) outlined two possible approaches to conducting (IPA): the case-study approach (which analyses one case in an idiographic way and then codes other interviews along these themes); and a shared-experiences approach (which looks to identify shared experiences across accounts via identifying broad themes which are then analysed in more depth). The approaches are similar in that a first case is worked through which then informs codes for the remaining interviews. However, the level of depth in the initial descriptive themes and the ensuing interpretation differs. The case-study approach is very detailed from the outset, whereas the shared-experiences approach looks more at broad themes across the dataset before then evaluating each shared theme in more depth – an approach better suited to larger data sets. The analysis moves from a descriptive to an interpretive stage which is an inductive and iterative process (Smith, Flowers and Larkin, 2009). Once the initial descriptive themes are generated via a process of familiarising oneself with the data and a line-by-line analysis, these themes are further scrutinised to uncover the meanings conveyed by the participant through linguistic analysis. Then conceptual coding is undertaken which draws on the meanings and feelings driving descriptive codes; how participant identity has influenced their experience and researcher reflexivity. Following this process shared themes are usually restored back to individual narrative accounts which articulate shared experiences at an individual level. However this component of the process was not utilised in this study, allowing the shared experience to be elevated through thematic conceptualisation. Explored themes reflected both introspective experiences towards the body and also provided focus on the ‘externalised’ experience of the body enacted in the world. The non-prescriptive approach of IPA allowed flexibility within this process enabling the analysis to be driven by the data and the project aims.

In this study the analysis was guided by a shared-experiences approach. The audio data were transcribed verbatim, 12 by the author and four by a transcription company. The data set was pseudonymised, then analysed by the author using NVivo 10 (QSR International,

2014). The coding of two interviews was examined by a separate researcher to ensure codes were applicable and to add rigour. A summary of the five phases of the analytic process is captured in Figure 4. An example of a coded transcript and in-depth detail of the coding process is included in Appendices: B.10 and B.11.

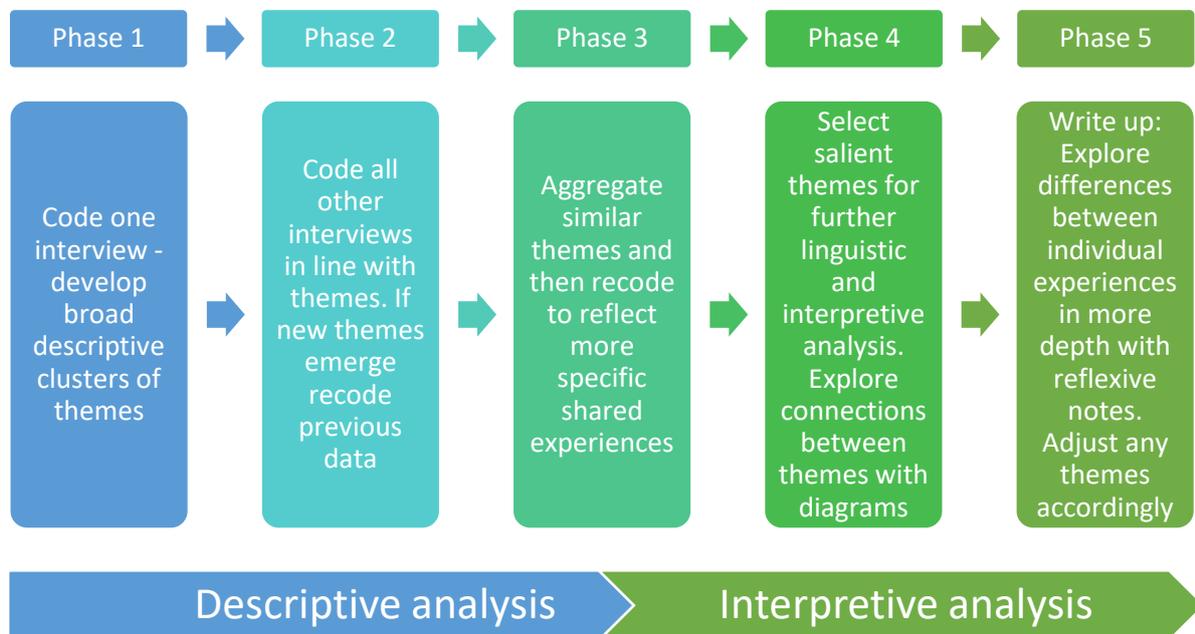
Firstly, the data were read through several times to ensure familiarity. The first phase involved analysing the first interview and coding it in terms of broad descriptive codes which clustered the participant's experience into areas such as: the experiences of altered body perceptions; the physical, social and emotional effects of these changes; ways of coping with the changes; health professional input and hope for the future. The sub-codes identified within these areas were more nuanced and reflected the specific identity of this participant. For example, sub-codes titles reflected characteristics such as: *'measuring progress'*; *'efforts at rehabilitation'*; *'making sense of changes'*; thoughts about *'amputation'*; not being able to *'control the body'*; living with *'uncertainty'*; *'retraining the brain'* and feeling *'conscious of the body'*. The codes were kept deliberately broad at this stage to enable all participants' accounts to be considered in relation to them. The second phase involved coding the other interviews along the lines of these codes. An iterative approach was used, so as new areas emerged, the previous data were recoded to take these into account. The homogeneity of the data meant that the majority of participants' accounts naturally fitted into the broad areas. Despite the successive coding of transcripts, the researcher ensured the coding process remained inductive and the data led the development of codes, as opposed to researcher knowledge of specified categories.

Once all interviews were coded into broad clusters, the third phase involved examining these codes to determine which areas naturally clustered together. These areas were aggregated and recoded into more specific themes which reflected shared experiences. For example, the initial theme of altered body perceptions was recoded into subthemes - *'it's not part of me'*; *'strange sensations'* and *'can't control body'*. The process of aggregating certain themes highlighted new clusters of data and patterns between themes, which had not been the focus of the interview schedule, thereby generating codes such as *'making sense of altered body perceptions'* or *'coping'*. This led to the fourth phase in which these patterns were explored through the use of diagrams and flowcharts to determine

connections between them. The fifth phase involved writing up the themes and focusing on differences between individual experiences. This phase was an important iterative component of the process and contributed to further development of the themes, as it gave space for in-depth analysis of specific text contrasted with other shared experiences. Reflexive notes were integrated into this phase to ensure participant context and meaning were reflected and any author interpretation was critically reviewed.

When writing-up, care was taken to ensure quotes were represented authentically and context was not lost, to retain focus on individual experiences. Although in many cases repeated phrases, stuttering of words and interviewer responses were removed to facilitate ease of reading and interpretation, care was taken to ensure the meaning of quotes was not changed. On occasions where these added to the meaning, context or understanding of the data they have been left in. In some instances, points of context have been added by the author with brackets - as follows: [example] - to facilitate reader understanding.

Figure 4. The analytic process



3.9 Rigour and quality

3.9.1 Patient and Public Involvement

Patient and Public Involvement (PPI) in research design and testing of data collection tools can aid the quality of data collection, largely because it can improve the effectiveness of interview discussion (Staley, 2009). Within this study, a PPI group experiencing altered body perceptions was involved at all stages of the research process. They contributed to the development of the research questions; reviewed the accessibility of the participant information booklet and consent form and oversaw the development of the interview schedule. Two PPI members took part in pilot interviews, to determine the flow of the questions, their language and their appropriateness. They advised that the interview schedule felt relaxed and that the questions were clear and well-paced.

Ensuring a sense of understanding and sensitivity between professional and participant is important for building rapport which is important in the collation of quality, honest and in-depth data. This is particularly relevant when the interviewer is able-bodied and not experiencing the same health difficulties as a participant (Staley, 2009). The PPI members provided essential input to facilitate a commonality of understanding of what it is like living with altered body perceptions after stroke, which undoubtedly improved the tact, sensitivity and rapport-building skills of the interviewer. They also emphasised the importance of an equal power dynamic between researcher and the participant, to ensure that the participant's voice is heard.

3.9.2 Reflexivity on the data collection process

Interpretive phenomenological analysis takes the view that because our understanding of the world is created through 'being' in and interpreting the world around us, it is impossible to remove or 'bracket' the researcher's presuppositions out of the research process. The researcher's awareness is intrinsic to their understanding of the phenomenon and cannot be removed (Reiners, 2012; Mauthner and Doucet, 2003). As such, it is important for

researchers to reflect on their role, to increase transparency and to reduce bias in the research process, thereby improving rigour and credibility (Clancy, 2013). Ignoring the subjectivity which generates researcher bias, devalues participants' authentic and subjective experience and misrepresents data (Ratner, 2002). To safeguard against this, researchers should reflect on how their knowledge has been constructed by acknowledging their 'positionality', thoughts and beliefs and professional influences (Clancy, 2013). Practically this could mean reflecting on one's age, ethnicity, gender, profession and other relational roles to identify how our behaviour affects the perceptions of others (Clancy, 2013). Mauthner and Doucet (2003) highlight how wider factors such as institutional contexts and ontological and epistemological assumptions can also influence research outcomes and should be addressed. Yet they also acknowledge that there are limitations to reflexivity, which is dependent on how self-aware it is possible for the researcher to be.

3.9.2.1 *Prior knowledge*

My professional background immediately prior to this PhD, was as a Stroke Care Coordinator for the stroke charity through which participants were recruited. This role involved outreach work with service users around practical and emotional problems related to stroke. As such, I had professional relationships with many of the staff and stroke survivors linked to this research. This relationship was useful in building links with staff to facilitate recruitment and to gain engagement from participants – a factor which may improve research engagement and therefore quality (Staley, 2009). During the recruitment phase I felt at ease and able to easily access many locations to promote engagement with the project. I felt that due to my established role with the charity, service users and charity volunteers were more willing to take part.

Professionally, I was initially concerned that I was not trained in a more specialist medical or rehabilitation field, as I felt that participants may expect me to have a broader medical knowledge of body changes after stroke. However, in practice it was useful to have no preconceptions about how participants understood and described their altered body perceptions because this meant I did not attempt to provide participants with terms or means of understanding their bodies, which may have influenced their narratives.

Four participants were volunteers at the charity and one participant I had directly supported in my previous role. Several of the remaining participants were known to me through attendance at local cafés and groups. Therefore, I felt I had a broader understanding of their stroke experience and difficulties, outside of a research context. This enabled me to understand their 'lifeworld' in more detail. During the interviews, particularly with volunteers, I did consider whether they may feel more inhibited sharing things with me because they may want to preserve a professional boundary. However, the interview content suggested this was not an issue and they were very open in the issues they discussed.

Prior to working in stroke, I was a Psychological Wellbeing Practitioner for the NHS where I was trained to conduct interviews. The training involved asking questions in a formulaic way to gather information about patients. The structure went through a funnelling process, from open questions to clarifying questions and then provided a summary of patients' difficulties. This approach was congruent to that advised within a phenomenological approach. I felt this was a useful and confidence building skillset to have when going into the interview process. However, it may also have been a constraint, as in my previous role I was used to finishing interviews in a set time frame and was taught to keep patients on 'topic' and not let them deviate from their 'main problem'. At times I felt conflicted. Although I knew I was supposed to let participants lead the interview, I was also fearful that if I stepped back too much I wouldn't get any useful data. In practice, I learnt quickly that it was impossible to keep patients completely 'on track' in interview and that there was merit in letting them lead the narrative and follow where it went. In the initial interviews I often felt I had 'failed' if they hadn't spent the whole time talking about the phenomenon of interest. However, this feeling subsided as I gathered more data and I could see the benefits of looking at the phenomenon across the dataset as opposed to in just one interview. I noticed that I often felt more comfortable discussing the psychological impact of altered body changes than the physiological ones. However, although this was my preference, participants often preferred to focus on the physiological and social implications of their body changes and found it difficult to consider the psychological effects.

3.9.2.2 Reflective journal

To engage in the reflective process, I recorded my mood, any concerns about the interview and my perceptions of participants before and after each interview. These notes were learnt from iteratively during the data collection period to improve the interview process. An example of one extract from the journal is detailed below:

“I feel like at times my questions felt like they reached a dead end and that he wasn’t opening up in ways I expected him to. There were no problems in the interview, but I didn’t feel it flowed as well. It could have been that we were talking about more sensitive and less positive issues in this interview [he talked about feeling hopeless and worthless]. I’m not sure how comfortable I feel about this kind of disclosure from an older man, in a context in which I am not in a helping role. Trying to stay neutral as a researcher when you want to try to help is hard. I also find it much easier to relate to women in these types of disclosures.” (Reflective journal entry, February 2017)

In this excerpt, I reflected on the age and gender gap between the participant and myself and about hearing difficult stories in a new role as listener and not ‘helper’. These issues caused some conflict within myself. It made me aware that my motivations for working in stroke research were to improve outcomes for people living after stroke and that to step out of my previous role as ‘proactive’ outreach worker into a new ‘passive’ role of researcher was difficult for me. Becoming aware of this feeling, allowed me to accept and enjoy my new role, which in turn, influenced how I felt and behaved in future interviews. It also made me reflect on how my role and demographic traits made me feel perceived, when in relation to another.

3.9.2.3 Reflection on power dynamics in interview

The balance of power is never going to be truly equitable in the research process. It often falls in favour of the researcher who controls how the process is explained, exposure to risk, consent processes, transcription, analysis and dissemination (Nunokoosing, 2005). Despite

the use of open questions, a flexible interview schedule and 'passive' interview style, it is impossible to avoid the fact that the interviewer has used other professional skills to develop rapport with the participant, or strategic questioning to access the narrative or 'data' they require (Nunokoosing, 2005). Information is shared in an artificial environment and knowledge is co-created with the influence of the interviewer.

Personal and professional identities of the researcher and participant influence the construction of knowledge and power dynamic during the interview process (Nunokoosing, 2005). These identities vary depending on factors such as gender, age, ethnicity, religion, sexuality, intellect, personality type and economic status of the people within the interaction. The ensuing power dynamics are fluid and can morph throughout the interview process (Nunokoosing, 2005). These factors can vary the researcher's status as an 'outsider' or 'insider' and vary the participant's sense of agency on a given topic. Although it is clear that for the most part, power dynamics are balanced in favour of the researcher, it is worth acknowledging the fluidity of this construct and the moments of vulnerability which may also be felt by the researcher.

Prior to the interviews, I reflected on my role and attitudes to the participant and the interview process, to consider how these factors influenced the construction of the narrative between us. At the time of interview, I was 35 years old, a white woman and a mother, with the 'status' of being associated with a University and working in a medical field. As such these varying performative identities influenced how I behaved, was perceived and therefore the power balance and narrative that developed during interview. I tended to introduce myself as a person who used to work for the Stroke Charity, but who was now studying a PhD in stroke research. I imagined that participants would perceive me as an 'expert' or someone with specialised knowledge in the field of stroke.

My sense of the power in the interviews varied depending on my sense of adequacy in relation to the participant. To some extent I felt at a disadvantage to the participant in all interviews, because having not experienced a stroke, I would never be able to fully understand their experience. I would always remain an 'outsider' and I was aware that this may affect the way they perceived me and discussed their experiences. To compensate for

this I was aware that I should not pretend I understood their situation as this may appear inauthentic. I utilised my 'outsider' status as a catalyst to generate interview prompts such as: *"I don't know what that feels like, can you tell me more about it?"* Tinker and Armstrong (2008) highlight how this strategy can empower participants, which may elicit more free and in-depth accounts. They also suggest that 'outsider' status may have other benefits such as producing a more comprehensive account and facilitating a more critical analysis of data. I was aware of how my feelings about power dynamics changed in response to participant's demographics and personality types. When participants were male, older and well-educated I tended to feel less confident both in myself and my role as 'expert', due to traditional cultural hierarchies which prioritise the values of masculinity, age and education. Conversely, when participants were female, parents and of a more similar age to me, I felt more confident and able to engage in rapport building. Both myself and participants undoubtedly acted out our cultural expectations to engage with each other and as a result the power dynamic ebbed and flowed between participants and during interviews. For example, four male participants with professional backgrounds in universities or rehabilitation, highlighted their interest in research or their association with universities, perhaps to engage at a more professional level and rebalance the traditional power dynamic. Whilst it was impossible to remove both mine and the participants' identities from the constructed narrative, reflecting on my 'positionality' in this process, minimised any projection of my 'self' and status into the participants' story, thereby allowing a less biased narrative to unfurl.

3.9.3 Validity

Yardley's (2000) criteria for assessing quality in qualitative research is a useful yardstick to determine validity and is congruent with a phenomenological approach (Smith and Osborn, 2007). Yardley's (2000) criteria are based on four principles. Firstly, the study should be sensitive to context, meaning where the study is situated in relation to the literature and the context in which participant perspectives are gathered. This study is framed within a context of relevant literature, as indicated by the scoping review. The primary data were gathered in a way which was sensitive to participant contexts, both practically through

conducting interviews in their own homes and through capturing a narrative which was focused on a holistic glimpse at their 'lifeworld'.

The second and third components suggest the research should be committed, rigorous, transparent and coherent. This is exemplified through the in-depth evaluation and review of the interview schedule; the interview skills used and the reflexivity which informed the process. The recording of methods and analysis has been transparent and there is congruence between the philosophical approach and method. The use of member-checking as a means to add rigour to this study was rejected and the rationale for this choice is included in Appendix B.9. To demonstrate the robustness of the data collection and demonstrate transparency in the coding process, an example of a coded transcript is contained in Appendix B.10. To aid transparency and rigour, within the analysis chapter (Chapter 4) all quotes were reported verbatim.

The final point focuses on the impact and importance of the research (Yardley, 2000). During interview participants articulated that the research felt important because it was often the first opportunity they had to talk about their experience of altered body perceptions. They highlighted the need for improvements in the stroke care pathway and recognition of the problems faced after stroke. This research aimed to contribute towards improving understanding of the experience of body changes after stroke for stroke survivors and professionals and improve the knowledge informing clinical interventions.

Chapter 3 has described the methods employed in conducting the qualitative phenomenological study exploring the experience of altered body perception and discomfort after stroke. Chapter 4 will present the analysis and discussion of the study.

Chapter 4: Analysis and discussion: A phenomenological study exploring experiences of altered body perception after stroke

4.1 Chapter introduction

This chapter provides a thematic presentation of the shared experiences identified via the interpretive phenomenological analysis of the interview data. Participants described five themes which reflect the physiological and psychosocial comfort of the altered body as manifested in participants' interactions with their inner and outer worlds. The efficacy of the term comfort is discussed in terms of bodily consciousness and the body-self divide. The congruence of the concepts of comfort and acceptance are explored in relation to the embodied experience of stroke. The embodied use of language to make sense of and communicate altered body perceptions is then discussed.

4.2 Analysis

4.2.1 Introducing the five themes

Five main themes were identified from the data: the 'Disappearing body', the 'Reappearing body', the 'Uncontrollable body'; the 'Isolated body' and the 'Hopeful body' (Table 8). The first three themes were centred on participants' experiences of focusing inwardly on their altered body perceptions; how comfortable these perceptions made them feel (physically, emotionally and socially); and how these altered perceptions impacted the ways they could use their bodies. Within each of these three themes participants reflected on the difficulty of describing and making sense of their body perceptions; they spoke of their body as 'weird' and 'alien' and used objectifying language to distance themselves from their unusual physical experiences.

The remaining two themes, the 'Isolated body' and the 'Hopeful body', captured participants' experiences of integrating their altered bodily experience into the external

world. The 'isolated body' reflected how the altered body limited participants' ability to access support from health professionals and participate in society. The reduced ability to access the world led to social and emotional discomfort. The 'hopeful body' was a reaction and coping strategy to manage the physical, emotional and social discomfort evidenced across the previous themes. In the absence of effective support, participants adopted the 'hopeful body' to draw on their own autonomy, independence and resourcefulness as they attempted to improve their experiences of altered body perceptions.

Table 8. Outline of themes

'Disappearing body'	'Reappearing body'	'Uncontrollable body'	'Isolated body'	'Hopeful body'
The body doesn't exist	The body feels strange and distorted	The body is uncontrollable	Altered body perceptions are isolating	Having hope is comforting
Physical discomfort				
Not usually physically uncomfortable: • I forget about it	Physical discomfort: • It hurts • It demands attention • It stops me doing things	Physical discomfort: • Body doesn't respond • Can't use the body as intended • Everything becomes conscious	Physical discomfort: • Pain, limb heaviness, reduced mobility • Limited participation	Reduce physical discomfort: • Fix the body • Take control
Psychosocial discomfort				
Psychosocial discomfort: • It's weird • It's inexplicable	Psychosocial discomfort: • It's weird • It gets me down • It's inexplicable	Psychosocial discomfort: • Can't trust the body • It's frustrating, the body is a battle • Reduced social opportunities	Psychosocial discomfort • Society validates the 'object' body, feelings (am I worth helping?) • Professionals can't help me • I don't fit into society • I am just a number	Reduce Psychosocial discomfort: • Stay positive • Make changes • Understand the body
Coping with the body and discomfort				
• Consciously attend to it OR try to forget about it • Objectify body	• Try to alleviate discomfort • Distract from it • Objectify the body	• Compensate with less-affected side • Avoid activities • Objectify the body	• I don't know what to do • I can't communicate it • Get on with it, its life • Cope alone	Factors affecting coping: • Financial • Health professionals' input • Family support • Ability to make sense of experience

4.2.2 The 'disappearing body'

4.2.2.1 *The body is not there*

Many participants described a body which they couldn't perceive in the way they had done prior to the stroke. Participants labelled affected body parts as: "missing", "not mine", "forgotten", "not there", "amputated" or said they "didn't exist". For some, there was a distinction between body parts perceived as 'not there' and body parts which could not be perceived due to a sensation of 'numbness'. The numb body was labelled as: "subdued", "dead" or "half" perceived. Experiences varied, with some describing no perception of tactile sensation and others describing only a slight loss of perception.

Becky, a 58-year-old woman, nine years post-stroke, who experienced hemiplegia and limited movement down her right side described the perception that her lower leg had disappeared.

"yeah, it's like I don't even think about it... my knee it stops there... which I would imagine it would feel like if you had it amputated I suppose" (Becky)

The absence of feeling in her leg did not demand her conscious attention and she did not think about it when the body was not moving. Her body was just not there. Explicit descriptions of perceptual loss were echoed between participants. Amal, a 54-year-old woman, 8 years post-stroke, who mobilised using a wheelchair and had very limited movement down her left side, used similar phrasing when describing the perceptual loss of her more stroke affected side in her mind's eye:

"[its] not good, she says 'nothing there'...and she said before... 'I [used to] feel like very energetic, I walk there, walk there'... now...she say 'I feel like there's nothing there'"
(Amal)

Amal lived alone and felt very isolated since her stroke, only leaving the house to attend a women's group once a week. Like Becky, her perceptual loss did not demand her attention,

the body was simply not there. However, this loss caused her enormous consequences. Her impaired mobility had made her virtually housebound which meant she was unable to engage with her community which caused her enormous emotional discomfort. It was through the loss of her ability to engage the body in action, that the perceptual loss demanded her attention.

Toby, was a 46-year-old man who experienced hemiplegia down his left side. He was 19-months into his recovery and had worked tremendously hard to improve his mobility, attending the gym almost daily. He captured his experience of the 'disappearing body' in terms of a sense of bodily disassociation.

"Inside your leg on the left one, it feels like there's a weakness...it feels like there's a loss of power... it feels as if, to be honest with you, it feels as if it's not mine...Is the best way I can describe it. Outside the leg with the feeling is not too bad ... But inside... that it's just not there" (Toby)

Unlike Becky and Amal whose body parts completely disappeared, Toby maintained a certain level of attention to the body, which he conceptualised as weak. The conflict in which his internal body felt *not there* was in stark contrast to his tangible external body. This was mirrored in his sense of separation with the affected body which was no longer part of *him* and referred to in the third person.

4.2.2.2 The body is not me

This 'othering' of the body as a result of perceptual loss, was highlighted by the majority of participants. Leah, who had her stroke in her early 30's, was 20 years into her stroke recovery. She experienced numbness down her right-hand side and described the sense of her body not feeling part of her.

"I can obviously move all my limbs, but I can't really feel them, it's like ...having Novocaine, the dentist's thing... I'd say I feel something but I don't know what it is... if I move it, if somebody tugs my arm I'm aware of it...but...it doesn't feel like me anymore

[laughs]... I suppose that side... it's not me...it's like [exhale/sigh] a parasite [laughs]...it is part of me but it's not what it was...[pause] it's who I am now...I don't hate it, it's just that that's what it is... I don't have to like it... [laughs]" (Leah, 51)

For Leah, her lack of perception of the 'disappearing body' created a psychological distinction in which it could no longer be related to her sense of her 'self'. Due to this division she ascribed her own meaning to this body area – that of a "parasite". The use of this negative term, the sigh and her resignation to having to accept the body as it is, highlighted the internal psychological tension she felt in managing her body over the long-term.

Becky, like Leah, years into her stroke recovery, also described her physical perceptual loss in terms of a psychological manifestation.

"It's like it doesn't belong to you...I know it is mine, I know it's there, I know it's part of me... 'cause I can see it... it's weird but it don't exist...just like you got a zip down [draws line with her finger down the middle of her body] ... I'd say I'm a person of two halves... like a split personality." (Becky, 58, 9 years post-stroke)

The conflict between her loss of physical awareness of the body and the emotional discord caused by this altered perception, led her metaphorical language to extend beyond her bodily perceptions and encompass her personality too. She described her 'self' as split. To make sense of the contradiction between her visual perception that her body was whole and her fragmented perceptual sense of the body, she reasoned that her 'self' and body had become separated; the body had become *other*.

4.2.2.3 *It's weird, if I think about it*

For many the 'disappearing body' was largely imperceptible and therefore not a cause of obvious, consciously demanding physical discomfort for participants. The lack of conscious attention to the body meant some participants experienced injuries to the affected limb which were problematic; some involving medical intervention. Participants universally found

the 'disappearing body' difficult to describe, 'weird' and hard to make sense of. In many instances, the body was so unnoticeable it became forgotten. Marc an active 64-year-old retiree, who experienced hemiplegia and a loss of bodily awareness down his right-side described:

"[my arm feels like] it's just away somewhere else ... you know unless my hand slips down ... you know like that, between my leg, I forget that it's there ..." (Marc, 2 years post-stroke)

In Marc's experience, the physical perception of loss was completely unremarkable, only becoming noticeable when the limb was observed in a surprising location. Whilst the static, absent body whilst not physically uncomfortable, it did cause some emotional tension for participants which Marc, reflected on when describing how he imagined his body with his eyes closed.

"well it would be half a body--I would be cut in half [down the middle] or whatever... [on the left there would be] nothing... it would be empty... [Interviewer: How does that make you feel?] Worse than I do if I don't think about it [laughs]" (Marc, 64, 2 years post-stroke)

When dwelling on his perceptual absence, Marc was unable to psychologically avoid his altered body. His use of understatement and laughter deflected conversation away from the negative emotion he felt about his inability to perceive his body and he went on to describe how he liked to keep busy to avoid considering these difficult thoughts. Like others he flitted between first and third person pronouns, again suggesting close links between the embodied physical and psychological sense of self. The physical loss was mirrored by the psychological desire to distance the self from the physical perception; both contributing to a lack of conscious awareness of the experience. Like the construct of the "object' body', this could be considered a coping strategy for managing the psychological impact of perceptual loss.

Dwelling on the 'disappearing body' could create a sense of psychological discomfort, yet for a few participants it also could change their physical perceptions.

"that's funny... all of a sudden, I'm getting numbness around the nose, funny, isn't it? That's because I'm talking about it - didn't have it before" (Tom, 56, 10 years post-stroke)

Tom referred to other instances when his emotional states gave rise to a change in his physical body experience and he also noted increased muscle tension in the arm on days when he felt worried or upset. For Tom, this association was clear and though not physically uncomfortable, it caused him surprise and unease.

For many, the 'disappearing body' could not be trusted to look after itself; making the less-affected side, alongside their conscious attention, the 'parent' which had to keep it safe. Leah, expressed looking after her more affected right side by using her less-affected arm to help identify sources of pain.

"if I have a pain on my right side, I have to feel it with my left hand... to find where the pain is... just by squeezing it to find where it hurts... that sounds weird... does it? [laughs]" (Leah, 51, 20 years post-stroke)

Here the limb was only brought to her attention by the experience of pain, yet despite her focus on the body, her perceptual loss created confusion and uncertainty about being able to fathom what the problem was. Remarking on how weird this process sounded, then questioning and laughing at her experience, demonstrated her emotional discomfort about conveying the experience and being understood.

For others a subtle awareness of the 'disappearing body' prompted attention to be given to this sensation. Alistair who experienced hemiplegia and reduced mobility described:

"there [pointing to his forehead, left cheek, lip and chin], that is not numb but its reduced sensation... I'm aware of it so I often do that [stretches mouth open] thinking

if I work it I can... I can work it to normality but it doesn't actually work" (Alistair, 72, 11 months post-stroke)

His conscious attention of his reduced perception and attempts to improve it suggested that, though this sensation was not painful, it caused some level of physical discomfort or unease, when juxtaposed with a goal of 'normal' sensation.

Physical discomfort occurred in the perceptually absent body at times when the individual was unable to maintain conscious attention and care towards the body, for example during sleep. Participants described instances of the affected limb becoming trapped and causing pain.

"[it is uncomfortable] when I turn over in bed and I forget to move my arm first. [I feel] a pain [laughs]... I have to turn back and pull this arm over. [It's gone] Behind my back." (Sarah, 56, 23 years post-stroke)

Sarah, a long-term stroke survivor, did not feel negatively about having to look after her 'disappearing body'. The mind adopted a parental attitude of care and she simply accepted the bodily demand and remedied it as best she could. Yet the strangeness of her experience and sense of her 'object' body was alluded to, with her laughter at the notion of feeling pain after forgetting to care for her arm.

Though many adopted an outsider's view towards the body, this attitude did not always negate complex feelings towards the 'disappearing body'. Lou, a mum of two young children, described being unable to perceive the sensation of nurses trying to put a needle in her arm for a drip.

"they were like putting pins in me and I couldn't really feel the pins in me down my arm...it was a bit weird. [I felt] a bit scared really... [it's like] 'oh, okay, what's happening?'" [Laughter] (Lou, 39, 17 months post-stroke)

Although she could not perceive the bodily discomfort of the pain, the visual information contradicting the perceptual loss was 'weird' and frightening and caused her emotional discomfort. For others, a lack of pain perception was not a source of fear, but surprise, as described by Tom:

"I burnt me thumb, didn't feel it at all... I had a whacking great big blister on it... I went to the doctors, they said "oh this is going to hurt", I put me hand up, they got a knife and they burst it... and I didn't feel anything, nothing at all... weird, I was waiting for the pain...no pain, weird... [I felt] just surprised [laughs]... I was expecting it and nothing happened" (Tom, 56, 10 years post-stroke)

The contradiction between visual and sensory information caused confusion and surprise as his mind tried to make sense of his experience. In both Tom's and Lou's accounts their emotional reaction was linked to when another person was intervening to care for their bodies. These points were a moment where they were forced to confront their lack of bodily perception, which caused confusing feelings and emotional discomfort.

The complexity of the emotional response to the 'disappearing body' was captured through an evocative description by Tom, in which he described in his mind's eye the perception of numbness down the whole right-side of his body.

"[It feels] like somebody stuck me in a bag of sand, I don't know why...like somebody stuck you in a bag of sand and half your body is sticking out...the other side's sticking in, the affected side is sticking in... it can make me feel I want to cry, sometimes... other times you don't think about it" (Tom, 56, 10 years post-stroke)

The metaphor of living in a body stuck in sand conveyed an emotive sense of entrapment. The free half of the body could perceive the world, yet it was constrained by the side of the body anchored in the sand – the sand inhibiting perception. The contrast between the free body and the trapped body shed light on what it is like living in a 'disappearing' body. Tom suffered with emotional lability after his stroke and he often found the perception of the

body trapped in sand triggered tearfulness. Yet his reflection that the 'disappearing body' can be forgotten highlighted the transient and complex nature of this emotional discomfort.

4.2.2.4 I don't know how to describe it

Throughout the interviews participants frequently struggled to convey their sense of the 'disappearing body'. This highlighted the absence of words in the English language to report on experiences of bodily loss. As a result, many relied on creative metaphorical language to convey their experience. However for those with mild aphasia, or those who did not think in visual terms this was challenging.

"Can't describe it in visual terms really, quite a normal sixty-year olds left-hand side and a fairly, not withered, but... however you would visually describe a... considerably weakened right-hand side, that's not very good but um... I don't know, it would be about a quarter of the size of the... of the left-hand side I suppose, I don't know... I mean, most of the time day-to-day... you just get on, I mean I don't know quite how to describe it... no I don't know how to describe it" (Stuart, 60, 20 months post-stroke)

Stuart, who experienced aphasia, managed to describe his perception of the 'disappearing body' in his mind's eye, yet his repetitive uncertainty was clear, illustrating his difficulty in conveying this experience. This difficulty in conveying his perception was experienced by nearly all participants, with many struggling for words, reaching for metaphors, expressing disbelief, laughing at and showing uncertainty over the images they verbally conveyed. Many just gave up attempting to portray their body perception altogether, with a simple *"I can't describe it"*. Often participants looked for reassurance that what they said was okay or laughed to express their understanding that what they said was unusual. Like Marc earlier, the desire to ignore the altered perception was phrased here as *'you just get on'*, suggesting a reticence to focus on a perception which is complex and difficult to understand.

The difficulty in making sense of the 'disappearing body' was articulated by Sarah, an independent and active woman, 23 years into her stroke recovery. Sarah experienced hemiplegia, foot drop and had problems with her balance.

"I have to put my foot down, it turns... so I have to put my foot down and kind of wiggle myself to get it in place... [Interviewer: can you feel that?] No... [Interviewer: How can you know that you're doing that?] I must be able to then... I feel fifty percent of anything that's down the right-hand side of me. I don't know how. I don't know... Maybe I can...I feel myself touching me" (Sarah, 56)

Sarah also experienced aphasia and found it difficult to visualise her body changes. Like Stuart her uncertainty in understanding and conveying her experience was obvious. Despite knowing her body well, the complexity of the perceptions created ambiguity when making sense of them.

Similarly Tom, 10 years post-stroke, found it difficult to describe and make sense of his changed body. He described the experience of trying to walk whilst experiencing numbness down his whole left side.

"feels weird, trying to push through the leg that is numb... 'cause you can't feel anything... [laughs] weird...really weird... like putting your foot [in]--I don't know, jam or something... that is really weird, honest... yeah, it's like something, like um soup, putting your foot in soup [or] something, it's weird" (Tom, 56, 10 years post-stroke)

His repetitive description of the experience as 'weird' permeated his narrative throughout the interview. It was also one of the most commonly used adjectives by all participants struggling to make sense of their experience. His creative metaphors demonstrated the inchoateness of his experience. Though he was not physically uncomfortable, it is clear how the experience permeated both his physical and psychological world creating an unease.

Many participants, when trying to find the words to describe the 'disappearing body', would use the less-affected side of their body as a benchmark. This created an interesting

juxtaposition to consider the differences between how a 'normal' body area is inherently absent from perception, in a similar way that the 'disappearing body' is not perceived. Toby attempted to convey this difference.

"I think the way to describe it is with the right leg, you're not aware of a feeling of inside in-depth... if you get my meaning... your muscles are just inside, your bones are inside, everything else is inside and it just works and we take it for granted... you just tend to ignore the left arm... you'll just do everything with the right arm" (Toby, 46, 19 months post-stroke)

For Toby the 'normal' and 'disappearing' body when static, were both imperceptible. However, his altered perception was tied to a sense of action and intention to utilise the body. His intention to act relied on a need to take his body for granted, to be reassured the body would respond. Without this reassurance, body areas contained no utility and became surplus.

4.2.2.5 Summary of theme

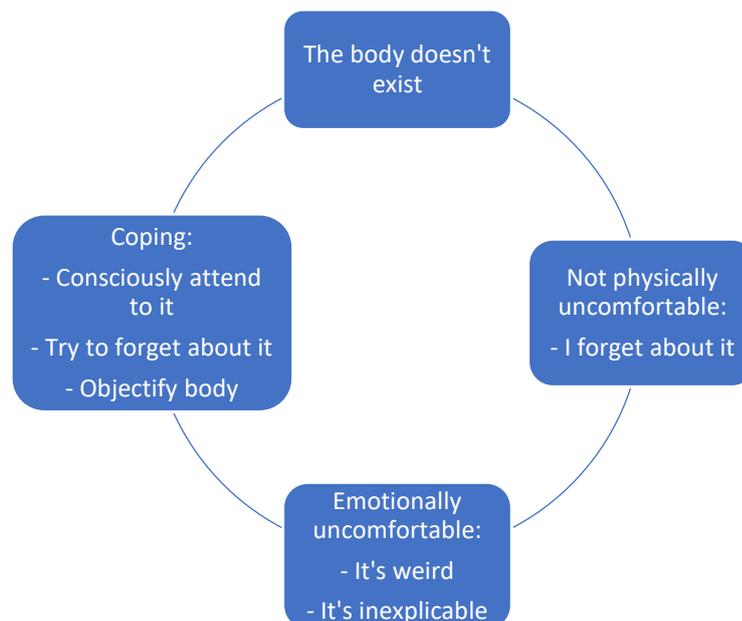
It became clear the experience of the 'disappearing body' after stroke was a complex and multifaceted phenomenon. Participants described a body which presented as absent in many ways: for some half the body didn't exist; for others perception was dulled and abnormal and as such was omitted from consciousness. This loss when the body was at rest, was not perceived as physically uncomfortable. The lost conscious connection with the body meant that it was easier for some to emotionally detach from the impact of living with a body impaired by stroke. This detachment was demonstrated as many relinquished body ownership and the affected body parts became 'othered'; the impaired body became perceived as separate from the sense of oneself as a whole.

However, this detachment could not be maintained when the participants had to acknowledge the body during injury, when the body needed to be taken care of and when the body was being 'done to' by others. The most obvious moment in which the 'disappearing body' became conscious was when it wouldn't respond to the intention to act

– which will be discussed in more depth in the ‘uncontrollable body’ theme. The bodily loss was hard to absorb emotionally and participants found the body weird and hard to integrate into the sense of their body as a whole. These instances raised complex questions to the participants about the nature of their body and themselves – if it’s not part of me what is it? Some participants attempted to rationalise this internal dialogue through describing the affected body parts as parasitic or themselves as having a split personality. For others, they made a conscious effort to ignore these questions and in turn ignore their perceptual conflicts. To cope with this array of overwhelming perceptions and emotions, participants often objectified the body, describing the affected limbs as not part of ‘me’; talking about it in the third person and perceiving the body as a ‘project’ to fix.

The complexity of their experiences were hindered by limited language to describe their abstract perceptual loss. It made it obvious how the very nature of asking someone to express their perception of something which doesn’t exist is inherently problematic. For those who could use metaphor to describe their experiences, they painted startling visualisations of bodily emptiness. Yet this was not possible for some with aphasia, or those unable to convey their bodily perceptions into visual or verbal terms (Figure 5).

Figure 5. Schematic illustrating the ‘disappearing body’



4.2.3 The 'reappearing body'

In the previous theme, the body became silent and disappeared from perception. However, the majority of participants also described experiences of altered perceptions in which the body 'reappeared', became demanding and clamoured for conscious attention. Participants reported perceptions of altered body size, shape, weight, increased sensations of pain and discomfort and bodily instability. Participants found these perceptions were often physically uncomfortable and affected their daily activities. They found these sensations more emotionally uncomfortable than the 'disappearing body', as the body consciously felt strange and abnormal. Similar to the previous theme, they found the perceptions hard to describe and make sense of. Again, to cope with bodily strangeness, they often objectified the body to preserve their sense of self.

4.2.3.1 The body is a burden

The majority of participants talked about the heaviness of the limbs on their more affected side. Many described the limbs through poignant visual similes, saying they felt like "a lump of lead" (Sarah); like having a "young child grabbing hold of your knee" (Ali); like the weight of carrying "your baby" (Leah); like "dragging a 10lb dumbbell behind you" (Tom); like having the leg "literally stuck to the floor" (Johan); like "wearing divers' boots" (Becky); and like a "dead weight" (Michelle). The limb was generally perceived by the participants as effortful – neatly described by Sarah who suggested that moving the heavy limb required so much "perseverance... to make it go...It probably does use up more calories".

A few participants unable to manage their limb heaviness, sometimes found themselves physically trapped by the weight of their bodies. Daniel, a 79-year old retiree with limited mobility, described this experience and worried that his legs were "too heavy to lift".

"I don't collapse, well I suppose I do collapse, like the undercarriage has given way...When I'm walking and it happens, I am saying 'I will walk on', but my legs are saying 'if you want to walk on, carry on without us' [laughs]... That's exactly how it feels... 'You might want to but we don't'". (Daniel, 79, 11 months post-stroke)

Daniel's experience reflected how his perception of limb heaviness made his body unresponsive; his inability to actuate his intention to mobilise brought awareness to this perception. Like others, he described it through the dichotomy of the body and mind, envisaging them as two opposing forces. Yet his conscious dialogue between the two, did not help him to achieve his goal. The body became a separate entity and no longer part of the self. For Daniel, the limb heaviness and fear of collapse meant he rarely left the house and felt incredibly isolated. Like many others, Daniel's physical and emotional discomfort was inextricably linked to social factors such as his lost independence and ability to engage in activities. He couldn't understand the cause of his mobility problems and a lack of input from health professionals created tremendous emotional upset, as he felt hopeless about his recovery.

"Well I've told them exactly the problem... and they don't know what it is... I am not going to give up but it makes you feel like giving it up sometimes... I am getting on a bit, but if there is some sort of cure, or some sort of way of reducing the discomfort I've got [but] that's all there is" (Daniel, 79, 11 months post-stroke)

This tight link between physical perceptual changes and psychosocial factors was demonstrated in other altered perceptions such as fatigue. For many, fatigue was described as a 'whole-body' sensation and usually worsened as the day progressed or with activity. Participants related tiredness to perceptions of heaviness, dragging the limb and sensations of aching muscles. Joel, who retained good mobility, but experienced problems in body awareness and processing movement, eloquently described his experience of fatigue.

"Sometimes you feel very tired, overwhelmingly tired... You feel your muscles are aching... like you've had a hard game of rugby or something... your body does feel very tired and beaten up... And when you feel tired, things are easy to become negative... [You think] 'is this ever going to change?... Is it worth it?... Is this too much?... Am I ever going to get better, back to my old self?'" (Joel, 64, 2 years post-stroke)

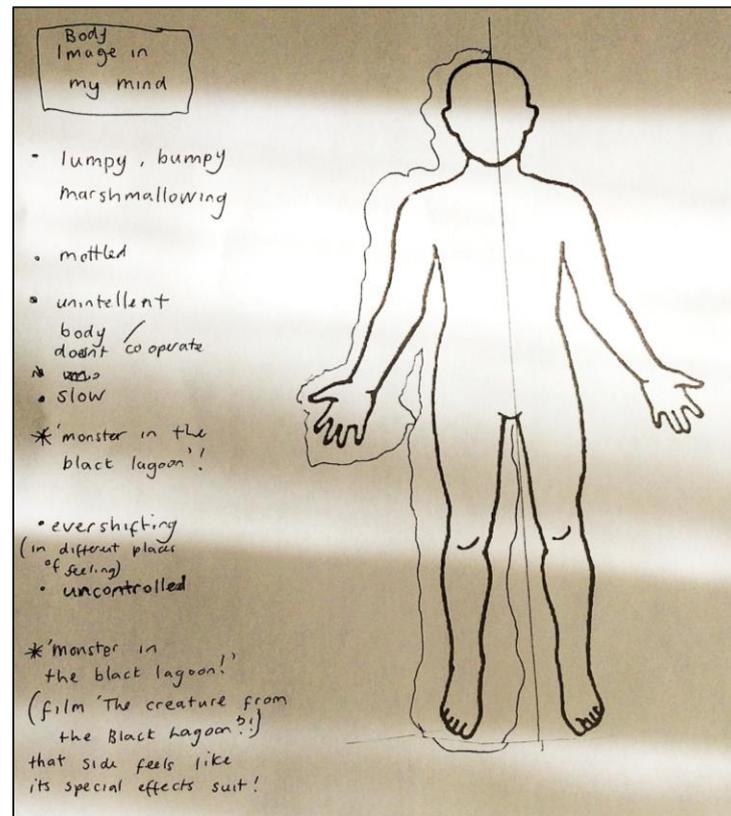
For Joel, the tired body demanded his attention because it constrained his activities and had a direct effect on his mood, directly impacting his positivity and sense of hope. Joel was a keen sportsman. His rugby metaphor highlighted the emotional discord he now felt at being unable to take part in his previous physically-able life, emphasising how he didn't feel able to accept his current body.

Several participants experienced body distortions which altered the size or shape of the body. The perceptions were diverse and unique to each participant. They impacted their emotional response to their bodies and how they used their bodies in activities. Leah experienced a perception of her body as much larger on the right-hand side.

"that side feels, it feels bigger... it's like, I'd say monster-ish [laughs]... [pause] it's like a marshmallowey, come sort of like bloated... not human... [mainly in the] hands, big and feet I suppose those are the two... [the rest of the right side feels] the same, but not so much...[laughs]." (Leah, 51, 21 years post-stroke)

After the interview, Leah emailed a picture of how she perceived her body which she had drawn onto a body map downloaded off the internet (Figure 6).

Figure 6. Leah's drawing and annotation on a body map



In this excerpt and annotated drawing Leah described her altered physical perceptions in evocative language. Previously, in Leah's description of her 'disappearing body', she likened her altered perceptions to that of having Novocaine at the dentist. In her description of the 'reappearing body' the extent of the distortion became more apparent. Her description of her body as a special effects suit made it easier to envisage the dual experiences of living in a deadened yet enlarged body. As in the previous theme, there was little common language to encapsulate her abstract experience, so she creatively searched for descriptors to convey her experience. Some choices of words she laughed at, perhaps conveying a sense of embarrassment or uncertainty at the unusual use of adjectives and the surprising image she verbally portrayed. Choosing a half-evolved monster such as the *Creature from the Black Lagoon*; using cognitive descriptors such as unintelligent and uncooperative to describe her body; and referring to the body in the third person, she demonstrated her objectification and sense of emotional distance from the body. The body was so far removed from her sense of 'self', she no longer perceived it as human. This use of metaphor, common cultural

references alongside a self-initiated drawing to illustrate his bodily experience was also used by one other participant when discussing his distorted body.

"I get... as if I got things growing between my fingers... it feels like... you know that film that got the blades come out? [laughs] [referring to Edward Scissorhands]... It feels something like that...it don't feel right. What I used to do, I used to keep doing this [interlinks fingers]... just touch down through like this...to tell myself that there isn't nothing there... as if you got fungus growing between your fingers or something you know... it just feels weird... it's just not right" (Tim, 65, 8 months post-stroke)

Tim was only eight months into his recovery and experienced a multitude of pain and distorted perceptions which were having a huge impact on his life. The character he chose to represent his experience had similarities to Leah's character – both creatures' half-human, isolated and unable to integrate into daily life. His reflection on the distortion as 'weird' and 'not right' conveyed his emotional discord with its strangeness. The body felt abnormal. His attempts to reduce the perception suggested it was physically uncomfortable and difficult to live with.

4.2.3.2 The strange and painful body

Whilst the body often became conscious and demanding due to body distortions in size, shape and weight, it also became arduous due to pain and strange sensations. The primary perceptions experienced were pins and needles, hypersensitivity to touch and heat, aching and stiffness in muscles and joints, cramps, burning sensation, sharp pain in movement, crawling skin, headaches and a perception of coldness in the more affected limbs. Pain fluctuated depending on time of day, body position and activity and was described as uncomfortable. It disrupted daily activities, mood and increased reliance on medication.

Dave, a motorcycle enthusiast who had to retire due to his stroke, experienced significant pain daily which was uncomfortable, both physically and psychosocially. Throughout the interview Dave struggled to assimilate living with his altered body perception with his sense of identity, not wanting to be perceived by others as less able. He was part of a biker

culture, so it was important to him to be able, independent and maintain a specific 'tough' masculine persona. He experienced multiple sources of pain and attributed the pain in his hip, neck and head to his stroke.

"I got a job to walk first thing in the morning...it's the hip, the back...the neck [laughs]... I think 'I know other people that get that that haven't had a stroke'... it's like warming up an engine almost... once I get going and get downstairs and try and do stuff... I feel ok, I'm still in pain, I'm permanently in pain... A day doesn't go by where I'm [not] in pain. If it's not the hip... it's the headache, if it's not the headache it's the neck ache... I think that can drag you down as well [laughs]... it's a two-edged sword I think the pain, 'cause it makes you a bit grumpy and it makes you tired."

(Dave, 65, 18-months post-stroke)

Like several other male participants, he perceived the body like a machine which his mind was trying to regain control over. His approach was mind over matter: the body uncomfortable and demanding of attention, had to be ignored to get the 'engine warmed up'. The disconnect between body and mind, alongside his desire to return to 'normal' suggested Dave had difficulty accepting his altered body perception.

Whilst Dave was able to push through pain to achieve the things he wanted, Tim described a pain experience which dominated his thoughts. Whilst he was speaking he drew an image of his body to illustrate the points he was making.

"I get a constant burning down here [points to inner thigh] ... which prevents me from sleeping.... the sensation on my right is very sensitive, but it's either painful...or it's just oversensitive... all round my eye... is like a black eye, right?...It pulses, like a black eye... the shoulder is out--it feels odd... it just feels out of place, as if it's not connected properly... the arm can feel very cold sometimes, I noticed between the two there's a difference in temperature... the fingers... its constantly tingling... my little toe on the right side all the way up the side, up to my ankle... can get hypersensitive and also I feel as though my ankle's broken... it just feels painful... I

know it isn't broken... and it's not swollen, but it just gives me the wrong information, it gets... quite painful” (Tim, 65, 8 months post-stroke)

Tim spoke hurriedly, keen for me to understand his experience. His bodily experience was complex, confusing and hard to describe. He described his discomfort as bearable but not something he would choose, stressing that it was irritating, unpredictable and affecting his sleep, activities and mood. He had tested alternative therapies to try and improve his discomfort but not found a long-term solution. Similar to several other male participants he was proactive in his rehabilitation and perceived his body as a machine he could fix – often referring to his body in objectified and mechanistic terms such as ‘remote controlled’ and ‘uncalibrated’. Yet, contrastingly at times, he spoke about his body in the first-person, suggesting a complex relationship between body and self.

The impact of pain on activities was highlighted by other participants including Alistair who described how he tried to avoid the sensation by reducing movement.

“I try to avoid putting it places where it’s likely to be hurt. So, if I’m mowing the lawn, then I would use my right arm to lead when the mower is going away from me, rather than have this mower wrench my left arm away from me... So I’ve learnt to accommodate it in ways like that...so I know how to avoid the pain” (Alistair, 72, 11 months post-stroke)

This protective attitude towards affected body parts echoed the approach many took towards the ‘disappearing body’ to ensure it was kept safe.

Alongside pain, participants experienced a wide array of ‘strange sensations’ which brought the body to conscious attention. The most easily and frequently described perceptions were pain, aching, stiffness, cramps, headaches, coldness and pins and needles. The majority of participants perceived that the more stroke affected side felt colder.

“Since I’ve had my stroke I always feel cold... never used to be, I used to be a hot morsel... [I feel cold] everywhere” (Michelle, 49, 4 years post-stroke).

Coldness for many was pervasive and perceived as uncomfortable and for Michelle was alienating in her household as she was always cold, whilst everyone else was warm. Leah equated this perception to an “ache” and the discomfort led her and several other participants to try to reduce this perception, by wearing gloves or using blankets. Perceptions such as coldness, pain, aching and cramps – terms which have a common meaning in conversation - were more easily described by participants. Whilst sensations like crawling skin and hypersensitivity were less easily described.

“sometimes it doesn’t feel as warm as the other side... sometimes the sensation if I were to have say extremes of cold or hot water on it, I think one physio once said to me, ‘does it feel like an electric shock?’... I said: ‘Yeah that’s it, that’s probably quite a good description that.’” (Alistair, 72, 11 months post-stroke)

Like others, Alistair’s difficulty in identifying terms to denote the experience demonstrated the difficulty of relaying strange altered perceptions. Yet his positive reflection of developing a shared understanding with a health professional highlighted the advantage of identifying terms to conceptualise experiences of the altered body.

Predominantly pain and ‘strange sensations’ were described on the more affected side of the body. However several participants also described uncomfortable aches and pains in their less-affected side as a result of having to overcompensate for their altered perceptions.

“the right side feels completely normal... absolutely no difference in sensory feeling ... in movement... in blood flow... in colour of the skin... The only thing I find now, is when I’m walking around, because I’ve become more right sided dominant... you can find that if you’re walking in difficult areas... then the calf muscle in the right leg can hurt because you’re dominating with the right leg” (Toby, 46, 19 months post-stroke)

These moments were the only instances when the ‘less-affected’ parts of the body drew attention to themselves, as the silent, dependable, ‘normal’ body, became noticeable and troublesome.

4.2.3.3 Making sense of demanding perceptions

Most participants had limited insight into the causes of their altered perceptions. Alistair conveyed his attempts to make sense of the perception of bodily heaviness.

“Yesterday I was feeling quite weak, heavy legged, sometimes it feels as if they're lead-like. Have you ever had a young relative grab you round the knee and hang...on and you drag your leg along?... that's kind of what it can feel like, it's really hard work y'know... and there's nobody hanging on...The leg is heavy for some reason, I don't know why... and I think well the leg is strong and I've been fortunate that I've had quite a bit of strength in the leg right from the start and it's improved... so if it's that strong why can't I just walk normally? And I don't know the answer to that”
(Alistair, 72, 11 months post-stroke)

The metaphor showed the demanding, effortful and constraining nature of the altered body. Alistair's questioning of the experience showed his confusion which was a source of emotional discomfort. This, along with his third person language, demonstrated his objectification of the dysfunctional body and its separateness from his sense of self.

Contrastingly, Johan, who experienced hemiplegia down his left side, was one of the few participants with real insight into his body perceptions.

“I will have been walking as well as I can all day and then suddenly I'm really crippled again... suddenly I can't bend my leg and suddenly it weighs a ton...the muscles in the knee seizing up and then as the muscles in the hip and the thigh get tired then the leaden feeling comes on... strengthening the muscles and improving my stamina gets round the leaden feeling, it doesn't stop the stiffness necessarily... but I understand now that the heaviness is what I feel because the muscles are weak or tired... and they feel like they're pulling up vast weights” (Johan, 66, 11 months post-stroke)

For Johan the physical impact on him was predictable yet the level of debilitation surprising.

He displayed an understanding and certainty towards his altered perceptions which gave him some control over his situation and gave his rehabilitation focus. Johan was highly educated, motivated and confident enough to question physiotherapists to develop his understanding. Whilst Johan was the only one to believe he could remedy limb heaviness, other male participants often demonstrated a perception that the impaired body was something they could work on and 'fix' through a systematic approach to exercise. This conscious sense of working on a project (the objectified body) gave many a feeling of control over a body which was inherently out of control.

To develop a sense of control over their unfathomable altered perceptions participants identified causative explanations for their changing experiences. Marc, attributed changes in his experience of pins and needles in the arm to a logical notion that getting the blood moving would be helpful.

"after you've had pins and needles... when the blood starts to circulate it sort of becomes jingly doesn't it...all up it, right from my toes right up to my shoulder.... It never goes away... I find when I'm under the shower it heats it up a bit... I don't know, it probably gets the circulation moving a bit" (Marc, 64, 2 years post-stroke)

Likewise, Sarah and several other participants referred to perceptions of aches and pains in conjunction with the weather.

"I get cold, a pain in my arm [referring to shoulder] when the weather changes... if I am carrying a bag you know, my arm gets a real pain in it you know. When the weather changes... I try and put my bag on the other shoulder but it puts me all out [of balance] [laughs]... that is when the weather changes from cold to hot or hot to cold you know... it is like a headache in my arm." (Sarah, 56, 23 years post-stroke)

Participants reflected the fluctuating nature and environmental factors influencing their altered perceptions. The shifting nature of the perceptions made them unpredictable which increased their visibility. Some experiences, by their very nature, were confusing and difficult to make sense of.

"when you stand up your feet are flat on the floor, but as that [the foot] swells in the day, it almost like my brain's saying it's falling over... but I know it's not because it can't [because of the brace]... It's my foot... that was twisted... it's only the brace that keeps it... [Its] like you're falling over on your ankle... my brain's saying 'your foot's not flat'... although I don't feel it... [it feels] strange, it doesn't make sense... if I'm home to be honest, I take [the brace] off... 'cause then I'm not getting that feeling... it stops that feeling of weirdness. In my chair, I always tuck that foot up under this one... and that's comfy... [It's uncomfortable] 'cause it feels like you're going to fall over... but you're not... It's weird I know... how can I say? Racking my brain... If you've ever gone in the sea and it's gone a bit boggy underneath... and your feet... like jelly and moving... I guess it's a bit like that really. Your eyes tell you one thing and your brain's shouting something else... it used to be [confusing], now I just look down and go 'Don't be stupid!' [laughs]." (Becky, 58, 9 years post-stroke)

For Becky, the miscommunication between her visual perception and her body sense, grabbed her conscious attention because it was physically and psychologically confusing and hard to make sense of. Her effort to find the metaphor of boggy sand, was relatable and insightful and highlighted the effort used in maintaining such a stance. Her need to override her physical perception with her visual input meant she had to objectify her body - her body was untrustworthy and needed to be corrected. Similarly, her behaviour of trying to stop the sensation by removing the brace and sitting on the leg demonstrated her physical and emotional discomfort arising from her altered perception.

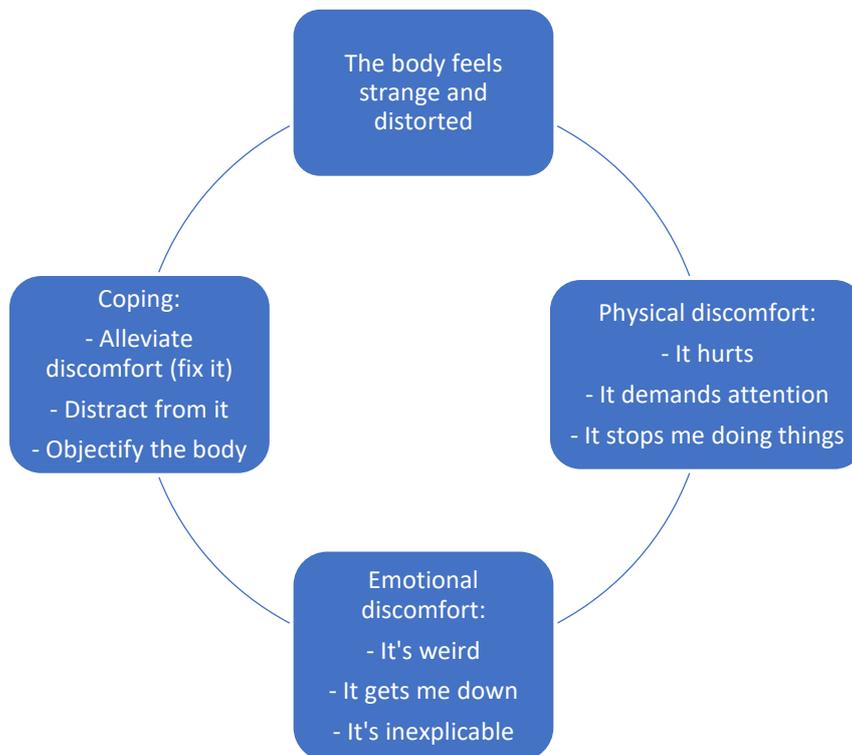
4.2.3.4 Summary of theme

The 'reappearing body' had much in common with the 'disappearing body'. Participants struggled to express their changes and reached for creative metaphors to convey their experiences. The body became a hindrance and was conceptualised as distorted, dense and effortful. Strange sensations such as pins and needles or hypersensitivity niggled at the edges of awareness, pushing their way into consciousness and repeatedly refocusing attention to the body. These body perceptions were more easily perceptually recognisable to individuals and did not fade into the background like accounts of the forgotten and

'disappearing body'. Burdensome and painful body perceptions clamoured for attention, disrupting activities and mobility and causing a more obvious sense of physical discomfort. The body was confusing, alienating and bizarre, which made it a source of emotional discomfort.

The mind and body were at odds with each other as bodily discomfort limited individuals' ability to use the body as needed. Participants attempted to make sense of, rationalise and ameliorate these body changes, indicating their unease with living with their current altered perceptions. To cope with these body experiences, as in the previous theme, participants objectified the body. The body became mechanistic and required 'fixing'. Emotional discomfort was clearly tied to the impact of these perceptions on self and identity. For some the body, which would not behave as needed, created a fatalistic attitude towards the body. For others this disquiet was hinted at through metaphors evoking monsters, the emotional impact brushed aside with laughter. The reticence to focus on the emotional impact perhaps creating a psychological distance between the sense of self and reality – a potential resource for coping with impact of the 'reappearing body' (Figure 7).

Figure 7. Schematic illustrating the 'reappearing body'



4.2.4 The 'uncontrollable body'

Participants frequently talked about the 'disappearing' or 'reappearing' body in terms of difficulty moving, using or controlling the body, which impacted independent activities and engagement in relationships. For example, the 'disappearing body' frequently did not respond to their desire and intention to move; or the 'reappearing' body often became more uncomfortable or unwieldy during movement. Maintaining awareness and dialogue with the 'uncontrollable body' created conflict between the body and mind. As participants willed their unresponsive bodies to respond they felt frustrated and found the experience hard to make sense of. The consciousness of the body, created by the conflict between the intention to act and lack of bodily response, led to an objectification of the body and a clear separation between the 'uncontrollable body' and the 'self'.

4.2.4.1 The unresponsive body

All participants talked about how the body was slow to respond to intentions and more difficult to move, a change they found uncomfortable. The relationship between the less-affected side of the body and the unresponsive side was complex. The pause between intended action and bodily response left participants frustrated, searching for hope that their body would improve and trying to make sense of the lack of bodily response. Participants felt the unresponsive side was uncoordinated, uncontrolled and struggled to keep up with the less-affected side during activities. Often the less-affected side supported the unresponsive limbs to achieve movement.

Becky articulated an experience of the unresponsive body.

"everybody else just... goes out grabs the head [rest] thing, gets up and walks out... whereas my first reaction is, 'help I can't move' ... 'I'm stuck' ... but I'm not, no more than they are... it just feels that way... [the body] doesn't just get yourself up and get yourself out... it takes longer to do those movements" (Becky, 58, 9 years post-stroke)

For Becky, the pause in her intention to move and the actualisation of that movement, made her feel panicked and in need of help. This anxiety persisted despite her knowledge that her body would eventually react and that she had the support of sitting next to a friend. The gap in response was a source of physical and emotional discomfort.

Stuart described this perception in more detail.

“in a way I feel utterly unchanged... you know utterly normal, I feel like I ought to be able to do everything I could do...and just suddenly [the feeling] it's not there on the right side... it's just not there... it doesn't make me feel different, but it's just not there and so, you know that's the whole effort, is making it sort of at least, imitate what it could do before. When I first had the stroke, I could feel my arm, I could feel everything about it... but it just wouldn't do anything, it just wouldn't respond... so it's that gap, that's the thing [the feeling of the body not being there means]... you can't find...anywhere in your brain, the signal that will move the arm... it feels like it should be able to do it, but somehow it just can't... in terms of the brain, you know if you knock out a portion of it... which unconsciously moves my arm or my leg and everything else, it's just not there” (Stuart, 60, 20 months post-stroke)

Previously Stuart described a sense that the body was missing on his right-hand side - a sensation he closely associated with the feeling of not being able to identify how to make the body respond. When static the body felt ‘normal’ and therefore comfortable. However, when the body was required for activity that bodily absence became present or conscious and effortful. The conflict between body and mind became apparent: the static body was filled with a sense of action or purpose, yet when the body was urged to move its absence was made obvious, the mind perceiving the body as effortful and a poor mimic of a ‘normal’ body. For Stuart the gap in response was his source of discomfort. Like many, he made sense of the experience through a neurological understanding of the objectified brain and unresponsive body.

For many, the inability to move the body was termed uncomfortable due to the loss of intentional movement, as opposed to a physically present sensation of discomfort.

"I'm not in discomfort if you see what I mean... I'm only in discomfort when I can't move it..." (Marc, 64, 2 years post-stroke)

For Marc and others, the effects of the unresponsive body caused psychosocial discomfort by disrupting their ability to meet their needs. At a bodily level the discomfort was experienced in the disconnect between intention and action, which led to consequences for activity and sense of identity.

Making sense of the unresponsive, 'object' body was problematic. Tim described this confusion, highlighting how the 'normal' side emphasised the lack of response in the more affected side.

"They suggested to me why don't I go swimming, I said "well how can I swim? I got two bodies, I'll be sinking or I'll be swimming round in circles"... 'cause I have no coordination between the two... it's like the right side is like if I was remote control... it would be like me controlling your body remotely... but the feedback would be not calibrated...I wouldn't know if you was picking up a glass... whether to adjust your hand for the grip... it's completely uncalibrated, I suppose it'd be like being a child... being born" (Tim, 65, 8 months post-stroke)

The mechanistic metaphors for the body; the perception of it being controlled by someone else; the notion that the body is broken, all suggested an objectification of the body and lack of common language to describe this phenomenon. The analogy of the child being born, conveyed the unintelligence of the infantilised body. Yet this metaphor also held hope that the body may recover - perhaps because Tim, only 8 months post-stroke still held hope for improvement.

4.2.4.2 Making sense of the unresponsive body

Many participants remarked on having to instruct, become aware of and talk to their unresponsive bodies to achieve control during movement. To achieve this, Marc manifested this dialogue through a visualisation of the cartoon character, Jiminy Cricket.

“I'm having a conversation with the person I call Jiminy Cricket...he's on my left shoulder...he's a little green cricket...he's there all the time...it's him that's saying 'move your left leg' and stuff...and then 'right you're going now, just keep going' you know 'eyes front and keep going'...he's an imaginary person obviously...he never answers back... you don't have a conversation with him, he just says 'do it' and you do it [laughs]... well that feels worse than the shoulder feels... because you've got no control over him... he's just a figment of your brain... sort of gets on your nerves”
(Marc, 64, 2 years post-stroke)

For Marc, delegating his conscious attention of his body to a third ‘person’, enabled him to maintain an objectified attitude towards his body. He could psychologically disassociate himself from the emotional discomfort of engaging in the effortful and frustrating task of regaining control over his body. This enabled him to protect himself emotionally by directing his frustrations towards an external entity, rather than towards himself.

Others attempted to rationalise the bizarre split between body and brain, through a neurological conceptualisation which also impacted the sense of identity.

“you have to work hard to make it [the body] move ... you're thinking in two halves ... it's a brain thing... 'cause you can see it's there ... but your brains like, cut in half ... so that side is harder to do things with, that takes lots of practice ... [it feels] I would say strange, but it's more than that...you can't really understand it ... you don't understand why it won't do what you want it to do, to begin with ... and then you understand that you are a person of two halves ... [you feel] schizophrenic sometimes [laughs]” (Becky, 58, 9 years post-stroke)

Visualising the brain as cut in half was troubling and confusing for Becky. She found it hard to separate this incongruent physical perception from her sense of self, leading her to conceptualise her 'self' as schizophrenic. The emotional discomfort resulting from this baffling body-mind disconnection was emphasised by Joel.

"Your brain, you need to... just pull your laces and it just doesn't happen. ... you think you would automatically do it without thinking. ...But you have to think and it doesn't work... [it feels] [pause] frustrating, frightening and puzzling... [it makes me think] 'Is this ever going to get any better?'... 'Why?'...So it's just frustration really... You get angry... 'I can't do it'" (Joel, 64, 2 years post-stroke)

4.2.4.3 The body is a battle

The majority of participants described a complex dichotomy between the unresponsive and uncontrollable body and the mind that was constantly trying to control it to achieve function. Discomfort arose from the "disabling effort" (Sarah, 56) involved in managing this dichotomy. Participants felt disappointed that the body relied on the mind to instruct it, which led to frustration as activities became compromised. Living with the unresponsive body was described across participant accounts, as "sheer frustration", "a waste of time", "useless", "difficult", "isolated", "terrible" and "weird". It made participants feel angry and depressed. The 'uncontrollable' body's refusal to cooperate, caused a complex disconnect between body and mind.

"your mind is being taken up with some other things and because it's being taken up with other things the leg doesn't want to bend because of the high tone in the quads... so it then becomes a bit of a battle and it then becomes very restrictive... it does become a pain in the neck... that can just be very frustrating... the mental mindset then gets irritated by it... which then just makes the problem worse... because the more irritated you get the more it won't work... so frustrations can lead to just lack of movement." (Toby, 46, 19 months post-stroke)

The body was again conceptualised as a constraint on the mind and intention to achieve activities. Toby described this as a bidirectional relationship – the body irritated the mind and the emotional discomfort worsened the altered body perception. Toby was incredibly active and motivated to improve his physical function and he independently utilised his bodily objectification to engage in rehabilitation. However, others dealt with this emotional difficulty in other ways.

“Well it just doesn’t feel... as though you could do anything with it... Flop it about... The whole thing is very debilitating and it makes me feel at times very sad... It’s a loss, it’s like a bereavement... It’s the same feelings go round and round again, I get angry, frustrated” (Joel, 64, 2 years post-stroke)

For Joel, unable to retain Toby’s positive mindset, the loss of bodily response and function in the unresponsive body was devastating. His frustration created conflict with the body which in turn affected his sense of self. His identity was keyed into his sense of function, whereas Toby, who had a remarkably resilient sense of identity was able to disassociate from any emotional discomfort by immersing himself in motivated activity and practical solutions.

For three male participants, Toby, Johan and Marc, the unresponsive and uncontrollable arm was perceived as so ‘useless’ that they had discussed the thought of amputation.

“it’s all a waste of time this arm now... because it won’t work, it’s there but it won’t work [laughs]... I often think ‘well should I just cut it off one day’... get it out the way... but then I think, well my shoulders still there so... [it makes me feel] bad” (Marc, 64, 2 years post-stroke)

The consideration of amputation was a fluid topic for all three participants, changing as time passed. Toby and Marc had considered amputation as a way of solving the problem of the unresponsive and useless arm and Johan had considered it as a way of alleviating the discomfort in his arm following shoulder subluxation. Unanimously amputation was a practical solution to a bodily problem. It represented the most obvious form of bodily objectification. The body was perceived by these men as a tool with which to achieve

activities. They had all had their employment and activities significantly disrupted by their strokes. As such they considered adapting the body to improve their ability to function and achieve their goals. The intentions of the self entirely prioritised over the encumbering, 'object' body.

"the problem is being an engineer by trade... I tend to look at a problem and try to find a solution... arm's not working, dead weight on your side, it's getting in the way, how would an engineer look at it? Right, get rid of it... it's not particularly uncomfortable... I would say it's just irritating how it won't go where you want it to... and it gets in the way, dressing is obviously more difficult" (Toby, 46, 19 months post-stroke)

For Toby, this body solution put psychological distance between himself and his disabled body. Through prioritising his public work persona over his altered body, he managed to preserve his sense of self. Paradoxically the unresponsive body whilst not conscious, did not become ignored and accepted. The impact of the emotional discomfort took priority, demonstrating the intertwined effect of bodily experience, psychological response and need for intentional movement and function.

4.2.4.4 The untrustworthy body

Nearly all participants talked about the impact of their altered perceptions on maintaining control whilst mobilising. Participants discussed how perceptual loss of the body and the environment led to instability and for many caused serious falls.

"I'm not particularly stable, I can walk, I'm fine, but if it's uneven... [walking with a stick] keeps people not knocking me over, 'cause I don't feel that side... I often bump into things and people... because I can't feel it. It doesn't bother me, but I do bruise... 'cause I can't feel my foot or my right side, I don't know how hard the pressure... I might slip... or trip... places that I know well [feel safer]... anything new is... it's not stressful but it's not comfortable either... certainly if I'm on my own... Places I know well, fine, others... I'd rather go to [with] somebody with me the first

time, so I know where everything is and... do a bit of a risk-assessment [laughs]"

(Leah, 51, 21 years post-stroke)

In negotiating her untrustworthy body, Leah brushed over physical discomforts such as bruising, instead focussing on psychosocial discomforts of feeling unsafe and not being able to independently negotiate new environments. Leah, chose not to attach explicit emotion to this situation, stating she was 'fine' and not bothered by it. Later she described her hatred of being dependent on others, suggesting that minimising the effect of this altered perception was useful to reduce her sense of emotional discomfort.

The necessity of being able to trust the body and feel safe was apparent across several accounts. Sarah described experiencing serious injuries due to falls and felt everywhere was unsafe for her.

"I feel it [balance], up here [shoulders and chest]. [It feels] scary, but I am quite used to it now and therefore, I know where my balance can go. I feel, I [need to] go for something to grab hold of... I tend to walk nearer to the shop window... I look for the pillars or posts or something that were going to be there if I needed it... all places I feel unsafe... I went down out the front there... I don't know how I tripped and I went down on my front two teeth... these are not my teeth... One time I tripped and fell into the hallway quite heavily ... and hurt my knee... I had various accidents" (Sarah, 56, 23 years post-stroke)

Like Leah, Sarah felt the need to risk-assess environments. She found the experience scary but not overwhelming, as it didn't prevent her from going out. Both Leah and Sarah were over 20 years post-stroke. They had experienced stroke whilst raising young children and had learned to adapt to continue with demanding lives. As such they didn't let their altered body perceptions psychologically overwhelm them or prevent them from engaging in activities. They had normalised the sense of unease associated with mobilising whilst living with altered perceptions.

Participants earlier on in their recovery, who were still learning to adapt to these problems expressed more difficulty with them.

“I no longer have a correct sense of what's vertical... I'm actually leaning on the right slightly... I need to be slightly off-balance in order to be vertical... and I'm therefore afraid I'm going to fall over... whereas I'm quite likely to fall over when I think I'm standing up right... there is a conflict... that leads to fear and anxiety... so that slows me down... walking across a carpark or something is terrifying... because... I'm in free space... and I think if my balance was right, I could make the rest work and I don't know how on earth to get my brain to get its sense of balance right again” (Johan, 66, 11 months post-stroke)

The altered perception of feeling off-centre when upright caused visual and perceptual conflict, leading to fear and emotional discomfort. Johan, who was able to make sense of most of his altered perceptions, was flummoxed by the experience of the off-balance and untrustworthy body. His inability to make sense of and improve his situation gave him no control over the perceptual experience, potentially adding to his terror. The ‘internal’ ‘whole-body’ perception of being off-balance, was predominantly described by participants in the first-person making it more difficult to create psychological distance from the impaired body. As a result, Johan made a distinction that his brain was at fault, objectifying his brain as the source of the bodily confusion.

Participants frequently described taking care with their bodies and maintaining awareness to avoid injury. Participants had to repeatedly deal with these challenging situations if they wanted to engage in activities.

“you got to be aware you got your body in the right place, your legs in the right place... otherwise you might do some damage to yourself or... which I haven't done, I'm always careful, but it's just one of those things you got to be wary of all the time...” (Tim, 65, 8 months post-stroke)

To mitigate for his perceptual loss and consequent 'uncontrollable body', Tim utilised his conscious attention to parent his unruly body.

Though participants were worried by their untrustworthy bodies they often felt they should use the more affected side to encourage their perception to return, creating a conflict between ability and intention.

"I don't carry things with my right hand because I'm frightened I might drop things...but it's gradually getting better... no, I do now, I might carry the odd small plate...but I'm frightened I might drop it..." (Michelle, 49, 4 years post-stroke)

The untrustworthy body was frustrating, frightening and inadequate. It was demanding and effortful and needed monitoring and constant attention to prevent accidents and injuries. Participants efforts to endure these challenging emotions demonstrated their desire to improve their altered perceptions.

For others, demanding and uncomfortable perceptions of pain and heaviness could strike suddenly, making the body completely unnavigable at surprising moments.

"[when I freeze when walking] it must be... my legs saying they've had enough... The message don't seem to be getting through to my legs. [I'm saying] 'Walk'... 'cause I enjoy walking... I've got an awkward gait, I can't seem to walk in a straight line... [The pain in the hip] it... make[s] me more uncomfortable walking... I got out the front door, got as far as the gate and I can feel... the discomfort, right hip and taking every step the discomfort increases. I thought bloody hell I am not going out with this discomfort and come home". (Daniel, 79, 11 months post-stroke)

Daniel described frequent occurrences of attempting to walk around his community but ending up stranded as his body would suddenly give up on him, or his pain would become unbearable. His untrustworthy and unresponsive body had led him to become housebound, leaving him feeling hopeless. He felt very isolated and a burden to his wife whom he felt he was restricting. Though he attempted to navigate the 'object' body by consciously

instructing it, his inability to retain his mobility meant, that his body had won the battle and – like one other participant in a similar situation - he was one of the few who appeared to have lost hope.

The interaction between the psychosocial effects of the altered and untrustworthy body were understandably complex and experienced in unique ways. Lou clearly demonstrated this distrust when changing her daughter's nappy:

“there was a few times that she ended up with bruises and I felt awful that she'd got like: it was literally finger marks like that sort of thing... Because... I haven't got the sensation in my hands to know... how strong I am gripping” (Lou, 39, 17 months post-stroke)

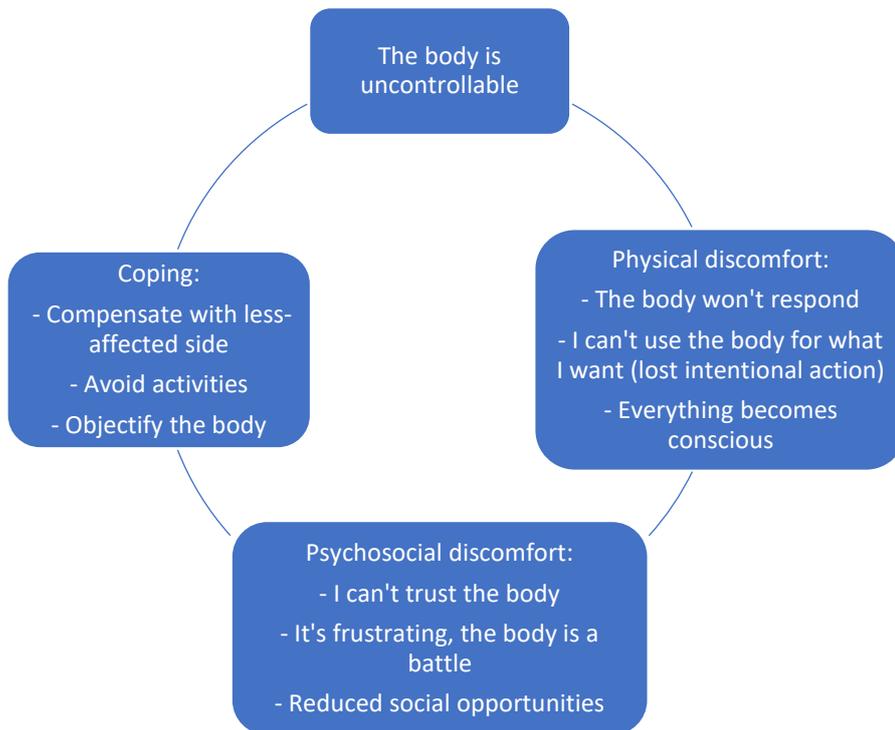
For Lou, her altered perception of grip strength had direct impact on her identity as a parent, causing negative emotions as she could no longer reliably fulfil her role.

4.2.4.5 Summary of theme

Within this theme the previous themes of the 'disappearing body' (perceptual loss) and the 'reappearing' body (strange and distorted sensations) merged with the need to functionally use the body. The body became uncontrollable and unresponsive. The 'disappearing body' which when static was not problematic, became conscious, frustrating and uncomfortable when it wouldn't respond to intended activity. The 'reappearing body' became more demanding, attention-seeking and uncomfortable once distorted perceptions of body size and pain were exacerbated by movement and had to be negotiated in relation to external stimuli. The loss of bodily intentionality, the perception of unconsciously using the body to achieve activities in which movement became conscious, was tremendously troubling and uncomfortable for participants. Emotionally, the uncontrollable body was frustrating and hard to trust. The psychological consequence of the body that wouldn't respond was a sense of conflict between the body and self. The untrustworthy body had direct implication for psychosocial comfort, impacting the perception of the self and whether participants attempted activities. For those who were able to normalise the abstract experience and the

emotional discomfort this was not a constraint, yet for those earlier in recovery the untrustworthy body severely limited activities. To cope with this discomfort participants avoided using the affected body areas. Again, the sense of bodily objectification was a coping strategy to manage the problematic body and preserve a sense of self and identity. Yet paradoxically the idea of bodily objectification was challenged as participants recounted the experiences of the unbalanced and unstable body in the first-person (Figure 8).

Figure 8. Schematic illustrating the 'uncontrollable body'



4.2.5 The 'isolated body'

The 'isolated body' captured participants' experiences of living with altered body perceptions in an external world; a world which had now become harder to access, navigate and integrate into. Their experiences of the 'disappearing', 'reappearing' or 'uncontrollable' body reduced their ability to participate, causing social discomfort. These physical constraints were exacerbated by negative emotions, as participants felt isolated and unable to fit in. All participants described having to cope with their altered body perceptions alone. Experiences of integrating into society and accessing health professionals, often validated these negative perceptions of the body, reinforcing a sense of isolation and the need to create separation between the disabled body and self.

4.2.5.1 Physically isolating body perceptions

The overwhelming majority of participants said that if there was a treatment for any of their altered perceptions, that limb movement or mobility would be their first focus.

"[Interviewer: if treatment existed... what problem would you get fixed first?] Leg... knee... don't shake this leg... I want to walk" (Amal, 54, 8 years post-stroke). The altered body perceptions affecting this goal were balance, foot drop, distorted perceptions of leg heaviness and shape, limb weakness or increased muscle tone, changes in pain and sensation and an inability to get the mind to move the body. The body was uncontrollable and untrustworthy. The effects of these physical changes caused social discomfort as participants were unable to access their environments and participate in society.

Alistair, who felt his activities were severely curtailed post-stroke described the impact of his altered perceptions on mobility.

"the lack of mobility in the left side, that's... 50% of the problem... what I'd like is just to be able to get up in the morning and have no heavy leg or stiff arm... just to get on with it, that's why I kind of work away at the gym thinking there may come a breakthrough moment when I get up one morning... and this leg doesn't feel heavy and I can just and walk smoothly" (Alistair, 72, 11 months post-stroke)

Despite the impact on his mobility, Alistair retained a relentlessly optimistic attitude towards his body. He avoided any emotional discomfort by focussing on a better future and ensuring he noticed any encouraging moments. Despite his attitude of acceptance of his altered perceptions, he still referred to bodily impairments in object terms; his use of the first-person in relation to a future, mobile self.

Similarly, Johan captured the perception of limb heaviness, which tended to worsen as the day progressed and made the body unreliable as it curtailed activities. Johan described:

“just going out to dinner with somebody, by 9 o'clock I'm thinking, 'by 10 o'clock I'll hardly be able to walk'... it's a bit like Cinderella's coach turning back into a pumpkin...” (Johan, 66, 11 months post-stroke)

The neat metaphor of comparing his legs to a coach turning into a pumpkin, conveyed the psychosocial discomfort associated with limb heaviness, as his mobility and social opportunities were constrained.

Participants expressed how factors other than mobility impacted their ability to participate.

“[I get headaches] occasionally... once or twice a week... [exhales] well I don't want to read or... I [sit] staring at the telly or [laughs]... certainly don't want to go out and I said with the kids that's [holds his hands over his ears and exhales with 'brr' sound]” (Dave, 65, 18 months post-stroke)

For Dave, his headaches were completely debilitating in terms of social engagement and family relationships. They also caused him psychological discomfort as they made him fearful he was suffering a further stroke.

Other activities were interrupted by demanding and uncomfortable altered perceptions, affecting many participants ability to function in day-to-day life.

“but this down here is terrible [referring to burning sensation in thigh], especially when you're trying to get to sleep... it really just plays up, it just keeps nagging at you all the time and it's so difficult to take your mind off of it... it's like having a toothache... you're trying to sleep on a toothache” (Tim, 65)

Tim's persistent pain disrupted his sleep to the extent that he was only getting two to three hours per night, affecting his mood and desire to access activities. The term *nagging* really highlighted the nature of the demanding body and his difficulty in remedying this problem.

4.2.5.2 The socially unacceptable body

Participants felt isolated and unable to access the world around them due to the physical experience of their altered body perceptions. Yet they also perceived the observable changes to be socially unacceptable in society. They internalised this sense of societal separation. This affected their psychosocial sense of comfort, which for some worsened their physical isolation. Michelle reflected this experience below.

“[if people see me with my hands clenched] they might think ‘there's something wrong with you’... ‘she's not thinking... she doesn't look normal... could be anything wrong with her’ [speech gets slower and more slurred]... sometimes it makes you feel that you think they're talking about you... [you want] them to realise that... everybody's not normal... sometimes you feel a bit sad 'cause they don't realise that you've had a stroke... it affects me going out, going in town... I'd never go in town on my own now... because people might look at you all the time... they might judge you differently.” (Michelle, 49, 4 years post-stroke)

Michelle appeared confident and happy to interact with people, so it was surprising that she curtailed her activities to such an extent. Her reflection that her physical changes may be interpreted as affecting her mental agility was problematic and emphasised the need to separate the impaired body from the self. The experience of the societally objectified body was more tangible in an account by Johan, in an incident early on in his stroke recovery.

“this couple rams past me... well, you get used to that sort of thing... what he then did was back straight into me and knock me down on the floor and his wife stood over me and said “if you're so crippled you're a danger to everybody, you shouldn't be allowed out of doors”... and I was very, very upset by that... that people can say these sorts of things still shocks me... I'm fascinated that people will... treat you as an object.” (Johan, 66, 11 months post-stroke)

Johan's account was shocking and his upset palpable, as his own sense of bodily objectification was validated by an external source. This external realisation of the altered body emphasised that Johan's self and his altered body were inseparable. The societal sense of the altered body impacted how some psychologically internalised their altered body and fed into a feeling of anger towards a society from which they felt ostracised and isolated from.

“[In society] how people see you is important... it's like you fall off the ladder... you just go zoomp, to the bottom... society as a whole, it doesn't value anybody who is different, do they? So, if you're different you don't fit in... you kind of slide down the scale... Sometimes [I feel] angry... like being punished for something you didn't do... and you can't fight back... you don't exist, you're not a person, you're just almost like I dunno, a digit... on a survey or something... they don't actually care how that affects you... I'll just get on with my life and stay out your way... then you can't hurt me... it's bound to [hurt] isn't it, I'm human... I'm in here, I want to shout that sometimes... [other people] they can't see past what they can see.” (Becky, 58, 9 years post-stroke)

Becky clearly outlined how her sense of societal separation, arising from her visibly altered body fed into her psychological discomfort. Her phrasing of “I'm human...I'm in here” captured her sense of entrapment living in a body impaired by altered perceptions. Her perception of society's views and her perception of herself became intermingled, reverberating off one another and reinforcing her perception of social isolation.

4.2.5.3 Health professionals don't understand

Participants' sense of isolation was worsened as they attempted to access health services to improve their experience of altered body perceptions. The majority of participants discussed feeling let down by GPs and hospitals who they believed didn't have the time, specialist knowledge or treatments to intervene and help them with their altered body perceptions.

"Health professional? What? Who? There isn't anyone [laughs]...my GP says, 'what can I do in ten minutes', she said, 'it looks like the [hospital] have dumped you onto the GPs... but we haven't got the time or the resources to help you'... which I agrees with her really... I'm not entitled to [physiotherapy]... there's nothing at all, there's absolutely nothing... isolated... you're left to your own means... so this National Health, so far has been absolutely useless for me" (Tim, 65, 8 months post-stroke)

Tim experienced multiple and debilitating altered body perceptions which were untreated. Yet, like others, he expressed a loyalty to his GP, sympathising with time and resources constraints and expressed a lack of faith in a health system which had let him down. Along with several other participants Tim could afford to try private therapies and had the cognitive ability and motivation to take responsibility for his own rehabilitation. As such his isolation from services spurred him into attempting to independently alleviate some of his altered perceptions, with limited success.

However, many other participants were less able to manage their own rehabilitation and became more trapped and isolated by the lack of health service response. This had a direct effect on their ability to improve their altered body thereby impacting their mood and social opportunities. Michelle was physically isolated by her hemiplegia on her right side and the perception of a heavy and elongated arm and leg which inhibited her walking. She described the interrelationship between these factors, health services and her mood.

"I did mention it about three years ago, down the doctors to say it would be nice to be able to walk better... and they said, we'll refer you and that's how long they've

taken... [I feel] angry in a way, I think... if you want to be referred to physio, they should not have a long waiting list, they should refer you even if it's like three months or six months... it should be a lot quicker... [feeling angry] doesn't help you get on with things...[like] going to the shops and walking... it feels like you haven't got any choice, you have to carry on and cope as best as you can... you can't ask anybody to help you, 'cause there's nobody around to help, you just got to get on with it and do it yourself... some days it makes you feel alright and some days if it's not a very nice day it might make you feel a bit depressed” (Michelle, 49, 4 years post-stroke)

Michelle’s isolation was exacerbated by a lack of attention to her altered body from both family and professionals. The negative feeling of rejection by health services echoed the physically isolating experience of living with altered body perceptions. Like Tim, Michelle developed a resilience and tried to cope with her altered body alone.

Many participants who were referred to professional support felt isolated by the perceived lack of knowledge or treatments available to improve their altered body perceptions. Some felt shunted between services as professionals tried to find solutions for them.

“I had a lot of visits now, from the physio and they concluded that they can't do anything for me... Because they don't know what's wrong... I've done all the exercises they told me to do, but no... And there's some hint that it might be purely up here [pointing to his head]... Like this fear of walking... [it makes me feel] a bit insecure in actual fact... because they tell me they can't do anything for you... They put it down, it's all in the mind then that's it, absolved, nothing to do with them... Then like the physio, the stroke specialist, they both want to palm you off to the other one saying 'no it's not us, it's them'... the physios... it took them a long time before eventually come down to see me at home... I think I am just a number. I get in there, they're thinking, not me, who am I seeing next.... well I have to accept it, they don't want to know”. (Daniel, 79, 11 months post-stroke)

For Daniel, the uncertainty about his treatment and his condition, gave rise to insecurity. The inability of health professionals to give him any answers or make him feel his care was person-centred worsened his emotional discomfort. This feeling was echoed by Becky.

“they say ‘yeah’ but they don’t listen... they’re just trying to shut you up... they don’t really care, they just... like a cattle market... you’re just the next one in the ring...if that makes sense... just get used to it don’t you?” (Becky, 58, 9 years post-stroke)

The disconnection between services and the lack of an adequate health professional response was internalised by both Daniel and Becky as a personal feeling that they were not important and were powerless to affect change in their condition. Becky compared herself to being in a cattle market, unremarkable, the health professional voice validating her sense of embodying the ‘object’ body. The impact of internalising this sense of irrelevance for Daniel, already isolated and housebound due to his altered perceptions, was really significant and he interpreted his condition as hopeless.

“Well they say they can't do anything for me... I suppose I could say it makes me feel like, I am not going to give up, but it makes you feel that way. They say let's get a counsellor... [they ask] ‘would you consider ending your life?’... Then you got someone say: ‘do you want to resuscitate?’ You think: ‘Bloody hell, are they saying that's it, I'm finished? They can't do anything for me?’” (Daniel, 79, 11 months post-stroke)

Participants often internalised and mirrored the lack of professional support, by not wanting to access services. They told themselves that their problems were insignificant.

“I’ll go down and see my doctor and then we talk it through. [I feel like] a prat... because I was taking up his time again and it’s, all you hear is ‘oh my God the doctors’ surgery, they’re all on their knees down there, don’t go’. And here I am again, talking to him about some rubbish”. (Joel, 64, 2 years post-stroke)

Joel – one of the few participants who did continue to access his GP - perceived his altered body perceptions as ‘rubbish’, as he prioritised the needs of the doctor over his own. This perspective led to emotional discomfort as he felt stupid. This perception, experienced by others, led many to utilise protective psychological strategies to cope with not feeling valued. They would avoid seeing health professionals as they didn’t want to be a burden and take up time or precious resources. These strategies protected participants from feeling rejected or misunderstood and any resultant negative feelings.

“[talking about taking muscle relaxant pills to help with shoulder pain] I'm a bit worried about that, because... if the muscle is relaxed all the time how will it [the arm] ever work again?... so that's why I want to get it moving so now... [I've taken the pills] since I came out of hospital two years ago... [I haven't spoken to a doctor] I feel a bit of a nuisance really just keep going back with all these little things...” (Marc, 64, 2 years post-stroke)

Marc who was living with very significant hemiplegia and pain, didn’t expect that doctors should respond to him. Two years post-stroke, he was looking into accessing support from a private rehabilitation centre. Personal insecurities such as feeling not intelligent enough, fuelled the belief that he shouldn’t bother doctors and should stay passive and consequently isolated in that relationship. This divide between the individual and health services, mirrored that of the self and the ‘object’ body.

Later Marc touched on his concern about being misunderstood by professionals, as he described his fear of sharing the idea of wanting to amputate his arm.

“[Interviewer: have you spoken to any health professionals about that feeling?] “no... I could go on and on and on for days and days, I could spend a whole day with them... just sitting there whinging and moaning about my body... and that is something definitely I can't do... well I'll be diagnosed as being schizophrenic or something... or depressed... they'd think I'd had a screw loose or something... I don't want to be labelled with that” (Marc, 64, 2 years post-stroke)

Like Becky in the 'disappearing body' theme, Marc compared the interplay between his altered bodily perception that half his body did not exist and the psychological sense-making of this perception to schizophrenia which he feared professionals would not comprehend. To protect himself from this uncertainty he didn't discuss any of these issues with NHS professionals.

Having to cope alone meant that many accepted that their altered body perceptions could not be helped and many felt uncertain about what activities they should do to try and improve their situation. Leah captured this when reflecting on why she hadn't gone to the doctor.

"[Interviewer: Is it anything you've ever mentioned to a doctor or health professional at all, that sensation?] No [laughs]... what are they going to do?... I think it's been twenty years and it would have been nice [for] somebody to come back and see if I need some more physio, whether I need some more help... you're sort of floundering around—for [all] I know, I could have made it worse. I do what I think I should be doing... I know my posture is not as good as it should be, I have problems finding a walking stick..." (Leah, 51, 20 years post-stroke)

Leah had no expectation that health services would help her. This was echoed by Sarah when explaining why she hadn't sought any support for her instability and falls following her stroke:

"Just I thought that that was to do with my stroke, it was a fact of life" (Sarah, 56, 23 years post-stroke)

Sarah valued her independence incredibly and found it very emotionally challenging to be dependent on others. As such she monitored her own health. She told doctors which checks she required, which problems were amenable to intervention and which issues needed to be addressed. By accepting that many of her altered perceptions could not be improved and by taking control of her healthcare which did require monitoring, she protected herself from feeling dependent on an unreliable health service. This experience was common amongst

participants, particularly in those a long time post-stroke. They had internalised the discourse that health services had no time or treatments available and as such had detached emotionally from the process of rejection by health services.

Others perceived themselves as needing to battle with health services to get the resources they needed. Becky who had coped with numerous rejections by health services, no longer personalised this feeling. Her sense of detachment from her altered body and self, enabled her to protect herself from feeling rejected by health professionals and she fought for the services she needed.

*[Referring to talking to health professionals about the achy feeling on her left side]
“they just say ‘it was the strokes’... that’s all they say, ‘it was the strokes’... [in] the beginning, I didn’t understand why they didn’t want to help... why they wrote you off almost... you have to fight to get... what you need... so I’m used to it now... fight back.” (Becky, 58)*

4.2.5.4 Communicating the altered body

As participants described their isolation from society and services, focus drifted away from the need to improve the altered body and ricocheted around the problems of being physically and verbally unable to access those services. This sense of isolation differed from the physical and psychological sense of bodily objectification touched on previously and reflected a need to gain support for the altered body which was hindered by an inaccessible system. Practical barriers were highlighted for those with language, cognitive processing or mobility problems as they struggled to access services. For example, Lou, found contacting the doctor quite cognitively challenging.

“I don't really like [calling the doctor]... it's a bit scary [laughs]... having to phone them up... My speech is a lot better but again it's that little bit of a worry about “okay am I going to be able to speak and get myself understood?”... I can't do months, I struggle with time, on the whole my speech is pretty good... I struggle to do days of the week sometimes... having to call the doctor to say: ‘oh actually he wanted to see

me in May', will actually be quite hard, probably get confused and takes me a while to be able to say the month that I want to say... I am going to see if they can send me an appointment... by the end of this month... So, I am putting it off which I suppose isn't a good idea [laughs]." (Lou, 39, 17 months post-stroke)

Lou was a mother to two small children and lived with a partner; she was well supported compared to some participants. Yet her inability to independently call the doctor increased her isolation from services. Her laughter demonstrated that she felt this should be an easy task, again suggesting a private and internalised component in the sense of difference experienced when not easily integrating into society.

Similar issues were experienced by Amal who didn't speak English as a first language and felt very isolated and unsupported. When asked if she had ever accessed health services about the perception that her arm felt heavy, she replied:

"Who should I go with, I don't have anyone to go with" (Amal, 54, 8 years post-stroke),

Amal felt isolated due to the triple limitations of being unable to mobilise independently, living alone with very little social support and being unable to speak enough English to communicate. She had had no rehabilitation since her stroke and felt abandoned and hopeless that her altered body perceptions such as limb pain, weakness, shaking and heaviness could improve.

The two participants financially able to access private physios and the one participant referred to an NHS physio reported feeling able to talk to these professionals about their altered body perceptions. Participants perceived these professionals as having the time and expertise to listen to them talk about their altered body perceptions and find appropriate solutions and they found some comfort in this relationship.

"the only professional I got to talk to these days is my private physio... when she asked me to do something, I'll invariably say: 'well which muscle actually is that? Oh,

what do you mean by my core; why are you telling me to push something down when all I can do is push something up or vice versa'... and then she laughs and says 'no-one's ever asked me that question before'... I suppose I could talk to the doctor, but he's not a stroke specialist... I don't have those sort of conversations with him..."

(Johan, 66, 11 months post-stroke)

Johan took pride in his depth of bodily understanding post-stroke and used this knowledge to put himself on a more equal footing with professionals. This was part of his identity and potentially an important facet in not feeling objectified by his body. Both participants accessing private physios reported significant improvements to body perception issues, due to this rehabilitation. These participants spoke fondly of this support and didn't express towards them the same feelings of inadequacy, frustration or insecurity which they did towards NHS services. This positive relationship enabled them to feel in control of, engage with and stay motivated with their stroke rehabilitation.

Many participants expressed the ease with which they could communicate with other stroke survivors about their altered body perceptions who were an important source of information and means to reduce their psychosocial sense of isolation.

"as we were driving up I was doing my twiddling my hand and moving my [arm]... [he said I was] showing off, 'cause his arm is much more affected than mine... and I explained... that if I didn't do that I'd end up with a leaden arm... and in fact I got him doing some exercises and using the FES machine... and his arm is actually [be]coming straightened it out... the trouble is you do not get this from the professionals, they abandon you" (Johan, 66, 11 months)

Yet some participants reflected on moments when they received more personalised support from NHS professionals, making them feel listened to; reducing the sense of isolation from services and providing psychological comfort.

"I changed neurologists 'cause one left... and the new one, he's been magic... total support... [he] treats me as a person and not as a stroke victim... I'm a person... he

always wants to know how I feel and what I need... [it makes me feel like] I'm not a freak [laughs]... I'm a human being, I am in here" (Becky, 58, 9 years post-stroke)

The interaction between the sense of body, self and the wider world became explicit in this excerpt. For Becky, the sense that professionals cared about her as an individual helped reunite her sense of 'object' body and self. This may have had an increased meaning for her because she lived alone and her wider family were not supportive of her altered perceptions. As such her sense of the objectified social body may have been less challenged through relationships, giving increased resonance to the voice of the health professional.

4.2.5.5 Summary of theme

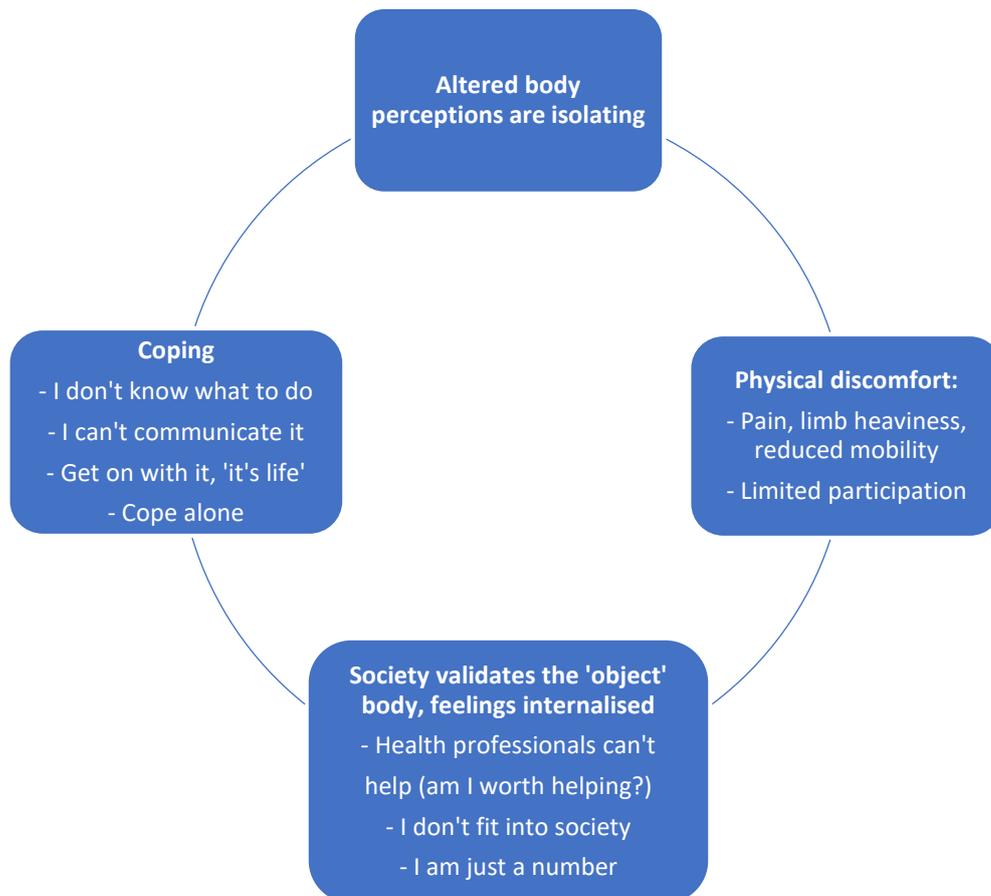
The experience of isolation when living with the altered body was multifaceted, spanning physical, psychological and social domains. Participants described instances where their altered body perceptions impacted their ability to physically access society, as they described overwhelmingly a desire to mobilise. Other perceptual changes such as headache and pain disrupting sleep also affected this access, contributing to a sense of social isolation.

From another vantage point participants were constrained by an internalised psychological discomfort that they were not acceptable to society. This led some to go out less and others into complex questioning of identity. Health professionals were inaccessible to many, compounding the notion that they were isolated and had to cope with the altered body alone. Participants internalised the discourse that the NHS was under pressure, leading to many to no longer seeking support from these channels in order to protect themselves from further rejection. Other barriers such as language, cognitive processing problems and mobility issues compounded the isolation experienced by some. Participants' conception of the 'object' body became validated by an external society, which objectified the body in a more extreme sense. This validation served to fuel uncomfortable internal beliefs about the body and self.

To cope with these complex emotions, participants tended to cope alone, relate to stroke peers or for the few who were financially able, access independent rehabilitation. Coping

alone was a protective and practical strategy to isolate the individual from uncomfortable and challenging feelings of rejection. Whilst many participants worked in their own ways to improve their experiences of uncomfortable altered perceptions, they were limited by factors beyond their control, such as not being able to make sense of or communicate their altered body perceptions. This compounded their experience of the 'isolated body' (Figure 9).

Figure 9. Schematic illustrating the 'isolated body'



4.2.6 The 'hopeful body'

The 'isolated body' led participants to establish ways to cope independently with the challenging, 'object' body. This led to the 'hopeful body', as many participants refocused on hopes for the future and possible treatment options as a way to cope with and reduce their psychological discomfort. Many devised independent rehabilitation goals. Participants who had high levels of understanding of the altered body, as well as motivation, autonomy, good communication, positive self-beliefs and the ability to finance their own rehabilitation developed beneficial and creative rehabilitation techniques. Those unable to understand or have belief in the potential for bodily improvement, found it harder to engage in successful rehabilitation. Those who didn't engage in independent rehabilitation but were mobile and were able to develop a psychological level of distance to their 'object' body, had a more positive sense of 'self'. Whereas others, unable to mobilise and engage independently in rehabilitation experienced more emotional discomfort.

4.2.6.1 *Get back to normal*

The majority of participants had a desire to improve their bodies and get back to normal. These participants were predominantly male, less than two years into their stroke recovery and had a hope that they would be able to achieve some meaningful change to how their bodies felt and functioned. They often used this belief as motivation to engage in rehabilitation.

"I've got loads and loads of goals... things I want to do again and... 'cause I don't look [at it] as... probably rubbish but, of it being permanent... I see that I can be cured [laughs]" (Dave, 65, 18 months post-stroke)

These participants were focused on a future that was different to their present situation. They were not ready to accept the body mired by unacceptable physical changes, so they threw their energy into changing the body any way they could. This proactive approach produced results for many and reinforced a sense of control over their situation.

Yet participants repeatedly described instances of negative predictions from health professionals about their likelihood of recovery post-stroke. These predictions were often at odds with their sense of drive and motivation to achieve rehabilitation goals.

“P'raps he knows that I won't [get better], he's just being truthful with me but... the trouble is, when somebody says that to you, you think right well I'm going to prove them wrong don't you... 'cause we never know do we?... I said to him 'I've been struggling with this pain for so long, I thought I was getting better' and he said to me 'well you'll never get better from a stroke'... [laughs] so that sort of knocked me back a bit... I'm going to keep bashing my head against a wall to get myself better and then I'm going to up and knock on that [doctor's] office door...and say: 'here look, two hands knocking on the door' [laughs]...” (Marc, 64, 2 years post-stroke)

It was important for Marc to not accept the altered body and he used this as a springboard to motivate himself to work hard. Despite feeling ‘knocked back’ – an embodied metaphor – his sense of identity retained resilience and he continued with his goal of ‘fixing’ the ‘object’ body.

A few participants described positive exchanges with professionals. For Johan, this was important in terms of providing hope and giving him a goal to work towards.

“ [the arm] was both 'not there' and incredibly painful because the subluxation had come... so the shoulder was incredibly sore and I remember saying 'well if you lopped it off would that stop all this pain?'... The doctor said... 'the feeling will come back, it will become useful'... that was good, because it was the first time anybody had suggested that something might get better.” (Johan, 66, 11 months post-stroke)

This account captured the importance of hope and psychological comfort in providing positive focus on the affected limb. The interplay between internal and external worlds is highlighted, as Johan internalised a view of his ‘object’ body which moved him towards a different future.

For many who were able to engage in independent rehabilitation, measuring progress in bodily recovery and activities was a key factor for improving psychological motivation and emotional comfort. It gave them a sense of control over their uncontrollable 'object' body. It was intertwined with their hopes of getting back to a sense of normality and fuelled their motivation to work hard.

"You achieve something for the first time... and the feeling is utopia, I'm not joking it is fantastic... I can come back from my dad's on cloud nine, I'm not joking it's absolutely fantastic... because you realise you have just made another step to getting back to normal life..." (Toby, 46, 19 months post-stroke)

For many, these successes became a primary motivator for rehabilitation, leading to some participants approached rehabilitation like a project, measuring and plotting their successes in incremental detail.

"On the cycling, I start off at 5 minutes and now I've got 8 minutes, so I can see there's an improvement... So I'm thinking, 3, it's only 1 more till I'm 4... When I'm at 4, that's halfway and when it's 5 I'm more than halfway... So, I have a high level of need for achievement... I've always pushed myself." (Alistair, 72, 11 months post-stroke)

Monitoring progress and noting improvements to body perceptions, gave many the motivation and the confidence to believe that they had the autonomy necessary to alter their current situation. It fed into their hope that they might be able to 'get back to normal'. They were means to objectify the body; making it a 'fixable' and separate from the self. It put the body back under control, maintaining a sense of hope that the current reality would not be the future reality.

4.2.6.2 Work hard

The majority of participants engaged in self-directed weekly rehabilitation activities, yet some engaged in more significant amounts of rehabilitation. These participants happened to

be male, had high levels of autonomy and education and had all had their work activities curtailed by their strokes. They felt empowered by rehabilitation and believed they could conquer the 'uncontrollable body'.

"they said to me your average stroke patient will use the gym about one hour a week... so I thought a couple more wouldn't do much harm...so I did three hours a day, five days a week... so fifteen hours a week in the gym and just really kept going..." (Toby, 46, 19 months post-stroke)

These men approached the body like a project and had a staged plan in how they would approach their physical deficits. The 'body project' replaced the role of employment in some sense, taking up significant time and mental focus. When Toby was asked to reflect on his use of third person language towards his body, he said:

"I suppose it's the same I would do with any project, it's 'the this or the that'... y'know because that's the problem, that's what I'm trying to work on, that's what I'm trying to get back... so, they're seen as two projects" (Toby, 46, 19 months post-stroke)

These participants among others, were resourceful and autonomous. They were able to make sense of their altered body perceptions and whilst maintaining a degree of hope that they could actualise a physical improvement.

"you can feel pissed off that the state doesn't have anything more to do... with helping me, but on the other hand you just get on and... find whatever solutions you can to continue the progress... I had to retire from work and rebuilding myself...is most of what I do... it's most of my energy... either in going to the gym or going swimming, or trying to... move my right hand as much as I can, or just walking, it takes up almost all my time really... I don't have much time to do things that aren't physical..." (Stuart, 60, 20 months post-stroke)

For these participants' bodily objectification was a factor which facilitated their rehabilitation. By separating the body from their sense of self they were able to engage with

it and improve it without dealing with a host of negative emotions. Stuart's phrasing of "rebuilding" his "self", highlighted the integration between the physical and psychological facets of the individual.

Michelle, four years post-stroke was the only woman who subscribed to this ideal of working hard.

"Since I've started doing the [physio course] and moving it more... you get a funny sensation... as though somethings doing something...I don't know, it's just like you get a bit of movement, you get a bit of like shaking a bit... could be anywhere... it's a weird sensation... the last six months it's started doing some funny things... it's weird... I just really don't know how to describe it.... there's... something going on... just makes me feel p'raps there's something[s] ...gonna work... who knows... feels alright... 'I think 'oo perhaps something is gonna to happen'... who knows... what you can do, but hope you can" (Michelle, 49, 4 years post-stroke)

Despite having lived with her altered body perceptions for several years, she had a renewed sense of hope that her condition might improve. The novelty of the sensations of *shaking* and the body feeling *weird*, were not perceived as troublesome or negative, but as a sign of potential which gave her hope. Again, the experience was indescribable. The sensation was closely linked with the ideas of getting the limb to function which had obvious impact on her emotional comfort.

4.2.6.3 Making sense of altered body perceptions

For several participants, having a good grip of the neurological reasons for their altered body perceptions was important to help them understand their bodies and feel a sense of control over their situations.

"on the right side... you're building new connections in your brain between the different muscles and your brain, but inevitably they're much fewer... than you have normally...so, although I'm quite strong in certain muscle groups... I know that's

dependent on fewer connections with the brain if you see what I mean...and I think I'm managing to build some more connections with the muscles to the brain, but there's no way that it's going to be the same amount as normal..." (Stuart, 60, 20 months post-stroke)

For Stuart, understanding the neurological reasons for his body changes meant he could justify his impaired function. This perception aided his motivation to engage in rehabilitation and seemed to foster a sense of understanding towards his body. Similarly, for Johan, his perception that he could measure physiological sensations to indicate improvements in perceptions and function gave him a sense of hope and control over his situation.

"I know it's madness, but... I get this curious sensation of the neurological pathway trackways working or not working [in the leg]... I [have] this curious sense that I can actually think my way down the arm, or isolate the arm in order not to feel too much pain in it... so now things that my right hemisphere used to do are having to be moved over to the other side... it feels exactly like trying to use a muscle. You have this sense that you're transmitting down the neural pathways... I don't know quite how to describe it. To begin with it felt like little worms crawling down... in my head as well... I think it's totally mad and I'm telling something I find slightly embarrassing" (Johan, 66, 11 months post-stroke)

Johan used this perception to motivate his engagement in rehabilitation, engaging in exercises – often thousands of repetitions of actions - until the perception of ‘worms’ abated, which coincided with a feeling the body movement had become less conscious and more automatic. Yet he felt obliged to reiterate that he knew it was strange and ‘mad’, ensuring his bizarre experience was not misconstrued by an observer. This strangeness led to embarrassment implying it was something not discussed in the public domain.

Whilst a few participants were able to make sense of their altered body perceptions, the majority were not able to. These participants also engaged in rehabilitation but it was accompanied by an uncertainty as to whether this would make a tangible difference to some altered perceptions.

"[Interviewer: have they given you anything to try and ... Improve those sensations [of stiffness and pain]?] Yes, exercises... But nobody has explained to me, if you like, the physiology of 'why does it feels as if it needs oiling? What is it?'... So, I look for signs of improvement... I'm hoping if I just keep working at it, I don't know, maybe I shall get the movement back..." (Alistair, 72, 11 months post-stroke)

For Alistair, in the early stages of recovery, his motivation for rehabilitation was tied to a sense of hope that his hard work would pay off and his body become more controllable. Yet, his language demonstrated a level of uncertainty about whether his endeavours would pay off. Nevertheless, his autonomy meant he diligently attempted to improve things at this early stage in recovery.

However, a few others were less able to engage independently, due to an inability to make sense of their altered perceptions.

"nobody bother about her...she say 'I'm alone, nobody bother for me'... she say 'one month I stay in one hospital, one month I stay another hospital and that's it' and after that... she say 'they never even came [to] me for exercise and things... she says 'nobody here...who will see my feelings, [and] what's going on' ... she says she feel like crying sometimes... she says 'nobody who I talk to'" (Amal, 54, 8 years post-stroke)

Amal had internalised a sense of rejection by health services which suggested she was not worth engaging in rehabilitation. Her sense of isolation, lack of control and understanding over her situation meant she could not engage in improving her situation. As such she was unable to create a recovery narrative for herself, leading to a lack of hope and psychosocial discomfort.

4.2.6.4 Re-imagining the 'self'

Three female participants, 9, 21 and 23 years post-stroke presented an alternative narrative and did not talk in terms of wanting to get back to normal or treating the body as a project to change. Their discourse was at odds with the idea of taking control of the body. They displayed a hesitating acceptance of their situation to improve their psychological comfort.

"[When asked if she has feelings towards her right arm] No, not really, no... Yeah, it doesn't work, that's fine". (Sarah, 56, 23 years post-stroke)

These participants presented an acceptance of their altered body perceptions. They had lived with the changes for a long time and did not have any expectation that their bodies would improve. Yet whilst presenting a sense of acceptance, these participants simultaneously described things they hated about their current situations.

"My independence has been curtailed... people have to pick me up and I... absolutely hate that... because that's what I used to [do]...yeah you got to accept it... life is slower... you can't rush around, which is probably a good thing... I think it's a gradual thing, I mean it irks now and again but it doesn't bother me... it's this old 'accept' [laughs]" (Leah, 51, 21 years post-stroke)

These participants didn't necessarily feel they could change their altered perceptions, so they no longer tried to get back to a pre-stroke version of normal. They verbally expressed that they could tolerate the body they had and were no longer emotionally conflicted by living in a disabled body. Yet, they also referred to things they found frustrating and difficult about managing their body changes. The expression of bodily acceptance was a way to avoid emotionally challenging thoughts, the dissonant ideas belying the emotional conflict of living with the altered body.

This conflict was highlighted as the participants articulated their privately composed negative feelings about the appearance of their altered bodies.

“I look in the mirror at myself naked, I don't like what I see... Because the redness of this foot, you know compared to this foot... It [the body] is held quite tight and just around my elbow I've got loose skin you know, it is [makes yuck sound] [laughs]... I just think 'get dressed and cover it up', you know?” (Sarah, 56, 23 years post-stroke)

When Sarah's physically altered body was made visible to her in the mirror, the reality of her altered body became unavoidable. To cope with the sense of disgust towards her changed body she distracted herself from it by covering her body – removing the offending object from her view. It seemed that for these women the sense of acceptance they expressed was not necessarily related to a true acceptance of their altered body after stroke. Rather, they had developed an ability to prioritise their sense of self to cope with their altered bodies. Becky reflected this in her sense of feeling emotionally comfortable with her body.

“[Talking about feeling comfortable in herself]... [I feel] happier...that I have bits that don't work, but that's not the whole of me, I am a person... and I have a personality... and if people can't see that they can't see past... the physical... that's not my problem it's theirs” (Becky, 58, 9 years post-stroke)

In her account there was a sense of resoluteness as she pitted her sense of self against the outside world. Her focus on her individuality was strong as it had to overcome her sense of the impaired physical self.

A sense of bodily acceptance was repeatedly highlighted by Alistair, an individual who also engaged enthusiastically in rehabilitation to improve his altered perceptions.

“I think of people whose arms have got even less mobility than mine... That's a pretty perverse way of gaining some comfort... I just accept the fact that sometimes in life things go wrong” (Alistair, 72, 11 months post-stroke)

Despite his viewpoint of acceptance, Alistair hinted at the need to gain comfort in his situation. When pressed further to elucidate his feelings towards his body he was

particularly hesitant to discuss any negative emotion, yet he explained the relationship further:

“It’s a negative thought in that I don’t like the way my left arm is, that’s not the way my left arm should be, that’s not what left arms are for... I don’t like the way it’s currently doing, I preferred it otherwise... It doesn’t drag me down in the sense...”
(Alistair, 72, 11 months post-stroke)

Alistair’s standpoint was important in upholding his positive mood. His objectification of his arm was psychologically comforting, enabling him to hold dual ideas of bodily dissatisfaction whilst retaining optimism about his potential.

Whilst most participants relentlessly focused on the positive to avoid dealing with negative emotions, some found it difficult and effortful to maintain the positive mindset in the face of such adversity.

“You see other people you think... I mean I’ve got a sad story to tell, but everybody else has got an even bigger, sadder story to tell... I get no pleasure out of thinking there’s people off worse than me... in the end you’ve got to say, “yeah but what about me?” (Joel, 64, 2 years post-stroke)

Joel, like many, tried to maintain a positive mindset through comparing himself to others worse off, yet this comparison only carried him so far. He acknowledged that it distracted him from his own emotions and meant he couldn’t acknowledge his own loss and emotional pain. Joel, was a self-confessed ‘negative thinker’, stating he could be “*negative for England*”. For him distracting himself from emotional discomfort was helpful but not the whole solution it was for other more positively minded participants.

It was easy to understand why participants separated the ‘object’ body from their sense of self. On the few occasions participants let themselves focus on the enormity of the trauma they had suffered, the emotional discomfort of living in the altered body came through clearly.

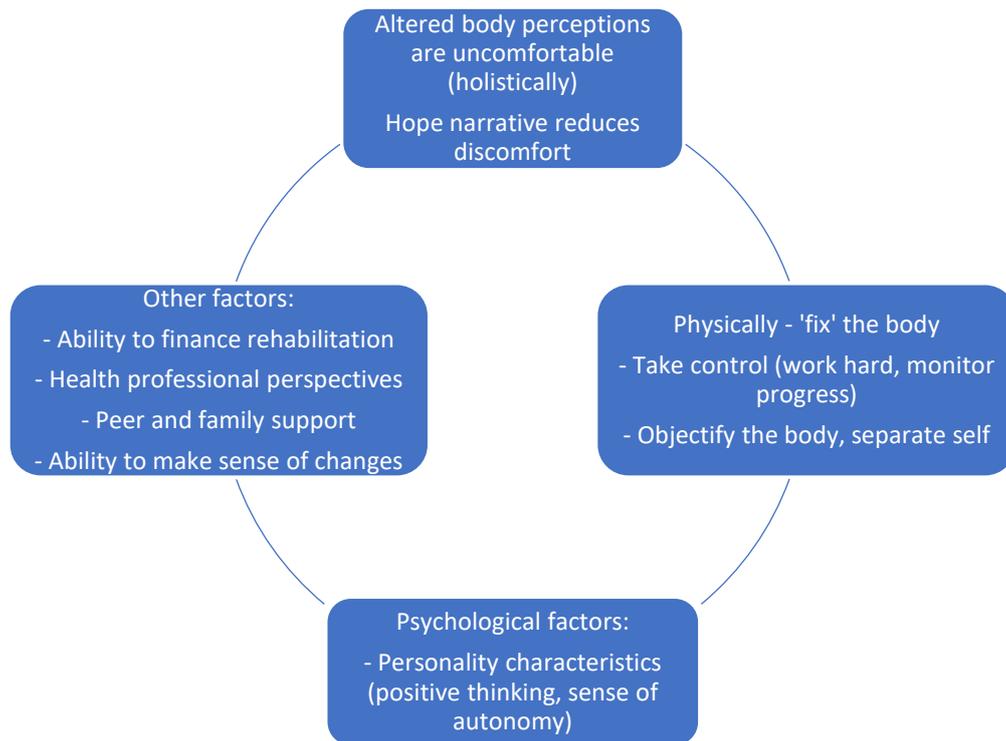
“you're on the outside all the time... you're an alien... I feel like I'm not quite a person really, not in what [I expect] my personhood to be... I've changed... now I'm a person with a stroke and you know, it was a pretty major stroke and... in a way that was the next phase of my life... however hard I try, [I'm] in a sort of parallel existence so that, when people come to the house or whatever, I'm not the person they would have encountered, I'm this other person” (Stuart, 60, 20 months post-stroke)

4.2.6.5 Summary of theme

The experience of the ‘isolated body’ in the previous theme led to many participants relying on themselves and adopting an attitude of hope that their altered body perceptions would become more physically and psychologically comfortable. Being hopeful about bodily recovery reduced psychological discomfort by providing focus, as participants sought to take back control of their rebellious bodies. Most participants had an overwhelming desire to physically ‘fix’ the body and get back to normal. This belief was useful for motivating engagement in rehabilitation and participants frequently expressed that they worked hard, set goals and monitored their own progress to gauge how successful they were, whilst trying to make sense of their altered bodies. Objectification of the body was key to this process. Distracting from negative thoughts and positive thinking, enabled participants to avoid internalising negative thoughts about themselves and the future.

These positive strategies were challenged when health professionals did not share the same ideas that they could get better, thereby challenging their narrative of hope. Other practical issues also affected participants’ good intentions, such as their ability to finance rehabilitation and understand how to address rehabilitation issues. Participants grappled with different ideas of acceptance to come to terms with their bodily change. Those who purported achieving acceptance often held ideas dissonant with this concept, suggesting accepting the body post-stroke is a multi-layered experience (Figure 10).

Figure 10. Schematic illustrating the 'hopeful body'



4.3 Discussion

4.3.1 Reflection on theme titles

The theme titles of the 'disappearing', 'reappearing' and 'uncontrollable' bodies were influenced by constructs originally put forward by Leder (1990). Leder's (1990) seminal book, *The Absent Body*, explored the embodied lived experience and considered the body in terms of presence and absence, reflecting the sense of bodily consciousness or awareness. For Leder (1990, p23), the experience of bodily presence was:

"fleshed out by a ceaseless stream of kinesthesias, cutaneous and visceral sensations, defining my body's space and extension and yielding information about position, balance, state of tension, desire and mood".

Leder (1990) reflected on a healthy body, subconsciously present in sensation and perception and often absent, recessive and largely concealed during intentional action. The experience of bodily absence can be inherently tied into the notion of intentionality, wherein the body becomes the means to access the world. Moments in which the body is motivated by intentionality, the embodied experience becomes absent from perception, *"forgotten in experience... The body conceals itself precisely in the act of revealing what is Other... Yet this absence is not equivalent to a simple void, a mere lack of being. The notion of being is, after all, present in the very word absence"* (Leder, 1990, p22).

When considering the body in illness Leder (1990) coined the term the 'dys-appearing body', referring to moments when the body becomes starkly present, as in moments of pain. He described the demanding nature of these sensory moments, which bring the body into focus and distract from or inhibit bodily intentionality. The perception is alien and forces the body to become apparent. At the loss of body intentionality, the body's relationship to its environment becomes compromised. The body becomes present in more than physiological terms. Attention is also brought to the body in emotional and social terms, as one has to re-evaluate the whole relationship between the body, self and society, resulting in a

multidimensional 'othering' of the body. This relationship highlighted the embodied experience of the world, emphasising the importance of perceiving embodied perception and comfort in terms of the body and the wider world.

Leder's (1990) conceptualisation of the body as absent, present and 'dys-appeared' in illness are relevant considering the relationship between bodily consciousness, loss of intentionality, bodily objectification and responding to problematic and demanding perceptions in the post-stroke body. Yet the embodied experience of the post-stroke body elucidated variations in bodily reflection that required specific focus. To facilitate this the concept of the 'Dys-appearing body' was adapted in this study into three areas: the 'Disappearing, Reappearing and Uncontrollable body'. This separation served to bring specific focus to these diverse post-stroke experiences. Using a specific term to highlight the experience of perceptual loss in the 'disappearing body' was helpful, as Leder's (1990) reference to bodily absence or disappearance differed from that experienced when the body is perceived as lost through neurological injury.

4.3.2 The term 'comfort'

The term comfort has not previously been used in the literature to describe the embodied, patient-centred experience of living in a body altered by stroke. In this study, a holistic conception of the term comfort, which incorporated the physical, psychological and social experience of altered body perceptions was adopted (Kolcaba, 1991). In line with this holistic construct, this study considered participants' experiences of 'internal', physical body perceptions and how these perceptions were enacted, lived and reflected on in the external world. The breadth of the concept allowed moments of discomfort to be interpreted by the author. For example, when participants expressed a physical sensation as uncomfortable or painful; moments the body was described as frustrating, confusing, upsetting or challenging to the sense of identity; and moments when the altered body inhibited interaction with the environment or social relationships.

Utilising a holistic perspective of comfort was helpful because it enabled participants to express experiences, which may not be perceived as explicitly physically uncomfortable. For

example, the term 'discomfort' tends to be used to describe moments when the body becomes more noticeable, for example in pain. However, exploring participants accounts of discomfort in more broad terms enabled the strangeness of altered perceptions after stroke to be captured. Being able to describe the loss of perception of a limb in terms of emotional discomfort, gave these experiences focus which otherwise may have been overlooked whilst aiding the embodied perspective of the altered body. Giving voice to the breadth of problematic experiences is key because terms may be interpreted in subjective ways. This was highlighted when a holistic perspective of comfort was adopted to explore patients' experience of undergoing perianesthesia, wherein they reported feeling comfortable whilst simultaneously describing experiences of pain (Kolcaba and Wilson, 2002). This affirms that the two terms are not synonymous and that psychological factors can outweigh physical experiences and vice versa.

Many participants freely used the term discomfort to refer to difficult physical sensations and states of emotional unease. The term was subjectively interpreted and understood in different ways by participants (Appendix B.12). It was therefore important to ensure participants were not conceptually limited by the term in describing their own altered perceptions and when responding to interviewer questions which utilised this word. To prevent this the use of the term comfort or discomfort was used as a conceptual aid to bring together understanding of difficult or challenging bodily and psychosocial experiences post-stroke. The term facilitated reflection on the body in easily comprehensible patient-friendly language. It evaluated impact holistically which enabled the observer to see the cumulative effect of experiencing multiple and, at times, conflicting altered body perceptions from holistic viewpoints. It is worth noting that Kolcaba's framework (1991) referred to the individual experience of discomforts in which they felt a sense of 'relief' or 'transcendence' when resolving discomforts, or in absence of discomfort, a sense of 'ease' (Section 1.7). This study suggested that after stroke, survivors were unlikely to experience 'ease' (the absence of any discomfort) and more likely be focused on 'relief' or 'transcendence'. Further research into the comfort experience after stroke, for survivors in the community (as opposed to the hospital and nurse care environment outlined by Kolcaba, 1991) would be interesting to illuminate this experience further.

4.3.3 Discussion of themes: Looking inwards

4.3.3.1 *The 'Disappearing, Reappearing and Uncontrollable body' and discomfort*

Throughout the 'Disappearing, Reappearing and Uncontrollable body' themes, participants captured the physiological perceptual changes that occurred during the embodied post-stroke experience. These changes involved a spectrum of physical and psychosocial experiences which conveyed a body which did not exist; a body which obviously felt bizarre or abnormal; or a body which could not be controlled in activity. Moments when these perceptual changes were acknowledged varied depending on how demanding they were of attention and how they impacted day-to-day activities. The level of perceived physical discomfort tended to worsen when the perceptual change demanded more conscious focus. So, perceptions of the body as distorted or painful, or a body which did not respond to intended movement were described as the most physically uncomfortable. The body which was perceptually lost caused psychological discomfort.

As noted in Section 1.7, comfort after stroke has only been briefly alluded to in the literature. When developing a scale to explore comfort in activities-of-daily-living in hospitalised stroke survivors, Rogeau et al. (2014, p106) highlighted that "*motor impairments, fatigue, limb stiffness, joint pain, unsteadiness and psychological difficulties [were] the mains sources of their discomfort*". The scale acknowledged the variety of altered perceptions which can impact discomfort, how these changes can be exacerbated during movement and multiple uncomfortable perceptual changes can co-occur. The findings of the current study (Chapter 4) provide explanation for how and why such body changes are experienced as uncomfortable and provides evidence for the use of a holistic understanding of discomfort to describe these experiences.

Many of the body changes described in the phenomenological study have been alluded to in other qualitative literature. Timothy, Graham and Levack (2016) captured the 'whole-body' stroke experience, in a small group of seven survivors less than four months into their recovery. They highlighted the physical perceptions of a body which was experienced as strange, effortful, unpredictable and uncontrollable, emphasising the impact of these body

changes on embodied perception. These findings built on stroke research by Kitzmüller, Häggerström and Asplund (2013), which captured the experience of living with spasticity, discomforting pain and fatigue; a body which was 'not me' and had become conscious. The findings of the current study (Chapter 4) explored the discomfort associated with body perception changes in more depth, which provided two areas of novel focus. Firstly, it deepened understanding of what perceptions were most discomforting to stroke survivors thereby providing focus for physical and psychological interventions. Secondly, it provided a nuanced exploration of these perceptions to pinpoint exactly which aspect of the altered perception was problematic for the stroke survivor and why. For example, in discussing the 'uncontrollable body' in-depth, participants described the gap in bodily response as a cause of physical and psychosocial discomfort.

Providing specific focus to certain experiences of the altered body provides valuable insight which can highlight issues important to the patient. For example, the extended focus on the 'disappearing body' in this study emphasised the experience of perceptual loss and the moments in which this became noticeable and uncomfortable physically and psychologically to stroke survivors. Research into other conditions has begun to look in-depth at specific instances of altered perceptions, such as the experience of stiffness in arthritis (Halls et al., 2015); or the experience of temporary paralysis from spinal anaesthesia (Bager, Konradsen and Dreyer, 2015). This has provided important information to help the clinician understand the patients' perspective in more depth.

Several researchers have provided in-depth focus on specific post-stroke conditions or areas of the body, such as: neglect (Tham et al., 2000; Klinker et al., 2015); apraxia (Arntzen and Elstad, 2013); spasticity and stiffness (Sabini et al., 2013); pain (Widar, Ek and Ahlström, 2004); the foot and ankle (Gorst et al., 2016); or the upper limb (Doyle, Bennett and Dudgeon, 2014). These findings provide important focus for clinicians, yet they also lose something as they are not able to reflect on the full complexity of the 'whole-body' experience of stroke. Conversely research which has adopted a broader focus, frequently describes altered perceptions in terms of their psychological and social embodied effects or stroke trajectory (Faircloth et al., 2004; Murray and Harrison, 2004; Nasr et al., 2016). Through exploring the altered body through the construct of comfort, this

phenomenological study bridges this divide. In-depth focus on the body utilising the construct of comfort provides a bridge linking how diverse physiological experiences lead to psychosocial impact, which can provide focus for clinicians.

4.3.3.2 The 'object' body

The experience of the 'object' body was described across themes and was an inherently multifaceted perceptual experience. Objectification of the body was both a consequence of physical changes in which the body was no longer perceived or responded to as normal and a psychological strategy to deal with these body changes. This understanding elucidated how bodily objectification protected the 'self' during different physiological perceptual experiences and explored how it motivated rehabilitation at different stages.

The body and self in health and illness have been conceptualised in the literature by Gadow (1980). Gadow (1980) described, in health, the self and the body as inseparable; the body-self united in a relationship with the external world. The lived body is perceived as harmonious and is the means for being in the world, it displays both vulnerabilities and an inherent agency to act in the world, which do not disturb the sense of body-self. Yet in illness, the lived body becomes impeded and constrained. The body becomes the site of constraint and the self gives meaning to this constraint, thereby creating a *"body and self at odds with each other"* (Gadow, 1980, p175). From this tension, the body is experienced as an obstacle *"the 'object' body emerges out of the primary unity of the lived body in the experience of feeling encumbered by oneself"* (Gadow, 1980, p176). Leder (1990) concurs suggesting that the conceptualisation of the 'object' body is intrinsic to coping with the cumbersome body in illness as *"when the affected part of the body becomes 'other' to the ego, one becomes more ready to take whatever means necessary to rid oneself of it"* (p77).

Gadow (1980) suggests that coping with the separation of the body and self, involves reuniting the disparate selves which can be problematic. The self tries to master the body, but if unsuccessful, the body becomes the oppressor and humiliates the self. The self may *"disengage concretely from the unwanted, oppressive body by negating its 'mineness' in emotional and perceptual terms. Neither level of detachment, however, reinstates the self as*

master" (Gadow, 1980, p179). The body-self opposition is only resolved when the self masters or feels unconstrained by the body. In illness, to restore harmony between the disparate selves, the individual must move beyond the self, subjugating the 'object' body. The self must recognise the 'subject body', so "*when the body is experienced as subject, it is considered a part of the self with the same intrinsically valid claims as any other part of the self (emotional, intellectual, etc.)*" (Gadow, 1980, p180). In this recognition, the self responds to the body in a complex manner and accepts the body as part of the self. Gadow's (1980) construction acknowledges the embodied nature of the self, describing how conscious experience can shed light on the dynamic between the self and 'othered' body.

The construct of bodily objectification after stroke has been well documented and the findings of this study resonate with the literature (Chapter 2). Doolittle (1992) documented the lived experience of 13 stroke survivors who experienced lacunar infarcts less than 6 months post-stroke and highlighted how participants referred to their bodies in passive, objectified language, which, in the early stages, served to encourage engagement in rehabilitation goals. In Tham, Borrell and Gustavsson (2000), four participants experiencing unilateral neglect less than 10 weeks post-stroke, described the hemiparetic side of the body as separated from the body and out of control. Faircloth et al. (2004) analysed male accounts of the body up to two years post-stroke and similarly described the experience of the 'object' body which needed to be 'talked to' to achieve mastery and control. Ellis-Hill, Payne and Ward (2000, p728) described the body-self separation of eight stroke survivors, up to two years post-stroke. They referred to a "*separate precarious body*" which had become "*out of control*" thereby creating conflict with the sense of self.

This phenomenological study (Chapter 4) adds to the literature providing a detailed exploration of the experience of the 'object' body by relating it to different altered perceptions, such as perceptual loss, pain and loss of bodily control. The findings also provided insight into the experience of bodily objectification as it evolved over a broad time-period post-stroke (six months to 22 years post-stroke). For most participants, particularly those less than two years post-stroke, objectifying the body served to motivate rehabilitation. It encouraged participants to engage in strategies such as hard work, measuring progress and goal setting, to improve the problematic and uncomfortable body.

For demanding perceptions, like those articulated in the 'reappearing body' and 'uncontrollable body' themes, alleviating and fixing these perceptions was supported by perceiving the body and self as separate. The importance of bodily unification in rehabilitation became apparent in the 'disappearing body' theme, as the sense of the body-as-object served to enhance a detachment from the body. The body was forgotten and easily ignored, its separation from the self became problematic as it did not demand attention, become conscious and was therefore not something the self needed to 'fix'.

Participants in the later stages of recovery tended to distance themselves from the rhetoric of trying to 'fix' the body. They expressed sentiments like 'that's just what it is' and described the body as 'fine'. They strived to achieve a sense of 'acceptance' and normality towards their bodies, yet their language and avoidance of their bodily sensations belied this goal. They tended to avoid reflecting on their altered body perceptions or attaching emotion to these bodily changes unlike those in the earlier stages of recovery. This may have been an adaptive coping strategy to living with altered body perceptions which they no longer perceived they had autonomy to change. One participant, Becky, described how she felt more "comfortable" in herself once she had prioritised a sense of her 'self' over her body stating, "I'm in here". Whilst these participants expressed that they had 'accepted' some of the bodily changes they had lived with for many years, interpretation of the objective language and negative metaphors they used to describe their bodies suggested the body and self were still conflicted.

Charmaz (1995, p663) suggested that as illness becomes chronic the individual may move beyond mastering the 'object' body. Instead of "*struggling against illness*" they move to "*struggling with illness*" and begin to live a new, altered body. This construct has much in common with the idea put forward by Gadaw (1980), of the 'subject body' – a subjugated version of the "object' body'. The findings of this study flesh out this idea in stroke survivors who expressed inconsistencies in their accounts of bodily acceptance. Their objective language and metaphors showed the complexity and fluidity of unifying the body and self in chronic stroke; the problematic nature of the body making any unification between body and self tenuous. This raises questions as to what constitutes acceptance of the embodied physiological experience of altered body perceptions post-stroke, querying whether this is

an important component of holistic comfort for stroke survivors (a discussion which continues in the Section 4.3.3.5).

4.3.3.3 Consciousness of the 'object' body and comfort

Throughout participants' accounts, the notion of using the mind to control the 'object' body was repeatedly emphasised. Conscious control of the body increased the sense that the body was an object, distant from the self and uncontrollable. The dualism of the mind controlling the body mirrored the divide between body and self. This research adds to the understanding of how bodily consciousness may be experienced after stroke, as participants described being aware of controlling the body as uncomfortable and maintaining a dialogue with the body as frustrating.

The experience of conscious bodily control has previously been captured in the qualitative stroke literature. Ellis-Hill, Payne and Ward (2000) discussed how it was the experience of the perplexing and unreliable body which brought the body into patients' conscious awareness. Doolittle (1992, p239) highlighted that *"Survivors frequently experience the need 'to tell the body what to do'. Doing this seems to increase their sense of bodily control"*. She captured how it was the lack of bodily control, an unpleasant perception, which brought awareness back to the body. Timothy, Graham and Levack (2016) suggested that it is the sense of bodily unfamiliarity which generated conscious awareness and contributed to objectification of the body. Within the current study, some participants suggested that it was the gap between directed intentional action and the lack of bodily response which was experienced as physically uncomfortable. This observation highlighted the absence of terminology to capture the experience of perceptual loss. For many, the loss was easier to describe in terms of its manifestation; the emotional and social discomfort which were the consequences of living in an 'uncontrollable body'.

In the 'reappearing body' theme the data highlighted bodily consciousness in terms of how perceptions such as pain, or strange and distorted sensations, demanded and dominated participants' consciousness. The fluctuating nature of this demand depended on activity or time of day causing psychosocial discomfort. Previous stroke research looking at post-stroke

pain, described these perceptions as unpleasant, intrusive and occurring both when the body was static and in movement and used terms such as burning, cutting, dull or numbness to convey their demanding sensory experiences (Widar, Ek and Ahlström, 2004). The conscious experience of the impact of sensory change in the upper limb after stroke has also been noted. In their study of 15 stroke survivors' experiences, Doyle, Bennett and Dudgeon (2014) briefly captured how they described a sense of numbness, heaviness, coldness and a loss of bodily awareness in their limb. These perceptions were described in terms of their impact on activities-of-daily-living and the body was described as exhausting and frustrating, as it demanded conscious attention and concentration. Grouping the bodily stroke experience into categories of the 'disappearing, reappearing and uncontrollable body' was helpful. It clarified how the body drew conscious attention towards itself – through demanding perceptions or loss of intentional movement or in the case of the 'disappearing body' emphasising the absence of conscious attention to the body.

4.3.3.4 Congruence between the body-self and embodiment

The issue of body-self separation after stroke has recently been discussed in an analysis of the experiences of seven stroke survivors one month after hospital discharge (Timothy, Graham and Levack, 2016). They emphasised the interplay between some of the physiological experiences of the strange, unpredictable and effortful body on this body-self conflict. Yet, they juxtaposed this with a suggestion that participants maintained a whole 'sense of self' despite their illness when they regained some bodily control, which helped provide a feeling of freedom and a clear sense of identity. They challenged the idea of the concrete and unidirectional nature of the body-self divide in illness, suggesting that in the early stages of stroke recovery participants were still able to hold multiple and contrary representations of their body and self; highlighting the dynamic nature of this relationship and giving some focus to the environmental factors which anchor the bodily experience. This highlighted factors which may contribute to a positive sense of self after stroke, whilst unveiling physiological perceptual factors such as knowing the body will respond as required, which may contribute to this cohesive embodied perception. This current study identified similar instances where participants tried to regain control over the body – for example, as they worked hard, measured progress and celebrated rehabilitation successes.

However, these factors were interpreted as indications that the self was trying to cope or remedy an 'object' body. Within this data, which looked at participants over a longer time-period post-stroke than Timothy, Graham and Levack (2016), the evidence that the body and self remained divided subconsciously during chronic stages, supported this notion.

Despite the evidence of the body-self divide discussed in stroke literature, it is useful to reflect critically on this theoretical construction, which appears to be embedded in a Cartesian dualist philosophy of the mind and body. This idea may be dissonant with a true understanding of patients' embodied experiences and Merleau-Ponty's (2001) holistic conception of the 'lifeworld'. To remain congruent with embodiment theory and participant experiences of the body as a physiological and psychological perceptual entity anchored in a physical reality, it is useful to begin to conceive these factors in more than binary, body-mind terms. As succinctly emphasised by MacLachlan (2004) *"Merleau-Ponty ties mind and body inexorably, not in seeing them as two sides of the one coin, but perhaps more in denying the possibility of the shape of the coin existing without the metal that constitutes it"* (p3). It may be that the mind is not separate from and in control of the body, but rather the sense of drawing attention to the body and achieving a bodily response is a physical and psychological process.

In stroke literature, research on embodiment and body ownership - in terms of survivor experience - is in its infancy. Altered sense of body ownership was briefly reflected on by Tham, Borrell and Gustavsson (2000) describing the experience of neglect after stroke. They discussed how perceptions of coldness and swelling in the limb may have contributed to the sense of unfamiliarity and bodily disownership experienced in four patients as they 'discovered' their neglect. Within the participants in the current research, the experience of strange sensations seemed to contribute to their sense of bodily disownership, as the body became conceptualised as problematic, uncomfortable and, for those in the earlier (less than 2 years) stages of recovery, in need of 'fixing'. Within the theme of the 'disappearing body' the sense of bodily disownership was reflected through accounts of emotional discomfort, as participants described experiences of forgetting or ignoring their affected limbs and stated the body as 'weird' and 'not part of me'.

Currently, it is not clear how the perception of the 'object' body, impacts on the experience of embodied physical comfort after stroke and how this relates to body ownership and body objectification. For example, the forgotten, 'object' body associated with perceptual loss may bring psychological comfort as the body is removed from focus, but also psychological discomfort as the body is perceived as abnormal. The 'object' body associated with 'reappearing' perceptions such as pain, may bring psychological comfort as the individual is disassociated from the upsetting sensory experience, yet also bring physical discomfort if the individual is unable to 'fix' the pain and must keep enduring it. It is also unclear whether the sense of emotional comfort which may occur when the body and self are perceived as reunited, is akin to the literature on acceptance of the body-self in disability.

Further research into the role of bodily objectification and body ownership after stroke as an embodied perceptual phenomenon is required to further elucidate the binary body-self construct. It is not clear whether stroke survivors feel bodily objectification and body ownership are relevant to them; how static or dynamic these concepts remain over time and how they affect the physiological and psychosocial perception of comfort associated with altered body perceptions. Further reflection could illuminate these relationships and consider how these factors influence experience of comfort and acceptance of post-stroke disability.

4.3.3.5 Embodiment, comfort and acceptance

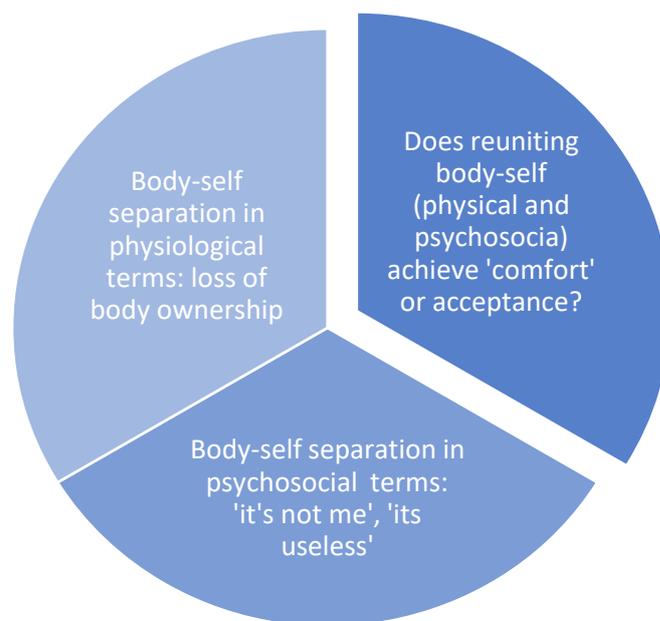
It is important to keep philosophical discussion of the object and conscious body relevant to patients and professionals and as such it is helpful to reflect on the relationship between this construct and the acceptance of long-term disability – something which many stroke survivors attempt to work towards. In my study stroke survivors in the later stages of recovery reflected on feeling that ‘accepting’ the body or self (described in terms of feeling happier in themselves and not attaching negative meaning to troublesome altered body perceptions) was a positive outcome which contributed to a sense of psychosocial comfort. So, as participants achieved an amelioration of their conscious, negative and uncomfortable experiences of bodily objectification, they related this to a sense of acceptance (in either the body or self).

Traditionally, literature about acceptance of the body-self has focused on evaluation of psychosocial measures of disability such as how patients conceptualise the meaning of their life, disability and the relationship between these factors and wider society (Groomes and Linkowski., 2007). Whilst these psychological factors evaluating the meaning of disability are important, they also draw focus away from the bodily experience of ongoing disability. Li and Moore (1998) agreed that the psychosocial experience of disability is intrinsic to the ability to accept the body in illness, yet they also noted how acceptance of disability was directly associated with success in rehabilitation outcomes. This finding suggests that a personal sense of bodily acceptance may also hinge on the potential of the body to improve and move beyond its current state. This questions the meaning of the term acceptance, which in this context is closely tied to a sense of hope that the body will change in the future. The concept of ‘self-acceptance’ is ill-defined but implies a sense of satisfaction in the present self. Ueda and Okawa (2003) emphasise that acceptance is more than a resignation to bodily impairment, but about retrieving a positive attitude to life despite disability.

Recently efforts to improve the psychosocial discomfort caused by altered perceptions after stroke have focused on psychological and cognitive interventions such as Acceptance and Commitment therapy (ACT) (Ivey-Williams, 2015). It posits that through using mindfulness

techniques to encourage acceptance of limitations, survivors may be able to move beyond the self which is trying to control or master the 'object' body. Ivey-Williams (2015) suggested that ACT has demonstrated a reduction in the impact of conditions such as fibromyalgia, multiple sclerosis and epilepsy through improving pain-related disability and fatigue, reducing depression, anxiety and improving quality of life. Yet, it was not able to improve the subjective ratings of experiences of altered body perceptions such as pain, seizures, fatigue. From a physical perspective, body awareness therapies have sought to address body ownership directly and have shown, in some studies, improvements in functional and motor outcomes in stroke survivors (Batson and Deutsch, 2005; Lindvall, Carlsson, Gard and Forsberg, 2015; Lindvall and Forsberg, 2014; Myers, 2016). These therapies involve using conscious awareness to become aware of the body and its limitations thereby addressing physiological and psychological components of the embodied experience of altered perception and potentially touching on the separation between body and self. Further research is required to explore the relationship between physical and psychosocial experience of acceptance, comfort and its relationship with the body-self, considering comfort (Figure 11).

Figure 11. Embodied perceptions, comfort and acceptance



4.3.3.6 Summary

Reflection on the embodied experiences of the 'disappearing, reappearing and uncontrollable body' post-stroke and their relationships with comfort, highlighted a link between the objectification, consciousness and ownership of the body within different altered body perceptions. Using the term 'discomfort' to describe these experiences was helpful to illuminate the varying experiences which may have been obscured by other terms, but it also emphasised the limitations of this term which has historically been used to describe perceptually 'presencing' sensations, such as pain. Looking at body perceptions in terms of discomfort ensures that conceptually abstract factors such as separation of the body-self, body objectification and body ownership remain grounded and practically applicable to stroke survivors. Re-conceptualising links between the bodily experience, comfort and acceptance of the body-self has the potential to create tangible therapies to improve patient experience.

4.3.4 Discussion of themes: Looking outwards

4.3.4.1 *The 'isolated and hopeful body' in the wider world*

The previous sections have focused on discussion of the physiological and psychological embodied experience after stroke. Yet the perceptual experience of the altered body was largely manifested and noticed in its engagement with the wider world. In the 'isolated body' theme, participants were isolated by their physical experiences of altered body perceptions. This isolation was threefold. Firstly, uncomfortable experiences such as distorted body perceptions, perceptual loss of limbs, pain, stiffness and weakness impacted participants' abilities to mobilise, act intentionally and access their lived world. Secondly, these issues were compounded as participants struggled to make sense of and communicate their altered body perceptions, restricting their ability to make meaning of their embodied experience. Difficulty understanding what was happening and the lack of vocabulary to 'give voice' to these experiences created a sense of emotional discomfort as the body was perceived as confusing and inherently isolated due to experiences which couldn't be fully shared with others.

Finally, poor responses from health professionals and a lack of treatment options meant participants felt physically and emotionally isolated from wider society, as they were left with a resigned sense that their 'object' body could not be fixed. They internalised shameful feelings that they were not worth professionals' time and that they were just a 'number'. Society and the health professionals became inaccessible as participants believed they did not have a place in or were unable to access these systems. This sense of exclusion became embodied as participants attempted to distance themselves from these complex feelings of rejection. Therefore, society's objectification of the disabled body validated the introspective sense of bodily objectification. Participants' bodily objectification, blinkered many to the psychosocial discomfort caused by their internal, incommunicable, inexplicable and isolating altered body perceptions, creating for many a sense of the 'hopeful body'. This sense of hope motivated many to work independently to change their current reality and attempt to get back to normal. Ultimately the body, physically isolated by altered

perceptions and experienced as conscious and confusing, was worsened through the experience of trying to integrate the body into the lived environment. The bodily experience was incommunicable and isolating. The lack of societal response mirrored, validated and contributed to this emotional discomfort (see Figure 12).

Figure 12. Internal and external embodied discomfort

'Internal' body experiences	Bridge between internal and external worlds	Lived body in 'external' world
<ul style="list-style-type: none"> •Body feels weird and uncooperative •Can't mobilise the body in the world •Physical discomfort (Body won't respond, it hurts) •Emotional discomfort (feel bad, frustrated, isolated, can't do what I want) 	<ul style="list-style-type: none"> •Lack of language to communicate altered perceptions •Lack of language to make sense of altered perceptions •Emotional discomfort (feelings of confusion, isolation) •Emotional comfort (body objectification) •Emotional comfort (hope that the body will change and become acceptable to self and society) 	<ul style="list-style-type: none"> •Poor response by health professionals to altered perceptions and lack of interventions •Don't fit into society •Emotional discomfort (rejection, validation of internal feelings)

Social discomfort, such as the isolation from health professionals and wider society caused by living with altered body perceptions, externally validates the internalised notion of the 'object' body. This disembodied approach is exemplified through the language of medicine and intervention within illness, as clinicians seek a physical origin for somatic experiences and treat an 'object' body (MacLachlan, 2004). Social discomfort may be exacerbated by the impact of altered body perceptions on stroke survivors' ability to participate in social activities. Arntzen, Hamran and Borg (2015, p311) noted how the lived experience of apraxia served to detach the body from its *"own biography, former sense of self and from the familiar activities, contexts and relationships established earlier"*. Timothy, Graham and Levack (2016) suggest that factors 'external' to the self such as knowledge and environment are very important in improving cohesion and connection between the body and self. They also highlight the importance of 'positive' personality factors in maintaining this cohesion,

such as those demonstrated by participants able to engage in a narrative of 'hope' in their recovery. As such the segregation between the individual and wider society is influenced by bidirectional individual and societal factors which are interpreted and lived in unique ways by the individual.

4.3.4.2 Language, comprehension and communication

Participants descriptions of their altered body perceptions were usually centred around creative metaphors and similes. Their bodies *were "trapped in sand", "withered", "old", "not there", "remote-controlled" or "monster-ish"*. Participants showed uncertainty that their descriptions would be understood, asserting phrases like *'does that make sense?'* to ensure a shared meaning. They were embarrassed by some of their descriptions, laughing at their use of words and at times dismissing the colourful visual images they created. Often, they simply found that language was insufficient to convey their experiences, settling for descriptors like *"it's weird" or "I can't describe it"*. Their confusion and embarrassment in describing their altered body perceptions elucidated a sense of emotional discomfort in reflecting on their embodied perceptions. The difficulty expressing their perceptions demonstrated their lack of understanding about their bodily perceptions. This was highlighted as the few participants with some understanding of the neurological causes of their sensations, asserted these experiences confidently and with clarity. The difficulty expressing altered body perceptions after stroke has rarely been reflected on in the literature. Arntzen and Elstad's (2013) study of six people with apraxia briefly highlighted participants' difficulty finding the language to express their experiences. Their descriptions improved as participants engaged in multiple interviews, suggesting it was important to have time to reflect on their experiences and to develop appropriate ways to describe them. Similarly, Timothy, Graham and Levack (2016) highlighted stroke survivors' inability to articulate their experience and their reliance on the word 'strange' to express their altered body perceptions or lack of bodily control.

Connell, McMahon and Adams (2014) highlighted how four out of five of their participants were unable to voluntarily express somatosensory deficit without probing by the researcher. They suggested the language was not available to convey their experience of

sensory loss and to compensate for this, participants expressed changes to somatosensory perception through recounting accidents, problems involving body parts or difficulty achieving functional tasks. These interviews utilised probes which directly asked participants about sensations such as numbness and pins and needles (terms often used in physiotherapy practice), which may have influenced participant perception of those experiences, or how easily participants were able to associate with those terms. Learning from this, care was taken in the current study to mirror participant language when describing altered sensations, to capture how they conceptualised and understood their experiences and to avoid putting professional terms in their mouths. However, it became clear in later interviews, that using probes which specifically asked about the temperature of the body or about pain perceptions elicited increased descriptions of these types of altered perceptions. This may have been because participants were unsure what type of body changes to discuss as relevant to the research or because they did not recollect transient altered perceptions when they weren't explicitly noticeable. Participants tended to describe perceptual loss in functional terms. This may be because there was little language to describe an absence of perception and it is through functional loss that this can become noticed and can be conveyed in verbal terms. Two participants, both of whom were at ease with providing creative verbal metaphors, voluntarily provided a visual image of their altered body perceptions. The fact that these individuals drew on such a variety of means of communication, encapsulated the difficulty of conveying the altered body.

4.3.4.3 Language as an expression of embodied experiences

In the current study participants' use of metaphor provided insight into the complexity of their physiological perception and the impact of this on their perception of themselves and their relationship with the world. For example, Leah's conception of her body as like living in a "*special effects suit*", or Tom's description of his body as being trapped in a "*bag of sand*" exposed much more than simple descriptors of biological sensations; one could sense the loss of self and the sense of entrapment caused by living with altered perceptions.

The use of metaphor to express embodied yet inexplicable phenomenon has been reflected on in the literature. A study by Faircloth et al. (2005, p932) of US stroke survivors highlighted this idea stating:

"The use of this metaphor also works to create a sense that Steve was indeed not himself at the moment of the stroke but someone else or some other thing. He was not in his "normal" body, his normal self, but, rather, in a strange and new creation, not even recognizable as human: now a fish with an elongated flipper, no longer human. His hand, as we conceive of this specific, physical bodily part, had disappeared as a phenomenological entity".

In illness, previous ways of comprehending and describing the bodily experience are changed and become inexplicable. As such, metaphor becomes a primary means to bring order to bodily sensation and action; an important tool to consider, frame and make sense of embodied physiological experiences.

"Metaphor allows one to move from the abstract and inchoate of lived experience to the concrete and easily graspable. ... In terms of this discussion, metaphor allows for the communication of otherwise senseless and unspeakable suffering" (Csordas, 2005, p143).

Discussion of embodied cognition furthers this idea, highlighting the importance of reflecting on how language, perception and cognition is embodied; grounded in both physical and emotional bodily states (Glenberg et al. 2005). In this framework, the body becomes the core receptor which generates how we perceive, conceptualise, communicate and anchor ourselves within the world; bodily experience becomes inherent to language production (Murray and Holmes, 2014). *"People's recurring bodily actions serve as the fundamental grounding for how and why people think and talk in the specific ways that they do"* (Gibbs, 2005). Embodied emotional states are both based on responses to body perceptions and have direct physical impact as they influence bodily intentionality and action (Prinz, 2005). The grounding of language in bodily experience was highlighted in the current study in which participants reached for abstract and unusual constructs to verbally

convey their bodily experiences. These new language constructs demonstrated how the changed body was being re-conceptualised and made sense of by participants. Faircloth et al. (2005) pointed to the use of metaphor as a useful tool for typifying and classifying bodily experiences, to enable new and abstract experiences to be framed in contexts which are already comprehended. The use of this categorisation process is to build a common, shared understanding through using familiar points of reference (Faircloth et al., 2005). In this study, participants use of abstract language and metaphor was a useful contextualising tool, yet it was interspersed with stumbling uncertainty in phrasing, laughter and dismissal of experiences. This highlighted how problematic it was conceptualising and verbalising the post-stroke body to achieve a shared understanding.

Whilst the role of language to express and make sense of embodied perceptions is evident, this relationship can be considered in another way; thought and cognition may also influence the physiological experience of embodied perceptions. A review into catastrophising chronic pain argued that this ruminative thought process about a physiological perception was an independent risk factor for chronic pain and reduced prognosis and was linked to reduced physical ability, fear of pain and reduced performance (Leung, 2012). This link between cognition and physiological perception, has also been explored in the impact of cognitive representations of illness on perception of ill health. A review by Petrie, Jago and Devcich (2007) pointed to studies in which participants' perception of conditions such as rheumatoid arthritis, Huntingdon's Disease and type 2 diabetes were associated with physical symptoms, psychosocial wellbeing, function and adherence to treatment, suggesting that how patients interpret their health condition affects their physical and behavioural experience.

Within the current findings, it was not clear how participants' use of language about their bodies, impacted their perception of bodily changes. Participants frequently used impactful terms, describing body parts as "*parasitic*" or "*dead*" which clearly indicated the lost physical perception and its impact on attitude and emotional feelings towards the body. However, it was not clear how the conceptualisation of this experience through the use of language affected sense of body ownership. Similarly, it was not known whether perceptions of fatigue or pain, conceptualised and consolidated in language, contributed to

the physical sense of these perceptions. Van Mierlo et al. (2015) looked at the role of illness perception in a population of 287 stroke patients at two months and two years. They found that maladaptive cognitions such as feeling helpless, limited and useless due to altered perceptions, continued into the chronic phase of recovery. These cognitions were correlated with a psychological measure, indicating worsened life satisfaction as a result of such thoughts. Further research into how conceptualising specific altered body perceptions can impact the experience of embodied sensations in physical and psychological terms would be helpful.

Patient understanding of illness is also important to enable patients to adapt to, cope with and manage their condition and proactively engage in treatment (Nunstedt et al., 2017). Understanding illness is a dynamic process hinged on evolving cognitive processes and attitudes towards illness and is influenced by the lived experience of illness and perception of psychosocial consequences (Nunstedt et al., 2017). Language is also key in making sense of an experience and when there are few words to describe something it may be more difficult to understand. One study in which neurological responses were examined to identify the level of comprehension of novel and easily interpreted metaphors, found that comprehension of novel metaphors was more cognitively taxing and difficult to interpret (Lai, Curran and Men, 2009). The consequence of having little common language to share and interpret an experience may also contribute to social discomfort as symptoms remain invisible to family and friends which may increase a sense of isolation (Ellis-Hill, Payne and Ward, 2000).

Having the language to make sense of and communicate the altered body after stroke is the bridge between how the individual and wider society understand the experience of altered perceptions. Being unable to explain and understand body changes may be related to the experience of body objectification and disownership after stroke. Yet it is unclear in what ways internal dialogue used to make sense of altered perceptions and the experience of verbally sharing this experience with others and professional affects the physiological and psychological perception and comprehension of those problems.

4.3.4.4 Language, comprehension and its role in accessing health services

This study showed a disconnect with how participants were able to express their altered body perceptions to health professionals. Some participants felt unable to talk to health professionals because of practical barriers such as aphasia, lack of English or difficulty remembering what they wanted to say. The majority avoided accessing health services due to a deep belief that they would be rejected by health professionals, who they felt did not have the time, resources or treatments to support them. This avoidance and belief that they would be rejected may have been reflected in how participants internalised feelings about their altered body perceptions in relation to the wider world. For example, some felt that their difficulties were trivial and easily dismissed, that they were a burden or that health professionals would think they were mentally unwell for describing their altered perceptions. Participants were not able to remedy uncomfortable altered body perceptions, due to psychosocially uncomfortable factors which inhibited the expression and understanding of these issues in wider society.

Research by Eames et al. (2010) exploring perceived barriers to accessing stroke information in acute hospital settings, showed patients highlighted personal factors as reasons not to ask staff about their condition. These factors included not being understood by professionals due to aphasia, cognitive or memory changes or because they didn't want to be perceived as a 'whinger'. The inherent power dynamic within the patient-doctor relationship meant patients assumed doctors would share relevant information. As such they don't seek out information, meaning they have relatively little autonomy in the information sharing process. The interplay between language barriers compounded by the passive role of the patient demonstrated the difficulty for patients in accessing information to better understand their condition.

This research emphasised the psychological beliefs which underpin this process. The embodied experience of emotional discomfort after stroke in which patients feel uncertain and lose their sense of self, may exacerbate practical barriers to communication such as aphasia, cognition and memory loss. The physiological strangeness and inexplicability of altered body perceptions create a secondary barrier to voicing these issues. Perception of

professionals who may be perceived as holding the knowledge and power, may instil a sense that patients should stay passive and wait to be offered services. Finally, rejection by a saturated health service in terms of GP time and treatment options, served to validate all these factors and maintain the passivity of stroke survivors (Majeed, 2015).

Amidst this myriad of factors, the use of language to describe and explain altered body perceptions provides a useful focus. It could equalise the flow of information between doctor and patient and begin to disentangle the physiological and psychosocial discomforts arising from altered body perceptions. Doolittle (1992) highlighted that:

“There was a disparity in language between patients and health care providers. This was because the patients described the bodily experience of stroke in natural language, whereas health care providers used neuroscience terms. Because the stroke was not lived according to the clinical neuroscience perspective, health care language was not beneficial in the lived experience of paralysis” (p239).

The benefit to patients of communicating their altered body perceptions with the support of clinicians was reflected on by Arntzen and Elstad (2013, p70). In their exploration of the bodily experience of apraxia they described *“a phenomenon at the edge of spoken language... [in which] participants had trouble in finding words that could express their disrupted experience of everyday life”*.

The use of ‘professional language’ to explain and understand altered body perception may influence how patients are able to process, conceptualise and describe their altered body perceptions. For example, health professionals frequently describe stroke impairments in terms of functional impact. Research by Levack et al. (2012) explored how rehabilitation goals were formulated between professionals and patients. This found that physician goals of improving physical function such as self-care in a short time frame to speed up hospital discharge, were prioritised over patient-centred goals and psychosocial outcomes. In these findings, attention was drawn to the body when it was unable to achieve functional tasks. However, it is unclear whether it is the lack of function which leads to discussion in functional terms, or whether it is the professional focus on functional impairment which

means this is how the survivor conceptualises these problems. The consequence is the body is considered in terms of loss of function, as opposed to a focus on the altered body perception causing the functional loss.

4.3.4.5 Summary of 'external factors'

In summary, the body altered by stroke was difficult to convey and make sense of in verbal terms. This contributed to a sense of emotional discomfort as the 'external' world validated internalised physical and psychological perceptions. Discussion of embodied cognition showed how the physical experience of altered body perceptions can be perceived and made sense of through language and how this understanding can influence perception. Being unable to express these issues may serve to increase a sense of isolation in the individual. This may validate negative feelings towards the body and self, exacerbate psychosocial discomfort and contribute to a sense of body disownership. These issues are poorly understood in stroke research, it is not known whether reunification of the body-self is desirable or possible in an altered body and what the impact of living in a disjointed body-self has on physiological and psychosocial discomfort.

4.3.4.6 Clinical implications

4.3.4.7 Embodied experience of altered body perceptions (internal and external factors)

This research demonstrated that stroke survivors find altered body perceptions uncomfortable in a myriad of ways, often depending on how conscious these perceptions feel. It is important for clinicians to focus on how survivors manifest these experiences of discomfort so that they may tailor rehabilitation to their differing needs. Exploring how body objectification and physical and psychological sense of body ownership can contribute to discomfort may be related to increased acceptance of the post-stroke body – a factor which has been related to improved rehabilitation outcomes (Li and Moore, 1998). Further research needs to be conducted to identify stroke survivor's perspectives on the importance of the body-self divide as a construct which influences comfort and acceptance post-stroke.

An embodied approach to treating perceptual changes in which facets of acceptance and body awareness therapies are more integrated, may prove helpful to reconcile uncomfortable physical and psychological perceptions which detach the body from the self.

The current study showed that when the lived body was contextualised in the 'external' world, physically uncomfortable perceptions manifested socially, limiting engagement and participation with health professionals. A key inhibitor in this relationship was stroke survivors' difficulty communicating and comprehending their experiences. Participants highlighted their distress that they could not access health professionals due to a lack of GPs and treatment options and they appeared to personalise these external factors and develop psychologically uncomfortable beliefs that were not worth spending time on. Further research into ways to communicate the altered body after stroke could benefit stroke survivors, improve patient-clinician communication and reduce psychosocial effects of altered perceptions such as isolation.

The clinical relationship perceives the observable patient body in its own terms which are potentially at odds with the lived experience and language adopted by the patient. Power imbalances may mean that professionals hold knowledge which they do not communicate to patients and patients may not be able to ask clinicians for support, instead living with worsened physiological and psychosocial discomfort. Defining a patient-friendly way to communicate information, inclusive of those with aphasia and cognitive and memory impairment, may aid patient formulation of meaning around their experiences, which may in turn impact the physiological and psychosocial perceptions of these experiences. Likewise, professionals need to learn what issues patients want help for as their altered body perceptions evolve throughout the course of their stroke trajectory.

The themes of the 'disappearing, reappearing and uncontrollable' bodies may be a useful template to group altered perceptions in clear and simplistic terms. By creating a tangible language to describe perceptual loss, stroke survivors may be able to better understand and reflect on this experience and how it may affect psychosocial discomfort and perception of body ownership. Use of the term discomfort was helpful in this study and it is recommended that clinicians evaluate the effects of the altered body in broad and holistic,

patient-friendly terms such as this. It was noted that the term discomfort was hard to ascribe to the experience of perceptual loss and it is therefore recommended that clinicians adopt alternative vocabulary when referring to this altered perception. Participants in the research also indicated that professional language and attitudes towards the patient affected their perception of 'hope' of recovery and they described it as an important motivator to engaging in rehabilitation. A systematic review by Bright et al. (2011) found hope was linked with motivation and better outcomes for patients after stroke. As such it is recommended that professionals address language which may dispel patient hope and utilise the concept of hope consistently in rehabilitation.

4.3.5 Reflection on method

This study utilised an interpretive phenomenological approach which was presented thematically. The large volume of in-depth, contextual data meant the analytic process could be tailored and accounts could be creatively explored and linked inductively. This flexibility is a strength of the method (Smith, Flowers and Larkin, 2009). However, the depth of analysis and focus on the individual has led to criticism that phenomenological analytical approaches may not be transferable because they are hinged on subjective interpretation through the 'lens' of the researcher (Pringle et al., 2011). In this study, credibility was added to the method through the grouping of shared experiences, the exploration of differences between participant accounts, researcher reflection and the anchoring of the interpretation in verbatim, contextualised participant accounts.

One tension which emerged through the analytical process was the focus of IPA on achieving a psychological interpretation which at times drew focus away from the research focus of the perception of the altered body. Smith et al. (1999) state the goal of IPA is to highlight the participant's view of the phenomenon in question, by understanding participant's cognitions and meanings through linguistic and interpretive analysis. As such the output of the analysis is likely to focus on a cognitive or psychological conception of the phenomenon as understood by the participant (Brown, 2018). This procedure is expertly exemplified by Osborn and Smith's (2006) interpretation of the experiences of the body

experiencing chronic lower back pain. Whilst they describe the experience of pain, altered sensation, lack of bodily control and muscular weakness, the interpretation is expressed in purely psychological terms emphasising the meaning and impact on the individual and their sense of self.

In the current study representing the data in purely cognitive and emotive terms felt like an incomplete representation of their embodied experience. Therefore, an effort was made to theme, reflect and interpret the physiological experience alongside the individual meaning ascribed to this body change. The difficulty of using IPA to represent 'non-cognitivist' experiences, has been alluded to in the literature. Murray and Holmes (2014) discussed the use of IPA to explore the experience of seclusion in a psychiatric setting. Drawing on Merleau-Ponty (2001), they highlighted how IPA assumes that descriptions contained in participant accounts constitute the lived experience which ignores the bodily experiences which influence meaning-making. They highlighted that speech is corporeal and not disembodied, emphasising how only interpreting cognitive aspects of accounts omits the dynamic interaction between language, embodied speech and context.

Murray (2004) used IPA to explore the embodiment of artificial limbs to bring the literature on prosthesis use away from its focus on body image and move it towards the embodied experience of perceptual and motor experiences. This study added to understanding of how prostheses are embodied and integrated into the corporeal structure. It demonstrated the advantages of using IPA to focus on the physical experience. Its focus was less on the emotional 'feelings' evoked by the prosthesis, but on factors such as awareness, conscious attention, 'naturalness' of the experience and sense of the limb as integrated into their sense of self. This novel approach provided an insightful embodied account of the experience of prosthesis. However, the findings omitted referencing the emotional perspectives of participants towards their limbs, so it could be queried as to whether this was a fully embodied perspective.

In this study efforts were made to integrate participants' linguistic representation and interpretation of their experience into their experience of bodily perceptions which were the anchor to the psychosocial meanings described. Interpretive phenomenology provided a

flexible approach to achieve this. Establishing an analytic strategy to work in a cohesive and embodied way alongside phenomenology is useful because of this methods congruence with embodiment theory and its use in uncovering patient perspectives (Gallagher, 2005; Øberg, Normann and Gallagher 2015).

4.3.5.1 Strengths and Limitations

The interviews were based on the recall of somatic memories which participants had been experiencing within a 'recent timeframe'. Participants often told an evolving story of recovery where they compared current perceptions with how they used to be straight after the stroke in order to recount progress in recovery. As such there may have been a blurring between accounts from the past and participants' more recent experiences and historic experiences may have been reframed by the individual. Whilst phenomenological accounts may not be subject to the same level of scrutiny regarding 'recall bias' as other methods, it is worth noting that the subjective experience of a recalled experience may evolve as it is reflected on over time.

Medical data about participants' stroke date, symptoms and any other exclusory comorbid physical conditions were captured by self-report. It is therefore possible that participants may have inaccurately assumed their altered perceptions to be attributable to stroke when they were actually attributable to other causes. Four participants reported comorbid conditions such as lower back pain (Dave); osteoarthritis related knee pain (Marc); historical wrist injury resulting in nerve damage (Toby) and non-stroke-related cramp (Leah). These participants were included because they were able to describe and reflect on their localised symptoms as separate and distinguishable from their stroke symptoms. However, in actuality there is likely to be blurring between some conditions prior to stroke, bodily experiences as a consequence of stroke and 'secondary' bodily effects of stroke which may arise for example, through reduced bodily movement. Whilst these comorbid issues were restricted during recruitment and reflected on transparently in the analysis, it is possible that some altered perceptions described may blur stroke-related perceptions with altered perceptions from other causes. Furthermore, participants were not screened for psychological illnesses (such as hallucinations, anxiety or depression) which may influence

perceptions of the altered body. One advantage of this approach was that the researcher was unable to tie participants' accounts to medical explanations for their altered perceptions in interview or in analysis, reducing the chance of the analysis being influenced by factors outside of the interview data.

The purposive sampling technique ensured diversity between participants. However not all categories were evenly represented - only one participant was not White British; one participant over 75 years old; and two participants were categorised as less independent. It would have been useful to collect more experiences from people within these less represented demographics. For example, seven out of the eight participants in the early stages (six months -2 years) of recovery were male. This meant that the majority of participants who felt hopeful and autonomous about their recovery and wanted to fix the 'object' body, were male. Whilst the sense of hope and getting back to normal has been documented as a facet of early stroke recovery, it would be interesting to note how this perspective relates to gender.

4.3.6 Conclusion

This study provided a nuanced look at the first-person experience of altered body perceptions post-stroke. It interpreted these experiences through the 'lens' of a holistic understanding of comfort and provided insight into the impact of these body changes on the individual. A novel use of thematically presented interpretive phenomenological analysis was used to root altered body perceptions in physiologically embodied, as opposed to psychologically interpreted terms. This approach tied the experiences of the body-self, bodily consciousness and body ownership to the perception of comfort, enabling discussion of embodied therapies which may influence these areas. This is the first time that discomfort has been used to focus on the physiologically, psychologically and socially isolated body after stroke. This has added to the notion, briefly noted in the literature, that language and understanding of altered body perceptions are key to reducing psychosocial and potentially physiological discomfort. This conception points to useful and practical ways that health professionals can improve dialogue with stroke survivors around their experiences of altered body perceptions.

Chapter 5: Methodology: A feasibility study of the acceptability of assessment tools to communicate altered body perception and comfort after stroke

5.1 Chapter introduction

The previous chapter captured participants' difficulty expressing and making sense of their altered body perceptions. This led to psychosocial discomfort and made it difficult to access support and engage in rehabilitation. To enable survivors to engage with others about their altered body perceptions, a study was devised to explore viable means to foster this communication. This chapter presents the methodology of a study which aimed to investigate the acceptability of three different clinical tools, determining how useful and accessible the tools were for communicating bodily experiences post-stroke.

5.2 Background

Findings from the previous chapters found that stroke survivors commonly perceived body parts as non-existent or distorted and experienced altered perception of sensations such as pain. These participants often described these perceptions as uncomfortable both physically and psychologically. They felt that they wanted more support from health professionals to cope with changes which they found abstract to comprehend and difficult to describe. Difficulty communicating altered perceptions was also highlighted as problematic for patients in the scoping review and patient communication of the bodily experience after stroke was emphasised as a key area for clinicians to develop (Section 0). However, it was also noted in this section, that little research has been conducted exploring what information stroke survivors want to reflect about their experience of the altered body.

Communication of these issues is problematic for stroke survivors, due to the nature of altered perceptions and the lack of language to describe the experience. Yet these issues are

compounded by communication and comprehension difficulties after stroke. Aphasia affects 21-38% of stroke survivors (Berthier, 2005); dysarthria is estimated to affect 30-40% of individuals (Miller and Bloch, 2017); and cognitive impairment affects 21% of individuals 5 years post-stroke (Douiri, Rudd and Wolfe, 2013), factors likely to impact individual opportunity to engage in clinical assessment. To ensure inclusion it is essential to take these difficulties into consideration when designing assessment tools and research which requires contribution from a patient perspective. Current stroke assessment tools are not suitable for those with communication issues (de Vries et al., 2017; Korner-Bitensky et al., 2006; Price, Curless and Rodgers, 1999). Similarly people with aphasia are often excluded from research due to barriers in communicating with this group and difficulties ensuring consent procedures are fully comprehended (Brady, Frederick and Williams, 2012; Palmer and Patterson (2011). To ensure rehabilitation outcomes are tailored to the individual, devising methods of communication with this group is vital.

Health professionals usually make sense of the multifaceted stroke experience through assessing bodily impairments in a focused, yet fragmented way. As highlighted in the Introduction (Section 1.5), assessment separately considers disparate impairments of cognition, perception, awareness, sensation, balance and strength and the focus of rehabilitation is on improving function and activity (NICE, 2013). The effect of this is that the cumulative experience of living with multiple altered perceptions, which can affect many body areas simultaneously can be overlooked. Patients may feel clinical focus prioritises functional outcomes over other perceptual problems (Connell, McMahon and Adams, 2014; Doyle, Bennett and Dudgeon, 2014). This may have consequences for rehabilitation outcomes (Normann, Fikke and Øberg, 2015). As such there is advantage to evaluating these body changes from the viewpoint of the patient. However, at present there is no stroke-specific tool to assess the patient experience of altered body perception and associated discomfort.

5.3 Aim and objectives

The aim of this study was to explore whether stroke survivors wanted to communicate their altered body perceptions and discomfort to health professionals. It explored the feasibility of using assessment tools to support this process. It determined the face-validity and acceptability of selected measures, whilst exploring the complexity of using these measures in a group experiencing communication difficulties. The research objectives are outlined below.

- Explore individual need to communicate their experiences of altered body perceptions and discomfort
- Explore the relevance and acceptability of a selection of diverse assessment tools for capturing the experience of altered body perceptions and comfort from the perspective of a person living with stroke
- Explore the use of these assessment tools in a group of people with aphasia

5.3.1 Epistemological perspective and research design

Feasibility study designs are a useful tool to determine the suitability of exploring a research question in a certain way. They can highlight any practical issues around participant engagement and troubleshoot issues which may impact the validity of a larger study (Tickle-Degnen, 2013). The term feasibility is ambiguous but is used here to denote a preliminary study (Whitehead, Sully and Campbell, 2014). In a feasibility study it is advised to descriptively assess and present basic data which is indicative of the workability of the research question (Tickle-Degnen, 2013).

Qualitative description involves representing the data as it is and provides a summary of an event which has not been interpreted through a researcher or philosophical 'lens' (Sandelowski, 2000). In this method data is taken at 'face value' to present a straightforward, uninterpreted response to a research question. This does not mean the

data is represented at random, it is still filtered and presented in a way that demonstrates broader thematic claims about the data collated (Sandelowski, 2010).

Qualitative description has been aligned philosophically to pragmatism (Neergaard et al., 2009). Pragmatism works to explore the 'nature of reality'. It assumes that truth is relative, fluid and inextricably situated in its context (Given, 2008). Neither objective or subjective, it emphasises the co-construction of knowledge through relational interactions, in the here and now (Given, 2008). This research question was well suited to pragmatism, as it required a flexible approach to collecting and treating data, which aligned well with a pragmatic, problem-orientated approach. As such the research design evolved as a consequence of treating the research question in a pragmatic way.

It has been suggested that qualitative descriptive study designs are not prescriptive in terms of sampling frameworks but are suggested to benefit from maximum variation purposive sampling to get a broad understanding of a phenomenon (Sandelowski, 2000). They align well with data collection methods which involve "*minimally to moderately open-ended individual*" interviews and a non-interpretive analysis technique which can be presented as a descriptive summary (Sandelowski, 2000, p338). However, qualitative description is open to criticism as it offers a descriptive and uninterpreted account of an experience; yet paradoxically this may also be its strength as findings remain closely grounded in the data (Neergaard et al., 2009). Importantly, it aligns well with a research aim intended to provide a descriptive account of a phenomenon and as such can provide insight into the need for further research in a given area (Neergaard et al., 2009).

5.4 Methods

5.4.1 Ethics

Ethical approval was granted by the University of the West of England Research Ethics Committee on 27th October 2017, Reference Number: HAS.17.10.028 (Appendix C.1).

5.5 Selecting the sample

In line with the focused needs of this feasibility study, a purposive sampling strategy was adopted. Participants were recruited to match the selection criteria and to represent variation in terms of their ability to communicate verbally. Participants were diverse in terms of experiences of: ‘altered body perception’; age; gender; ethnicity; time since stroke onset and level of independence.

5.5.1 Selection criteria

The selection criteria are summarised in Table 9 and were similar to those used in the previous study (See Chapter 3, Section 3.5). The only difference was that in this study participants experiencing significant communication issues were included.

Table 9. Selection criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> ▪ Participants who experienced cerebral ischaemic or haemorrhagic stroke. ▪ Participants who were at least six-months post-stroke. ▪ Participants who reported motor, sensory, attentional, proprioceptive or spatial impairment following their stroke. ▪ Participants of any age, gender, nationality, ethnicity and ‘level’ of disability. ▪ Participants with communication problems such as aphasia, which prevented them from communicating verbally. 	<ul style="list-style-type: none"> ▪ Participants who experienced Transient Ischaemic Attack or spinal stroke. ▪ Participants who experienced any condition other than stroke, which caused pain or altered sensation e.g. Diabetes causing sensation changes; Complex Regional Pain Syndrome before their stroke; Rheumatoid arthritis. ▪ Participants who experienced now or in the past any neurological conditions that affect the brain or nervous system (other than stroke). ▪ Participants with significant executive function and memory impairment affecting capacity to give informed consent.

5.6 Recruitment strategy

5.6.1 Recruitment procedure

A purposive sample of 10 participants were recruited to take part, a proportion of whom experienced moderate to severe communication problems. Participants were recruited via two channels. Firstly, five participants known to be eligible to take part from the previous qualitative study (Chapter 3), were approached. All participants of this study agreed to be contacted in the future and were contacted by phone or email depending on their preference. Some of these participants experienced mild to moderate aphasia, yet they were able to communicate verbally and were not counted amongst those with more significant communication difficulties. Participants experiencing the widest variety of altered body perceptions which they were able to describe in the most evocative terms, were contacted first. The first five participants contacted agreed to participate in the study.

Additionally, a further five participants were recruited via the same stroke charity used in the previous study, which runs stroke groups and cafés (See section 3.6). The author promoted the study at one stroke café and two stroke support groups, which were attended by a total of approximately 70 stroke survivors. Potential volunteers were presented with ‘aphasia friendly’ flyers (Appendix C.2). These flyers contained a tick box to enable individuals unable to communicate verbally to express their interest in the project. The project was described verbally to the whole group by the author and then described again one-to-one to individuals who expressed an interest in taking part. Individuals who appeared during initial conversation to be eligible, were given a participant information booklet which explained the project further (Appendix C.3). All written materials utilised large print, clear layout, plain language and pictures to increase accessibility to those with aphasia.

Participants’ communication difficulties were not formally assessed. Following consultation with a Speech and Language therapist, categories were devised to describe the communication needs of the sample, which were graded in line with the therapists’

suggestions. The categories were: 'none', 'mild to moderate' and 'moderate to severe' aphasia. These categories provide descriptive and contextual information about participants' communication ability and do not denote diagnosable criteria. Participants who fell into the 'mild to moderate' category were those able to make themselves understood in cohesive sentences but were experiencing stilted, significantly slurred, poorly enunciated speech or had difficulty with word finding. Those in the 'moderate to severe' category had significantly impacted speech and struggled to make themselves verbally understood. This category reflected an inability to speak in sentences, due to an inability to identify or articulate words.

Eight potential participants assented to be contacted to discuss taking part in the study. One of these individuals with 'mild to moderate' aphasia, was identified during initial conversation as being unsuitable to take part due to not experiencing altered body perceptions, so was excluded at this stage. Of these individuals, three had 'moderate to severe' aphasia and one had significant dysarthria. Of these participants, two asked to be contacted via a carer whose details they shared at this initial meeting; one asked to be contacted via text message, and one was happy to be contacted via phone call. The remaining three volunteers who had 'mild to moderate' aphasia, agreed to be contacted via phone. Of these seven volunteers, one individual with 'mild to moderate' aphasia passed away prior to contact, which left six individuals who were assessed face-to-face in their own homes, against the selection criteria. Potential participants were screened against the same eligibility questions used in the previous study (Appendix B.2) and all were identified as being suitable to take part. The author informed them of their suitability and went through the participant information booklet at this stage. Volunteers were then given a 'cooling off' period to give them time to consider the project information, discuss it with friends and family and decide if they would like to participate. The author called them a few days later to determine if they would like to go forward and all six agreed. Overall, 11 individuals agreed to participate. However, one individual was unable to take part after experiencing a suspected stroke on the day of interview.

5.6.2 Consent

Volunteers who were able to read and process written information were given the 'standard' written consent form prior to interview, which was verbally reiterated on the day of interview (Appendix C.4). Seven individuals gave informed consent to interview via this form, as they demonstrated that they could comprehend written information. Carers were present in the eligibility interviews of the three participants with 'moderate to severe' aphasia and oversaw the explanation of the study and participant information booklet. These participants went on to take part in the consent process and interview independently. To ensure that these participants were able to fully understand the study, their communication and comprehension difficulties were explored via the Consent Support Tool which was designed to enable people with aphasia to understand information as fully as possible and engage in the research and consent process (Jayes and Palmer 2014; Jayes and Palmer 2016). Once participants were identified as being able to comprehend information, the simplified consent form, specifically designed for those with more significant aphasia, was described slowly and concisely (Appendix C.4). Throughout this phase and subsequent interview, participants were offered breaks and their understanding of information was continually assessed. It was made clear to participants before and after interview that they were able to withdraw their information for up to two weeks following interview.

5.7 Data collection

5.7.1 Selection of data collection tools

The author conducted a search of the literature in August 2017, to identify any relevant tools to assess body perception in stroke, as well as in other conditions in which body perception disturbances have been established (Lewis and McCabe, 2010; Valenzuela-Moguillansky, Reyes-Reyes and Gaete, 2017; Wand et al., 2014). Searches were conducted in five databases (AMED, CINAHL, MEDLINE, PsychARTICLES, PsychINFO) using the terms: ‘Stroke OR pain OR arthritis OR fibromyalgia’ AND ‘Assessment OR tool OR measure OR scale OR questionnaire’ AND ‘Body perception OR body awareness OR body distortion OR body consciousness’ (Appendix A.1). This led to the identification of 249 studies which were screened on title. The full text of relevant studies were reviewed leading to the identification of 21 assessment tools related to body perception (Appendix C.5).

There were no stroke-specific body perception measures but several tools explored body image, body awareness and body consciousness in conditions other than stroke. This resulted in an exploration into how these terms related to the types of body perception issues experienced post-stroke (Appendix C.5). The tools were evaluated in relation to the exclusion criteria outlined below (Table 10) and discussed amongst the research team, resulting in the exclusion of 17 tools (Appendix C.5). The four useful Body Perception Tools identified were: The McGill Pain Inventory (short form) (Melzack, 1987); The PainQuILT™ (Lalloo, Henry et al., 2013; 2014); The Bath Body Perception Questionnaire (Lewis and McCabe, 2010) and the Body Perception Tool (Turton, Palmer et al., 2013).

Table 10. Assessment tools exclusion criteria

Exclusion criteria
Tools not related to the experience of exteroceptive body perception changes
Tools requiring adaptation for use in this study

This process did not identify any measure which captured both body perception and comfort. To identify a measure of comfort, additional searches in the same five databases (AMED, CINAHL, MEDLINE, PsychARTICLES, PsychINFO) using the terms 'Comfort' [in title] AND 'Assessment or tool or measure or scale or questionnaire' AND 'Patient' were conducted. Seventy-six studies were identified which were screened on title and then potentially useful studies were screened on abstract. Many studies referred to the use of generic Visual analogue scales to assess patient comfort. One study made reference to Kolcaba's (1991) comfort theory, but no reference to assessment (Koehn, 2000); and another to Rogeau et al.'s (2014) pilot scale of stroke – which was later excluded due to its focus on activity and function over patient perspective (Appendix C.5). Due to the dearth of identified comfort measures and awareness of Kolcaba's (1991) influence on this field, the Visual Discomfort Rating Scale was obtained from Kolcaba's website: Comfort Line (2010).

5.7.1.1 Patient and Public Involvement

The study was shaped by consultation with the Patient and Public Involvement (PPI) group. They oversaw the development of the aims and methods and concurred that this was an issue pertinent to individuals after stroke. They discussed the four body perception assessment tools identified from the selection process outlined above (Section 5.7.1). The group concurred that the tools needed to be broad enough to reflect an array of altered body perceptions and easily accessible - highlighting the advantages of the tools utilising visual methods for those with problems with language, reading or concentration. Following this discussion and due to the similarities between the pain experiences captured in the PainQuILT™ and the McGill Pain Inventory, the latter was excluded at this stage.

PPI members felt that 'comfort and discomfort' were useful terms to describe body experience and that the term was broad enough to encompass both pain and the plethora of other altered perceptions after stroke. They agreed Kolcaba's (2010) Visual Discomfort Rating Scale would be accessible for those after stroke and that it would be a useful adjunct for the Body Perception Tool which does not include a measure of severity of altered perception. They felt it was important to be able to rate the physical discomfort of specific altered body perceptions, as opposed to asking about how comfortable they were generally.

They suggested that though it is important to assess emotional and social comfort, this should be looked at separately to physical discomfort. PPI involvement continued for the duration of the study.

5.7.2 Body perception assessment tools

The three body perception assessment tools: The PainQuILT™; The Bath Body Perception Questionnaire and the Body Perception Tool (Lalloo, Henry et al., 2014, Lewis and McCabe, 2010; Turton, Palmer et al., 2013) are described in more detail below.

5.7.2.1 PainQuILT™

The PainQuILT™ is a digital online pain assessment tool devised by Lalloo and Henry et al. (2013; 2014). The tool comprises a body map and visual icons which describe different pain perceptions (Appendix **Error! Reference source not found.**). The pain icon selected can be applied to specific body areas and the severity of the pain can be rated on a visual analogue scale from 1 to 10. There is a comments box to add further information about the pain experience. Once all pain experiences have been applied, the tool goes through seven 'impact' questions, in which the effect of the pain on day-to-day experiences is rated on a scale from 1 to 10. Once these are completed the tool provides a visual summary of the body map areas selected, the pain icons, severity rating, any comments made and a visual impact graphic. It is easy to understand, takes no training and was freely available (at the point of data collection).

The pain icons were developed and refined based on qualitative interviews with 30 adults and teenagers experiencing arthritis pain (Lalloo et al., 2013). It was rated in a study of 50 participants experiencing chronic pain as significantly easier to use than the McGill Pain Inventory and the Brief Pain Inventory and pain type and intensity correlated well with these other validated measures of pain. The tool was found to be quick and easy to use and preferred by the majority of participants (Lalloo et al., 2014).

To protect participants from any potential data sharing the researcher's email address was used to access the tool and multiple anonymous pain reports were generated via one account. E-mail contact with the app founder confirmed that the app does not collect or store any personal health information (Appendix C.7). This tool required internet connection to use. During interview with a rural participant it was not possible to access internet and a paper version of the tool was completed.

5.7.2.2 Bath Body perception disturbance scale[®] (BBPDS)

The BBPDS is a clinical measure used to support patients with Complex Regional Pain Syndrome (Lewis and McCabe, 2010). It captures body perception changes such as altered perception of size, temperature, pressure and sense of limb ownership (Appendix C.8). The assessment includes a section in which the facilitator can draw the patient's mental image of their limb which they describe with their eyes closed. The severity of distortions can then be rated and translated into a quantified score. The BBPDS has yet to be evaluated in terms of construct and content validity.

The BBPDS was the only text-based tool used in this study. The author consulted with a Speech and Language therapist beforehand to determine the suitability of using this tool with a population with communication and comprehension difficulties. The therapist suggested to ensure emotional sensitivity that the researcher emphasise that this tool may be difficult to understand and that participants may be unable to answer some questions. This approach was adopted with individuals with significant communication needs.

5.7.2.3 Body Perception Tool (BPT)

The BPT is a digital media application created by Turton, Palmer et al. (2013) at the University of the West of England (UWE). It allows patients to visualise their altered body perceptions in the form of an avatar (Appendix C.9). The tool has been explored and its usability evaluated in a proof of concept study involving 13 people with Complex Regional Pain Syndrome (Turton et al., 2013). In this study participants reported the tool was an

acceptable way to communicate their body changes. Participants identified some limitations of the tool, such as issues with the size of body areas which could be selected and requested the addition of some altered perceptions. The BPT's construct and content validity is yet to be evaluated. The data generated via the Body Perception Tool was not web-based and therefore not problematic in terms of data protection.

5.7.2.4 Rating comfort

The Body Perception Tool does not yet have a severity function, so was used in conjunction with the Visual Discomfort Rating Scale (Comfort Line, 2010). The tool is a simple visual analogue scale to capture perceived discomfort, comprised of a straight line with integers rated from '0', 'no discomfort' to '10', 'highest possible discomfort', alongside a tapered red block (Appendix C.10). The tool was identified via the website of the prominent Comfort theorist, Katharine Kolcaba. However, it is not clear who created the tool.

Visual analogue scales (VAS) to rate the intensity of the subjective experience of pain have been established as valid and reliable, they relate well to other measures and are easy to use (Alghadir et al., 2018; Gallagher et al., 2002; Haefeli and Elfering, 2006). They have been shown to be accessible to those with aphasia (Haley et al., 2015; Korner-Bitensky et al., 2006). Kolcaba (2003) argued for the use of visual analogue scales to measure discomfort, due to the need to quantitatively represent an array of patient discomforts in clinical practice. However, she acknowledged the difficulty of creating a holistic VAS to measure comfort, noting that if a low score of comfort is obtained, this finding should be explored to uncover the cause. As yet the measurement of comfort requires further development and is yet to be validated (Pearson 2009; Tosun et al., 2015).

The PainQuILT™ and the BBPDS contained severity rating scales within them, so did not require additional comfort rating to determine the impact on the individual of the altered body perception.

5.7.3 Acceptability questionnaires

Acceptability questionnaires were devised to assess the acceptability of the body perception tools. These were based on the framework of the acceptability of healthcare interventions, which were formulated following a systematic review of acceptability questionnaires (Sekhon et al. 2017). This review identified seven areas which are important to evaluate when determining acceptability of healthcare interventions, based on the emotional response before or during the intervention. These assess aspects including: how the individual feels about the intervention; how much effort is required to participate; how well the participant understands the intervention and the confidence they have that they are able to take part. These focus areas were used to map relevant questions (Appendix C.11).

The first questionnaire was designed to assess the acceptability of the tools individually (Appendix C.12). Questions were designed to reflect how much the measures explored participants' experience of both altered body perceptions and comfort; how easy, comprehensible and timely the tools were and any suggested improvements. The second questionnaire explored overall preferences between tools (Appendix C.13) This included exploration of any negative experiences of the tools; whether it is important to discuss these changes with health professionals; when should this be done and which tools can best support this. The questions utilised text-based rating scales to support the exploration of participant perspectives through textual analysis. The font and colour of these rating scales were bold and easy to understand to ensure they could be understood by people with aphasia.

5.7.4 Interview procedure

Interviews were conducted in participants' homes by the author and ranged from 50 to 90 minutes in length. Participants were offered breaks throughout and these were particularly encouraged in those with more significant communication problems. The interview process involved asking participants to go through three assessment tools. The order in which these tools were presented were rotated between participants. However, participants with more significant communication problems were offered a visual tool first (BPT or PainQuILT™) to

support their communication. The PainQuILT™ was offered first most often because it contained a very clear visual icon chart which could be explained and understood easily. Two participants were presented with the BPT first; five the PainQuILT™ first, and three the BBPDS first. After each tool was presented participants went through a short acceptability questionnaire (Appendix C.12). Once all three tools were completed, participants went through the second short questionnaire to assess their overall preferences of each tool's acceptability (Appendix C.13).

The interviews were audio-recorded and written notes were taken via paper copies of the Bath Body perception disturbance scale[®]; the two acceptability questionnaires; the digital tools and the Visual Discomfort Rating Scale. The interviewer brought a laptop to each interview and used this to capture the Body Perception Tool and PainQuILT™ text and visual data. All tools were read out and filled in by the interviewer, though participants were encouraged to take part in understanding and engaging with both computer and written data sheets. Participants unable to comprehend these scales or what the tools were asking, were supported with visual communication aids to encourage their comprehension of key points (Appendix C.14). Communication aids were designed to: support comprehension; ensure participants' needs were met; facilitate autonomy and aid expression of difference of opinion in the interview process. Data captured by the interviewer was repeatedly described back to participants to ensure this was an accurate representation of their experience.

Data collection using computer tools was facilitated by the interviewer due to the technical skill required, except in one instance where a participant wanted to co-input the data via her own touchscreen tablet device instead of the computer provided. The features of the computer software were described to each participant and an example of how the software could show body perception changes was demonstrated. Participants were then asked to describe how they would like to represent their body perception changes on the software. On the Body Perception Tool where there were multiple ways to visualise experiences, suggestions were sometimes made as to how body perception changes could be captured. For example, if participants expressed a perceptual change such as numbness and weren't sure how to visually capture this, it was suggested to either make the body area transparent

or use a colour to indicate the perceptual change in this body area. Following completion of each perceptual change on the Body Perception Tool, participants were asked to rate their experience of discomfort as a result of this altered perception and these ratings were noted down.

During the interview and soon after, the interviewer made brief reflective notes about how well the participant was able to engage with the materials; how any communication problems impacted on the interaction and how congruent their responses were between using the tool and completing the acceptability questionnaires. Participants were not aware of any of the tools prior to participation in the study. They were not informed that the Body Perception Tool was designed by the researcher's institution, so as not to bias their attitudes towards the measures. Nine out of the ten participants were known to the researcher prior taking part in the research, either through engaging in the previous research project or through the researcher's previous role at the charity through which recruitment was conducted. These previous relationships were not thought to affect the data collection in any negative way and facilitated an easy sense of rapport with participants.

5.8 Analysis

5.8.1 Participant characteristics

Ten participants took part in the study and their characteristics are summarized in Table 11. There were seven male and three female participants. Their ages ranged from 43 to 81 years, with six participants under 65 years. Eight participants identified as White British and two as Asian. Both Asian participants spoke English as a second language. Participants' time since stroke onset ranged from 11 months to 22 years, with nine participants over 2 years post-stroke. Five participants were able to conduct daily activities independently, as they were physically able to mobilise and not experiencing significant communication difficulties. Five participants required assistance in activities due to communication and/or mobility problems. The three 'moderate to severe' aphasic participants relied on support from family carers to negotiate day-to-day activities.

Four participants were considered to have no significant speech and language issues though one participant required information to be presented slowly and clearly in order to understand fully. Three were considered to have 'mild to moderate' difficulties as a result of aphasia or dysarthria. Comprehension was also affected in these participants and information had to be presented slowly, clearly and in small amounts. However, they were able to understand several key words in a sentence, read and comprehend text and visual information and interject in interview to ensure they were well understood. These participants were able to make themselves understood verbally, though often clarity had to be sought by the researcher.

Three participants had 'moderate to severe' aphasia, which meant they had significant difficulty in both expressive language and comprehension. These participants were able to understand and read language at a complexity of two to three key words per phrase and had very limited expressive language. They were able to respond to interviewer summaries and able to challenge the interviewer to make sure their experiences were accurately represented.

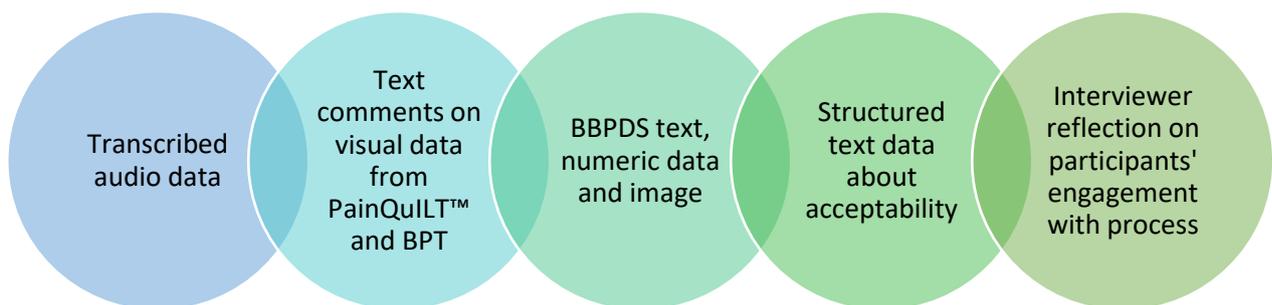
Table 11. Individual participant characteristics

Pseudonym	Gender	Age	Ethnicity	Speech	Time since stroke onset	Side of body most affected	Independence
1: Seth	Male	67	White British	None	2 years 5 months	Left side	Walks with stick. Independent in activities.
2: Jodie	Female	52	White British	Mild-moderate	22 years	Right side	Walks with stick, requires assistance in new places due to hemianopia and lack of bodily awareness. Independent in activities.
3: Ivan	Male	65	White British	None	3 years 1 month	Left side	Walks with stick, some confusion at times. Independent in activities.
4: Maud	Female	43	White British	Moderate - Severe	5 years	Right side	Walks independently, though has limited movement in right leg. Significant aphasia affecting both comprehension and expressive language. Requires assistance in activities.
5: Trevor	Male	66	White British	None	11 months	Right side	Walks independently, some confusion at times. Independent in activities.
6: Janet	Female	59	White British	None	9 years	Right side	Walks with stick indoors, uses electric scooter outside. Independent in activities.
7: Alexander	Male	81	White British	Mild-moderate	12 years	Both	Walks with frame indoors, uses electric scooter outside. Some confusion at times. Requires assistance in activities.
8: Samuel	Male	51	White British	Mild-moderate	2 years 9 months	Left side body, Right side face	Uses electric wheelchair at all times. Dysarthria makes speech hard to understand. Requires assistance in activities.
9: Arjun	Male	47	Asian Indian	Moderate - Severe	5 years	Right side	Walks with stick, significant aphasia affecting both comprehension and expressive language. Requires assistance in activities.
10: Sai	Male	54	Asian	Moderate - Severe	7 years	Right side	Walks with stick, significant aphasia affecting both comprehension and expressive language. Requires assistance in activities.

5.8.2 The analytic process

The audio interview data set was anonymised, transcribed verbatim and exported into qualitative data analysis software, NVivo 11 (QSR International, 2016). The transcribed audio data were then explored by the author alongside text data on the visual images from the PainQuILT™ and Body Perception Tool; the numeric, text and visual data captured on the Bath Body Disturbance Questionnaire; written interviewer observations and the text data indicating acceptability of tools. The data sources are summarised in (Figure 13). The structured text acceptability data were amalgamated via simplistic bar charts to give a general impression about participant perceptions of the different data collection tools (Appendix C.15), and patterns were explained through the text data. The visual data were used to illustrate written or verbalised data and were not analysed independently. Researcher reflections were noted on: participants' reactions to visual images; how well participants engaged with and understood the materials and congruence between their engagement with tools and their reporting on the acceptability questionnaires. Instances where author reflections were used to clarify meaning were clearly identified to aid transparency (Phillippi and Lauderdale, 2018).

Figure 13. Data sources



All text data were incorporated into an inductive qualitative content analysis which was conducted by the author (Elo and Kyngäs, 2007). Content analysis is an established and flexible means to analyse text data obtained from a variety of sources, including interviews, observations, survey responses and visual methods (Elo and Kyngäs, 2007; Hsieh and Shannon, 2005). It focuses on the content of the text to provide insight and understanding of the phenomenon being explored (Hsieh and Shannon, 2005). Content analysis is aligned with the aims and philosophy of qualitative description and is a robust method for conducting descriptive analysis (Vaismoradi, Turunen and Bondas, 2013).

The analytic process went through several stages. Firstly, the data were read and familiarised, then initial inductive open codes were generated. These codes were then grouped, categorised and refined into themes. Words and phrases were distilled into units of analysis and care was taken to ensure that participant's meanings were not fragmented or lost during this process. In line with the expectations of a qualitative descriptive feasibility study, units of analysis were analysed at the 'manifest' level without interpretation, to provide a descriptive and explicit representation of participants views (Elo and Kyngäs, 2007). Alongside the themes, participant responses have been displayed graphically to provide clarity for the reader around participants' consensus towards specific tools.

Chapter 6: Analysis and Discussion: A feasibility study of the acceptability of assessment tools to communicate altered body perception and comfort after stroke

6.1 Chapter introduction

This chapter includes a content analysis of the interview data which showed that participants wanted to be able to communicate their altered body perceptions and discomfort post-stroke. They described both advantages and disadvantages with all three tools and advised on ways to adapt them to suit a stroke population. The analysis is presented as relating to the accessibility, acceptability and functionality of each tool, followed by participants' preferences which highlighted a need to communicate their altered body perceptions ideally through visual tools. Discussion of the study follows and recommendations for tool development are suggested.

6.2 Analysis

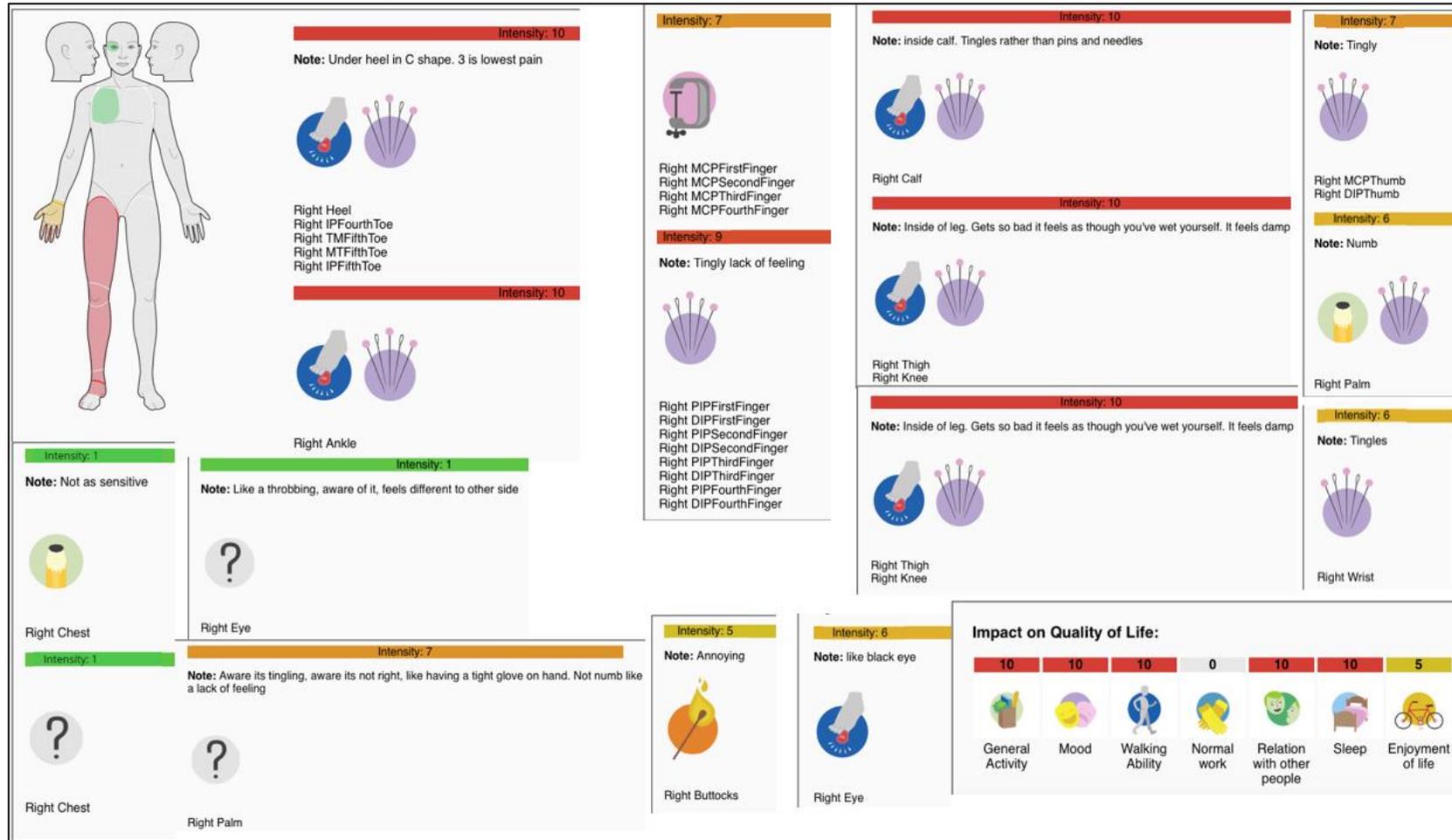
Two themes were identified: 'Acceptability and accessibility after stroke' and 'Functionality of the tool for stroke survivors'. These are presented first and are focused on each tool individually. Following this the tools were compared, and three subthemes were developed which reflected a: 'Preference for visual tools'; the need for tools to 'Reflect the stroke experience' and the desire to 'Communicate altered body perceptions'.

6.2.1 PainQuILT™

The PainQuILT™ which utilised an online two dimensional body map and visual icons to illustrate pain experiences, followed by a rating out of ten of the severity of the pain experience, is discussed first (**Error! Reference source not found.**). To exemplify the use of the tool, Trevor's PainQuILT™ image is included below (Figure 14) and a further example of Janet's image is attached in Appendix C.16 (Figure 50).

Figure 14. PainQuILT™ image

Trevor (66, 11 months post-stroke). Image cut and paste in analysis onto one screen (PainQuILT™, 2017).



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6.2.1.1 Acceptability and accessibility after stroke

The PainQuILT™ scored most highly in several domains of the acceptability questionnaire (Appendix C.15). Eight participants stated they were able to understand *all* of this tool and said they were *very satisfied* with it. Nine participants said it captured *most* or *all* of their body perception changes post-stroke. However, scores for how much it could reflect experiences of discomfort were rated lower, with only two participants stating it could capture *all* experiences of discomfort and eight suggesting it could capture *some* or *most* of their discomfort. The most commonly reported altered body perceptions were perceptual loss (9 participants); pain sensations (7 participants described stiffness, aching, pinching, electric shock, throbbing, burning, shooting, sharp or pounding pain); coldness (5 participants), pins and needles (5 participants) and heaviness (4 participants). The tool was devised to capture pain experiences and as such it could not capture the diversity of the experiences of altered body perception described.

Participants appeared to understand the PainQuILT™ fairly easily and it was very quick and easy to use. In the opinion of the interviewer, three participants would have been able to complete the tool independently, once the functions had been explained to them. Janet (59, 9 years post-stroke) who did feel able to use the tool independently said *“I think it’s good... I could use that when you go to the surgery and they say: ‘what’s wrong?’... I could just colour it in for them, rather than trying to explain”*. The participant who used a touchscreen version of the tool (who had ‘moderate to severe’ aphasia), seemed to benefit from this interface and was keen to be involved in inputting the data. Two participants expressed that they would not be able to use the tool independently.

For participants with ‘moderate to severe’ aphasia, the interviewer asked overall questions and provided visual aids to help them to communicate their altered body perceptions and to translate these perceptions onto the icons described by the tool. For example, asking: *“if you close your eyes can you feel your right side?”* to determine the extent of individuals’ perceptual loss. To facilitate understanding with one participant the interviewer used the term ‘discomfort’ instead of the term pain suggested by the tool, when asking him how his body felt during movement. This was because he had not reported any pain perception, yet

he was trying to express the discomfort he experienced when trying to move his hands when eating. In this instance where language comprehension was problematic, the interviewer used direct terms to facilitate discussion of the problem.

6.2.1.2 *Functionality of the tool for stroke survivors*

A few participants expressed that they liked having the pain icons to choose from. One participant noted how having the icon stimulated him to discuss certain altered perceptions he otherwise wouldn't have mentioned: *"I wouldn't have said that... no, but I do get cold [Interviewer: did seeing that picture trigger you to think about it?] Yes, yeah, it did."* (Alexander, 81, 12 years post-stroke). Some participants noted that some altered perceptions were not included in the icons. *"To me it would be nice to see a picture of a whole person of you know... using, if its spikey or rounded or fat or tight or pulling...when you haven't got the words, I see in pictures... and colours and much more visual"* (Jodie, 52, 22 years post-stroke). Another participant suggested adding in icons to represent *"loose... missing... swollen... and floating"* (Seth, 67, 2 years post-stroke). Several participants expressed the need for an icon to represent the *'not there'* feeling and noted how this perception wiped out other sensations. Some icons were described as not quite representative of body perceptions – participants tended to describe coldness in limbs, rather than *'freezing'* and they had to clarify whether the limb was cold to touch or felt cold to them *'internally'*. Other body changes were only mentioned by participants once discussion had moved to the *'impact section'* and may have benefited from being explicitly represented via icons, such as bladder function and fatigue - both common issues post-stroke. Participants responded well to the body map in this tool, though Trevor expressed the need for more detail in body segments, such as being able to select the inside of the leg.

The wording on the PainQuILT™ asked patients to rate the intensity of their pain according to a ten-point visual analogue scale (VAS). Four participants were unable to rate their discomfort on the tool because they did not conceptualise their post-stroke experience as being *"painful"*. *"Discomfort is more prevalent than pain... actually if you're asking about pain, I don't really think I'd honestly be able to say I had pain anywhere, except in the shoulder... if I carried about logs and yanked it out of its socket, then I'll get pain in my*

shoulder" (Seth, 67, 2 years post-stroke). In these cases, participants either chose to not rate their sensations at all, or the interviewer suggested they rated them as one (so the perceptions appeared on the body map summary) and provide descriptions of their experiences in the comment box. This issue was most obvious with the six participants who attempted to capture their experiences of numbness or perceptual loss. For this perception there was no suitable pain icon and in most cases the interviewer suggested using the 'dull' icon or the 'other' icon alongside verbal description to capture this sensation. When Ivan (65 years old, 3 years post-stroke), described the reduced perception of his left leg, he did not give it a pain icon and rated it as a 1 in pain intensity. However, he said *"It doesn't feel part of me, I've got to tell it what to do, I get cross with it and sometimes hit it"*. This highlighted how the PainQuILT™ body map was useful for promoting discussion about different body sensations, yet the icons were unable to fully reflect the post-stroke experience and the use of the word 'pain' limited rating of other types of discomfort.

Rating of perceptions was entirely subjective and appeared to vary depending on how ambiguously terms were interpreted by the individual. Two participants emphasised that they would like the tool to be more objective in rating their perceptions. The perception of 'heaviness' was rated by two participants as not painful – *"I suppose the whole thing always feels heavy... It's not a pain, it's just what it is... when I'm tired that whole arm drops... it doesn't hurt, but it just [drops]"* (Jodie, 52, 22 years post-stroke). Yet, two others rated heaviness as 8 and 10 on the VAS indicating the most pain possible - for one person this was because it prevented him from being able to walk. For others when scoring the intensity of perceptual loss, the rating again varied significantly. Ivan, (65, 3 years post-stroke) rated the perception of numbness in his left hand as a '10' in pain intensity, describing: *"it's just a quiet numbness, it's there all the time and it's in the wrists as well, really bad... especially when I try to move it"*. Janet (59, 9 years post-stroke) rated the perception of numbness down her right side as a '1' in pain intensity, commenting: *"It's not an actual pain, it just stops where it is... I'm guessing no pain is reduced sensation... it's different, it's less than my right side... it's just an annoying feeling"*.

Participants used all of the pain icons on the PainQuILT™ with the exception of the icon for 'stabbing' pain. They frequently used the 'other' icon to indicate experiences not captured

by the tool. For example, Arjun (47, 5 years post-stroke) used this icon to describe his altered perception of his right arm which felt *'dead, not there when eyes open or closed'* [Author summary of experience – participant severely aphasic]. Sai (54, 7 years post-stroke) highlighted how he struggled to interpret the meaning of the pain icon for *'pins and needles'* as this is not conceptualised in the same way in his first language.

The tool was good at capturing multiple altered perceptions in one body area. However when participants described pain intensity it became clear that they often required an option to capture the changes during movement, over time or due to weather. Trevor, (66, 11 months post-stroke) highlighted the lack of clarity around what the tool was intended to capture: *"[the pain] obviously varies from day-to-day... or do you want the worst?... If it's really bad it would be a ten... it always hurts me between one and ten."* Discussions about pain variance were sometimes stimulated during the section about impact, as one of these questions related to the impact of altered perceptions on walking. For example, Sai, 54, 7 years post-stroke said: *"Sometimes I feel when walking... I can't take my right side with me...because of heavy and I can't walk"*. Alexander (81, 12 years post-stroke) rated altered perceptions such as burning pain, coldness, dulled sensations and aching as between 1-2 in intensity when the body was static, yet other altered perceptions of muscle weakness and balance problems, which were silent when the body was static became obvious during movement. He identified that these sensations interfered enormously with his walking ability, rating their impact at '10' on the VAS. Similarly, Ivan (65, 3 years post-stroke) noted his numbness was problematic during movement and when talking about his lower arm he mentioned: *"if I bash it, it's like an electric shock"*, highlighting how some perceptions are only experienced in a mobile body.

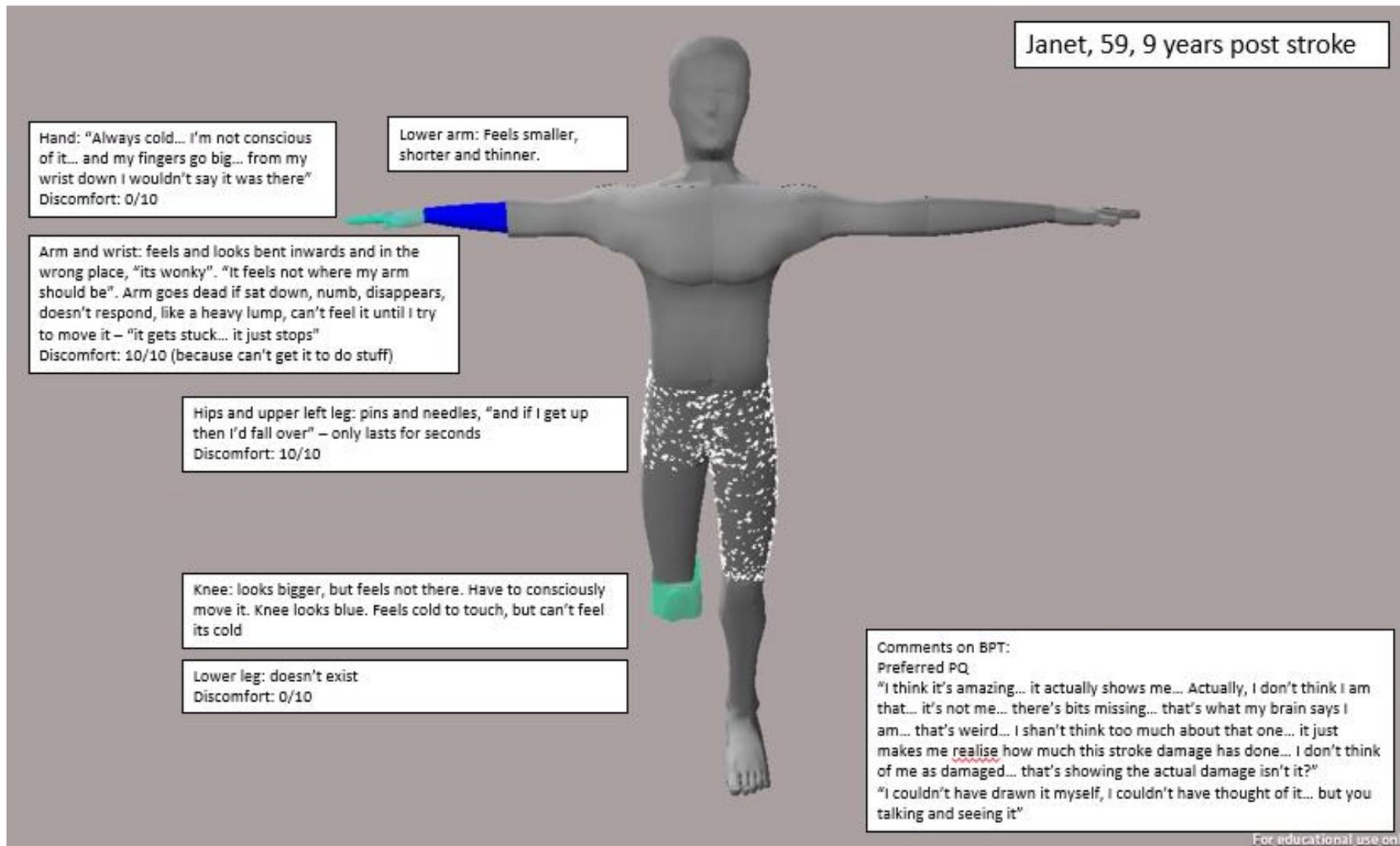
Again, interpretation of the 'impact' section of the tool varied between individuals. For example, one participant rated her altered perceptions as having no impact on walking because she no longer walked outside, but now used a scooter (Janet, 59, 9 years post-stroke). What was noticeable was how the impact section stimulated conversation about the body in different and useful ways, highlighting what was important to the individual and directing potential areas to consider intervention. One other factor to note, was that the tool reflected altered perceptions from comorbid conditions, for example for Alexander (81,

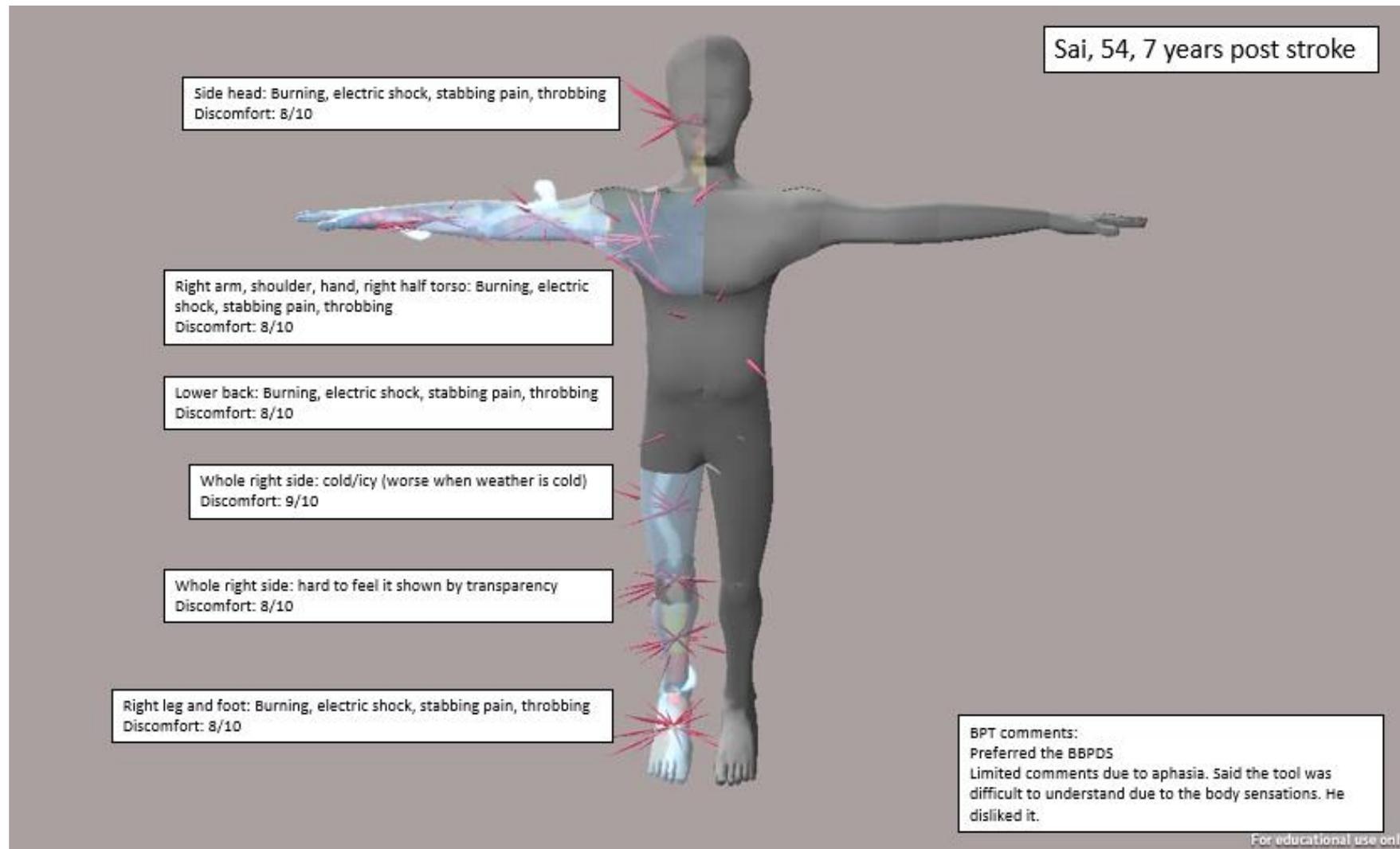
12 years post-stroke), talked about body changes as a result of both stroke and osteoarthritis (though these comorbid sensations were excluded from his final image).

6.2.2 The Body Perception Tool

The Body Perception Tool (BPT) utilised digital software to allow participants to describe their body changes using a three-dimensional avatar (Appendix C.9; Turton, Palmer et al., 2013). To exemplify the tool two images of Janet and Sai are shown below and the remaining images are included in Appendix C.17.

Figure 15. Body Perception Tool images: Janet and Sai





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6.2.2.1 Acceptability and accessibility after stroke

Participants rated the Body Perception Tool very positively overall (Section 6.2.4.1). Nine participants said it captured *all* or *most* of their altered body perceptions and all participants said it captured *all* or *most* of their discomfort. Seven participants said it was easy to understand and easy to use. Four participants rated it as their preferred tool (though two of these rated it equally with the PainQuILT™). However, participants rated this tool as slower to complete and overall satisfaction ratings were marginally lower than the PainQuILT™. Participants reported altered perceptions such as coldness, pins and needles, perceptual loss (represented by transparency – in one participant the limb disappeared completely), altered size and scale of body areas, disconnected body parts or a sense of body dis-ownership heaviness, pain and tension. The images were startling and impactful for the interviewer and some participants.

One participant expressed the shock and disbelief of seeing a visualisation of her body in which her lower leg had disappeared.

“I think it’s amazing... it actually shows me... Actually, I don’t think I am that... it’s not me... there’s bits missing... that’s what my brain says I am... that’s weird... I shan’t think too much about that one... it just makes me realise how much this stroke damage has done... I don’t think of me as damaged... that’s showing the actual damage isn’t it?”

(Janet, 59, 9 years post-stroke)

Several participants expressed that the tool was more difficult to understand. The final participant, Sai (54, 7 years post-stroke), who had ‘moderate to severe’ aphasia, rated this tool poorly because of this issue, stating it was *“too difficult”* because he couldn’t comprehend the body sensations, which he could easily comprehend with the visual icons on the PainQuILT™. Jodie, (52, 22 years post-stroke) highlighted the difficulty of scanning the screen whilst experiencing hemianopia and emphasised how she would not have been able to complete the tool independently. Interviewer reflections highlighted that potentially only two participants would be able to complete this tool independently after demonstration, due to the complexity of the functions and level of text comprehension and

computer skill required. However, this is not a criticism of the tool, as at this stage it has only been developed to use with facilitation.

The use of the Visual Discomfort Rating Scale was considered positively by participants. Participants appeared to relate well to the term and used it to capture experiences of obvious pain, loss of movement, changed balance, pins and needles, tension, heaviness, numbness and coldness. Like the PainQuILT™, participants' rating of the intensity of the discomfort varied and was subjective. The discomfort scale was independent from the tool and as such there was no visualisation of discomfort to display to participants at time of interview. In the images (Figure 1) the discomfort scores and the text comment boxes have been added during the analysis phase. As such participants' comments about whether the tool captured their experience of discomfort were based on memory of the discussion during interview.

6.2.2.2 *Functionality of the tool for stroke survivors*

One significant advantage of this tool was the function to convey perceptual loss, or a sense of detachment from the body which could be expressed via changing the transparency or colour of body areas. Ivan (65, 3 years post-stroke) was clear about how he wanted to represent this perception:

"[Interviewer: for the numb... 'it's not part of me' feeling... would it be okay to do that with making it a bit see through?] No. [Interviewer: We could do a colour?] Do a colour on there, yeah... oh that red one at the top"

Being able to alter the size and shape of the body was also useful for half of the participants – with three participants conveying a decrease in limb size and two participants showing an increase in scale. One participant used the function to move the arm, creating a separation between the arm and the shoulder.

There were some technical issues with the tool which affected the images that participants were able to generate. For example it was not possible to select small or sufficiently specific body areas to capture some experiences.

“I would say if you’re dealing with stroke patients, who are going to have spasticity and muscle tone, you shouldn’t devise a system which separates things without being able to pull out the knee and the elbow, because those joints are actually where we struggle” (Seth, 67, 2 years post-stroke)

Participants expressed the need to add multiple altered perceptions to certain body areas, which was sometimes not possible due to the complexity of some graphics. For example, it was not possible to add the visual for coldness, to areas that had been made semi-transparent as it overrode that function. Participants expressed mixed views about the colour function, which was used to denote perceptions for which there was no obvious visual such as altered movement, tension and weakness. Some participants enjoyed the experience of being able to freely use visual functions, whereas others found this alienating and chose to make text notes.

Participants expressed a preference for having visual icons (as in the PainQuILT™) to denote perceptions, as opposed to text. Jodie (52, 22 years post-stroke) who experienced mild to moderate aphasia said *“I’m much better with visuals... there were lots of words rather than [visuals]... and I don’t want that, how you say that? [Interviewer: Having icons would have been better rather than words?] Yeah.”* She also emphasised the need to capture more body changes than were available. Trevor (66, 11 months post-stroke) said: *“bit limited wasn’t it? It lacks the sensations on it... and also the body parts... in fine detail”*. Several participants were unsure which perceptions to put on the Body Perception Tool image. To generate discussion, participants were asked directly about perceptions such as coldness or heaviness, often using the icons for the PainQuILT™ to trigger reflection.

One issue with describing the tool functions was ensuring that participants, particularly those with aphasia, were not being overloaded with information. This meant it was difficult to describe all the tool capabilities at the interview outset and descriptions of the tools

capabilities were limited and targeted to ensure comprehension. From the perspective of the interviewer, a more simplistic and visual interface would have aided the comprehension of participants and facilitated their participation.

Participants said that they experienced changes to their body during movement and over time and being able to capture these changes was important. Maud (43, 5 years post-stroke, 'moderate to severe' aphasia) said that her right leg wasn't uncomfortable, but that it would swing from the hip and at times it would kick her left leg. With the BPT it was possible to add a note to capture this. Ivan (65, 3 years post-stroke) said: *"the pains not always there... it's just when I lift up in a certain position... a stabbing pain... yeah 'red' pain"*. Janet rated the discomfort in her arm at about '5' stating this was due to a lack of movement response.

"it's awkward to get it to do stuff... sometimes it gets stuck...I'm not conscious of actually doing it until I go to reach... I can't quite do what I want to do with it... You feel... 'why aren't you doing what you should be'". (Jante, 59, 9 years post-stroke)

Alexander (81, 12 years post-stroke) highlighted how other factors influenced his altered perceptions. The burning pain in the back of his thigh happened when he got up in the morning, or when he got out of a chair; the coldness in his hands changed with the weather but remained in his fingers all the time. Importantly he highlighted the sensation was *"nearly all the time... but I can't say for sure because I'm used to it"*. This emphasised the variance in awareness of altered perceptions, which is likely to depend on how long post-stroke they are and whether they believe these are perceptions which need focus because they may benefit from intervention or that these are perceptions they must learn to live with.

6.2.3 Bath Body perception disturbance scale[®]

The Bath Body perception disturbance scale[®] (BBPDS) was a text-based tool which utilised visual analogue scales to capture participants' responses to body changes (Appendix C.8; Lewis and McCabe, 2010).). It also included an image which was hand drawn by the

interviewer as participants described their sense of their body with their eyes closed (see Figure 16, further images in Appendix C.18).

6.2.3.1 Acceptability and accessibility after stroke

This scale was rated well by participants, with seven stating it captured *most* or *all* of the experiences of altered body perception and discomfort; this rating was lower than the other two tools (Appendix C.15). Participants perceived their discomfort had been evaluated, despite the tool's focus being on the intensity as opposed to the discomfort of their perception. Half the participants stated they understood *all* of this tool, which is lower than the understanding of the other two tools, though they rated it equally easy to use.

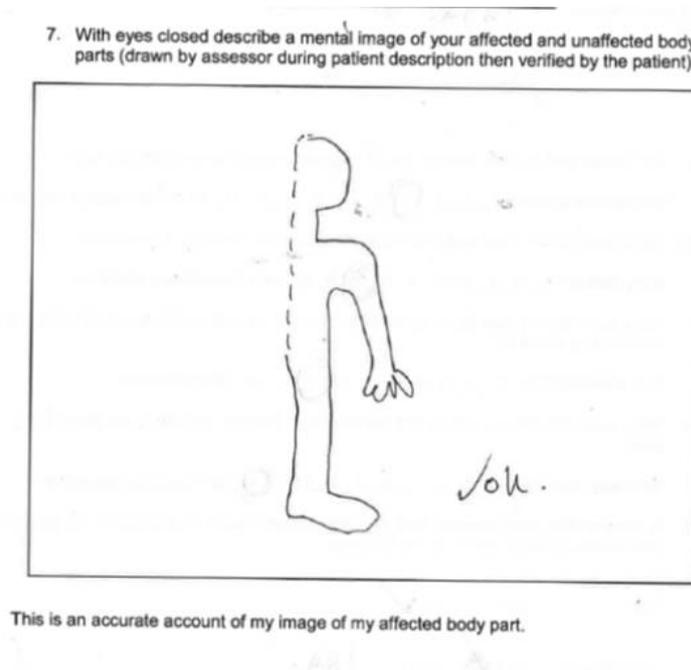
Participants found this tool more time-consuming to complete. However, their overall satisfaction with the tool showed similar outcomes to the Body Perception Tool – with seven participants stating they were *quite* or *very* satisfied with the process. Jodie (52, 22 years post-stroke) who experienced mild to moderate aphasia responded very negatively to this scale, saying it made her feel “*stupid*” and her “*heart sunk*” when she saw it because it was a written scale and she struggled to understand text-based information.

Two participants rated it as their preferred tool. One participant like that it enabled him to describe how his altered strength and balance caused him problems when moving. He felt this was because of the broad opening question which asked which body areas are affected. The other participant preferred it because he liked using a VAS to rate his altered perceptions. However, most participants expressed preference for the visual tools. Janet (59, 9 years post-stroke) said “*it was harder... there's not so many pictures... there was no visual... [I had to] try and transfer the thoughts into words... I didn't like that one*”.

Whilst participants reported the tool was easy to use, there were some questions which may have been interpreted ambiguously. Arjun, who had ‘moderate to severe’ aphasia reported that his right-side felt fully attached to his body and he was aware of the position of this area, however when describing his mental image with his eyes closed to be drawn by the interviewer, he described his right side as entirely absent (Figure 16). Whilst his

description may reflect the interpretation of the body with and without visual input, it may also reflect a misinterpretation of the questions due to his aphasia.

Figure 16. Mental body image: Arjun (Lewis and McCabe, 2010)



It was also important to reflect on which perceptual changes led to participants becoming aware of the body and how these changes may have affected their emotional feelings towards the body area. For example, participants reported perceptual loss, which affected their sense of attachment, awareness, level of attention and emotional feelings they had about the body. Yet three out of the four participants who expressed negative emotions towards their affected body area were also experiencing significant pain which may have influenced these responses. Participants also expressed frustration with lack of movement and emotional lability as factors which affected their emotional attitudes towards their bodies. As such the experience of negative emotional feelings towards the physical feeling of perceptual loss could not be solely attributed the sense of physical change and may have been influenced by other factors.

6.2.3.2 *Functionality of the tool for stroke survivors*

The BBPDS begins by asking the individual to focus on and select up to three affected body areas, which was problematic for many who had more than three areas to focus on.

Participants tended to select certain areas to focus on, which meant they had to ignore the issues occurring in other body areas or alternatively refer to the whole side of the body as one area.

This tool was very useful in terms of capturing unique data about body perception which was not provided by the other tools. The question explored sense of body ownership which provided a real insight into how participants perceived their bodies, physically, perceptually and emotionally and captured fascinating information about attitudes towards limb amputation. Four participants (three with significant perceptual loss and one with pain) stated they had had a desire to amputate their affected limbs, with two saying they still had this desire at times.

Whilst participants were able to report changes in limb size, temperature, weight and sense of pressure on this tool, this information was less detailed. Instead participants provided more detail around sense of body ownership, such as sense of attachment to limbs; awareness of body position; level of attention given to the limb and emotional feelings towards body areas. These questions gave opportunity for participants to describe how they related to their bodies post-stroke. The answers in this section were varied and provided a new insight into the experience. Half the participants rated that they were more aware of the physical position of their affected limbs and these participants expressed they gave these limbs more attention. The remaining half rated they were less aware of their limb position and they gave their affected body areas less attention. These findings were not related to how much participants rated the affected body area as being part of or detached from their sense their body. Half the participants expressed a sense of detachment from their affected body areas. Equal numbers of participants rated positive and negative feelings about their body parts, which were not related to sense of limb awareness, attachment or attention.

Some of the participant reports were surprising and incongruent to the interviewer's preconceptions about stroke experience. For example, Janet (59, 9 years post-stroke) expressed a sense of detachment from her right side and had little awareness of her limb position, yet she gave this area her full attention and reported having positive feelings towards her right side. Conversely, Sai (54, 7 years post-stroke) reported feeling detached from his right side, unaware of his limb position and said he gave the body area no attention yet reported negative emotions towards the body area. The responses were very nuanced, individualised and subjective. The complexity of rating perception of body ownership in individuals with stroke was obvious, as participants were grappling with lost sensation, bodily detachment, lost movement and an altered level of conscious attention towards the body. Ivan (65, 11 months post-stroke) when describing his limb awareness said: *"I don't feel unaware of it, I'm aware of it all the time... because that's fixed in my mind, I've put it where it [the arm/hand] is you know... there's always a place that I put it every time, because I've got to protect the shoulder as well"*. Similarly, Trevor (66, 11 months post-stroke) when describing his body awareness said: *"obviously that side does not feel the same as this side... so it feels abnormal... a bit like having your arm in plaster, you'd be aware of it all the time"*. Samuel, (51, 2 years post-stroke) explained his body felt *"not detached, but different...[I] feel very aware... its numb, so I can't tell what I'm doing"*.

Several participants struggled to understand the wording of some questions on the scale. Question five which asked: *"Is there a difference between how that side of your body looks or is on touch, compared to it feels in terms of... [size, temperature, pressure, weight]"* was queried by many participants. The interviewer simplified this question in many cases to: *"Is there a difference in how it feels in temperature, compared to when you touch it?"* Whilst many participants were able to grasp this version of the question, those with 'moderate to severe' aphasia still struggled to comprehend. Additionally, inconsistency in the VAS measures whereby some questions rated as 10 demonstrated presentation of a perception and at other times a rating of 10 reflected absence of a perception added to confusion about what questions were asking.

The visual component of this tool was particularly interesting, as it was the only hand-drawn image collected. Two participants did not describe a mental image of their bodies: Trevor

stated that he wasn't able to see a visual image of his body and Alexander said his image was the same as a 'normal' body. This was the only tool that asked participants to reflect on their body image with their eyes closed and the images created for several participants were different to those created on the other tools in which participants used visual input. When Sai, Arjun and Janet described their perception of bodily loss with their eyes closed, they described images in which the right-half of the body was completely missing, and Maud described her arm as missing. The remaining four described altered perception of body size, scale and shape – which were less successfully translated into images, by the interviewer (Appendix C.18). From the interviewer's perspective, completing these images was challenging artistically, because it involved capturing a 'whole-body' image. Also, the abstract nature of many altered perceptions did not translate easily onto paper.

Certain aspects of this scale were very relevant to the stroke experience. The sections looking at integration of affected limbs which explore sense of bodily attachment were relevant to the stroke experience and participants frequently describe perceptions such as:

"It's just that it doesn't seem to be part of me some days... every time I move it, I have to tell it to move... it won't just do it naturally like it used to". (Ivan, 65, 3 years post-stroke).

This was also clear in the question relating to the level of attention patients gave to affected body areas.

"I guess I give it a lot [of attention] because I'm moving it... I often bang into stuff on there... so I have to check that... is there just a bruise or is it really bleeding... I guess I give it a lot... because I don't think about what I do with this side of me" (Janet, 59, 9 years post-stroke)

Including an emotional component in exploration of sense of body ownership also provided useful insights into the embodied stroke experience. For example, Ivan described instances of feeling frustrated towards and hitting his affected limb.

6.2.4 Overview of the three tools

When viewed side-by-side the advantages and disadvantages of each tool became more apparent, creating subthemes wherein participants indicated a: 'preference of visual tools'; the need for tools because 'it's hard to explain' altered body perceptions; and a desire to 'communicate altered body perceptions'.

Four participants expressed that they had difficulty reflecting on their body changes post-stroke and three stated it made the body changes feel worse (either physically or psychologically). [Referring to the BBPDS] *"There wasn't much I did like about it... in fact I didn't like any of it, because I had to think about my own body"* (Ivan, 65, 3 years post-stroke). However, no participants said that this feeling would stop them using a tool like this and they all stressed the importance of clinicians assessing these types of body changes post-stroke. Participants expressed these difficulties when using both the visual and text-based tools.

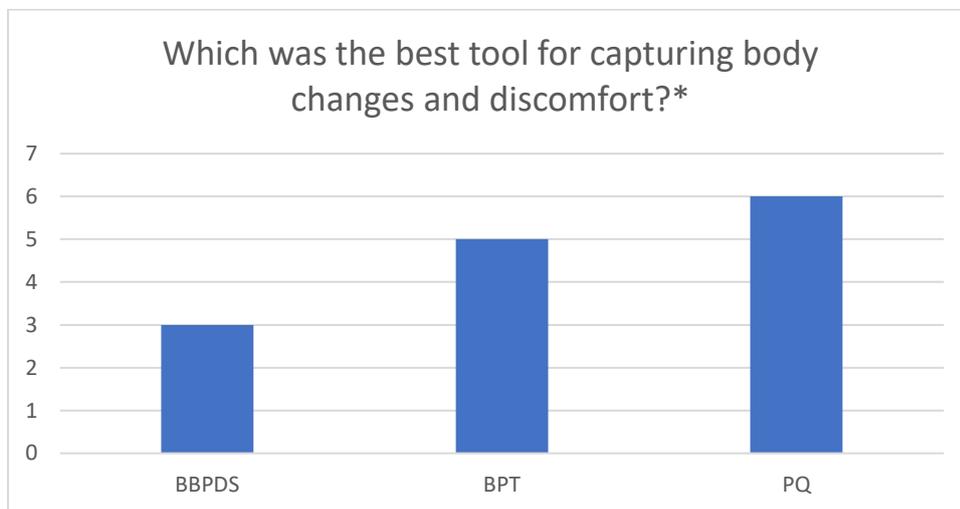
When using all tools participants demonstrated the need to describe the altered body through action and movement. The PainQuILT™ was advantageous for this as it included a section on impact. Yet these aspects were also elucidated for one participant, through the first question on the BBPDS – *'tell me which body areas you would like to focus on'* – which enabled him to describe weakness and balance issues which affected movement. This is a factor which should be considered in the development of a tool to assess the body post-stroke.

6.2.4.1 Preference of visual tools

Seven participants rated the Body Perception Tool or the PainQuILT™ as their preferred tools; two rated the BBPDS as preferred and one said they were all equally good (Figure 17 and Appendix C.15). Nine participants rated that the two visual tools - the BPT and the PainQuILT™ - captured *most* or *all* of their body changes (Figure 18). The BPT was rated as more successful in capturing discomfort post-stroke. Ten participants said it captured *most* or *all* of their discomfort, as opposed to seven in the PainQuILT™ (PQ) (Figure 19) which was

designed to score ‘pain intensity’ but didn’t have icons which related to perceptual loss or changes in body size and scale. Two participants independently described needing the types of features available in the BPT prior to seeing this tool. *“You could start with... an image that you could stretch in places and you could shrink in places... and I think I’d like control of it”* (Seth, 67, 2 years post-stroke). Participant preferences for visual tools did not seem to relate to their communication and comprehension ability, as both participants with and without these difficulties showed a preference for the visual tools.

Figure 17. Preference of tools



**Three participants cast more than one vote per tool (two participants said BPT and PQ equally good, one participant said all three tools good – therefore total votes here is 14)*

Figure 18. Success of tools in capturing body changes

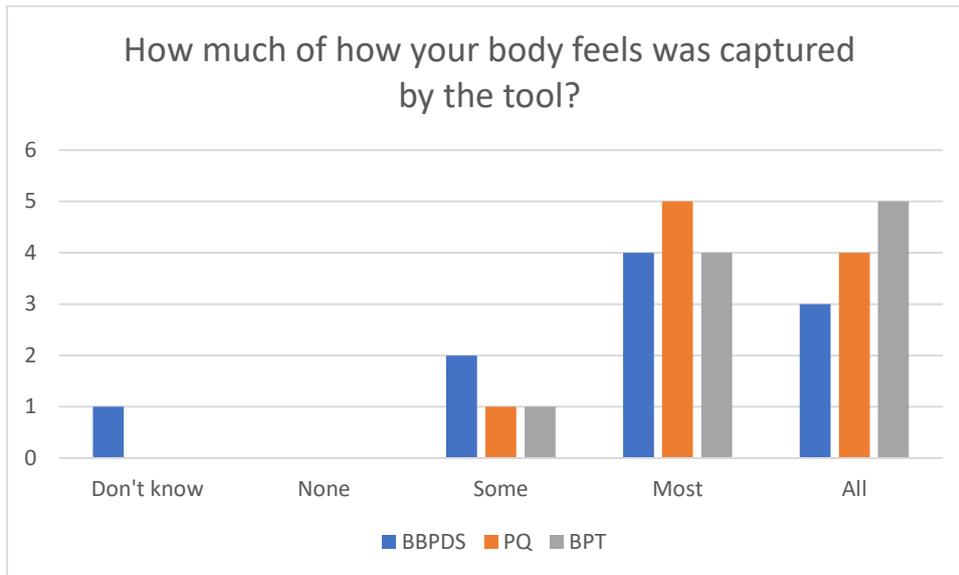
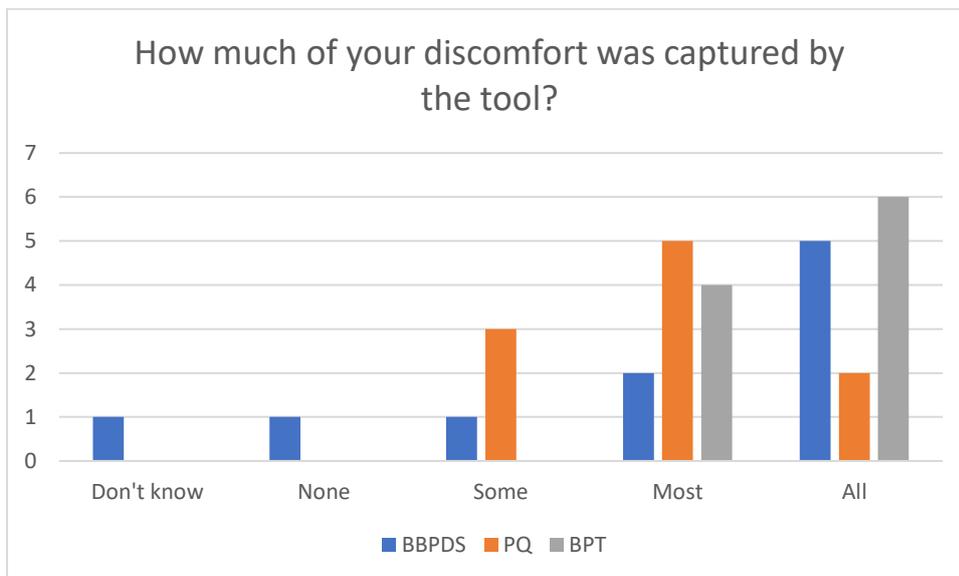


Figure 19. Success of tools in capturing discomfort

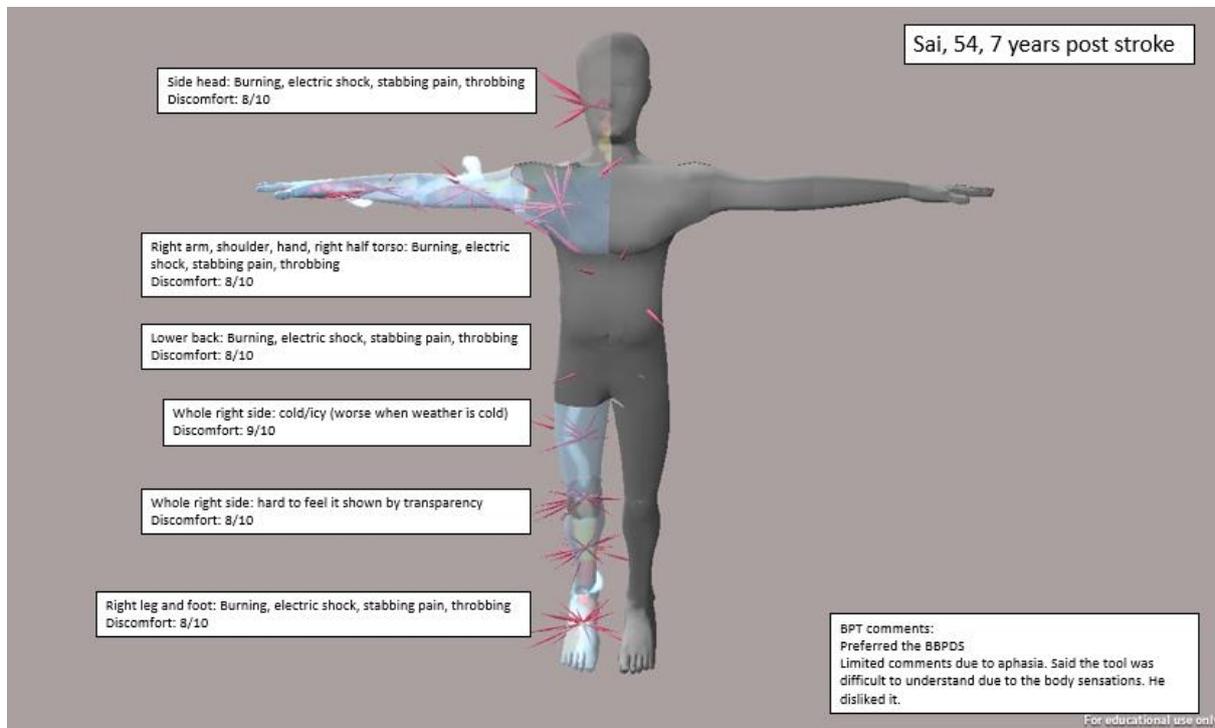


Participants were not asked to reflect on the final images created by the tools. However, from a researcher’s perspective the final image on the PainQuILT™ was difficult to navigate due to its summary in text and list format and the body perception changes not being applied directly to the body map – only colour was used to denote intensity of pain sensation (Appendix C.16).

When comparing the final images from the BPT and the PainQuILT™, the BPT images appeared to the author, to be more impactful and to provide a more effective summary of experience. Important differences were noted in the content of the images captured between the BPT and PainQuILT™ over that captured in the BBPDS. The image created for Sai in the BPT, which portrayed the body with the eyes-open, showed a ‘whole-body’; whereas the image captured via the BBPDS, which visualised the body with the eyes-closed, depicted body parts as absent (Figure 20). The PainQuILT™ image is not attached as there was no option on this tool to alter the visual representation of body areas. It is unclear which data is most useful in terms of reflecting stroke experience for the patient and directing rehabilitation, yet this is clearly an important area to consider in the future development of any tool.

Figure 20. Comparing images from BPT and BBPDS

BPT image Sai (54, 7 years post-stroke, body described through discussion with eyes open using visual aids)



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BBPDS image – Sai (54, 7 years post-stroke, body described with eyes closed, drawn by interviewer) (Lewis and McCabe, 2010)



6.2.4.2 *It's hard to explain*

Participants frequently struggled to describe their altered body perceptions during interview. They preferred having visual options to prompt recognition of their perceptual changes and to aid understanding of which experiences were relevant for the task.

Discussion with the facilitator also appeared to aid this process:

[Reflecting on the BPT] *"I couldn't have drawn it myself... I couldn't have thought of it, if that makes sense, but you talking and seeing it [the options on the tool]... it was like 'oh yeah, it [the leg] really does not feel like it's on there'"* Janet (59, 9 years post-stroke)

From the perspective of the interviewer, using visual communication aids to denote weakness and perceptual loss with participants with aphasia also supported this process. Some participants identified that there was a lack of icons to capture the post-stroke experience.

"Although those [the visual icons] are helpful, it's hard to describe... does that make sense? I don't know what else you could do." (Jodie, 52, 22 years post-stroke)

For some this was partly because some stroke experiences created multiple, complex and sometimes conflicting sensations in one area and there were not terms in the English language to describe these experiences.

"The fingers and the thumb... that's the worst... feels like tightness...squeezing... it's like pins and needles... it blinds out the sensation to a certain point.... sensitivity ain't there... on the backside... I've had... well not numbness, burning sensations... it ain't too bad but it's annoying... it's funny... I mean how can you explain something when we ain't got the words for it?... That's the problem isn't it? Unless someone... figures out a word that'll go between lack of sensation, pins and needles and a bit of throbbing. If you could design a word to fit that... that'd be great wouldn't it?... Something people understand."

Not long words, but simple words that anyone can associate with” Trevor (65, 11 months post-stroke).

This highlighted the issue of practically applying multiple visual icons to one body area and also for participants in choosing which is the most prevalent perception to describe – demonstrating the changing and competing nature of altered perceptions and how they impact on one another.

Janet highlighted another important factor; the difference between tactile and perceptual body changes. She emphasised the difficulty in expressing perceptual loss alongside physically demanding body changes such as perception of coldness.

“This hand is always cold... it’s when I touch it, because it’s not there. I’m not conscious of... feeling like this, but I know when I touch something... My fingers go blue.... [but with my eyes closed] I guess from my wrist down I wouldn’t say it was there... it’s no [discomfort] ‘cause I’m not conscious of... it... I don’t actually feel it, I see it” (Janet, 59, 9 years post-stroke).

This highlighted the complexity of the post-stroke experience, in which ‘internally’ perceived experiences (such as feeling cold) are hinged on the extent of perceptual loss, which may change the perception of coldness to a tactile or visual experience, therefore impacting the level of associated discomfort. These types of descriptions highlighted the complex and conflicting nature of altered body perception post-stroke.

This raised the issue of how to categorise body changes post-stroke which may provide increased awareness, or alternatively decreased perception of the body. Trevor, who was keen to provide some kind of quantification of body perceptions provided an interesting suggestion for categorisation which could be worth exploring in the development of any future tool.

“You’ve got to say: ‘What’s normal to a person?’ because everyone’s different... then you’ve got to say... if it’s ‘burning or pins and needles’ then there’s a plus... then if it’s

a 'I can't feel it' then it's a negative, isn't it? It's like having your gums numbed when you're having an extraction or something... so if your leg is like that... that'd be minus wouldn't it?" Trevor (66, 11 months post-stroke)

Taking this suggestion forward it is possible to imagine grouping body perception changes post-stroke into sensations which are demanding and those which are less obviously perceived. This may provide a means of visualising these changes in a way which is accessible and navigable for those experiencing comprehension difficulties post-stroke.

The term 'pain' which is used to denote intensity of perceptions in the PainQuILT™ was problematic to describe perceptions which were not explicitly painful. Using the term 'discomfort' in the BPT was helpful for participants as they were able to relate experiences of perceptual loss more obviously to this term. Whilst participants did not articulate a need for the discomfort scale to appear on the graphic in the BPT, rating the intensity of the perception on the PainQuILT™ was useful to ensure clarity in understanding for both participant and facilitator. Both the terms 'pain' and 'discomfort' created ambiguity in how problematic individual perceptions were and why. When using the PainQuILT™ ambiguity was created as it was unclear whether when participants rated a perception as high in 'pain intensity' that the perception was actually 'painful' or whether it was problematic in other ways. Using the term 'discomfort' with the BPT created similar difficulty, as although it was more encompassing than the term pain and participants related to it more easily, it left ambiguity about why a perception may be experienced as highly uncomfortable or whether participants required interventions. This highlighted the importance of ascertaining clarity around these issues in any future development of a tool to direct interventions.

6.2.4.3 Communicate altered body perceptions

Nine participants felt it was important to assess body perception changes, comfort and emotional changes post-stroke. Three participants highlighted physical and functional benefits to assessment such as how it would improve the effectiveness of rehabilitation, increase motivation to engage and help them to regain function. However, eight participants expressed the importance of assessment for psychological factors, such as

understanding and coming to terms with the stroke; to feel reassured; to prevent fear and sadness; to feel valued by health professionals; and to reduce the impact of pain on mood. The rationale for the only participant who did not want these changes assessed, who experienced 'moderate to severe' aphasia, said this was because her arm had "gone" and was "dead" and she was scared that if she had rehabilitation the arm would become painful.

Seven participants said they felt their preferred tool would help them talk to a doctor about their body changes. Of the three remaining participants, two were unsure whether these tools would help communication: one because he only experienced body perception changes when moving and the other because he felt he didn't need help communicating. Both of these patients experienced 'mild to moderate' communication problems. One participant with 'moderate to severe' aphasia said she didn't need them because her mum conducted her communication for her. However, the majority of participants felt strongly that they wanted health professionals to assess the body perception changes they experienced.

"[Interviewer: after stroke, is it important to assess how your body feels?]" A hundred percent...because they can't move on with your improvement you see... but I didn't have the opportunity of this tool, but I'm sure things would have got better... that would give each individual determination to get better... it would make you understand that you didn't have to cry every time you talked about it, you know how you felt... I think it needs to be assessed continuously... you have to continuously tell doctors what's going on" (Ivan, 65, 3 years post-stroke)

Eight participants stated they felt that altered body perceptions should be assessed at multiple time points during stroke recovery because these perceptions evolve over time. Identified time points were in hospital, once home, once rehabilitation has stopped and yearly thereafter. Seven participants also expressed also wanting emotional health to be assessed regularly post-stroke.

6.2.5 Summary

This study showed that participants wanted to be able to convey their altered body perceptions to professionals and that using assessment tools was a feasible means to achieve this even for those with communication problems. Participants experienced complex and conflicting altered perceptions that were hard to describe. They preferred visual tools to depict these perceptions. Each tool provided unique data but no tool at its current stage of development was able to fully reflect the experience of altered body perception and comfort post-stroke. Assessing impact through rating the severity of the perception provided clinical focus. Developing more comprehensive methods to assess the extent of body perception changes post-stroke experience is important to stroke survivors.

6.3 Discussion

Currently assessment of the altered body after stroke is problematic as it does not assess patient experiences, meaning there is little clinical understanding of what issues patients would like intervention to support. This also means that a wealth of subjective patient body-experience data, such as physical and psychological perceptions of the whole-body, is not used to influence rehabilitation plans. This is partly due to flaws in assessments or inconsistencies in their application which has consequences for how well-informed health professionals are when planning rehabilitation (Pollock, Hazelton and Brady, 2011; Sibley et al., 2013).

Exploration of rehabilitation therapists' opinions of somatosensory assessment post-stroke found that only half were satisfied with current assessment and the majority frequently relied on unstandardised methods and observation to inform treatment and discharge plans (Pumpa, Cahill and Carey 2015). A study of UK therapists found similar findings and highlighted the disparity between bodily testing sites and methods of testing between clinicians (Winward et al., 1999). Assessment of the body awareness after stroke is also problematic due to the complex interaction between cognitive and behavioural processes of some perceptual conditions. For example, standard neglect assessment such as the Star-cancellation task, a component of the Behavioural inattention test, may be insufficient to clinically identify all types of neglect (Appelros et al., 2002; Maxton et al., 2013; Wilson, Cockburn and Halligan, 1987). This may be because neglect assessment tends to focus on awareness of extrapersonal as opposed to peripersonal space (Cocchini, Beschin and Jehkonen, 2001); or because assessment cannot replicate the complexity of a real-world environment (Donoso Brown and Powell, 2017). Likewise, it can be difficult to isolate causes of balance problems using measures such as the Berg Balance scale, as they may be related to changes in sensory, motor, vestibular, visual or body awareness function (Oliveira et al., 2011). New approaches to assessment of sensory and motor impairment and conditions in which body representation is affected suggest that incorporation of an understanding of how these issues are experienced by the individual is key (Dieguez and Lopez, 2017; Normann, Fikke and Øberg, 2015).

One area of assessment which requires the collation of subjective ratings of perceptual changes after stroke, is evaluation of pain. The 'Faces-of-Pain' scale has been shown to be suitable for capturing experiences of shoulder pain post-stroke and was recommended as potentially more suitable for those with communication issues (Dogan et al., 2010). However, it wasn't clear if the sample in this study included a population with such difficulties. A systematic review of visual pain assessment tools post-stroke recommended the use of the 'Faces-of-Pain' scale and visual analogue scales in people with aphasia, but also suggested the need to develop a specific tool for this population (de Vries et al., 2017). Likewise, a comparison of visual analogue scales, alongside verbal rating and the 'Faces-of-Pain' scale showed the validity and reliability of the latter measure in stroke patients with left hemisphere stroke (Benaim et al., 2007). These studies are interesting because they highlight the need and feasibility of collating subjective patient experience information to inform treatment and rehabilitation.

Due to the difficulty of easily assessing complex perceptual body changes through observable measures, it could be useful to develop a structured way to incorporate the patient-voice into the rehabilitation picture. These tools should be accessible to those with communication and cognitive limitations post-stroke; able to encompass the broad, complex and 'whole-body' experiences of living with these body changes and be practically useful to real-life experiences in terms of assessing impact, discomfort (in the short and long-term) and directing useful rehabilitation outcomes.

6.3.1 Recommendations for tool development

Some recommendations for the development of a tool to communicate the experience of altered body perceptions are detailed below. These recommendations are based on the body changes which stroke survivors in this study felt were important to communicate.

6.3.1.1 Portraying the altered body after stroke

In this study participants responded well to the visual icon chart element of the PainQuILT™ tool. From the perspective of the interviewer, using this chart alongside the visual communication aids to trigger bodily reflection prompted discussion, focused conversation and clarified understanding of the body perception changes experienced. However, this chart was limited to pain experiences and did not reflect many body changes after stroke. As such it would be useful to develop a stroke specific visual aid to categorise body changes and facilitate mutual understanding.

These categories should be developed in further consultation with stroke survivors and discussion with health professionals to develop a shared understanding. Drawing on the findings from the previous phenomenological study, a possible grouping might involve: experiences of perceptual loss (such as the body feels numb or dead); demanding and uncomfortable perceptions (such as pain, heaviness, pins and needles, changes in body scale or shape); and experiences of the body during movement and activity (such as balance, weakness or muscle tension). As many perceptual changes are noted during activity (Carlsson, Gard and Brogårdh, 2017; Chatterjee and Mennemeier, 1996; Doyle, Bennett and Dudgeon, 2014; Tham, Borrell and Gustavsson, 2000), different scenarios could be discussed with stroke survivors to promote discussion of which perceptual issues are experienced and how they become apparent. Furthermore, consultation with culturally diverse participants is advised to ensure icons are relevant and comprehensible to all groups.

It is useful to understand individuals sense of body ownership post-stroke to direct rehabilitation (Dieguez and Lopez, 2017). Questions highlighted in the BBPDS about sense of attachment and awareness of their body, the attention given to body areas and their emotional response to the body, proved useful tools to facilitate this discussion. However, it is worth noting that the rationale for questions in the BBPDS is very different to the rationale for capturing post-stroke experiences. For example, question three (Appendix C.8) which discusses the attention given to a limb during an experience of chronic pain, is useful because it establishes if an individual is 'over-attending' to a limb and thereby contributing to a worsened sense of body perception. Whereas establishing the level of attention to a

limb post-stroke, may establish if a limb is being ignored due to perceptual loss and therefore requires conscious attention to aid reintegration into the body schema. It may also highlight beneficial or problematic strategies being employed to attempt to regain control over a dysfunctional limb. Further exploration with clinicians around which body ownership questions pertaining to body image are useful to capture via such a tool.

The BBPDS also differed from the other tools in that it asked the individual to describe their body image with their eyes closed, which led to the portrayal of more perceptually altered bodies for some participants. This data is intended to reflect representations of the body in the body schema, which can be a useful area to target rehabilitation efforts. For example, body illusion tasks demonstrate how malleable body schema is and how amenable it is to multisensory or virtual-reality interventions (Dieguez and Lopez, 2017). As such, it is likely that it would be useful to capture body images with and without visual input during assessment. However, further consultation with health professionals about how this information would inform treatment plans is required. Adding a digital function to achieve this would also ameliorate the challenges of drawing these 'whole-body' images for the facilitator.

It is also worth considering further the varying impact and accessibility of the final images provided in this study. From the authors perspective, as an 'outsider' to the stroke experience, the Body Perception Tool provided the most powerful and quickly accessible information to understand the stroke survivors' experience. This was because the digital image included visual representation of the altered perception on the body map – unlike the image provided on the PainQuILT™. The final BPT image created in the analysis stage, was particularly impactful as it provided text description and discomfort ratings alongside visual representation of the change on one screen. This provided a swift snapshot of the participants' altered body, which required minimal effort to decode and comprehend. The final image should be considered in the development of any tool. However, further consultation with stroke survivors about how they are affected by viewing an image of their body perception changes is required, considering the emotional impact of seeing perceptual body changes.

6.3.1.2 Assessing the impact of altered perceptions

This study showed the advantage of capturing the impact of altered body perceptions, through the use of rating scales which assess differing aspects of impact, effect and discomfort between the three tools. These scales were helpful to determine the intensity of specific altered body perceptions and identified their impact on different quality of life domains such as mobility, sleep and mood. Kolcaba (1991) highlighted the advantage of using a holistic concept of comfort to help professionals determine which elements are causing patients discomfort and give direction for care. As such inclusion of a holistic means to assess and interpret the impact of an altered perception on the individual is vital. However, rating the multifaceted experience of discomfort as a homogenous concept should only be a precursor to a conversation about how discomfort is experienced. Discussion is important, as impact may not fit into commonly used categories of functional impairment (Poltawski et al., 2016). It would therefore be useful to include a comment box in this section to record how the altered perception causes this impact. The experience of body perception changes post-stroke fluctuates. For example, pain can occur intermittently or worsen over weeks or during the course of a day (Widar, Ek and Ahlström, 2004). Participants should be asked to note how often they experience a perceptual change to determine whether it is a problem for them which requires intervention. It is also important to maintain clarity when using subjective ratings to determine what these mean to the individual. For example, a high level of discomfort resulting from perceptual loss may be attributable to a changed sense of body ownership, movement or emotional feelings towards affected limbs. As such these ratings could serve as a prompt to focus clinical discussion.

This study highlighted the experience of multiple and complex or contradictory altered perceptions occurring in one body area. For example, coldness in a limb which may be perceived internally or externally; or a sense of perceptual loss or numbness which may be experienced with pain. Therefore, any tool should allow multiple altered perceptions to be applied to one area and special consideration should be given to how perceptual loss would impact the visual display of multiple perceptions. In the cases where this is used, individuals should rate which issue is most perceived by them and most problematic, to direct

rehabilitation. Body changes resulting from comorbid conditions such as arthritis should also be considered and may increase understanding between patient and clinician about what body changes are most problematic to the individual and how perceptual changes from differing causes impact on one another.

6.3.1.3 Accessibility of the tool

Consideration should be given to the multitude of ways stroke can impact individual's ability to interact with digital media. For example, aphasia, visual and cognitive issues, mobility problems or changes such as hemiplegia can affect the perception and comprehension of text and the ability to input text or touch visual icons (Menger, Morris and Salis, 2016). In line with recommendations of how to design 'aphasia-friendly' resources and the suggestions of the participants in this study, the tool should be designed with a simplistic and visual interface (Palmer and Patterson, 2011; Brady, Fredrick and Williams, 2012). There is limited evidence to suggest which interfaces are most suited to those with aphasia (Menger, Morris and Salis, 2016), yet intuitively a visual platform seems like the most logical interface to suggest due to its simplicity. Recent research with two aphasic individuals, exploring the benefits of layout of imagery on a digital interface suggested advantages for conveying meaningful images with context, however further research is required (Brock et al., 2017). Further consultation with stroke survivors is required to determine whether an interface could be designed which could make a tool independently accessible to those with aphasia. This would be an advantage in terms of giving individuals autonomy when communicating their condition and freeing up health professional time.

6.3.2 Strengths and limitations

There were several limitations to this study which are useful to explore. Due to the nature of a feasibility study the research included only a small sample, purposively selected to demonstrate a variety of altered body perceptions. Furthermore, the tools chosen to explore the altered body were newly developed and have therefore not been fully validated. As such the findings of this study do not indicate which altered perceptions are most

problematic for stroke survivors and the findings are not generalisable to the wider stroke population. Although the sample demographic was not intended to be representative of the general stroke population, to inform future recruitment it is worth noting that the sample contained a higher number of young stroke survivors. Six participants (60%) were under 65, which is higher than the 25% represented in the general population (Royal College of Physicians, 2016). This is likely to be because three of the newly recruited participants were from a 'younger persons' stroke support group. Inclusion of participants from a non-White British population was advantageous because it highlighted different interpretations across cultures of visual icons denoting pain perceptions.

During interviews the level of facilitation was high and tailored to each participant. This was essential to enable participants with comprehension and communication issues to participate fully and not lose confidence in the process. When introducing the BBPDS to several participants, the tool was introduced as being potentially more difficult to understand so that participants who did find it challenging didn't feel stupid or disengage with the tool and give generic answers in order to move on quickly. However, it may also have affected participants' acceptability ratings of the tool. As the interview progressed, facilitation involved reminding participants to portray previously mentioned altered perceptions, as the shared cumulative knowledge of the altered body grew. This could be construed as leading participants to portray perceptions. To mitigate for this, participants were always given opportunities to refute interviewer suggestions, as the interviewer explicitly sought clarity from participants using closed questions (to support those with aphasia) once a perception had been recorded. Asking participants to rate 'how easily they understood the tool' and 'how easy it was to use' reflected both their comprehension of the tool and the way in which it was facilitated. The majority of participants did not rate the quality of the final image (presented in the analysis) for capturing their body perception changes. Instead they rated the process of completing the image which comprised both experience of the tool and experience of facilitated discussion. Some participants freely expressed that they wouldn't have been able to complete the tool independently and some gave feedback to improve the tool, suggesting a level of reflection on the tool which surpassed facilitation by the interviewer. Any further research in this area would need to

focus on creating a more systematic approach to interview to ensure that ratings fully reflect the assessment tools and not the interview and facilitation experience.

The tools were administered successively during interview and as such the participant and interviewer developed a cumulative knowledge of the altered perceptions which were being represented. This meant that by the time the third tool was administered the interviewer was able to provide additional prompts and encouragement to enable participants to portray their altered body perceptions. To mitigate for any bias in perception of acceptability, the order of tools was rotated between participants. The ratings for the tools did not vary depending on which was presented first and despite the PainQuILT™ being more frequently presented first, this did not affect whether the tool was rated more preferably.

This study required participants to maintain concentration for a significant period of time as they rated overall tool acceptability at the end of interview, meaning participants had to remember tool preferences for the duration of the interview. Some participants appeared to struggle with concentration or fatigue as the interview went on, which may have impacted their level of reflection on the acceptability questions. Participants' enthusiasm and ability to engage with the interview process did not appear to be related to their level of communication problem. Whilst the interviewer was confident that participants retained this information over the duration, in any future study it would be worth ensuring that this is the case and considering alternative ways of presenting this volume of information, by using, for example, multiple interviews.

6.3.3 Conclusion

This study has shown that stroke survivors want and are able to engage with tools to communicate their altered body perception and as such, conducting further research into this area is both important and feasible. The discussion has addressed complexities in developing a tool and working with this population and given suggestions to overcome some of these difficulties. Current issues with assessment of the body after stroke suggest that clinicians would benefit from additional information to inform treatment plans.

Utilising patient perspectives may be a useful avenue to explore in terms of deepening clinical understanding of subjective body changes or understanding more about changes to body schema after stroke. Assessment of discomfort and impact may also prove useful to direct rehabilitation and interventions.

Participants in this study indicated their preference of a visual, simple and accessible tool to convey their body changes. Such a tool could prove useful for patients and clinicians and improve shared understanding about problematic body changes after stroke. The impact of improved patient-clinician understanding of associated psychological variables such as attitudes towards the altered body or reducing uncertainty about the causes, treatment and impact of living with the altered body is unknown. Yet the findings of the BBPDS used in this study, suggest that it may be worth exploring psychological variables such as participants' emotional reactions to affected limbs to understand more about sense of body ownership. Exploring ways to communicate stroke survivors' embodied perspectives of their altered perceptions has the potential to bridge gaps in clinical understanding. It could provide a holistic idea of body changes and elevate the patient-voice when developing rehabilitation plans.

Chapter 7: Thesis discussion

7.1 Chapter introduction

This chapter draws together the findings from the three studies to focus on the parallels between them. It highlights methods and theoretical constructs which worked well, emphasising the congruence between theory, terms and methodological approaches. Clinical implications and areas for future research are discussed. These recommendations focus predominantly on the value of developing tools and language to facilitate effective patient-clinician communication and aid understanding of body perception changes after stroke.

7.2 Thesis synopsis

The overarching aim for engaging in this programme of work was to expand the literature and clinical understanding of the patient experience of body perception changes and discomfort after stroke. Highlighting the lack of patient-voice in clinical understanding of the altered body emphasised the advantages of developing an embodied and holistic understanding of the body to direct rehabilitation.

This programme of work addressed the research questions by reviewing the literature capturing first-person accounts of changes to the perception of the body after stroke. The literature review identified 28 studies that suggested that stroke survivors often experienced problematic changes to the perception of their bodies. Concurrently, 16 stroke survivors were interviewed using a phenomenological approach to explore their altered perceptions and experiences of discomfort. Findings from this phase of research indicated that stroke survivors experienced changes to how they physically and psychologically perceived the body which were uncomfortable, hard to describe and difficult to make sense of. This provided a rationale to explore whether assessment tools were a useful and acceptable means to support the communication of the subjective experience of altered perceptions and discomfort after stroke. Ten stroke survivors took part, including

participants with aphasia. They emphasised the importance of communicating the altered body and discomfort. They agreed assessment tools were a feasible and acceptable means to achieve this and they highlighted their preference for using visual tools.

7.2.1 Key findings from the scoping review

Being able to draw together and reconceptualising conditions under the term 'altered body perception' in the scoping review (Chapter 2), highlighted the advantages of blurring the clinical boundaries between these body changes. Blurring these boundaries facilitated a holistic interpretation of experiences which was key in illuminating the patient perspective. This emphasised that first-person accounts could elucidate theoretical constructs exploring sense of body ownership or how awareness of perceptual changes develop (Baier and Karnath, 2008; Chatterjee and Mennemeier, 1996). The patient perspective also refocused discussion onto the bodily experience of the altered perception, as opposed to its psychosocial consequences. It brought focus to how stroke survivors relate to their bodies, emphasising gaps in clinical understanding of these experiences such as how patients become aware of deficits in perceptual loss. The term 'altered body perception' brought attention to the experience of the 'whole-person', as opposed to focusing on the affected body area or a singular condition (e.g. neglect or pain). This had the effect of highlighting the interaction between holistic factors and the individual's embodied experience of living with these changes. As such, creating the term 'altered body perception' added to current understanding of how to interpret the literature to give weight to first-person accounts.

Qualitative accounts were particularly useful to get an embodied sense of patient experience. Yet, mixed-methods approaches which used descriptive survey responses alongside clinical examination provided another perspective, often postulating on the neural causes of certain perceptual experiences (Baier and Karnath, 2008). Through exploring patient experiences collectively, it was highlighted how little is understood about these difficulties. It emphasised the importance of understanding more about problematic perceptual changes for patients and deepening understanding of the relationships between perceptual experiences and their causes.

This scoping review brought attention to problems in patient-clinician communication, for instance noting that patients may not report altered perceptions to professionals for fear of being perceived negatively. No studies reflected which altered perceptions were problematic from the patient perspective, highlighting that researchers and clinicians drive the rehabilitation agenda. Therefore, using an embodied umbrella construct of 'altered body perception' would be advantageous to professionals and patients, as its fundamental goal is to achieve a deeper and more complex understanding between individuals of their embodied post-stroke experience. This has implications for patient-clinician communication, patient-centred care and rehabilitation.

7.2.2 Key findings from the phenomenological study

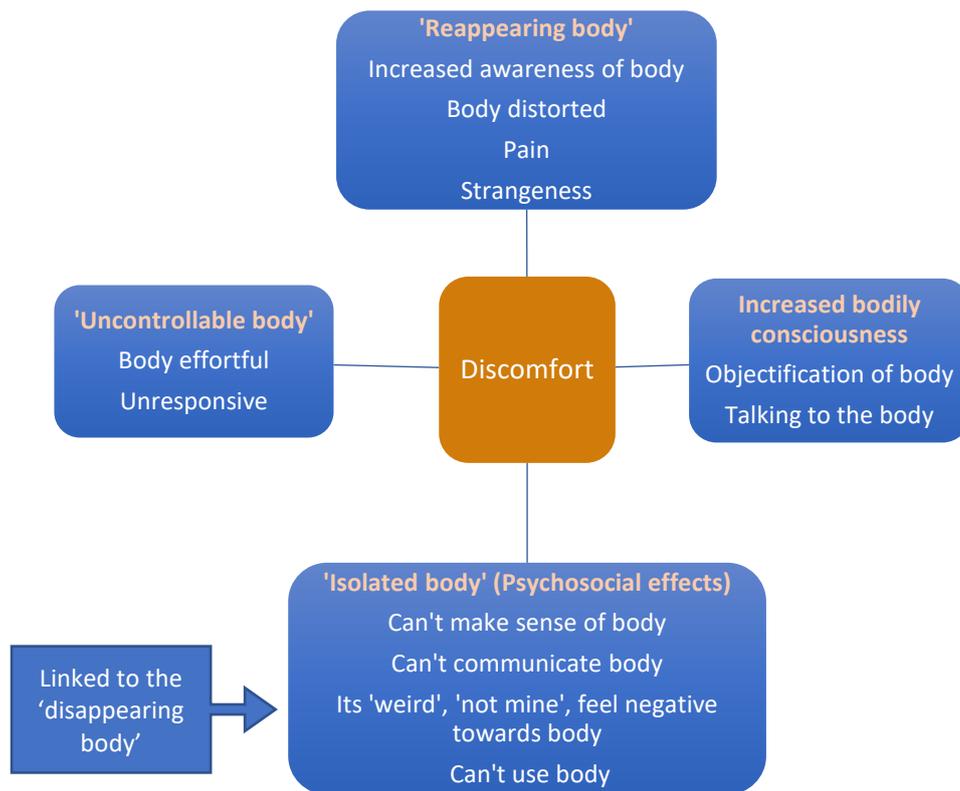
The findings of this study (Chapter 4) demonstrated the complexity of altered body perceptions and the limited language and understanding of these perceptual changes. In the current study many participants used creative metaphors or were simply unable to find the right words to describe their unusual body changes (see Section 4.3.4). Difficulty communicating altered perceptions were noted in the literature, as some individuals were reportedly fearful of being misunderstood when describing unusual perceptual experiences, or simply did not have the language to convey their experiences (Antoniello et al., 2010; Connell, McMahon and Adams, 2014; Klink et al., 2015; Section 2.6).

The effect of this in current stroke care may be that patients do not communicate body experiences to health professionals and likewise professionals may not elicit this type of information due to a lack of knowledge about how these perceptions manifest. As a result, patients may have poor understanding of the causes of their experiences and the treatment options available. Deepening clinical understanding of changes to perceptual experience is vital, to facilitate a more holistic understanding of the patient experience and develop appropriate interventions. Although providing patients with useful and accessible information to understand their condition is a key aspect of stroke care, patients report dissatisfaction with the information they receive to make sense of their experience (Eames et al., 2010). As such, improving patient understanding and ability to communicate is a pertinent area to improve patient experience after stroke.

The theoretical construct of comfort applied to investigate this phenomenon, was well placed and helpful for eliciting the embodied experiences affecting the experience of altered body perception. The construct aided discussion of body changes and facilitated some idea of the impact and priority of different experiences for the individual. It also highlighted discussion of bodily experiences which had not previously been considered in terms of comfort, such as the lack of bodily response and the dialogue with the body. This 'lens' added weight to the experience of these body perception changes, which otherwise may just be side-lined as a natural consequence of stroke.

A summary of the issues pertaining to the experience of discomfort and altered body perception are captured in the graphic below (Figure 21). It highlights the different domains in which individuals described discomfort (including synonyms of discomfort, such as pain, upset or frustration) and emphasises the holistic and embodied nature of these experiences. This 'lens' is useful and could be a starting point to capture body image and body schema-related disturbances post-stroke (the links between embodiment, discomfort and body representation is discussed in more depth in Section 7.2.5). Its advantage is that it is an easily understood, patient-friendly term, which can encompass holistic perspectives about the body including physical and psychological manifestations of perceptual changes. The disadvantage is it may be exclusionary to undemanding experiences such as perceptual loss. This term is congruent with the idea of moving beyond purely functional assessment of body changes after stroke, providing a holistic and non-compartmentalised focus which is compatible with embodiment theory. It would benefit from additional research determining patient perspectives of its use and how easily it could map to concepts of body image and body schema.

Figure 21. Potential sources of discomfort after stroke



7.2.3 Key findings from the feasibility study

The feasibility study (Chapter 6) highlighted that participants wanted to communicate their altered body perceptions and demonstrated the feasibility and preference of using visual tools to capture their experiences. It created discussion around what kind of perceptual experiences need to be conveyed to professionals after stroke and highlighted the potential of using visual and digital methods to capture altered body perceptions. Further research with stroke survivors is required to determine which visual icons are suitable to reflect body changes. Developments in the assessment of other conditions demonstrate the advantages of using technology to collate subjective patient information. Recent research has shown that asking patients to complete a virtual-reality computer game involving completion of daily tasks was acceptable to patients and a potential screening tool for Alzheimer's disease (Vallejo et al., 2017). Likewise using digital methods to collate self-reported information about symptoms of lung cancer was found by patients to be acceptable, enjoyable and time-saving (Tang et al., 2017). Using digital methods to collect subjective patient information has

the potential to access novel information about the patient and if inputted independently, could reduce the burden on healthcare professionals.

Through utilising the Bath Body perception disturbance scale[®] participant experiences were explored in terms of body ownership. This was achieved by asking patients 'body image' related questions such as how much attention they paid to limbs and how attached the limbs felt to the body. They were then asked to describe their 'body schema' representation by describing their body without visual input. This provided fascinating input relating to body schema and body image which is rarely documented in stroke literature. It may be that participants who described a sense of having to provide conscious attention to the affected body area were exploring their disorder of body schema by compensating with more conscious body image strategies (Gallagher, 2005). Whilst those who described a sense of limb detachment and no sense of attention towards the limb were not yet using those conscious compensatory strategies to aid limb integration. Research into anorexia nervosa has used computer avatars alongside questions about attitudes towards the body to understand more about this relationship and disturbed body perception (Mölbart et al., 2018). Virtual-reality body illusions have also shown promising results in challenging disturbed attitudes to body image in this population (Keizer et al., 2016). Combining the use of 'body image' questions with digital and visual technology highlight the unique window these methods provide to better understand how disturbances to body image and body schema manifest. These methods may provide a may provide a useful avenue for research to understand more about body perception after stroke.

7.2.4 Embodied experiences after stroke

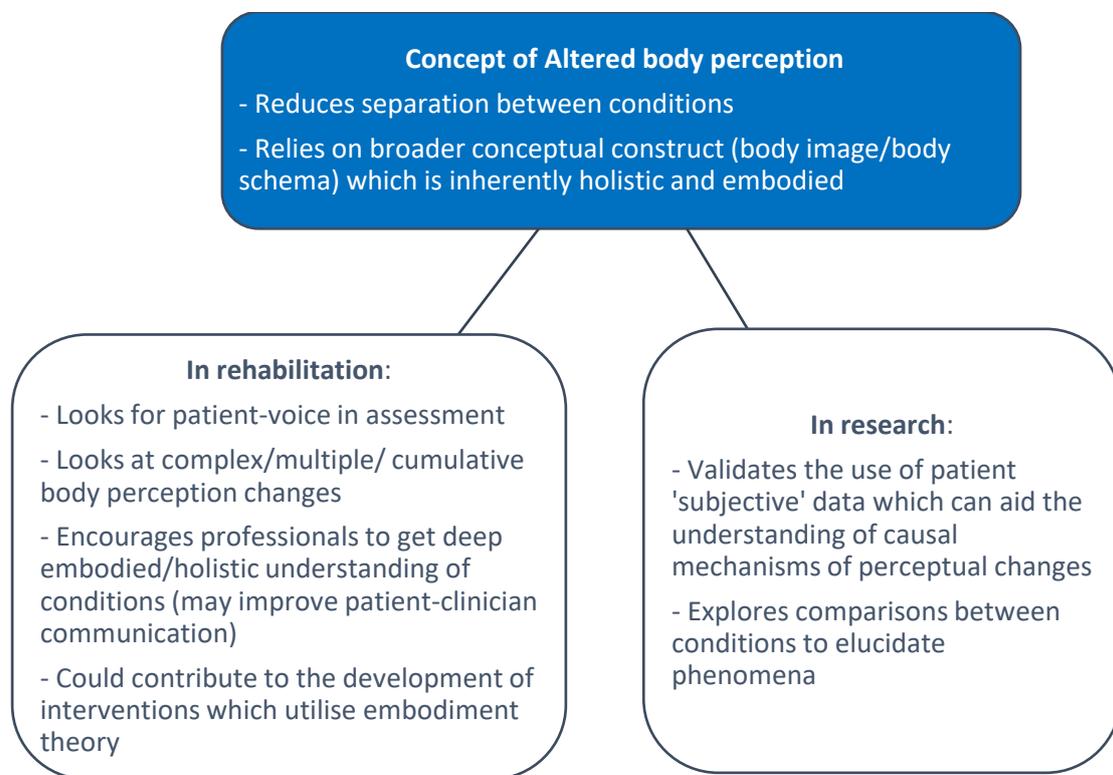
This programme of work demonstrated that changes to body perception after stroke do not occur in a vacuum. The body is affected by a plethora of perceptual and sensory changes which are closely tied to the psychosocial experiences of living with these changes, which affect how the body is communicated in the world. This link has been demonstrated through the exploration of qualitative accounts of stroke survivors experiencing incontinence who clearly articulated the sense of fear and shame around their experience (Kohler et al., 2018). This was exacerbated by a sense of dismissal from health professionals and led patients to feel unable to communicate these changes and access appropriate support. This highlights the need to acknowledge that the patient exists in a 'lifeworld'; they are embodied within an environment. Taking this perspective elevates the subjective bodily experience, recognising the complexity of interaction between the 'internal' and 'external' worlds. Recent research integrating 'lifeworld' theory into the use of assistive devices, exemplified this relationship, pointing to how these devices alter the corporeal structure and therefore the sense-experience of the body, yet their use is hinged on complex psychosocial meanings of the way these devices are interpreted in the world (Berndtsson 2018).

In this programme of work, the term 'altered body perception' was useful to group these bodily experiences thereby facilitating a cohesive, holistic and embodied approach. The scoping review and phenomenological study supported this, pointing to commonalities between bodily stroke experiences when experienced from the first-person perspective. Evaluating body changes under this broad conceptual umbrella, emphasised pertinent areas for further consideration such as: the link between body ownership, movement and intentional action from a first-person viewpoint. It also illuminated the experience of bodily objectification and the sense of the body-self from a multimodal, embodied perspective. This pointed to potential advantages of reintegrating the disjointed body schema using holistic rehabilitation techniques.

The potential advantages of utilising such a broad concept is outlined in Figure 22. This diagram outlines how using a holistic perspective to reframe body perceptions changes

(built on theoretical constructs of the body image and body schema) could give weight to the patient-voice in terms of clinical assessment and research data. In terms of rehabilitation this could improve and deepen patient-clinician communication and understanding and encourage a more embodied approach to treatment and interventions. In research, exploring accounts of patient experience could elucidate mechanisms perpetuating the experience of altered perceptions and exploration of commonalities between conditions may also provide further insights.

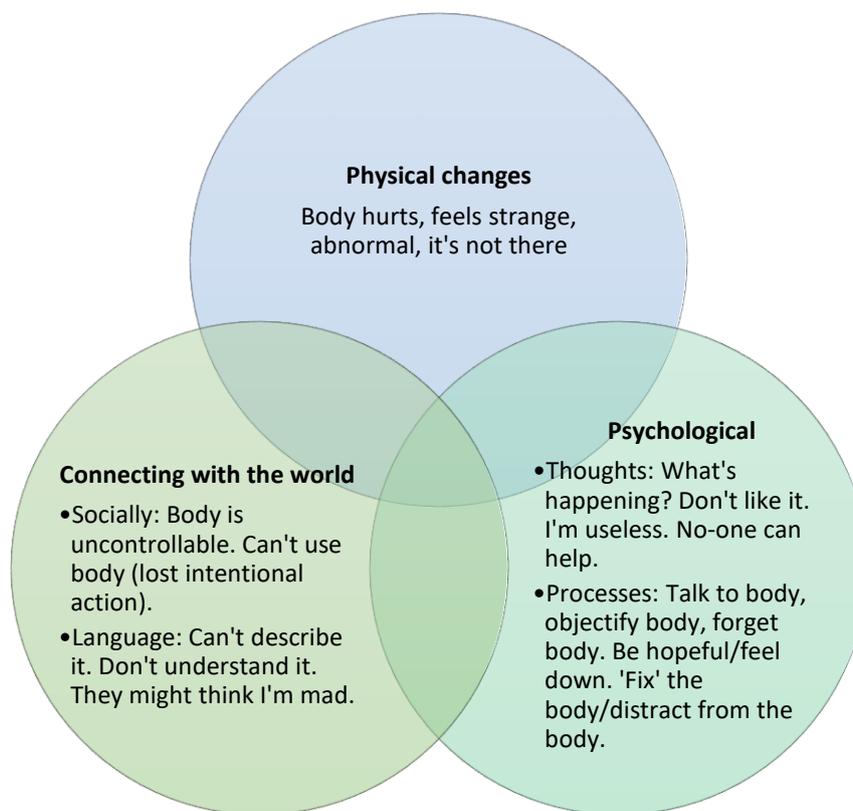
Figure 22. Advantages of the concept of altered body perception



The concept of 'altered body perception' allowed for exploration of the holistic post-stroke bodily experience in the phenomenological study (Chapter 4), highlighting the interaction between factors. This diagram below (Figure 23) describes the experience of physically altered perceptions as outlined in the phenomenological study and their interaction with the 'lifeworld'. It brings together how the physical experience can lead to negative thoughts and how management of these thoughts, through processes such as bodily objectification, can often increase the distance between the body and the self. Socially, the consequences

of the altered body fed into this cycle as the body was experienced as uncontrollable, unresponsive and incommunicable. Recently the experience of the body and self after stroke and its relationship to the outside world has been further explored using blogs (Thomas, Allison and Latour, 2018). Blogs can provide a unique insight into this relationship as they portray the 'internal' self in a public sphere. Exploring blogs highlighted the complexity of the relationship of the 'public' self in the world, emphasising how frustrations with health services can affect the experience of the 'internal' self.

Figure 23. The individual embodied experience of altered perceptions



The impact of language on this process was an unforeseen factor within this dynamic. Yet it was made repeatedly evident in the phenomenological study that having no terms to describe perceptual changes, alongside the belief that a stretched health service was unable to respond to the minutiae of body experiences, were key factors affecting individuals' perception of their experience. Language was therefore highlighted as a key embodied process underpinning connection with others and the ability to make sense of experiences. The difficulty of describing disability was recently addressed in a large study of reported

disability by Morris et al. (2018). They found that the majority of those with a lower limb disability described their disability in terms of an activity limitation. They highlighted the variation between individuals of how they perceived their disability and the need for professionals to consider how terms affect their understanding and communication when developing treatment plans. This supports the role of language and communication as important areas for understanding individual illness perceptions and ensuring a commonality of understanding between patient and clinician in the development of rehabilitation plans.

The final study explored communication in tangible terms, determining whether it was feasible to adopt a more embodied and holistic approach to communicate the altered body in stroke assessment. This is important considering the difficulty providing holistic communication within current health care systems which are orientated around a biomedical focus (Malik, Hilders and Scheele, 2018; Zamanzadeh et al., 2015). Through trialling various means to capture the altered body after stroke, useful information was gathered. This highlighted the embodied nature of this experience and emphasised the need to look at this in terms of comfort, impact and psychological and attentional attitudes towards the body. Participants were passionate about the importance of describing their physical and psychological changes to professionals. An embodied model of assessment would facilitate a deeper understanding of individual's relationships with their post-stroke bodies. It has wide ranging implications for patients' post-stroke experience; professional practice and research and begins with using holistic communication to deepen understanding of patient experiences.

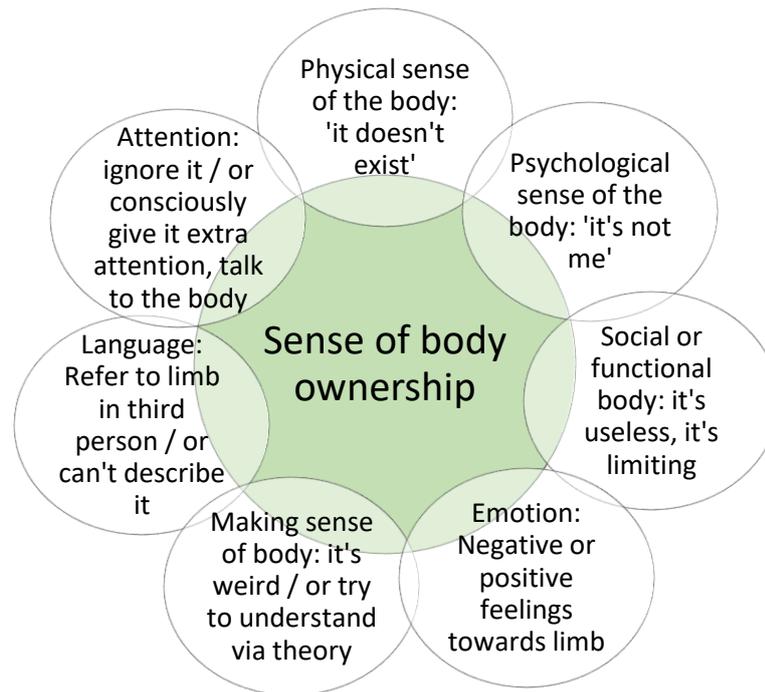
7.2.4.1 Body objectification, ownership and awareness

The embodied experience of body objectification arose throughout this programme of work. In the scoping review across all post-stroke experiences the body was described as strange, conscious and something that required a dialogue between body and mind. In the phenomenological study participants reported similar occurrences. They also referred to the physical sense of the 'disappearing body', described affected body parts in the third-person and used negative terms reflecting their psychological sense of disconnection between the

body and self. In the final feasibility study the sense of bodily objectification was explored from physical and psychological perspectives via the Bath Body perception disturbance scale[©] which reflected changes in the sense of physical bodily integration, attentional and emotional responses to the body. Collectively these findings demonstrated the enormity of the change in body experience post-stroke and how it is comprised of holistic experiential components. For instance, in perceptual loss, the body change can be mirrored psychologically as the mind ignores or over attends to the body whilst also responding emotionally to the altered sensation. The experience is 'lived' in its environment, affecting how the body navigates and engages with the world and causing additional discomfort due to the strange and incommunicable nature of the experience. These changes to body representation have not previously been demonstrated to be so tangibly present across diverse post-stroke experiences including perceptual loss, experiences of body distortions or strangeness and the body during movement.

Below is a diagrammatic representation of the ways in which participants described the multifaceted experience of altered body awareness and ownership in the phenomenological study (Figure 24). This diagram highlights the interconnected ways in which an altered sense of the body may manifest and demonstrates the subtle ways in which physical and psychological perception of the body can blur. For example, the sense of the body as 'it's not me' is an embodied representation of a psychological experience and is distinct from the emotional response to the body.

Figure 24. Multifaceted experience of body ownership and awareness in stroke



Instances of body objectification have been noted in the literature but predominantly explored in terms of the psychological impact on the sense of self and how this affects recovery (Ellis-Hill, Payne and Ward, 2000; Faircloth et al., 2004). The physical experience of body ownership has been reflected in literature pertaining to specific conditions such as neglect or anosognosia (Baier and Karnath, 2008; Burin et al., 2015). Awareness of the body, conscious attention and attitudes about body perception are tightly linked to changes to body schema and body image (Section 1.3). If the body feels strange and abnormal, then the body image (conscious reflection on the body) is forced to compensate for deficits in the body schema. This highlights the importance of considering altered perceptions in holistic terms, as individual's conscious awareness of the altered experience, the attention they give to the body and their emotional feelings towards the change can all impact on how the altered perception is neurally represented and experienced (Ferri et al., 2017).

The complex relationship between body movement and becoming aware of body deficits illustrates the interconnected nature of altered perceptions in stroke. In Chatterjee and Mennemeier's (1996) account of patient retrospections of anosognosia they captured how bodily deficits such as weakness, were discovered through failed intentional actions, stating

that it was through discovering these deficits that patients' attention was brought to them. They described the complex physical and psychological aspects of this process as patients became aware of and conceptually understood the deficit yet maintained unrealistic ideas of the impact of the deficit on their lives and ability to control the body. The interconnected experience of perceptual changes on different aspects of processing have been outlined in other conditions. The experience of chronic pain can affect mental representation of the body (body schema), impacting how individuals perceive body movement. Bray and Moseley (2011) conducted a motor imagery task on 21 patients with back pain, asking them to judge the degree of rotation in images of body trunks. Those with back pain were less accurately able to accurately judge rotation of the images, suggesting disruption to the body image (the ability to mentally map the affected body area). The authors suggest this may also contribute to motor impairment associated with this type of pain. Little is known about the process of understanding bodily limitations and how this interrelates with individual's ideas, attitudes and understanding of the body post-stroke. Sensorimotor rehabilitation has been shown to influence cortical reorganisation and neurological function post-stroke (Acerra, Souvlis and Moseley, 2007). Furthermore, research by Moseley (2008) in which sense of limb ownership was psychologically disrupted, led to disturbance in temperature regulation of specific limbs, suggesting that this is likely that this is a bidirectional system (Moseley, 2008²). Considering the interaction between body schema deficit and compensatory body image strategies, developing a deeper understanding of this relationship may prove fruitful to stroke survivors and professionals devising rehabilitation strategies to aid limb reintegration.

To understand how the attention to body experiences can impact body representation, it is useful to look at research into body dysmorphia and eating disorders which explores the impact of conscious bodily objectification on these processes. The rubber hand illusion experiment – which tests how quickly participants perceive a rubber hand to be incorporated into body schema representation through synchronous touch on the rubber hand and the participants' hand – was conducted on a group of individuals with eating disorders who described a negative attitude towards their body image. Eshkevari et al. (2012) found that these individuals experienced the rubber hand illusion more strongly in both their physical sense of proprioception and in subjective measures. It suggested that

those with a more negative self-image were more receptive to the sense of embodying the rubber hand, due to the greater sense of *“self-objectification, [which] distorts the interoceptive experience of the bodily self”* (p826). It also suggested that this is due to an increased sensitivity to visual processing of body perception in this population, which may be balanced in therapy through increasing focus on other facets of perceptual experience such as proprioception or interoceptive processes.

Similarly, in body dysmorphia research, Kaplan et al. (2014) found that the self-reported effect of the rubber hand illusion was stronger in this population and they supported the notion that more substantial negative beliefs about bodily self are related to a more malleable body representation. Recent research into fibromyalgia exploring the links between body schema, body esteem and body perception found that patients with fibromyalgia, who had more negative attitudes to their body than controls, were more likely to integrate a rubber hand into their body representation (Martínez et al., 2018). They reported increased sense of body ownership (the rubber hand belongs to me), belief in agency (I could move the rubber hand) of the hand and sense of proprioception (the rubber hand is in the place of my hand), demonstrating increased neural plasticity in patients with this condition. Research into irritable bowel syndrome illustrates how the interaction between altered perception of sensory processing and a heightened awareness of interoceptive body experiences may influence neural processing of body representation (Longarzo et al., 2017). They point to the use of disentangling embodied patient experiences to deepen understanding about how body perception processes evolve and maintain one another. Understanding the role of conscious awareness of body processes within body representation offers a fruitful area to direct therapeutic approaches (Longarzo et al., 2017). Working in an embodied and holistic way may be key to understand how body representation is experienced and effected from not just the inside-out, but also from the outside-in.

By adopting an embodied and patient-centred account of experience of the altered body it is possible to understand in more depth successful and unsuccessful strategies to manage the altered body after stroke. As such research and clinical approaches may benefit from exploring in more depth how stroke survivors make sense of their bodies, how they ‘talk’ to

them and how much attention they give to them to facilitate function. Increased understanding of the objectification and sense of body ownership may illuminate understanding of the psychological impact of altered perceptions, which may be a useful strategy to support rediscovery of the body.

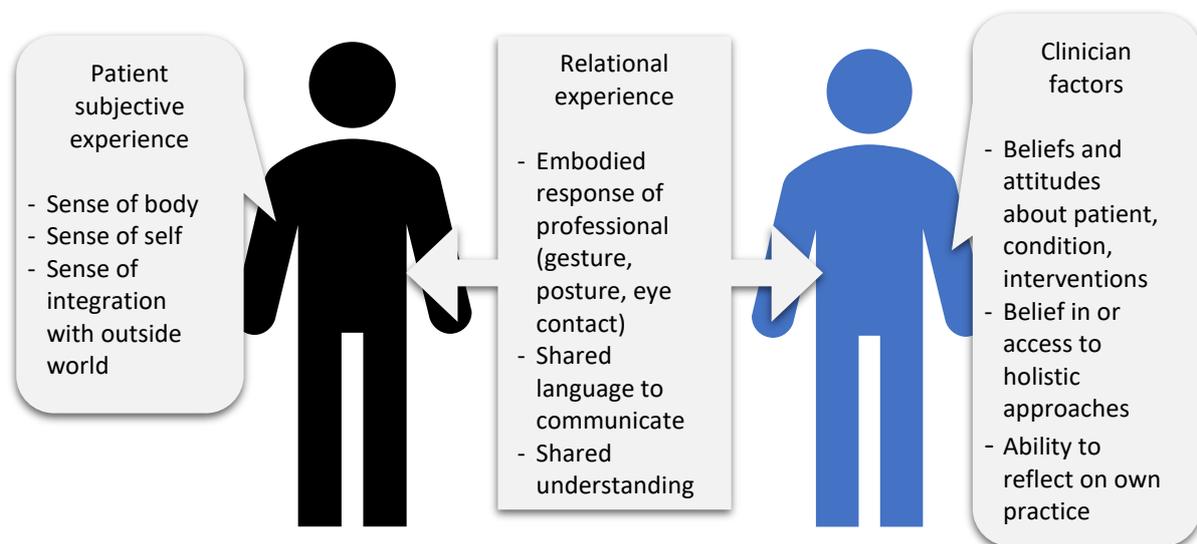
7.2.5 Embodied stroke care: application in practice and research

An embodied approach to stroke care would seek to conceptualise the patient as a whole-person and consider subjective accounts to inform understanding of their situation. A recent study into objectivity and subjectivity in health settings highlighted the need for mental health clinicians to take into account and describe subjective contextual experiences in clinical recommendations (Solli and Barbosa da Silva, 2018). As highlighted in the Introduction (Section 1.5) the subjective patient experience can add significantly to clinical understanding of health experiences. Adding a subjective dimension to stroke care would facilitate understanding of how patient attitudes and beliefs about their bodies, environment and self, shapes their experience of illness or bodily dysfunction. The effect of this approach could be threefold. Firstly, patients might feel clinicians have a deeper understanding of their experiences and therefore feel better supported, more involved in decision making (patient-centred care) and may display better management of their condition. Secondly, clinicians with a deeper understanding of patients' bodily beliefs may be able to tailor interventions more appropriately, delivering more effective interventions. Thirdly, research may be able to build on a deeper and more holistic understanding of post-stroke bodily experiences, thereby deepening understanding of causative mechanisms of patient experience.

However, it is important to anchor this approach in realistic and practically applicable terms. As cited by clinicians, a lack of time and resources is consistently problematic in implementing evidence-based practice recommendations (Malik, 2016). As such, it is important that actualising an embodied approach to health care is not hugely costly in terms of time and resources. As demonstrated through the Bath Body perception disturbance scale[®], it is possible to explore ideas about body perception in terms of body schema and image quickly and efficiently through visual analogue scales (Lewis and McCabe,

2010). Similarly, visual tools can be impactful way to quickly convey the bodily experience after stroke and the images would be easily transferable within a multidisciplinary team (Lalloo et al., 2014; Turton et al., 2013). As highlighted within the findings from the phenomenological research in this programme of work, the embodied experience is held within the individual but affected by how that experience is translated and communicated with the outside world. The stroke survivors' embodied experience is 'relational', meaning it is affected by its relationships with the outside world (Rejeski and Gauvin, 2013). As such the role of communication and understanding of experiences from those outside the subjective experience such as clinicians becomes more significant. The diagram below (Figure 25) highlights the possible interaction between clinical relational experience and the subjective experience of altered perceptions after stroke. The boundaries of the body and self create a literal separation of the experience from the outside world, yet the social and communicative nature of the clinical environment play a pivotal role in penetrating this sense of separateness and may have significant impact on the lived experience of altered perceptions. It is also key to enabling patients to access appropriate rehabilitation.

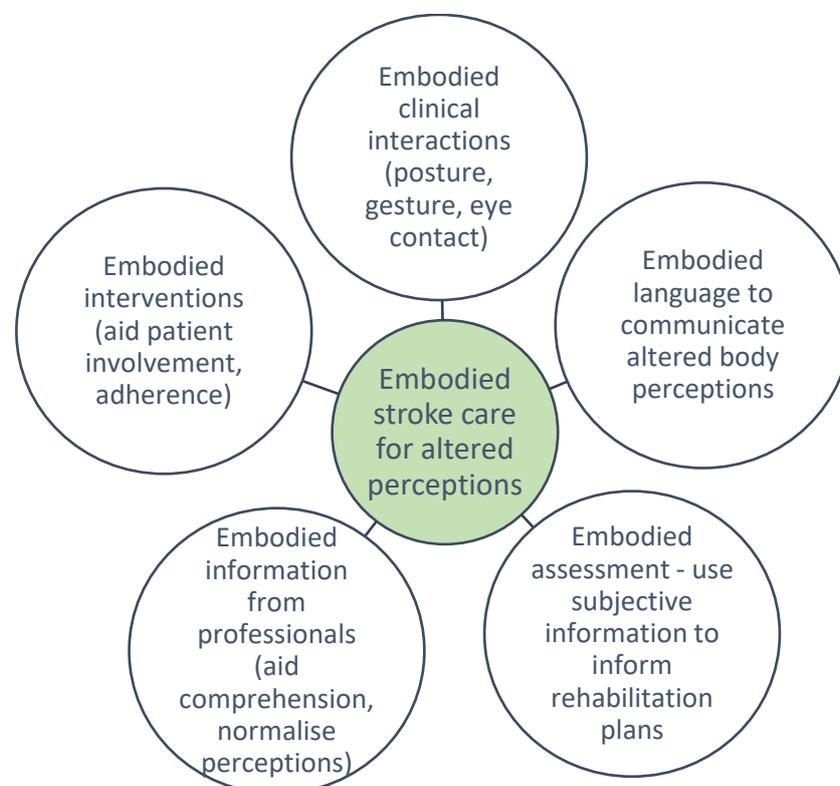
Figure 25. From disembodied to relational understanding



The ways in which the clinical model could adapt to better integrate embodied practice are outlined in more detail in the diagram below, which emphasises moments of contact between the patient and clinician (Figure 26). It highlights embodiment in terms of how the

clinician relates to the patient and uses language to create shared understanding about the altered perception; how embodied knowledge from the patient is explored in assessment; and how information and interventions can influence the embodied experience of altered perceptions. Improving patient-clinician communication is important because it is linked to functional and emotional well-being, reduction in symptoms and pain, improved treatment adherence and it is a vital facilitator of patient-centred care (Ghane and Sweeney, 2013). Ghane and Sweeney (2013) suggest that considering an embodied perspective in all aspects of this communication is beneficial. They emphasise the embodiment of the clinical interaction, discussing how clinician body language and non-verbal cues can convey empathy and attentiveness, which in turn can increase patient satisfaction. They discuss how involving patients in the bodily components of interventions can increase their sense of control and involvement in medical procedures and how grounding information or instructions via engaging the sensorimotor system can help to make clinician instructions more tangible and comprehensible.

Figure 26. Embodied approach to altered body perception after stroke



7.2.6 Embodied stroke care and patient-centred care

Currently, NHS strategy recognises the importance of including the patient-voice in health care decisions (Department of Health, 2012; NICE², 2018). Commonly used terms such as ‘shared decision-making’ and ‘patient-centred care’ highlight the necessity of communication and understanding between patients and clinicians (Armstrong, 2017; McClain, 2005). However, despite these expectations, patient-led initiatives may meet barriers which affect how much the patient perspective is noted. For example, a qualitative study by Rosewilliam et al. (2016) found stroke survivors may feel disempowered in goal-setting processes due to stroke-related impairments (e.g. speech or concentration); feeling a need to please the professionals and a lack of information which meant patients were unaware of this process. Professionals tended to focus on developing goals to address short-term functional impairment at the expense of emotional and social factors (Rosewilliam et al., 2016). Brown et al. (2014) concur stating that to better understand the often divergent objectives of goal-setting between patients and professionals, the latter *“need to receive training in what the experience of stroke is like for patients, both psychologically and physically and how this affects their perspectives on engagement with health professionals and on rehabilitation planning”* (p1025).

The disparity between the objectives of the patient and clinician reflect the constraints of a health system which focuses on objective measurement of stroke experiences and fails to truly understand the subjective experience of the altered body. There is a mismatch in how the goals of patient-centred care can be practically enacted in a health system which does not prioritise the patient-voice. Fredericks, Lapum and Hui (2015) found in a systematic review that the effects of patient-centred interventions were less effective in those with chronic conditions (such as asthma and diabetes), suggesting that these patients may have developed their own self-care behaviours. This may suggest that patient-centred care needs to be developed to understand changing patient motivations and coping behaviours which adapt as chronic illness persists. Judging the effects of patient-centred care in terms of improved clinical outcomes have found little correlation (Rathert, Wyrwich and Boren, 2013). However, patient-centred care has been reported to reduce the likelihood of ongoing tests and referrals and can result in a feeling of shared understanding between patient and

clinician (Stewart et al., 1999). This reflects how patient-centred care affects outcomes beyond clinical objectives. Clinician understanding of patient experiences is related to patient satisfaction, adherence to treatment and belief in care outcomes and increased participation by patients in clinical interactions (Street and Haidet, 2011). Taking a holistic approach focused on individual identity in conjunction with patient-centred care could be key to actuating embodied rehabilitation outcomes (Pallensen and Roenn-Smidt 2015).

Creating an embodied interaction between clinician and patient is hinged on practitioner reflection on the dynamic they bring to any interaction. Faircloth et al. (2004) suggested that therapist attitudes towards older patients may skew their rehabilitation goals which can in turn reduce their expectations of rehabilitation outcomes. Likewise, health professional attitudes towards lower back pain have been associated with patients' beliefs about their condition and treatment recommendations - as practitioners with a biomedical standpoint were more likely to suggest patients reduced their activity (Darlow et al., 2012). Faircloth et al. (2005) emphasised that ignoring individual experience of stroke is reductionist, leading to impairment focused rehabilitation which does not consider how patients interpret the meaning of what has happened to their bodies. The assessment of health-needs in a population of older adults, found that although clinically-assessed and patient-perceived needs were similar, there were also differences, as many patients assessed as not needing services requested them and those assessed as needing services didn't request them (Cohen-Mansfield and Frank, 2008). These findings highlighted the direct impact of clinician beliefs and attitudes on rehabilitation outcomes and the need for effective communication to ensure objectives were clearly reflective of patient needs. Patients perceived two-way communication to be a fundamental component to ensure understanding of health beliefs and values between patient and clinician (Kennedy et al., 2017).

7.3 Conclusion

This programme of work has captured the first-person experience of the altered body after stroke both within the literature and from the experience of stroke survivors. It found that perception of the body is uncomfortable in complex holistic ways and that stroke survivors require additional support from health professionals to manage these changes. From this, novel methods to assess and improve communication of the altered body between patient and clinicians were explored, providing evidence to visually elucidate the experience of the altered body after stroke. Utilising embodiment theory, the conception of 'altered body perception' and a holistic understanding of 'discomfort', provided a new 'lens' through which to make sense of the stroke survivors experience of the body as the "*vehicle for being-in-the-world*" (Merleau-Ponty, 2001, p82).

A subjective and holistic understanding of the altered body after stroke in the clinical environment is key to improving patient and clinical understanding of altered body perceptions. Understanding of holistic and multimodal influences on the constructs of the body image and body schema remain poorly understood but are likely fundamental elements affecting how the body is perceived after stroke. Practical recommendations of ways to integrate holistic and embodied approaches into clinical stroke care are suggested below (Table 12). Subjective accounts are essential to extricate these processes by providing a window into the experience of body awareness. As such improving communication of the experience of altered body perception is key to deepening clinical knowledge of how the body is perceived and experienced after stroke.

Table 12. Key recommendations for further research

- Identify key, patient-friendly, terms to describe experiences of altered body perception after stroke (to aid communication and understanding between patients and professionals)
- Develop a visual tool to communicate body perception changes after stroke which is accessible to people with aphasia
- Develop a 'comfort framework' (or similar), to enable patients to describe their experience and prioritisation of body changes after stroke and assess the impact of living with these in holistic terms
- Explore what patient data related to embodiment theory (body schema/body image) is useful to collect in stroke survivors to inform clinical approaches
- Explore ways to integrate embodied approaches to communication and rehabilitation into clinical practice

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Appendix A.

Exploring experiential accounts of 'altered body perception after stroke: A scoping review

A.1. Databases

The published literature databases included in the scoping review search process are described below, alongside their search platforms.

-
- Applied Social Sciences Index and Abstracts (ASSIA) via ProQuest
 - Journals covering health, social services, psychology, sociology, economics, politics, race relations and education
 - British Nursing Index (BNI) via ProQuest
 - Journals covering nursing and midwifery and selective content from medical, allied health and management titles
 - Cumulative Index to Nursing and Allied Health Literature (CINAHL) via EBSCO
 - Journals covering the fields of nursing and allied health
 - Cochrane database of systematic reviews (CDSR) via Cochrane Library
 - Considered to be the best single source of reliable evidence on the effects of health care
 - Excerpta Medica (EMBASE) via OVID
 - Journals covering biomedicine, psychiatry and pharmacology
 - International Bibliography of the Social Sciences (IBSS) via ProQuest
 - Journals covering politics, sociology, economics and anthropology
 - MEDLINE via EBSCO
 - Journals covering Health management, including health service policy, management and administration, the quality of health services, the planning, design, construction and maintenance of health service buildings; occupational health; control and regulation of medicines; medical equipment and supplies; social care and personal social services
 - PsychARTICLES via EBSCO (used in feasibility study in Chapter 5 only, not scoping review)
 - Journals covering psychology and behaviour by American Psychological Association and affiliated journals
 -
 - PsychINFO via EBSCO
 - Journals covering nursing, psychology, medicine, sociology, pharmacology, physiology and linguistics
 - SAGE via Sage Journals
 - Journals covering health, social and life sciences
 - Web of Science via Clarivate Analytics
 - Journals covering multidisciplinary information from sciences, social sciences, arts and humanities
-

Unpublished databases

The unpublished, grey literature databases included in the scoping review search process are described below.

-
- OpenGrey
 - Covers science, technology, biomedical science, economics, social science and humanities
 - National library of Australia (Trove) – previously Australian digital theses
 - Covers Australian resources
 - The National Institute for Health Excellence (NICE)
 - National guidance and research to improve health care services
 - UK Clinical Trials Gateway – previously UKCRN study portfolio
 - Information about current clinical trials
 - Involve Research project database
 - Information about current published and unpublished research projects in health, public health and social care
 - Ethos (British library E-theses online service)
 - Access to UK doctoral theses
 - Google Scholar
 - Broad search engine of scholarly literature
 - ProQuest Dissertation and Theses
 - The largest single repository of graduate dissertations and theses
 - Index to Theses: Doctoral theses from the United Kingdom and Ireland
 - Doctoral theses from the United Kingdom and Ireland
-

A.2. Search terms

The synonyms for the search terms used are listed under the categories below.

Stroke	Altered	Perception	Body
Stroke OR cerebrovasc* OR cva OR poststroke	disturb* OR disorder* OR dysfunction* OR distort* OR impair* OR deficit* OR Illusion* OR Illusory OR Phantom* OR Alter* OR change* OR abnormal*	image* OR concept* OR represent* OR identif* OR ownership OR experience* OR percept* OR perceiv* OR aware* OR inattention OR attention* OR neglect OR feel* OR sens* OR pain OR propriocept* OR sensation* OR somatosensory OR position* OR movement* OR afferent OR tactile OR touch OR self OR schem* OR embod*	Body OR Bodies OR Bodily OR Limb* OR shoulder* OR arm* OR wrist* OR hand* OR finger* OR hip* OR leg* OR ankle* OR foot OR feet OR toe* OR face OR back OR postur* OR trunk OR torso

A.3. Search strategy

The search technique used in AMED, ASSIA, BNI, COCHRANE (CDSR), CINAHL, EMBASE, IBSS, MEDLINE, PsychINFO, SAGE, Web of Science is described. In these databases the terms in the 'Altered' and 'Perception' categories, along with the terms in the 'Perception' and 'Body' categories were associated more closely to ensure that returned searches were relevant. These terms were searched so that there was no more than 3 words between them, using the 'Near' or 'Adjacent' function. Categories were paired using the 'AND' function.

e.g. Altered N3 Perception AND Perception N3 Body

In SAGE the 'NEAR' function was not applied as it was not an option.

A typical search is demonstrated below.

- "Stroke OR cerebrovasc* OR CVA or poststroke"
- **AND**
- "disturb* OR disorder* OR dysfunction* OR distort* OR impair* OR deficit* OR Illusion* OR Illusory OR Phantom* OR Alter* OR change* OR abnormal*" **N3** "image* OR concept* OR represent* OR identif* OR ownership OR experience* OR percept* OR perceiv* OR aware* OR inattention OR attention* OR neglect OR feel* OR sens* OR pain OR propriocept* OR sensation* OR somatosensory OR position* OR movement* OR afferent OR tactile OR touch OR self OR schem* OR embod*"
- **AND**
- "image* OR concept* OR represent* OR identif* OR ownership OR experience* OR percept* OR perceiv* OR aware* OR inattention OR attention* OR neglect OR feel* OR sens* OR pain OR propriocept* OR sensation* OR somatosensory OR position* OR movement* OR afferent OR tactile OR touch OR self OR schem* OR embod*" **N3** "Body OR Bodies OR Bodily OR Limb* OR shoulder* OR arm* OR wrist* OR hand* OR finger* OR hip* OR leg* OR ankle* OR foot OR feet OR toe* OR face OR back OR postur* OR trunk OR torso"

A.4. Screening to increase exclusion criteria

Authors (HS) and (AT) screened the first 50 titles and abstracts of six selected databases to review the type of literature obtained, establish which databases produced the most relevant results and determine the rate of agreement between authors of which studies to include.

After the screening, the two authors reached an agreement rate of 97%. This was calculated by observing the difference in the inclusion rate between the two researchers; so, 8 conflicts out of 260 abstracts led to a 'conflict' in 3% of studies. Studies in which there was uncertainty as to whether to include them or not were discussed and a mutual agreement obtained. Conflicts were resolved through discussion and reviewing the methods sections of these studies to clarify their adherence to the exclusion criteria.

Database	Number screened	Total number in database	AT screening			HS screening			Conflicts
			Included	Excluded	Unsure	Included	Excluded	Unsure	
AMED	40	40	6	34	0	7	31	2	1
ASSIA	20	20	12	8	0	10	10	0	2
BNI	50	3532	0	50	0	0	50	0	0
Cochrane	50	357	0	50	0	0	50	0	0
Medline	50	218	18	32	0	16	33	1	2
PsychINFO	50	173	27	23	0	24	26	0	3
Total	260	4340	63	197	0	55	200	5	8

A.5. Ancillary information

The key information extracted from each study in which a full text screening was undertaken is identified below.

Number	Ancillary information
1	Author
2	Title
3	Journal
4	Year
5	Body perception issue addressed
6	Recruitment, location
7	Sample size
8	Data collection method
9	Time since stroke onset
10	Aims
11	Methodology
12	Themes or findings
13	How data relates to research question
14	Clinical implications and gaps
15	Critical appraisal: Limitations and strengths

A.6. Rationale for excluding 25 studies

In total 25 studies were excluded because they provided a focus on psychosocial factors as opposed to bodily experiences after stroke. For example, Kirkevold's (2002) exploration of the 'Unfolding illness trajectory of stroke' contained first-person qualitative data about bodily changes after stroke, referencing changes like *"I couldn't move. My legs wouldn't carry me"* (p892); *"the body is hindering me"* (p895); *"everything goes much slower and the dizziness makes movement more laborious and demanding"* (p896). However, in this study, the data on the bodily experience was limited and the focus was on the recovery trajectory - these changes were discussed in terms of their psychological and social impact, rather than as a reflection on the bodily experience of living with these altered perceptions. The rationale for excluding all 25 studies is included in the table below.

Author, title, year of publication	Reason for exclusion
Ahuja et al. (2013) The journey to recovery: experiences and perceptions of individuals following stroke.	Nothing on first-person bodily experience. Body referred to in terms of emotions e.g it's an ongoing battle. Author summarises the types of impairments people had.
Arntzen, Hamran and Borg (2015) Body, participation and self transformations during and after in-patient stroke rehabilitation.	Little on first-person bodily experience. Mention of weakness, shakiness, exhaustion but in terms of impact on activities. Focus of study is on managing psychological factors during transition to home (feeling 'safe' as an inpatient, focus on hope) and how home brings out factors such as uncertainty, difficulty doing things, problems participating and fragmentation of self.
Arntzen, Borg and Hamran (2014) Long-term recovery trajectory after stroke: an ongoing negotiation between body, participation and self.	Little on first-person bodily experience. Some reference to pain, exhaustion, body not moving as desired but this is secondary to focus on impact of this on conceptualisation of self and participation.
Backe, Larsson and Fridlund (1996) Patients' conceptions of their life situation within the first week after a stroke event: a qualitative analysis.	Little on first-person bodily experience. Only first theme mentions changed perception of the body, mentions feeling half the body, sense that body won't work and feeling of falling. All other themes about loss of life, emotional consequences and social support.
Beal and Millenbruch (2015) A qualitative case-study of poststroke sexuality in a woman of childbearing age.	Little on first-person bodily experience. Mentions, protecting the 'non-working' arm, feeling fragile not wanting to be touched and the body not working properly. Most focus is on emotional issues related to this.
Bergström, Eriksson, Asaba et al. (2015) Complex negotiations: The lived experience of enacting agency after a stroke.	Little on first-person bodily experience. One theme talks about disrupted body, not in-depth about any specific issues, briefly mentions pain, fatigue, reduced balance, weakness but focus is on recovery trajectory and coming to terms with altered body and enacting agency. The rest of study is about negotiating old and new identities, changed roles with others and how they transformed themselves psychologically to keep enacting agency.

Author, title, year of publication	Reason for exclusion
Burton (2000) Living with stroke: a phenomenological study.	Little on first-person bodily experience. Brief reference to body not responding as desired. Issues described in psychological terms - about what they want or what they've lost, not physical experience.
De Guzman et al. (2012) Self-concept, disposition and resilience of poststroke Filipino elderly with residual paralysis.	Little on first-person bodily experience, all discussed in terms of psychological interpretation.
Doolittle (1992) The experience of recovery following lacunar stroke.	Little on first-person bodily experience, experiences summarised by author. Talks about bodily recovery in terms of time post-stroke, setting, focus on limb awareness.
Flinn and Stube (2010) Post-stroke fatigue: a qualitative study of three focus groups.	Little on first-person bodily experience. Descriptions of needing to sleep and tiredness, not in detail. Lots of focus on trying to understand it and the impact of this on activities.
Jongbloed (1994) Adaptation to a stroke: the experience of one couple.	Little on first-person bodily experience. First theme mentions weakness, non-responsive arm, the rest is about psychological impact.
Kirkevold (2002) The unfolding illness trajectory of stroke.	Little on first-person bodily experience. Few quotes about body not responding but focus is on recovery trajectory, not reflecting on bodily experience.
Meijering, Nanninga and Lettinga (2016) Home-making after stroke. A qualitative study among Dutch stroke survivors.	Talking about altered body and abilities in terms of the home and relationships.
Murray (2004) The meaning and experience of being a stroke survivor: an interpretative phenomenological analysis.	Little on first-person bodily experience. One quote about body perception - feeling stuck. Interpreted in purely psychological terms. Rest of study about psycho-social issues.
Nanninga et al. (2015) Place attachment in stroke rehabilitation: a transdisciplinary encounter between cultural geography, environmental psychology and rehabilitation medicine.	Little on first-person bodily experience. Few quotes about the body, but not reflecting on them in terms of bodily experience, only in terms of reintegrating into home and family life.
Norris, Allotey and Barrett (2010) 'I feel like half my body is clogged up': Lay models of stroke in Central Aceh, Indonesia.	Little on first-person bodily experience. Recognises patient-centred stroke term – 'half dead body', but otherwise focused on participant reflection of cause for their stroke not bodily experience.
Nasr et al. (2016) Exploring the experiences of living with stroke through narratives: Stroke survivors' experiences.	Little on first-person bodily experience. A tiny bit about the body, mainly about role changes, getting used to changes, fitting into the world.
Pallesen (2014) Body, coping and self-identity. A qualitative 5-year follow-up study of stroke.	Little on first-person bodily experience. The first bit about forcibly present body and discomfort is relevant, but study focus is not on reflection of bodily experience.
Poltawski et al. (2016) Assessing the impact of upper limb disability following stroke: a qualitative enquiry using internet-based personal accounts of stroke survivors.	Little on first-person bodily experience. A few quotes at beginning about experience of unresponsive, unaware body and objectification, but mainly about psychological aspects of coping with bodily changes.

Author, title, year of publication	Reason for exclusion
Pound, Gompertz and Ebrahim (1998) A patient-centred study of the consequences of stroke.	Little on first-person bodily experience. Mostly about psychosocial aspects and activities-of-daily-living and relationships. End of last theme mentions body not feeling whole and body feeling strange.
Rhoda (2012) Limitations in activity and participation experienced by stroke patients: a qualitative inquiry.	Little on first-person bodily experience. First theme has a few quotes about body but not in-depth and no reflection on them. Other themes reflect on psychosocial aspects.
Simeone, Savini, Cohen et al. (2015) The experience of stroke survivors three months after being discharged home: a phenomenological investigation.	Little on first-person bodily experience. A little focus on body perceptions such as: Can't stand and being slow, but not depth or reflection. Mainly focus on how it's changed their lives.
Kouwenhoven et al. (2011) The lived experience of stroke survivors with early depressive symptoms.	Little on first-person bodily experience. Experience briefly mentioned, but whole study about emotional factors and depression.
Snoeys, Vanhoof and Manders (2013) Living with locked in syndrome: an explorative study on health care situation, communication and quality of life.	Little on first-person bodily experience. Some reports of pain, but not described or reflected on. The rest of study is about quality of life.
Taule et al. (2015) Striving for a life worth living: stroke survivors' experiences of home rehabilitation.	Little on first-person bodily experience. One brief mention of weakness, but rest of study focus on psychological factors.

A.7. Details and rationale for 28 included studies

Author	Body change	Aim	Sample	Time since stroke	Method	Findings	Relevant findings to research question	Critical appraisal
Antonello et al. (2010)	Phantom limb	<i>"Investigate the frequency and perceptual characteristics of phantom limb experiences"</i> (p1115)	27 out of 50 described phantom limb sensations	Average of 51 months	Quantitative, Phone or face-to-face structured questionnaires	22 participants described postural phantoms; 14 kinaesthetic phantoms and 10 combined postural and kinesthetic phantoms. No participant reported seeing their postural or kinaesthetic phantom. Beliefs persisted until contradictory evidence was obtained such as visual or observer input. Only 4 reported these perceptions to a clinician	Participants reported lots of phantom limb experiences, which were more common than previously recognised. It may be underreported because patients fear being labelled 'crazy'. Participants find it hard to make sense of	Recall of somatic memories. Small sample. Question style quite closed
Baier and Karnath (2009)	Anosognosia (hemiplegia)	<i>"Investigate the clinical relationship and anatomy of abnormal attitudes"</i> of anosognosia, somatoparaphrenia and asomatognosia towards paretic/plegic limb (p486)	12 out of 79 described altered sensations	Acute stage post-stroke	Quantitative. Questionnaire about body perceptions and MRI scan	<i>"92% of the patients with AHP showed additional 'disturbed sensation of limb ownership' (DSO) for the paretic/plegic limb. The patients had the feeling that their contralesional limb(s) do not belong to their body or even belong to another person. Analysis of lesion location revealed that the right posterior insula is a crucial structure involved in these phenomena"</i> (p486)	Patients often experience disturbed sense of limb ownership in the plegic/paretic limb. Awareness of movement and sense of limb ownership appeared to be linked	Some leading questions; small sample

Chatterjee and Mennemeier (1996)	Anosognosia (hemiplegia)	Investigate patients' retrospections about resolved anosognosia to explore how it is possible to be unaware of weakness	3 patients with resolved anosognosia	Less than 1-week post-stroke	Retrospective case-series, 'open' interviews	<i>"1) anosognosia for hemiplegia can be domain specific; 2) weakness must be discovered; 3) discovery of weakness is impeded by a feed forward intentional deficit which probably interacts with notions of 'body schema' in complex ways; and 4) awareness of deficit emerges in a graded fashion"</i> (p221)	Patients underestimated their body weakness. Body awareness is discovered and linked to intentional movement	Retrospective accounts. Small, male sample. Clinical perspective, methods not transparent
Ellis and Small (1994)	Anosognosia (eye closure)	<i>"To document the frequency and phenomenology of denial of eye closure in acute stroke"</i> (p1958)	5 out of 43 patients with denial of hemiplegia	Acute stage post-stroke	Case reports, structured interviews, neurological exam	<i>"Five of 43 patients with denial of hemiplegia after acute stroke were also found to have denial of eye closure (12%). Denial of eye closure was associated with drowsiness and in all but one patient with disorientation... Three subjects confabulated as to what they saw through their closed eyes"</i> (p1958)	Patients demonstrated little insight into their body change and were unable to reflect on their experience	Leading questions, clinical perspective, small sample, patients were very unwell

Klinke et al. (2015)	Neglect	"Explore how hemi-spatial neglect... affect the patient's experience of self, other and world within the first month after stroke" (p1625)	12 participants	Up to 3 weeks post-stroke	Phenomenological study part of a larger longitudinal study	"The experience of neglect was captured in the overarching theme of "getting the left right," reflecting disruptions of usual habits and relations to other people and how the patients responded to such disruptions. Two subthemes were disclosed: (a) surreal awareness of the left and (b) emergence of a different world. Within the subthemes, there were four representative features: (a) misconceiving own body and surroundings, (b) brittle attention, (c) pursuing the left and generating stability and (d) bewildering responses" (p1627)	Patients bodies felt unreal and strange. They didn't have language to describe experiences and were concerned about being perceived as 'having lost their minds'. Talking about experiences was helpful to make sense of condition and feel understood	Good quality study. Clear reporting and in-depth analysis
Tham, Borrell and Gustavsson (2000)	Neglect	"To describe and understand... how persons with unilateral neglect experience, discover and learn to handle their disabilities in daily life during rehabilitation" (p399)	4 participants	17-70 days post-stroke	Phenomenological, Occupational Therapy perspective 5-7 interviews each over 16 weeks and field notes	Themes included: Discovering neglect (Experiencing the new and unfamiliar; Experiencing the left body parts as objects; Unpleasant bodily experiences; Disorganisation in daily life; New behaviour in the social environment); Comparing the old with the new (Experiencing the consequences; Searching for explanations; Feelings of failure); Becoming more familiar with the new; Understanding the disabilities; Learning to handle disabilities in daily life; Incorporating the new strategies	Participants reported alienation towards the body and environment. Neglect was discovered, and rehabilitation can support this. Sense of bodily alienation is important to explore as the body is the medium for being in the world	Participants were engaged in an intervention programme - though not the focus of the study, this may have affected accounts, otherwise good quality

Carlsson, Gard and Brogårdh (2017)	Sensory impairment	"Describe stroke survivors' experiences of sensory impairment in the upper limb, the influence of such impairment on daily life, coping strategies used and sensory training for the affected hand" (p46)	15 participants	6 months-11 years post-stroke	Qualitative, semi-structured interviews	"The 5 categories that emerged from the analysis were: "Changed and varied perception of the sensation"; "Affected movement control"; "Problems using the upper limb in daily life"; "Various strategies to cope with upper limb disability"; and "Lack of sensory training" (p45)	Participants reported feelings of strangeness, altered sensation and movement in upper limb. There is a need more research on sensory impairment of upper limb	Good quality
Connell, McMahon and Adams	Sensory impairment	"Gain an insight into how stroke survivors experience somatosensory impairment" (p151)	5 participants	1-18 months Post-stroke	Qualitative and phenomenological analysis. Interviews and sensory assessment	"Three superordinate themes (i) making sense of somatosensory impairment, (ii) interplay of somatosensory impairment and motor control for executing tasks and (iii) perseverance versus learned non-use" (p152)	They described altered sensation and awareness of body which was difficult to describe. Rehab needs to address somatosensory deficit considering its interaction with motor deficit	Leading questions, using professional terms, methodology incongruent and not clearly reported

Doyle, Bennett and Dudgeon (2014)	Sensory impairment	"Describe stroke survivors' experience of sensory impairments, its impact as well as their experience of sensory rehabilitation and recovery" (p994)	15 participants,	6 months - 16 years	Qualitative description, interviews	"(1) What happened to my hand?: Sensory impairment and its impact. This captures the descriptions of the experience of sensory impairment and its functional implications. (2) I was only just getting started: Readiness for rehabilitation. This theme provides a description of the rehabilitation experience. (3) If I work hard then maybe someday: Hope for recovery. This theme explores the concepts of working toward recovery and hope expressed by survivors" (p995)	Participants described altered sensation and awareness of body. Improving sensation was as important as improving motor function. Sensory impairments were not often addressed by clinicians. Participants wanted remedial and compensatory rehabilitation	Participants may have had other body awareness conditions such as neglect. Some incongruence in methods but member-checking used
Bashir et al. (2017)	Pain (central post-stroke pain)	"Look at the profiles of Central post-stroke pain and gender difference in the profiles among stroke survivors in Kano, Nigeria" (p2)	6 had central post-stroke pain out of 120 examined participants	Not clear, likely to be 1-6 months post-stroke	Quantitative, cross sectional, observational. Pain descriptors and pain assessment record and clinical examination	5 participants described moderate pain, 1 severe on the stroke affected side. Four reported continuous pain. Factors affecting pain were hot/cold temperature, movement and stress. They described pain as burning, like an electric shock and knifelike. They also described altered sensation such as numbness, pins and needles, allodynia and hyperalgesia	Participants described problematic pain and altered sensations after stroke in descriptive terms. Clinicians need to identify central post-stroke pain to reduce burden on patient	Small sample. Not clear what assessments used. Impact of pain was reported retrospectively

Jönsson et al. (2006)	Pain	<i>“Determine the prevalence, intensity and location of pain from the patients’ perspectives, as well as the evolution of pain with time and predictive factors”</i> (p590)	297 participants, scored at 2 time-points	4 and 16 months post-stroke	Quantitative. Assessment via VAS scores of pain at 4 and 16 months post-stroke	Pain was persistent and ongoing. Although the prevalence of pain after stroke decreased with time, after 16 months, one in five patients had moderate to severe pain. Late pain after stroke was on average more severe and affected wellbeing and physical activity	Patients commonly reported continuous or frequent bouts of pain, which many described as moderate to severe. Four patients had central post-stroke pain. Health pros need to recognise and treat pain after stroke. Some participants reported pain prior to stroke	Good methods, large sample, screened relatives for patients unable to respond, also screened for depression and central post-stroke pain
Widar, Ek and Ahlström (2004)	Pain	<i>“To describe pain, coping strategies and experienced outcome of coping with the three previously classified long-term pain conditions after a stroke”</i> (p216)	43 participants (15 with central post-stroke pain; 18 with nociceptive pain and 10 with tension-type headache)	2 years post-stroke, 2 time points, 3 months apart	Qualitative, 2 semi-structured interviews each	<i>“Pain-related problems described were incomprehensibility regarding the pain, disturbed sleep, fatigue, diminished capacity, mood changes and stress in relationships... Changing body position, making comparison and enduring the pain were common in central or nociceptive pain, rest and relaxation in tension-type headache. Communicating pain gave a feeling of perplexity and resignation”</i> (p215)	Participants described pain as <i>“unpleasant, troublesome, annoying and tiring”</i> (p217). Those with central post-stroke pain described pain on affected half of body and used terms like dull, cutting and numbness. Pain was linked to both the static and moving body. Pain was incomprehensible and hard to make sense of. Better assessment of pain is needed	Good quality study

Widar et al. (2002)	Pain	<p><i>"To classify and describe the characteristics of different long-term pain conditions after a stroke"</i> (p165)</p>	43 participants with long-term pain	2 years post-stroke	Quantitative. Clinical examination and pain assessment using the Pain-O-Meter and a Pain questionnaire	<p><i>"Pain was classified as central post-stroke pain (n = 15), nociceptive pain (n = 18) and tension-type headache (n = 10). In 65%, pain onset was within 1–6 months and the pain intensity revealed individual differences. Many pain descriptors was common, some were discriminating as burning in central and cramping in nociceptive pain and pressing and worrying in headache. More than half with central or nociceptive pain had continuous or almost continuous pain. Cold was the factor mostly increasing the pain in central, physical movements in nociceptive pain and stress and anxiety in headache. More than one-third had no pain treatment and two-thirds of those with central pain had no or inadequate prescribed pain treatment"</i> (p165)</p>	Patients described pain in terms of sensory descriptors using phrases like cramping, dull, aching and burning. Pain was problematic and some participants experienced more than one type of pain. They had little understanding of causes for their pain	Good quality study
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Arntzen and Elstad (2013)	Apraxia	<p><i>“Explore the phenomenon of apraxia as it appeared in the habituated activities of six participants diagnosed with apraxia”</i> (p64)</p>	<p>6 participants with apraxia (2 died, 1 withdrew from study, data included). Plus secondary participants including professionals and family members</p>	<p>From 2-6 months post-stroke</p>	<p>Phenomenological approach. Open Interviews, videos and field notes. 22 interviews total – 12 were repeat interviews with same participant</p>	<p>Participants described changes in intentionality. Themes were: 'Gap between intention and bodily action' describing how apraxia interferes with performance of an activity; 'Fragmented awareness in action' reflecting the need to maintain attention to an activity; 'Peculiar actions and odd bodies' capturing the strangeness of the body; and 'Fighting against tools' describing the difficulty of using objects</p>	<p>Describes loss of intentionality, exploring in specific detail attention, bodily response and the experience of body in the world. They suggest the <i>“need for further phenomenological research on experiences of specific neurological impairments after stroke, to illuminate the complexity of the phenomena through detailed and contextualized descriptions”</i> (p71)</p>	<p>Good quality study. Rigour added through triangulation of methods</p>
Blijlevens, Hocking and Paddy (2009)	Dyspraxia	<p><i>“What does dyspraxia mean to people who experience it in their everyday activities?”</i> (p467)</p>	<p>5 male participants</p>	<p>4 months-5 years post-stroke</p>	<p>Qualitative. 'Show and tell' interviews: videoed activities and then interviewed straight after - talked about activity and general experiences</p>	<p><i>“Three major themes were identified: struggling with their world, which encompasses aspects of tools, space, time, receiving help and the way requiring help changed their relationships; the being of struggle, which has three aspects – their body, thoughts and limited ability to give voice to their experience; and overcoming the struggle by talking their way through tasks, pacing themselves, persevering and limiting the barriers they face”</i> (p469)</p>	<p>Participants talked about the body being a struggle, unreliable and found it hard to make actions conscious when thought evaded them. They talked to the body. They struggled to use the body in the world and perform intentional actions. Better diagnosis of dyspraxia is needed</p>	<p>Study sample only included men</p>

Da Silva et al. (2014)	Fear of falling	<p><i>“What are lived experiences of survivors of chronic stroke about falling and Fear of falling,”</i> how does their balance confidence relate to this and what are relatives concerns? (p355)</p>	6 interviews with survivors and spouses from a larger study	6-8 years post-stroke	Mixed methods. Phenomenological, semi-structured interviews and 16 item (quantitative) questionnaire embedded into interview	<p>All participants had experienced a fall since their stroke and half of participants had sustained an injury as a result. Themes were described in terms of physical and emotional/cognitive adjustment. Physical components were the environment, equipment usage and physical self which captured experiences of activity limitations, impairments and injuries. <i>“Two participants described fear of falling when asked, but most indicated impaired balance confidence”</i> (p353)</p>	<p>Participants described an unresponsive and unreliable body which affected the bodily experience of balance. Talks about incongruity between fear of falling and balance confidence - people answered differently to these two aspects. Clinicians should provide information to patients about fall prevention and balance confidence</p>	<p>Triangulation of methods was reported as a strength, but quantitative questions in phenomenology create incongruence in methods. Member-checking added rigour. Presence of spouses may influenced data</p>
Gorst et al. (2016)	Foot, ankle, balance, mobility	<p>To explore the nature of the foot and ankle impairments experienced; how these contribute to mobility; balance and falls; look at their impact and healthcare advice and interventions</p>	13 participants	4 months - 20 years post-stroke	Qualitative, semi-structured interviews	<p><i>“These themes were termed (1) Impact which described the nature of impairments and how they contributed to mobility and balance; (2) Standing out which described feelings of standing out, perceptions of disability and a desire to be “normal” and (3) Help which described the nature and extent of help and advice received”</i> (p591)</p>	<p>Participants described altered sensation, reduced feeling and a feeling of strangeness in the foot and ankle. The foot was at times unresponsive and participants had to focus on achieving actions. They mentioned stiffness, slowness and swelling</p>	<p>Good quality. Clear, rigorous methods</p>

Schmid and Rittman (2007)	Fear of falling	"The purpose of this study is to describe Fear of Falling as an important emerging issue of post-stroke recovery" (p46)	42 of 132 participants involved in the 'parent' study	1 and 6 months after discharge	Secondary analysis of qualitative data. In-depth semi-structured interviews	"Analyses indicate three important factors may be associated with the development of post-stroke Fear of Falling: (a) the initial fall coinciding with stroke onset, (b) perception of post-stroke body changes and (c) a pervasive everyday fear of future falls" (p46)	Participants talked about losing bodily control, legs 'giving out', weakness and dizziness. Falls reported predominantly in terms of physical body changes which is a primary theme e.g. hemiplegia or paresis, balance	Convenience male only sample, from larger study and secondary analysis
Kirkevold et al. (2012)	Fatigue	describe how fatigue is experienced by stroke survivors, how they understand and deal with fatigue and how fatigue impacts on their daily life.	30 participants including both 'fatigued' and 'non-fatigued' from larger study of 165 participants	10 days, 3 months 1 and 2 years post-stroke	Qualitative with grounded theory analysis. 4 interviews each at 4 time - points, over 2 years	Two manifestations of fatigue emerged: "(1) tiredness as an ordinary life event and (2) fatigue as a poststroke life condition" (p667). Over time, some participants moved between these two manifestations, whilst other experienced worsening fatigue over time. Three fatigue-transforming strategies were identified, 'being on a mission', 'settling for less' and 'stalling'	Participants talk about feeling exhausted and as a result experiencing worsened body changes such as spasticity, leg twisting, foot gets bigger. Fatigue felt like being 'over-medicated', like being in 'low gear'. They reported a lack of outside understanding of fatigue. There is a need for earlier screening and improved support of fatigue	Good clear reporting, but not fully grounded theory because concurrent methods and theoretical sampling not used

Doolittle (1991)	Embodied experiences	Explore <i>“the progressive experience of bodily recovery and practical knowledge gained...”</i> (p235) How is the habitual body experienced and bodily integrity regained?	13 participants (with lacunar infarct)	From 72 hours post-stroke to over 6 months	Qualitative. Average of 9 interviews each	<i>“The survivors experienced a paralyzed self secondary to bodily immobility, the shock of the stroke onset and fear of not knowing what might happen next. The terrifying loss of control over bodily movements led to an experiential breakdown”</i> (p235). The themes were: Stroke as bodily experience; Stroke in evolution; Meaning of hospitalization; Living with uncertainty; Differing medical and personal views; Facing the night; Discharge home	Refers to stroke is an evolving bodily experience describing immobilisation, weakness, lack of control, being trapped at night with insomnia. Objectification of the body and frustration of body described	Good quality. Good data collection and triangulation
Eilersten et al. (2010)	Embodied experiences	<i>“Examine older women’s experiences and the characteristics of their recovery process in the first two years following a stroke”</i> (p2005)	6 female participants	2 weeks - 1 year	Longitudinal, phenomenological approach. 12-14 qualitative interviews each (78 interviews)	<i>“In the first phase (0–2 months post-stroke), the participants’ main concerns were their bodily changes; in the second phase (2–6 months), activities of daily life; in the third phase (6–12 months), self-understanding and in the fourth phase (12–24 months), going on with life”</i> (p2004)	Participants talked about bodily changes, the body was unreliable and unpredictable, unpleasant, strange, bothersome and embarrassing. There is a need for early, home rehabilitation	Good quality. Only female participants, who were mostly single, however this is congruent with the method
Ellis-Hill, Payne and Ward (2000)	Embodied experiences	<i>“To explore the life narratives of people following a single stroke to understand how they constructed the meaning of the stroke within their life story and to identify the main issues that they were facing”</i> (p726)	8 participants,	3 weeks - 1 year	Qualitative. Functional measures and life narrative interview. 3 interviews each at different time points	<i>“The main issue was a split between themselves and their body. In hospital their body appeared to become separate, precarious and perplexing. By one year the majority still found their body unreliable and their physical ability influenced by social setting”</i> (p725)	Participants talked about an unresponsive body, unreliable and perplexing. The body was out of control and confining. The body was objectified and rebellious. Professionals need to consider the meaning of the body in the social context, to explore rehabilitation outside of the hospital environment	Good quality. Congruent methods and researcher reflexivity used

Faircloth et al. (2004)	Embodied experiences	Explore bodily practices after stroke and how the body informs stroke patients' understandings and everyday recovery practices, considering mind body dualism	51 participants	1 month after discharge	Secondary analysis of qualitative in-depth interviews already collected for an ongoing study	The body was discussed in terms of being: a subjective and objective phenomenon; a passive foreign object; an active familiar subject; testing the body in everyday practice; creating coherence in the biographical body. Participants <i>"use[d] three specific technologies of bodily management and meaning-making. These are managing the body within a mind-body dualism, testing the body in its everyday practices and orientating o the body as a biographically informed phenomenon"</i> (p71)	Participants talked about the body feeling strange and foreign, telling the body what to do; and bringing conscious focus to the body; and testing the body's abilities. The body was slow. There is an ongoing dialogue between the body and self	Methods poorly reported and use of secondary data – sociological focus in study. Mainly male sample
Faircloth et al. (2005)	Embodied experiences	Explore how experience of stroke is constructed through narrative	111 male participants	1, 6, 12 and 18 months after discharge	Secondary analysis of qualitative in-depth interviews already collected for ongoing study	<i>"Three narrative mechanisms are used in the construct of the sudden-onset event itself: the use of typifications to construct the body during stroke, stroke as an internal communicative act and stroke as a physical sensation and the mechanisms used to minimize bodily concerns"</i> (p928)	Description of the body as feeling unresponsive, strange, unresponsive and talking to the body. Focus on physical sensations and the body feeling 'gone'. There is a need for researchers to understand how individuals make sense of their stroke experience	Methods poorly reported and use of secondary data – sociological focus in study. Male only sample

Kitzmüller, Håggerström and Asplund (2013)	Embodied experiences	"Illuminate the significance of the long-term influence of bodily changes on the perception of self after stroke" (p20)	23 participants	3-25 years	Phenomenological hermeneutical Narrative interviews (17 individual stroke survivors, 6 with partners)	"Stroke survivors perceive their bodies as fragile, unfamiliar and unreliable and tend to objectify them. The weak and discomforting body that 'cannot' demands constant comprehensive awareness to keep itself in play. These long-term and often permanent consequences of bodily weakness may turn stroke survivors' intentionality inwards, away from external activities and projects and relationships with others" (p19)	Themes reflected 'Living a fragile body'; 'the discomforted and vulnerable body' and 'the body in need of support'; 'increased attention to bodily functions' 'Living a body that is not me'; 'the strange and unreliable body'. Professionals need to help patients develop positive perceptions of the body and self	Good quality. Robust methods, transparent reporting. Large sample for phenomenology
Kvigne and Kirkevold (2003)	Embodied experiences	"An investigation of how a stroke can influence the lived body in women's life world" (p1294)	25 female participants	Up to 6 weeks - 1.5/2 years	Phenomenological Up to 3 interviews each (5 didn't finish study)	"Stroke survivors' experiences of their bodies were characterized by profound, disturbing and in part unintelligible changes during the onset and process of recovery from stroke" (p1291). Themes were: 'The unpredictable body' (the non-spontaneous body, the vulnerable/defenseless body, the unreliable/betraying body); The demanding body (the time-consuming body; the limiting body; the conspicuous body); The extended body; Towards re-embodiment	Participants described the body as strange and unfamiliar, unreal, unresponsive and unreliable and requiring conscious awareness. Fatigue was described as feeling 'empty'. Patients need support to 're-own' their bodies after stroke	Good quality. In-depth analysis, large sample for phenomenology . Feminist perspective

Taule and Raheim (2014)	Embodied experiences	<i>“Explore stroke survivors’ experiences of living with mild stroke in the context of Early supported discharge and continued rehabilitation at home”</i> (p2108)	8 participants selected from a larger trial	6-8 months post-stroke	Qualitative interpretive, semi-structured interviews. Medical information was collated from RCT data	<i>“Life changed profoundly. Differences and similarities in experienced changes were related to: self-perceived health, the body, practical activities, taking part in society and self-perception”</i> (p2107)	Participants described the body as bothersome and unreliable, untrustworthy and unfamiliar. They described pain. The body was demanding and confusing	Clear and reflexive reporting. The authors suggest phenomenology might have been useful to understand more about the phenomenon
Timothy, Graham and Leveck (2016)	Embodied experiences	<i>“To explore embodiment and stroke through understanding participants’ bodily experiences and how this related to their lived experience during their first month at home”</i> (p1566)	7 participants with change in body function	1-3 months post-stroke, 1 month after discharge	Grounded theory, semi-structured interviews	Two main themes in the embodied experience of stroke were: (1) “a divergent body-self,” where participants referred to an objective physical body, separate from their sense of self and (2) “a cohesive body-self,” reflecting a sense that “it’s all me.” The theme “a divergent body-self” included subthemes of a body that was “strange,” “unpredictable,” and “effortful.” “A cohesive body-self” comprised the subthemes “freedom,” “control,” and “self-identity,” reflecting experiences of bodily movement, personal independence and self-identity	Participants described the body as strange, unreal, effortful, out of control and unpredictable. They discussed the body in the third person and found their experiences inexplicable	Good quality. Robust methods and transparent reporting

A.8. Email from JBI about methods

JBI Synthesis <jbisynthesis@adelaide.edu.au>

Reply |

Sun 25/02, 11:40 PM

Hannah Stott

Inbox

Dear Hannah

I have now enlisted the help of the chair of our Scoping review Methods Group, Dr Micah Peters has advised the following:

Here is something to send Hannah on my behalf. Do feel free to pass on my email address:

It's probably easiest to explain that the results of a scoping review should be presented in ways that best and most appropriately fit the particular objective/s of the individual review. Summarising the results is likely the most appropriate way as opposed to a typical synthesis that would be expected of a traditional systematic review. For example; a scoping review would not attempt to determine the overall and comparable effect of a drug on a particular outcome using results from a number of included studies – that would be something a typical systematic review may attempt to do after establishing the relative quality of included studies and appropriateness of the data to be combined statistically in that way. A scoping review may instead be conducted to establish a broad picture of what kinds of patients receive the drug and what outcomes are measured in order to determine its effectiveness. Here it would not be necessary to synthesise the results in the same manner as a systematic review; though some basic synthesis could be performed to demonstrate combined results from included studies (e.g. 25% of studies used clinical outcomes A, B and C measured at 12, 24 and 48 hours to measure drug effectiveness).

Ultimately, it comes down to the authors having to think about the best and most appropriate way to present their results in relation to their objectives. This is because scoping reviews tend to be broad and answer rather more uniquely varied questions than traditional systematic reviews.

I hope this helps!

Cheers

Micah

Dr Micah D J Peters PhD |
E: micah.peters@unisa.edu.au

Kind regards

Pam

A.9. Mapping constructs and devising theme titles

CONSTRUCT: The body is strange and unfamiliar

Body perception area	Author	Themes and quotes adding to rationale for thematic framework constructs
Body awareness conditions (neglect, anosognosia)	Klinke et al. (2015)	Features of themes: <i>“dreamlike, unreal experiences”, “strange bodily sensations”, “bewildering responses”, “self-alienation”</i> (p1627)
	Tham, Borrell and Gustavsson, (2000)	Themes: <i>“Experiencing the new and unfamiliar”, “Experiencing left body parts as objects”; “Unpleasant bodily experiences”</i> (p401)
	Baier and Karnath (2008)	<i>“The limb does not belong to the own body”</i> (p487)
	Antoniello et al. (2010)	<i>“postural illusion...the phantom... a negative experience”</i> (p1117); <i>“it feels like it’s moving even though I know it’s not”</i> (p1118)
Sensory impairment	Carlsson, Gard and Brogårdh, (2017)	<i>“Several participants reported a strange feeling in their hand, such as numbness or tingling...some reported the upper limb was not alive”</i> (P46)
	Connell, McMahon and Adams (2014)	<i>“And I would feel it... my left hand on my right leg and it was like somebody else’s hand in bed feeling me up”</i> (p153)
	Doyle, Bennett and Dudgeon, (2014)	<i>“Many participants described post-stroke sensation as being altered in some way: as a ‘strange, odd feeling’, ‘feeling numb’”</i> (p995); <i>“What happened to my hand? It was gone... I didn’t even remember that it was a part of my body”</i> (p996)
Balance and mobility	Gorst et al. (2016)	<i>“the lack of control in the toes was... to do with the toes ‘having a mind of their own’”; “just not feeling right... doesn’t feel like it belongs to me”</i> (p591)
Movement processing (apraxia)	Arntzen and Elstad (2013)	Theme: <i>“Peculiar actions and odd bodies”</i> ; Quote: <i>“Participants’ struggles as their bodies appeared peculiar and unpredictable, tools appeared strange and the environment unfamiliar”</i> (p69)
‘Whole-body’ experiences	Eilersten et al. (2010)	<i>“experience of an unpleasant... unreliable... unpredictable... embarrassing... body”, summarised as the theme: “bodily strangeness”</i> (p2008)
	Ellis-Hill, Payne and Ward, (2000)	Themes: <i>“Separate precarious... unreliable...perplexing... body”</i> (p728-729)
	Faircloth et al. (2005)	<i>“He was not his not in his ‘normal’ body, his normal self, but, rather, in a strange and new creation, not even recognizable as human: now a fish with an elongated flipper”</i> (p932)
	Kitzmüller, Häggerström and Asplund (2013)	Themes: <i>“Living a body that is not me; living an unfamiliar and unreliable body”</i> ; Quote: <i>“Stroke survivors viewed their impaired body parts as strange and unfamiliar”</i> (p24)

Kvigne and Kirkevold (2003)	Title: <i>“living with bodily strangeness”</i> ; Quote: <i>“Unfamiliar or strange body”</i> (p1298)
Taule and Raheim (2014)	Theme: <i>“The changed body: bothersome, unreliable, or recovered”</i> ; Quote: <i>“He struggled to trust his own body, which had become unfamiliar”</i> (p2112-2113)
Timothy, Graham and Levack, (2016)	Themes: <i>“bodily strangeness; an unpredictable body; an effortful body”</i> ; Quote: <i>“it’s just strange... unreal”</i> (p1569-1570)

CONSTRUCT: Noticing altered body perceptions during movement

Body perception area	Author	Themes and quotes adding to rationale for thematic framework constructs
Body awareness conditions (neglect, anosognia)	Blijlevens, Hocking and Paddy (2009)	<i>"In my own mind I could do it but when I went to do it, it wasn't do-able"</i> (p471)
	Chatterjee and Mennemeier (1996)	<i>"he states that he specifically became aware of his weakness when asked to move or 'activate' his by his therapist"</i> (p235)
	Tham, Borrell and Gustavsson (2000)	<i>"The women gradually discovered new disabilities when confronted with their limitations... 'for example when you can't come and go whenever you want'"</i> (p402)
	Klinke et al. (2015)	<i>"They asked me to turn – but I literally fell it as if I am expecting to enter a free fall"; "When asked to raise the left foot while resting in bed, she still elevated her right foot"</i> (p1628)
Sensory impairment	Carlsson, Gard and Brogårdh (2017)	Sub-theme: <i>"Affected movement control"; "I think I have it but when I pull back the peeler it jumps out of my grasp"</i> (p47)
	Doyle, Bennett and Dudgeon (2014)	<i>"I would be putting more and more and more force on them... that it would erupt all over the counter top... The feeling of being able of feel force and being able to feel position are just huge. That without those it becomes very difficult"</i> (p996)
Movement processing (apraxia)	Arntzen and Elstad (2013)	<i>"how odd is was to know that he used the table knife to slice the bread, without being able to change the operation and pick up the bread knife that lay by"</i> (p69)
Balance and mobility	Gorst et al. (2016)	<i>"I have to be careful where I'm walking... I'm likely to sort of trip... because this wretched foot doesn't lift up"</i> (p592)
	Da Silva et al. (2014)	<i>"I went to step down...my ankle kind of turned like this when I stepped down"</i> (p359)
	Schmid and Rittman (2007)	<i>"After I walk so long, the feeling that any time now, the hip and leg are gonna give out"</i> (p50)
Whole-body experiences	Ellis-Hill, Payne and Ward (2000)	<i>"I can move it about a bit you know I keep lifting it up... I let go and it drops"; "I've always tried to be careful but I mean if your balance goes or my head let me down there's nothing you can grab hold of you just go"</i> (p729)
	Faircloth et al. (2004)	<i>"I try things, you know, I find out if I can do it or can't do it"; "I do what I can. I don't say I can't do nothing. I'll, I'll try or attempt it and then, I'll get frustrated"</i> (p80)
	Kvigne and Kirkevold (2003)	<i>"The pain was related to 'doing something wrong' with her weakened right side when she was trying to get up from the bathtub"</i> (p1299)
	Eilersten et al. (2010)	<i>"My body feels so heavy... didn't I notice the changes earlier? I'm unable to turn around quickly, I'm unsteady"</i> (p2009)
	Taule and Raheim (2014)	<i>"I find myself slow and realise I did the work a lot faster before"</i> (p2113)

	Kitzmüller, Hæggerström and Asplund (2013)	<i>"I have to use all my concentration on walking... step by step in order not to tumble and fall"</i> (p23)
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CONSTRUCT: Talking to the body

Body perception area	Author	Themes and quotes adding to rationale for thematic framework constructs
Body awareness conditions (neglect, anosognia)	Blijlevens, Hocking and Paddy (2009)	<i>"I talk to it. 'Right you, move!'...Come on leftie pick up and get on with it"</i> (p472)
	Tham, Borrell and Gustavsson, (2000)	Theme: <i>"Experiencing the left body parts as objects"</i> (p401). <i>"They could no longer rely on 'automatic' competence"</i> (p401) <i>"Look to the left, look to the left, I tell myself"</i> (p404)
	Klinke et al. (2015)	<i>"I often try to explain to myself that something is wrong by imagining that my body is like the body of inseparable Simamese twins"</i> (p1630)
Sensory impairment	Doyle, Bennett and Dudgeon (2014)	<i>"I had to constantly be visually assessing the hand. Am I sitting on it? Am I in a bad position?"</i> p996
Movement processing (apraxia)	Arntzen and Elstad (2013)	<i>"He commented that if he did not keep his hand under surveillance, he worried that it would start to live its own life"</i> p69
	Blijlevens, Hocking and Paddy (2009)	Theme: <i>"Talking to my body"</i> p472
'Whole-body' experiences	Doolittle (1991)	<i>"Interviews across all individuals were laden with discussions of the involved limbs as 'it' or 'they'"</i> (p237)
	Faircloth et al. (2005)	Theme: <i>"Stroke as an internal communicative act"</i> (p933); <i>"The stroke survivors engaged in self-communication with their affected body parts, encouraging them to perform tasks adequately"</i> (p933)
	Faircloth et al. (2004)	<i>"I just can't get up like I used to. I just got to sit there... For a while my body tell me...' you just sit there'... then it'll say 'Get up!' And I get right on up"</i> (p77). <i>"The mind is telling the body – which does not listen – what to do"</i> (p75)
	Kvigne and Kirkevold (2003)	<i>"I have to say to my foot: now you must help me"</i> (p1299)
	Ellis-Hill, Payne and Ward (2000)	<i>"One day... I'll just get up like you do without thinking about walking"</i> (p730)
	Kirkevold et al. (2012)	<i>"it feels like my body says that 'now I can't anymore'"</i> (p667)

Appendix B.

A phenomenological study exploring experiences of altered body perception after stroke

B.1. Ethical approval

UWE REC REF No: HAS/16/03/114

21st March 2016

Hannah Stott
Faculty of Health and Applied Sciences
University of the West of England
Glenside Campus, Blue Lodge
Blackberry Hill
Stapleton
Bristol, BS16 1DD

Dear Hannah

Application title: Exploring the nature of body perception and comfort after stroke

Your ethics application was considered by the Faculty Research Ethics Committee and, based on the information provided, has been given ethical approval to proceed.

You must notify the committee in advance if you wish to make any significant amendments to the original application using the amendment form at

<http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx>

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web:

<http://www1.uwe.ac.uk/aboutus/departmentsandservices/professionalservices/marketingandcommunications/resources.aspx>

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

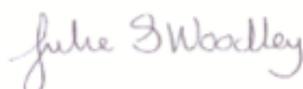
1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.
2. You must notify the University Research Ethics Committee if you terminate your research before completion;
3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please remember to populate the HAS Research Governance Record with your ethics outcome.

We wish you well with your research.

Yours sincerely



Dr Julie Woodley
Chair
Faculty Research Ethics Committee



Amendment to Existing Research Ethics Approval

Please complete this form if you wish to make an alteration or amendment to a study that has already been scrutinised and approved by the Faculty Research Ethics Committee and forward it electronically to the Officer of FREC (researchethics@uwe.ac.uk)

UWE research ethics reference number:	HAS.17.10.028
Title of project:	Exploring the acceptability of assessment tools to communicate altered body perception and comfort after stroke: a pilot study
Date of original approval:	27.10.17
Researcher:	Hannah Stott
Supervisor (if applicable)	Dr Mary Cramp

1. Proposed amendment: Please outline the proposed amendment to the existing approved proposal.

The original proposal stated recruitment would be conducted via BASF stroke groups and cafes, however I would like to extend this to include a Stroke group which is not run by Bristol Area Stroke Foundation (BASF). There would be no other changes to the recruitment process.

The suggested group is called ReVoice and is run by and based at UWE on a Wednesday. The group was suggested by a ReVoice member at a BASF stroke café. It is a choir for people experiencing communication problems (aphasia) after stroke. I have made contact with the choir leader and she is happy for me to attend and to facilitate recruitment.

2. Reason for amendment. Please state the reason for the proposed amendment.

The choir is a valuable resource to recruit people with aphasia to the study. Currently I have attended 2 BASF groups and 2 BASF cafes to recruit participants. I have had several people with aphasia volunteer to take part, but I would like to identify a few more people in case not all volunteers are eligible.

3. Ethical issues. Please outline any ethical issues that arise from the amendment that have not already addressed in the original ethical approval. Please also state how these will be addressed.

There are no additional ethical issues identified.

To be completed by supervisor/ Lead researcher:

Signature:	H Stott
Date:	24.11.17

To be completed by Research Ethics Chair:

Send out for review:	<input type="checkbox"/> Yes <input checked="" type="checkbox"/> No
Comments:	<i>This additional venue raises no further ethical issues</i>
Outcome:	<input checked="" type="checkbox"/> Approve <input type="checkbox"/> Approve subject to conditions <input type="checkbox"/> Refer to Research Ethics Committee
Date approved:	<i>28th November 2017</i>
Signature:	<i>Dr Julie Woodley (via e-mail)</i>

Guidance on notifying UREC/FREC of an amendment.

Your study was approved based on the information provided at the time of application. If the study design changes significantly, for example a new population is to be recruited, a different method of recruitment is planned, new or different methods of data collection are planned then you need to inform the REC and explain what the ethical implications might be. Significant changes in participant information sheets, consent forms should be notified to the REC for review with an explanation of the need for changes. Any other significant changes to the protocol with ethical implications should be submitted as substantial amendments to the original application. If you are unsure about whether or not notification of an amendment is necessary please consult your departmental ethics lead or Chair of FREC.

Risk-Assessment

Prior to interview, a risk-assessment was completed to ensure that the primary researcher and participant did not put themselves in any unsafe situations during the recruitment and interview process. A plan addressed moderate hazards such as risk of harm from people or pets within the household visited, risk of fall and emotional impact on both researcher and participant due to interview content. The risk-assessment was submitted in line with UWE² guidance and stored in the Health and Safety Repository. The author has completed lone worker training through the Suzy Lamplugh Trust in a previous role.

B.2. Eligibility criteria sheet



University of the West of England

Eligibility Questions

To take place as informal conversation.

I need to ask you some questions to see if you are suitable to take part in this study. Lots of people I speak to will not be suitable for this study because it is about quite a specific type of experience. Please don't feel you have done anything wrong if we don't ask you to take part in an interview. I really appreciate you taking the time to talk to me. You may still be suitable for another study we are conducting next year.

I will assess if any speech or cognitive problems are likely to impact their ability to take part.

First name:

How long has it been since your stroke? (At least 6 months)

Are you experiencing any of the following since your stroke? (Currently)

<ul style="list-style-type: none"> • Movement or coordination problems <i>Can you walk/can you use your arm or leg?</i> 	✓ Y/N
<ul style="list-style-type: none"> • A change to body sensation <i>Have you noticed a change to the feelings you experience within your body?</i> 	✓ Y/N
<ul style="list-style-type: none"> • A change in your awareness of your body <i>Do you know where parts of your body are without looking at them?</i> 	✓ Y/N



University of the
West of England

Eligibility Questions

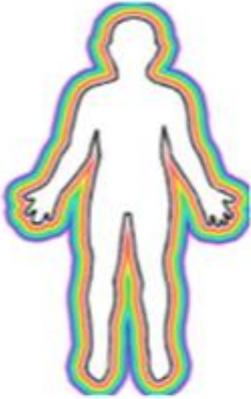
Do you have any of the following conditions? [EXC. = Exclusion criteria]

Other neurological Conditions (apart from stroke) e.g. MS or Parkinson's [EXC.] <i>'Conditions affecting your brain or nervous system'</i>	✓ Y/N
Diabetes Does it affect sensation? [EXC.] e.g. peripheral neuropathy	✓ Y/N ✓ Y/N
Joint pain – arthritis or lower back pain Osteoarthritis or rheumatoid arthritis? [Rheumatoid EXC.] Does it cause severe pain?	✓ Y/N ✓ Y/N ✓ Y/N
Complex Regional Pain Syndrome (before stroke) [EXC.]	✓ Y/N
Any other condition which may affect body sensation or body awareness [EXC.] e.g. phantom limb pain	✓ Y/N
Any other comments:	

Thankyou

B.3. Participant information flyer

We want to hear about what your body feels like since your stroke



- Have you had a stroke at least 6 months ago?
- Are you experiencing changes to the sensation or awareness in your body?
- Would you like to take part in research to help improve the lives of people who have had a stroke?

We are looking for people to take part in one interview about what their body sensations have been like since their stroke.

If you would like to share your experiences then you can...

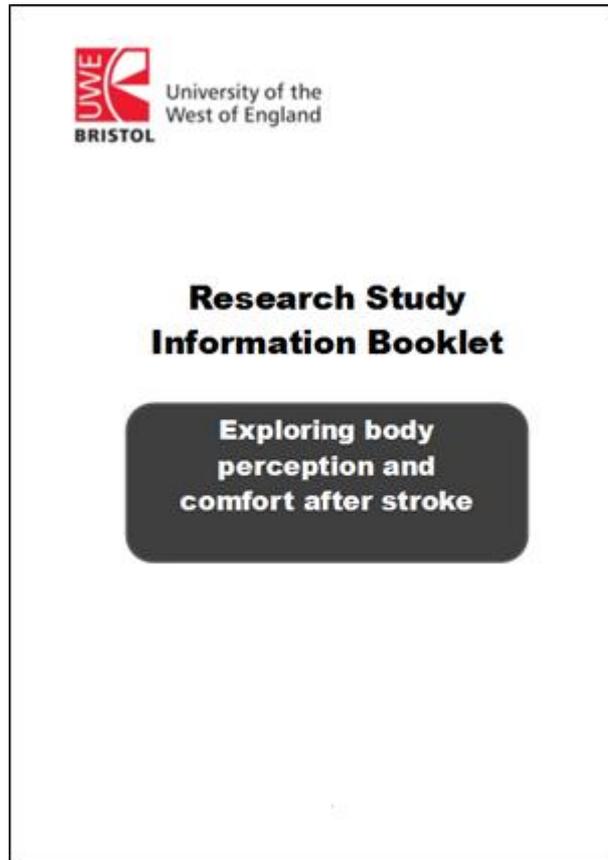
- Tell your **worker** that you would like them to pass on your name and number to us
- **Call or text** Hannah Stott on:
- **Email** Hannah Stott on:
- **Post** your details to: Hannah Stott
UWE Glenside Campus,
Blue Lodge, Blackberry Hill,
Stapleton, Bristol, BS 16 1DD



University of the West of England

This project is conducted by a team at: **BRISTOL**

B.4. Participant information booklet



Part 1: What the study involves

Who we are

I am Hannah Stott. I am a Post Graduate Researcher working with a team at the University of the West of England. We are conducting a research study about how peoples' bodies feel after their stroke.



What this booklet includes



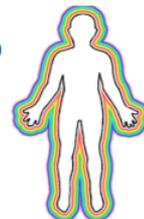
This booklet contains details about the study and what it would involve if you decide to take part.

- ◆ **Part 1** includes practical information about what the study involves.
- ◆ **Part 2** includes technical details about the information we will be collecting.

Please read this information carefully and show it to anyone you think may help you make your decision. If you choose to be contacted, Hannah will go through the booklet with you and answer any questions you may have.

About the project

We would like to talk to up to 20 people who have had a stroke at least 6 months ago, who are currently experiencing changes to sensation or awareness in their bodies.



- We want to find out what changes to sensation people feel in their bodies after they have had a stroke
- We want to know if these changes are comfortable
- We want to know how these changes to body sensation affect your life

Not many people have researched this before and not much is known about it.

Once we know more about these changes we can start working towards improving life for people after stroke.



What would I have to do?

Volunteers would have a short meeting with Hannah to discuss the study and to see if they are suitable to take part.

Those suitable would then meet again with Hannah for a face-to-face interview.

- The interview is expected to take up to 1½ hours and will be held at a time that suits you. The interview will be conducted at your pace, and time will be made if you feel you need a break.
- The interview can take place at your home, or at another location if you would prefer. Any transport costs will be paid for by the University.



What are the benefits?

The research will not benefit you directly. However the project hopes to improve the lives of those affected by stroke.



Are there any disadvantages?

We don't believe there are any risks to taking part in this study. There is a chance that you may feel emotional if talking about stroke experiences that have been difficult for you.

If you feel distressed please tell Hannah, and the interview will be stopped. Hannah is a trained therapeutic practitioner and has worked supporting those affected by stroke, so she will be able to refer you to further support if needed.

Do I have to take part?

You do not have to take part in this study. If you decide you would like to take part we will go through this information booklet with you and then ask you to sign a consent form.



Can I discuss it with anyone first?

Time will be given for you to discuss the study with people close to you to decide if you want to take part. You can also choose to have someone with you during the interview.

Can I change my mind?

If you decide not to take part or to withdraw from the study then we will respect your decision and will not put any pressure on you.

Will my information be kept confidentially?

All information you provide will be kept confidentially and anonymously. Nothing will be shared without your consent. More information about this is in Part 2 of this booklet.

Part 2: About my information



How will my information be kept confidential?

Any information collected from you will be strictly confidential. Your personal details will not be shared with anyone outside of the study. Your interview will be made anonymous so you cannot be identified. If you agree, your anonymous interview information will be kept for use in future research.

Where will my information be stored?

Your interview will be audio recorded on a Dictaphone. Within 48 hours it will be downloaded into a secure password-protected electronic file on the University server, and deleted from the Dictaphone. Your contact details will be stored separately from your interview information on the same secure server.

Who will see the results of this study?

The results of this study will only be known when all the interviews are finished which will be by September 2016. Hannah will send you a copy of the results. These results may be reported in professional publications or meetings.

What will happen to my information if I withdraw from the study?

If you withdraw from the study, information collected about you may still be used if you agree. If you don't agree, tell Hannah within 2 weeks of your interview and your information can be destroyed. After this date, your interview will have been analysed and put together with the findings from other participants and it will not be possible to remove your information.

What if something goes wrong?

It is extremely unlikely that anything would go wrong, but if something did happen during the study and you were harmed due to someone's negligence you may have grounds for legal action against the University of the West of England to claim compensation. You may have to pay your own legal costs.

What if there is a problem?

If you are concerned about any aspect of this study, you can contact Hannah whose details are at the end of this booklet.

If, after you have spoken to Hannah, you wish to make a formal complaint, you can contact:

<p>Dr Mary Cramp Research Supervisor</p> <p>UWE Glenside Campus Blackberry Hill Stapleton Bristol, BS16 1DD</p>	<p>The Complaints and Appeals Team</p> <p>Academic Services UWE Frenchay Campus Coldharbour Lane Bristol, BS16 1QY</p>
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Is this study approved?

A panel of experts at the University of the West of England Research Ethics Committee have reviewed and approved this study.



How do I take part?

- ⇒ **Call or text** Hannah Stott on:
- ⇒ **Email** Hannah Stott on: hannah3.stott@uwe.ac.uk
- ⇒ **Post** your details to:
Hannah Stott
UWE Glenside Campus
Blue Lodge
Blackberry Hill
Stapleton
Bristol, BS16 1DD
- ⇒ Tell your **Stroke worker** that you would like them to pass on your name and number to us

Local stroke services



Version 3:25.2.16

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further details available upon request

B.5. Assent information

Participants expressing interest in the study following face-to-face contact, provided verbal assent for further contact and their details were recorded. Participants who declined to participate were not asked for an explanation and their details were not recorded. Assent guidance was formulated to ensure participants recruited by third parties were informed of the study in a consistent and impartial manner which would not influence the content of their potential interview (see below). Individuals approached via a third party were asked to provide written permission assenting to contact from the author. This ensured that those experiencing memory difficulties would not feel their personal information had been shared without their knowledge.

Assent information for practitioners

Don't give out to participants

What you should tell potential participants about the project (please only give out page 2 of this document to participants)

What the study is about

- Exploring how people's bodies feel after they have had a stroke

Who we would like to talk to

- People who have had a stroke at least 6 months ago
- People who are experiencing changes to the way their bodies feel e.g. changes to the sensations they're experiencing or changes to how aware they are of their bodies
- People who **do not** have problems with their communication
- People who **do not** have other neurological conditions which may affect how their bodies feel

How will we do it?

- In an interview with Hannah Stott (a post graduate researcher at UWE), which will take a maximum of 1.5 hours (breaks will be given if needed)
- This can take place at their home or at UWE

If they are interested

- They should fill out the 'agreement to contact' form and **sign it**.
- You can send completed forms to:
Hannah Stott
University of the West of England,
Glenside Campus, Blue Lodge,
Blackberry Hill,
Bristol, BS16 1DD
- Any problems then give Hannah a call on 07342 894802 or email on hannah3.stott@uwe.ac.uk.

Thank you very much for asking people!

Don't give out to participants

Assent form for stroke survivors

Agreement to Contact

I agree that my coordinator can pass my contact details onto Hannah Stott at University of the West of England, to be contacted about taking part in a research study exploring how peoples' bodies feel after they have had a stroke.

Name:.....

Preferred name:.....

Address:.....

.....

.....

.....

Phone number:.....

Best time to contact:.....

Email:.....

Signature:.....

B.6. Consent form

Participant information booklets were distributed to individuals either at first contact or by post after the appointment phone call. They were left with potential participants to give them time to consider participation and discuss it with their carer or family. An interview appointment was then arranged afterwards by phone. Verbal information was presented slowly, clearly and concisely in short sentences to ensure full comprehension of the project and mitigate against any potential cognitive difficulties participants may have been experiencing. The consent form (see below) was described again prior to the interview commencing and the participant provided consent it at this stage.

Within this study the impact of the stroke on individuals' cognition was not assessed. Following PPI consultation, it was decided that the author would informally assess ability to give informed consent, based on how easily individuals comprehended and engaged with the project. The author attended training in Good Clinical Practice (National Institute of Health Research) and the Mental Capacity Act. As indicated by the Mental Capacity Act (2005) the factors which may suggest an individual is unable to make an informed decision, are an inability to: understand and retain information; to use that information to make a decision, and to communicate the decision. As such, if a potential participant appeared confused, or unable to remember the purpose of the project then they were deemed unable to give informed consent. In practice, some included participants were identified as having relatively 'minor' cognitive difficulties such as short-term memory loss; difficulty identifying dates and times and confusion when conducting day-to-day tasks, however they were all able to retain information about the study over time and make an informed decision. There is some grey area around the ability to give informed consent in older or vulnerable populations, such as those experiencing physical, cognitive, emotional or social difficulties. Corrigan et al. (2009) argue that that marginal groups can be used in research if the consent process is conducted clearly and sensitively. They suggest that a person should be presumed to have mental capacity and maintain that older and vulnerable people should be included in research to promote diversity.

One participant did not speak English as her first language and was only able to comprehend some English phrases verbally and in print. The author met with her and an interpreter who described details of the study, the participant booklet and consent form. The participant took the participant booklet to share with family members. She was given a week to consider whether she took part in the project and gave her assent for interview via the charity through which she was recruited. Prior to interview the consent form was explained again and agreed on via interpreter. It is highlighted by the Royal College of Physicians (2007) that pragmatic solutions to the difficulty of gaining consent in another language must be sought to encourage inclusivity and BAME participation in research. They point out that it may be unrealistic to suggest that research projects must get their material translated into other languages. They also advise training for researchers working with interpreters. The author has undergone training and has experience of working with interpreters. Interpreters were contacted prior to meetings to ensure understanding of the study, stroke generally and ensure that phrases were interpreted directly to avoid meanings being lost. To safeguard the participant the interpreters used were employees of the BAME charity and were bound by a strict confidentiality policy.

Reflecting on the consent process, it is worth noting that whilst participants provide prior consent they do not know what they will be asked or what information they will share about themselves. This puts the interviewer in a position of power which needs to be handled sensitively. Nunkoosing (2005) highlight that whilst participants are aware of the transactional nature of the interview process, they are at risk of sharing more information than they are comfortable with in interview; as they try to express themselves in conversation and due to a therapeutic feeling, which may be invoked when sharing their story. To protect participants, they were reminded they could withdraw their data for two weeks after interview. The data set was also cleaned of any identifiable characteristics or place names; the name of the charity through which they were recruited removed and the location only referred to regionally.

Consent FormUniversity of the
West of England**Exploring Body perception and Comfort after Stroke**

<i>Please tick the appropriate boxes</i>	Yes	No
Taking Part		
I have read and understood the project information booklet dated 25/2/2016.	<input type="checkbox"/>	<input type="checkbox"/>
I have been given the opportunity to ask questions about the project.	<input type="checkbox"/>	<input type="checkbox"/>
I agree to take part in the project. Taking part in the project will include being interviewed and audio recorded.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my taking part is voluntary; I can withdraw from the study at any time and I do not have to give any reasons for why I no longer want to take part.	<input type="checkbox"/>	<input type="checkbox"/>
Use of the information I provide for this project only		
I understand that my interview data and personal details will be stored in an electronic file on the secure UWE computer system.	<input type="checkbox"/>	<input type="checkbox"/>
I understand my personal details such as name, phone number and address will not be revealed to people outside the project.	<input type="checkbox"/>	<input type="checkbox"/>
I understand that my anonymous words may be quoted in publications, reports, web pages, and other research outputs.	<input type="checkbox"/>	<input type="checkbox"/>

If you have any questions then please contact **Hannah Stott** via Tel: 07342 894802 or Email: Hannah3.stott@uwe.ac.uk

Consent Form



University of the
West of England

I understand I can only withdraw my words from the project up to 2 weeks after my interview.

Use of the information I provide beyond this project

I agree for the typed out data I provide to be archived, this data may be used for future research.

I understand that other genuine researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.

I understand that other genuine researchers may use my words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in this form.

So we can use the information you provide legally

I agree to assign the copyright I hold in any materials related to this project to Hannah Stott.

.....
Name of participant [printed]

.....
Signature

.....
Date

.....
Name of researcher [printed]

.....
Signature

.....
Date

If you have any questions then please contact **Hannah Stott**
via Tel: 07342 894802 or Email: Hannah3.stott@uwe.ac.uk

B.7. Interview schedule

1. INTRO AND OTHER AREAS

INTRO	<ul style="list-style-type: none"> • How long ago was your stroke? • How has your stroke affected you? • How has your stroke affected your body? • Has one side of your body been more affected since the stroke?
WHAT? Less affected side	<ul style="list-style-type: none"> • How does your less affected side feel? • Have the feelings in these areas changed since your stroke? • Do they feel like they did before your stroke?

2. AFFECTED AREAS

WHAT?	<ul style="list-style-type: none"> • What changes have you noticed in your body since your stroke? • How comfortable are these changes? • What does that area look like in your mind's eye?
WHEN? BETTER or WORSE?	<ul style="list-style-type: none"> • When did you become aware of the changed 'sensation'? • How long do they usually last for? • Do they change over day / night? • Does anything trigger it? • Is there anything that helps with you to manage the 'sensation'?
HEALTH PROF'S	<ul style="list-style-type: none"> • Have you told a health professional? • Have you been offered any intervention? • Do you feel you have you been offered enough support with this issue? • What does it feel like managing your own rehabilitation?

3. PHYSICAL IMPACT

WHAT	<ul style="list-style-type: none"> • Can you describe how this 'sensation' affects your daily life? • How comfortable do you feel managing these difficulties? • Does anything make it easier or more difficult to manage?
ENVIRONMENTS	<ul style="list-style-type: none"> • Any places that make it easier or more difficult to manage 'sensations'? • Are there any times you feel unsafe because of the 'sensation'? • Any places feel more comfortable?
HEALTH PROF'S	<ul style="list-style-type: none"> • Told health professional? • Have you been offered any aid/intervention?
AIDS	<ul style="list-style-type: none"> • If you use an aid, how does this affect how your body feels? • How does the aid affect your comfort?

4. EMOTIONAL IMPACT

WHAT	<p>Can you describe the kind of thoughts or feelings you have about your body changes since your stroke?</p> <p>How do changed 'sensations' affect how comfortable you feel emotionally?</p> <ul style="list-style-type: none"> - What thoughts run through your mind? - How do thoughts make you feel? - Is there anything that makes these thoughts or feelings better or worse? <p>If sensations are in conflict - How does it make you feel?</p>
HEALTH PROF'S	<ul style="list-style-type: none"> • Have you told a health professional? • Have you been offered any emotional support for body changes?

5. SOCIAL IMPACT

WHAT	<p>Can you describe how the changed 'sensation' affects the type of places you go to?</p>
RELATIONSHIPS	<p>Do you feel that other people understand your experience of changed 'sensation'?</p> <ul style="list-style-type: none"> • How has the changed 'sensation' affected your relationships with friends and family? • Does the changed sensation affect how comfortable you feel socially? • Has the changed 'sensation' had any effect on intimate relationships with partners?
COMMUNITY	<ul style="list-style-type: none"> • Do you feel able to be part of your community in the same way as before?

6. CONCLUSION

OVERALL IMPACT	<ul style="list-style-type: none"> • How much impact are these body changes having on your life? • Which issue is currently having the biggest impact on your life? • How have your priorities for treatment changed during your recovery? • What does recovery look like to you?
TREATMENT	<p>If treatment existed, what sensations would you treat?</p> <ul style="list-style-type: none"> • In what order or priority?
ANYTHING ELSE	<ul style="list-style-type: none"> • Do these body changes affect / impact you in any other way that we haven't talked about?

Complete self-evaluation before and after interview

B.8. Sample frame characteristics

The sections detailed below provide a rationale for the inclusion of the criteria of age, gender, ethnicity, time since stroke onset and level of independence within the sample frame. In the case of these variables it is likely that these traits will have a bidirectional relationship with the stroke narrative; they may affect the characteristics of the stroke experience, whilst also affecting how the stroke experience is made sense of and which narrative is formed. For example, as detailed below, age can affect stroke risk and functional outcomes, whilst also being a key factor varying narratives about experience. As such it was helpful to identify poignant characteristics which may vary survivor's experiences after stroke and therefore diversify their narratives.

The effect of age on stroke experience

The likelihood of experiencing stroke increases with age. The national average age of stroke in the England, Wales and Northern Ireland is 74 for women and 80 for men (Stroke Association, 2017). In England estimates suggest that 3% of strokes occur in those under 40; 38% in those between 40 to 69 and 59% in those over 70 (Public Health England, 2018). The Royal College of Physicians (2016) reports an alternate estimate of 75% occurrence in those over 65 and 25% in those under 65.

Therefore, stroke is often perceived to be a condition which affects older people and is rare in the young. Differences of self-perception, life expectations and lifestyles between these age groups mean that the effects of stroke can be interpreted in varying ways. One study showed that when older people recounted a memory which defined their identity they reported stories with a more stable sense of self, whereas younger people described moments in which change and transition were a more dominant features, making age a useful marker to diversify narratives after stroke (McLean, 2008).

Younger people who experience stroke often feel that services are designed for older people and are not suited to their specific needs (Royal College of Physicians, 2016). They may also feel increased exclusion from activities with peers due to fatigue and have difficulty reconciling the stigma of having a disability more usually seen in older people (Stone, 2005). Leahy et al. (2016) found that those experiencing stroke under 50 felt old before their time and isolated due to lack of peer support. Stroke patients under 60 have been shown to experience more significant feelings of anger or emotional lack of control than their older counterparts (Huang et al., 2014) and younger age has also been shown to contribute to incidence of post-stroke depression (Poynter et al., 2009). Alternatively, whilst stroke has been shown to reduce quality of life for patients at any age (Morris, 2011; Niemi et al., 1988), older people are likely to experience worse rates of recovery which may provide an alternative stroke narrative from this age group (Kotila et al., 1984).

There is little consensus over how age groups after stroke should be categorised. Often stroke services and research studies categorise people over 65 as 'older' and those under 65 as 'younger' stroke survivors. However, this grouping may overlook the differences in stroke experience at different life stages. For example, some authors now group those under 45 as 'young' (Marini, Russo and Felzani, 2011; Griffiths and Sturm, 2011). Additionally, increasing life expectancy means that age classifications are changing and it may be insensitive to

classify 65-year-olds, who may not feel 'old' in the same bracket as their 80 or 90 year-old counterparts. At the other end of the spectrum, it may be hard for a 20-year-old stroke survivor to feel their experience is comparable to someone in their 60's who may have had a career and a family and is preparing for retirement. To recognise how age can diversify the stroke narrative, the sample frame for this study utilised three age categories: 18 to 54; 55 to 74 and over 75's to ensure a breadth of experiences were reflected.

In the study sample the average age of participants was lower than the national average and was 59 years (Stroke Association, 2017). This could have been because the four participants who were also volunteers at the charity were younger (49-58 years) than the general service users of the charity, which could have reduced the average age of the sample.

The effect of gender on stroke experience

The risk of stroke, stroke type and experience of disability after stroke differs significantly between men and women, making gender a useful diversifier of stroke narrative. Women are more likely than men to have a more severe or fatal stroke, however men are more likely to have a stroke and more likely to have one at an earlier age (Appelros, Stegmayr and Terent, 2009). Roquer, Rodríguez Campello and Gomis (2003) found that *"Women were, on average, 6 years older than men and had a different profile of vascular risk factors and a different distribution of stroke subtypes. Women had a longer hospital stay and remained more disabled than men"* (p1581).

Poynter et al. (2009) conducted a systematic review of sex differences in prevalence of depression post-stroke found that depression was common in both sexes but was more common amongst women. The suggested reasons for this disparity may include, the increased risk for women of depression in the general population, psychosocial inequalities, issues related to recovery, levels of support and ability to access rehabilitation. Mazure et al. (2014) concurred, finding that after stroke women showed higher levels of stress, which was linked to higher levels of depressive symptoms. Men are also likely to experience altered moods after stroke, one study of stroke patients in Taiwan, showed that male patients were more likely to experience psychological distress such as anger and 'emotional dyscontrol' than female patients (Huang et al., 2014).

Whilst variations in the physical and psychological stroke experience are clearly altered by gender, gender can also alter the experience of illness by influencing how individuals' respond to and understand their experience. One study exploring gender narratives in cardiac patients found Israeli women were less likely to seek treatment, received less support and had higher social expectations of their role meaning they engaged in shorter recovery periods after cardiac incident (Rassin, 2009). Stroke has been shown to disrupt the sense of identity associated with masculinity though affecting masculinised traits of physical strength, independence and being a breadwinner (Kvigne et al., 2014). Gender also influences how stories are described. One study exploring the gendered nature of chronic illness narratives identified differences between the sexes in storytelling such as vividness and imagery in language and reference to emotions and relationships (Andersson et al., 2008). As such gender is an important characteristic which can alter experience and narrative after stroke.

The gender represented in the sample was broadly consistent with sex differences in the worldwide stroke rate, which suggest that the incidence of stroke in men is 33% higher than women and the prevalence is 41% (Appelros, Stegmayr and Terént, 2009). Within this study, 37.5% more men than women were represented in the sample (10 men to 6 women).

The effect of ethnicity on stroke experience

Ethnicity has been associated with the risk of stroke and stroke recovery outcomes, meaning that understanding, experience and consequent narratives of stroke may vary depending on ethnicity. In the UK black people are more than twice as likely to experience stroke compared to white people (Stewart et al., 1999). Likewise, in the US stroke rates are higher in ethnic minority groups and their clinical outcomes are more variable (Stansbury et al., 2005). In 2014, a systematic review of racial disparities in stroke outcomes in US populations showed that individuals from ethnic minority groups were less likely to achieve the same rehabilitation outcomes despite receiving equivalent rehabilitation (Ellis et al., 2014).

Culture may also have an influence on the experience of illness, as illness is conceptualised and understood in different ways. Research into the reporting of medically unexplained symptoms by European American (EA) women and South Asian (SA) women, showed there was disparity in how symptoms were classified (Karasz, Dempsey and Fallek, 2007). EA women were more likely to state they were suffering with psychological problems, whereas SA women were more likely to classify these issues as physical – reporting higher incidence of physical pain and changes in body temperature. Cultural factors may also influence community attitudes and understanding of health conditions. One study into the experiences of Punjabi women experiencing rheumatoid arthritis living in the UK, found that these women experienced a sense of shame in their communities due to the impact of illness on their role as women. They discussed notions that illness was associated with bad karma and dealt out by fate or was God's will - the implication being that if you were ill you were not moral.

To reflect these variants of illness experience, ethnicity was included in the sample frame. The categories were based on those outlined in the Bristol City Council Equalities monitoring form (2011). The list outlined below summarise the ethnic groupings from the form, though a more detailed version was available to participants in the data collection stage of the study.

- White
- Black/African/Caribbean/Black British
- Asian/Asian British
- Mixed/multiple ethnic groups
- Other ethnic groups
- Prefer not to say

Ethnicity within the sample was roughly representative of regional population averages, which see 95% of the population in the South West of the UK identifying as White British (Office for National Statistics, 2011). Within this study 94% of the sample identified as White

British (15 participants); and 6% (1 participant) as Asian Indian. However, considering the incidence of stroke in London BAME populations is double that of white populations (Stroke Association, 2017) and that many participants recruited in this study resided in urban areas with higher BAME populations, minority ethnicities could have been more highly represented in this sample. This may have occurred because individuals from minority ethnic groups may be less likely to access community health care services and so may have been underrepresented in the sites identified during the recruitment phase (Latif, 2010).

The effect of time since stroke onset on experience

A further variable which may affect stroke experience and narrative is the time since the stroke occurred. Typically, the functional and neurological impact of stroke is worst at the point of stroke and lessens as time goes on. One study based in Denmark looked at functional stroke recovery in 1,197 acute patients, within the first six months of stroke onset (Jørgensen et al., 1995). They found that progress stabilised in 95% of patients at 12 weeks; that comparatively little functional progress was made between three- and six-months post-stroke; and that functional recovery should not be expected after five months. A more recent multi-time-point study of 20 patients concurred, finding the most important phase of stroke recovery is the first three months, in which 48 to 91% of neurological and functional recovery occurs, however recovery continues in all areas apart from motor leg function for up to six months (Lee et al., 2015). Similarly, recovery of somatosensory function fluctuates during the first six months of stroke. Connell, Lincoln and Radford (2008) found that perceptual abilities such as object recognition and sense of touch were likely to show increased improvement in the first four months, whereas proprioception may take up to six months to recover. The psychological impact of living with stroke can also fluctuate over time. Huang et al. (2014) found that patients living with more than a three-month duration of stroke symptoms experienced higher levels of psychological distress, such as helplessness, indifference and inertia.

A longitudinal study looking at longer-term outcomes beyond the six-month marker found that between six months and five years after stroke, patients across Europe exhibited worsening motor and functional outcomes and at five years outcomes were equivalent to those at two months post-stroke (Meyer et al., 2015). A similar picture of declining outcomes was found in Godwin et al. (2013) study of 30 stroke participants who were interviewed between 12 months and three to five years post-stroke. They found that participants demonstrated decreases in Health-Related Quality of Life as rated on Stroke Impact Scales. Although participants showed improving levels of depression up to 12 months post-stroke, these scores declined as time went on. These studies suggest that although there is an initial period of intense recovery after stroke, the longer-term picture may be less clear cut, with patients experiencing a range of functional, psychological and social impacts which may worsen as time progresses. Focus groups with stroke survivors showed how they described different challenges and sense of adjustment to the stroke experience as time went on, depending on emotional distress, perceived support and acceptance of their situation (Ch'ng, French and Mclean, 2008).

To reflect the evolving nature of functional and psychosocial outcomes and the perception of self within the stroke experience, the sample frame included participants who were at least six-months post-stroke and at any time point thereafter. Through excluding

participants who were in the fluctuating early stages of recovery it was hoped to capture narratives of the experience of altered body experiences which were more stable in nature. Including anyone at any time point post-stroke, meant short and long-term experiences of living with an altered body were reflected. Participants were categorised into those between six months and two years post-stroke and those over 2 years post-stroke to ensure a range of time post-stroke was reflected.

The impact of level of independence on stroke experience

The final factor included in the sample frame reflected participants' level of independence after stroke. This ensured diversified narratives in terms of the physical and psychosocial effects arising from body changes post-stroke and how the individual comes to terms with these different experiences. In England, one third of people after stroke (33%) are dependent on additional care after hospital discharge to meet their daily needs (Stroke Association, 2017). However, there are no figures for how this figure alters as stroke recovery progresses. Independence in activities is frequently compromised after stroke with many experiencing difficulties in personal care and mobility after three months of rehabilitation (Morone, Paolucci and Iosa, 2015). Physical changes such as hemiplegia, a key factor affecting independence in mobility, have been related to lower scores in Health-Related quality of life (HRQoL) measures (Min and Min, 2015; Morone, Paolucci and Iosa, 2015; Nichols-Larsen et al., 2005). HRQoL refers to *the "physical, psychological and social domains of health, seen as distinct areas that are influenced by a person's experiences, beliefs, expectations and perceptions"* (Testa and Simonson, 1996, p835). HRQoL research uses tools like the Stroke Impact Scale to assess individual's perception of their physical functioning, memory, emotions, communication and participation (Duncan et al., 1999; Duncan et al., 2003). Individuals' perception of their HRQoL reflects all domains of their experience, is clearly related stroke impact or key demographic variables, and is therefore a likely to diversify perspectives after stroke. Dependency in activities-of-daily-living and ongoing motor dysfunction is associated with reduced quality of life three years after stroke (Choi-Kwon et al., 2006). As such, it is useful to reflect varying levels of independence in the sample to diversify the perspective gathered.

The sample frame category of 'level of independence' was adapted and simplified from the Modified Rankin Scale (Rankin, 1957; Van Swieten et al., 1988). This is a six-point scale which assesses functional outcome after stroke. The existing scale descriptors are detailed in the figure below (Figure 27). In this study these descriptors were adapted and simplified into two 'levels' (Figure 28), as it was not necessary to the study to acquire the level of detail outlined in the original rating scale. 'Level 1' was comprised of categories one to three and 'Level 2' was comprised of categories four and five – categories zero and six were not relevant to this study.

Within this study sample two participants (12.5%) were dependent on additional care, which is lower than the national average of care after hospital discharge. This could be because participants were recruited from activity groups and cafés, which are likely to attract those who are more mobile and easily able to attend. Conversely it may be that the actual figure for those requiring additional care reduces as stroke recovery progresses.

Figure 27. Modified Rankin Scale (1957)

Score	Description
0	No symptoms at all
1	No significant disability despite symptoms; able to carry out all usual duties and activities
2	Slight disability; unable to carry out all previous activities, but able to look after own affairs without assistance
3	Moderate disability; requiring some help, but able to walk without assistance
4	Moderately severe disability; unable to walk without assistance and unable to attend to own bodily needs without assistance
5	Severe disability; bedridden, incontinent and requiring constant nursing care and attention
6	Dead

Figure 28. Simplified version of scale

Level of independence	<ol style="list-style-type: none"> 1. No disability to slight disability. Able to look after their own affairs without assistance, may be unable to carry out all previous activities. 2. Moderate to severe disability. Requires help in some or many activities. May or may not be able to walk independently.
-----------------------	--

B.9. Rejecting member-checking

Member-checking is often seen as a useful method to increase credibility in qualitative research. It involves asking participants to check and validate the content of their interview to ensure shared understanding has been achieved. However, in this study member-checking was not considered appropriate, due its potential negative impact on participants' wellbeing; the likelihood of changing experiences through the recovery process and its incongruence with the epistemological and methodological perspectives adopted. Firstly, due to the impact of stroke on memory, comprehension, concentration and energy levels, it would be impractical and insensitive to ask participants to go through long transcripts after interview. There was also a concern that due to the emotional content accessed in interviews, participants may find it upsetting to go through transcripts again. Goldblatt, Karnieli-Miller and Neumann (2011) highlight that conducting member-checking around sensitive topics can cause embarrassment and disappointment and can leave the participant feeling exposed and vulnerable, particularly as it is usually conducted independently, without researcher support.

Secondly, due to the evolving recovery experience which varies over time and place, it is likely that between the interview date and reading the transcript, participants will experience changes in the nature of their altered body perceptions and their perception of self and identity (Goldblatt, Karnieli-Miller and Neumann, 2011). This may lead to participants re-reading their accounts and feeling they are inauthentic and no longer match their current experience. Lastly, McConnell-Henry, Chapman and Francis (2011) argue that member-checking is not congruent with interpretive phenomenology. They highlight that this method is inherently about capturing the raw and un-interpreted version of a participant's story, which is expected to change between situations and over time. They argue that rigour can be achieved through using clarification and summary during interview to achieve a shared understanding. In accordance with this critique, these communication techniques were utilised in interview to ensure a common meaning was understood between interviewer and participant thereby rectifying any errors in understanding as they occurred.

B.10. Example of a coded interview

Verbatim transcript: Leah, 51, 21 years post-stroke, right-side affected, mild aphasia	Code
INTERVIEWER: First of all, could you tell me a little bit about how your stroke has affected you?	
14_F_51_RS: how long you got?	
INTERVIEWER: [laughs]	
14_F_51_RS: um, lost half of my sight with hem--ianopia...	Body changes Awareness of body Vision
INTERVIEWER: hemianopia yep	
14_F_51_RS: um, loss of feeling on my right side...	Body changes Awareness of body Loss of feeling
INTERVIEWER: mm	
14_F_51_RS: um aphasia...	Context
INTERVIEWER: yeah	
14_F_51_RS: um that's it I think	
INTERVIEWER: ok	
14_F_51_RS: [laughs]	
INTERVIEWER: so just thinking a little bit then about your left side, has there been any changes to your left side at all?	Less-affected side Compensating
14_F_51_RS: um, the left I have--I get tennis elbow...	
INTERVIEWER: mm	
14_F_51_RS: I've had--couple of times I've had a nerve in my back...	
INTERVIEWER: mm	
14_F_51_RS: whatever, um and my left hand takes all the work, so I get aches and pains...	
INTERVIEWER: mm, talk to me a little bit about the aches and pains in the--in the left side	
14_F_51_RS: elbow is probably the worst worst one...	
INTERVIEWER: mm	
14_F_51_RS: um just for pulling, carrying things and trying to support that with the right, but being lopsided	Body changes Lopsided
INTERVIEWER: yeah	
14_F_51_RS: does that make sense?	Can't describe it
INTERVIEWER: yeah yeah absolutely yeah, so it feels lopsided	
14_F_51_RS: yeah	
INTERVIEWER: yeah	
14_F_51_RS: yeah	
INTERVIEWER: so where in the body feels lopsided?	
14_F_51_RS: um, torso and shoulders...	
INTERVIEWER: yeah and you're pointing to the left side there, is it different on the left to the right?	
14_F_51_RS: um, I think--because my walking--I'm all on the flat, but not going up hills and uneven...	Body changes Feel unstable
INTERVIEWER: mm	

14_F_51_RS: um I tend to lurch [laughs]	Changes during movement Physical impact
INTERVIEWER: yeah yeah	
14_F_51_RS: rather than walk	
INTERVIEWER: yep	
14_F_51_RS: because I can't feel my right side...	Body changes Awareness of body
INTERVIEWER: mm	
14_F_51_RS: I compensate on the left...	Less-affected side Compensating
INTERVIEWER: ok, so that's interesting, so when you lurch can you describe that pattern of walking to me?	
14_F_51_RS: I--I think I--I don't put so much pressure on my right side...	Making sense of it
INTERVIEWER: mm	
14_F_51_RS: and I put pressure with my stick to steady myself I think...	
INTERVIEWER: ok and you hold your stick with which side?	Using aids
14_F_51_RS: um I--left, 'cause I can't hold it with my right [laughs]	
INTERVIEWER: yeah, so you've got your stick in your left side...	
14_F_51_RS: yeah	
INTERVIEWER: and you feel like you've got more pressure on your left foot...	
14_F_51_RS: yeah yeah	
INTERVIEWER: is that right?	
14_F_51_RS: yeah	
INTERVIEWER: yeah and what affect does that have on your left foot?	
14_F_51_RS: um, foot no, not necessarily with my foot	
INTERVIEWER: no	
14_F_51_RS: no	
INTERVIEWER: any other changes in the left leg from that?	
14_F_51_RS: knees! [laughs]	Body changes
INTERVIEWER: [laughs] yeah, tell me about your knee	
14_F_51_RS: um, it--it aches I don't know whether that's old age...	Making sense of it It aches
INTERVIEWER: [laughs]	
14_F_51_RS: I don't know--I don't know it's--it's definitely over the years ago it's got--got worse	
INTERVIEWER: and that's on the left knee	
14_F_51_RS: yeah	
INTERVIEWER: yeah	
14_F_51_RS: yeah and elbow and shoulder	
INTERVIEWER: so, left knee elbow and shoulder, there's some extra aching...	Less-affected side It aches Compensating
14_F_51_RS: yeah	
INTERVIEWER: in those areas and you think that's because that sides working a bit harder	
14_F_51_RS: I think so, because I can't feel the right very well, I'm never quite sure if it's one side or the other...	Body changes Awareness of body Uncertainty Strange sensations It hurts
INTERVIEWER: yeah, tell me a bit about that	
14_F_51_RS: or whether it's both...	
INTERVIEWER: yeah	

14_F_51_RS: um, if I have a pain on my right side, I have to feel it with my right-- no my left hand...	
INTERVIEWER: mm	
14_F_51_RS: to find where the pain is	
INTERVIEWER: yeah, ok and how does that help?	
14_F_51_RS: um, just by squeezing it to find where it hurts...	Coping
INTERVIEWER: yeah	
14_F_51_RS: that sounds weird	It's weird
INTERVIEWER: no no no	
14_F_51_RS: does it? [laughs]	
INTERVIEWER: no it doesn't sound weird, so you have a pain in the right side...	
14_F_51_RS: it's--yeah	
INTERVIEWER: er and to identify where the pain is in that arm...	
14_F_51_RS: yeah	
INTERVIEWER: you touch it with the left hand to...	
14_F_51_RS: yeah squeeze it to find where it hurts	Body awareness Strange sensations It hurts
INTERVIEWER: and how do you know when you've found it?	
14_F_51_RS: because then I--it--it hurts...	Strange sensations It hurts
INTERVIEWER: ok	
14_F_51_RS: so I do that on--on--where on my-- [sound of her patting arm]	Body awareness Coping
INTERVIEWER: so it hurts more when you touch it with the left hand when you find it?	
14_F_51_RS: yeah yeah	
INTERVIEWER: right ok	
14_F_51_RS: [laughs]	It's weird
INTERVIEWER: no no that's ok that's ok. So then, before you touch it with the left hand, how does the pain feel in the right side?	
14_F_51_RS: it--it--I know there's a pain...	Body awareness Strange sensations It hurts
INTERVIEWER: mm	
14_F_51_RS: but I don't know where it is...	Making sense of it Uncertainty
INTERVIEWER: mm	
14_F_51_RS: um, I will know whether it's the leg or the arm...	
INTERVIEWER: mm	
14_F_51_RS: which it didn't used to be, used to didn't know where it was, whereas...	
INTERVIEWER: ok yeah	
14_F_51_RS: um, so if I've got a pain in my left side, I'm not sure wi-- if I've got it on the right and if I have I don't know whether it's the same, worse or left [laughs]	
INTERVIEWER: yeah, ok yeah absolutely. So sometimes when you have pain in the left side, you can be unsure if it's only in the left side and there can be a sensation of pain in the right as well...	
14_F_51_RS: yeah	
INTERVIEWER: yeah, ok, so sometimes that pain can feel like it's on both sides of your body...	
14_F_51_RS: yeah	

INTERVIEWER: how often are you getting pain?	Making sense of it
14_F_51_RS: um, it's certainly got worse in the last couple of years I think, again I don't know whether that's age...	Changes over time
INTERVIEWER: mm [sound of paper rustling]	
14_F_51_RS: um, my posture is possibly not as good as it should be...	Body changes
INTERVIEWER: mm	
14_F_51_RS: um	
INTERVIEWER: is there any part of your body you're getting more pain	Strange sensations
14_F_51_RS: um, shoulders...	It hurts
INTERVIEWER: mm	
14_F_51_RS: um, wrists, this wrist, not so much that one...	
INTERVIEWER: your ri--so more in your right wrist...	
14_F_51_RS: yeah	
INTERVIEWER: yeah	
14_F_51_RS: um, that's like tennis elbow, that and then again	
INTERVIEWER: mm, so how often are you getting pain in your right wrist do you think?	Body changes
14_F_51_RS: my right wrist	It aches
INTERVIEWER: yeah	Changes over time
14_F_51_RS: [exhale] certainly most weeks...	Weather
INTERVIEWER: mm	Cold
14_F_51_RS: at some stage...	
INTERVIEWER: mm	
14_F_51_RS: um and weather affects...	
INTERVIEWER: weather	
14_F_51_RS: yeah, if it's cold...	
INTERVIEWER: mm	
14_F_51_RS: and damp I ache, probably all over [laughs]	
INTERVIEWER: yeah ok, so cold weather has a bit affect	
14_F_51_RS: yeah	
INTERVIEWER: ok, is there anything that helps the pain?	What helps
14_F_51_RS: nice warm bath...	Coping
INTERVIEWER: mm	Talking to health professionals
14_F_51_RS: paracetamol...	
INTERVIEWER: mm	
14_F_51_RS: um, the doctor gave me some ven--um some gel...	
INTERVIEWER: mm, you sort of rub it on	
14_F_51_RS: yeah	
INTERVIEWER: yeah and do you use that in all the places that you get pain?	
14_F_51_RS: um, shoulders mostly, um and wrist...	
INTERVIEWER: Mm	
14_F_51_RS: but not often, usually I just you know, ignore it [laughs]	Coping - distraction
INTERVIEWER: yeah, how do you cope with--how do you manage to ignore it?	Got used to it
14_F_51_RS: if I did something for every pain ache I did, I'd be doing it [laughs]	Identity
INTERVIEWER: [laughs]	

14_F_51_RS: it's just--it's not--an ache is different to a pain	Body changes It aches
INTERVIEWER: yeah yeah, ok	
14_F_51_RS: a fine line	
INTERVIEWER: a fine line and if it's pain is that something you would then treat or manage?	
14_F_51_RS: er yeah, I'd either put some gel on or I'd take paracetamol, or...	Coping - alleviate
INTERVIEWER: yeah	
14_F_51_RS: um, heat...	
INTERVIEWER: mm	
14_F_51_RS: wheat	
INTERVIEWER: yep, one of those things you put in the microwave?	
14_F_51_RS: yeah	
INTERVIEWER: yeah, I know what you mean. So that goes around your shoulders?	
14_F_51_RS: yeah	
INTERVIEWER: and that's helpful	
14_F_51_RS: yeah	
INTERVIEWER: ok, so sounds like you've spoken to the doctor about the pain, is that right?	
14_F_51_RS: um, not for a couple of years...	Health professionals
INTERVIEWER: yeah yeah yeah, how does it go when you talk to the doctor about those things?	
14_F_51_RS: um, well just fine "here's some cream"	Emotional effects
INTERVIEWER: [laughs] do you feel that you've had enough support from the doctor to manage your pain?	
14_F_51_RS: um [exhale] I don't like going to the doctor unless I have to...	
INTERVIEWER: yeah	
14_F_51_RS: if it was--if it's really painful then I will go to the doctor...	
INTERVIEWER: mm and have you had um enough treatments or remedies to manage it from your doctor?	
14_F_51_RS: yeah	
INTERVIEWER: yeah	
14_F_51_RS: [laughs]	
INTERVIEWER: [laughs] ok, um talk to me about why you try not to go to the doctor	
14_F_51_RS: um, [exhale] zillions of reasons I suppose. One, because of the aphasia I can't talk to the doctor on the phone, so somebody has to ring the doctor...	Health professionals Coping Identity
INTERVIEWER: mm	
14_F_51_RS: [exhale] I don't think it's serious enough to worry them...	
INTERVIEWER: yeah	
14_F_51_RS: um, yeah things like that I suppose	
INTERVIEWER: ok and how do you feel about managing those kind of things on your own?	
14_F_51_RS: [exhale] I think because of having a stroke in my head I'm lucky to be here...	
INTERVIEWER: mm	
14_F_51_RS: so a bit of a pain isn't-- [laughs]	Identity
INTERVIEWER: yeah yeah	

14_F_51_RS: so what	Coping - others worse off
INTERVIEWER: yeah yeah, so it feels like because you've survived the stroke, is that right, that the pain isn't so--isn't such a big deal	
14_F_51_RS: yeah yeah	Physical impact
INTERVIEWER: yeah, ok, um does the pain stop you doing anything	
14_F_51_RS: yes	
INTERVIEWER: what sort of things?	
14_F_51_RS: um, craft things...	
INTERVIEWER: mm	
14_F_51_RS: um, I can't do things I used to do...	
14_F_51_RS: 'cause it hurts...	Body changes It hurts
INTERVIEWER: yeah	
14_F_51_RS: so I've had to do different crafts...	Changes during movement
INTERVIEWER: yeah, so what is it about the craft activity that's painful?	
14_F_51_RS: um joints...	
INTERVIEWER: in your joints	
14_F_51_RS: yes yeah	
INTERVIEWER: and kind of moving your fingers there, is that suggesting that it's sort of um doing little things that's difficult?	It's weird
14_F_51_RS: um, paper cutting and um weird things really	
INTERVIEWER: weird things [laughs] um, so that's had a bit of an affect on your crafting, does the pain effect anything else in your day-to-day life?	Body changes It hurts
14_F_51_RS: um, obviously I can't carry things...	
INTERVIEWER: mm	
14_F_51_RS: um, if they're--they're too heavy, cooking, putting things in the oven...	
INTERVIEWER: mm	
14_F_51_RS: um big things like car--I--I can't do...	
INTERVIEWER: mm and that's to do with the pain?	
14_F_51_RS: and vacuuming	
INTERVIEWER: and vacuuming	
14_F_51_RS: yeah, that--that hurts my shoulders quite	
INTERVIEWER: ok, yeah so there's quite a few things that are affected by the pain that you experience	Emotional effects Coping - acceptance
14_F_51_RS: yeah	
INTERVIEWER: ok, um and how does that make you feel, not being able to do those things?	Identity
14_F_51_RS: it's a bit of a--well it's just part of it...	
INTERVIEWER: mm	
14_F_51_RS: I don't like vacuuming so...	
INTERVIEWER: [laughs]	
14_F_51_RS: [laughs] so I don't, er yeah sometimes it--it's "oh yeah" somebody else has to do it, but it's not the end of the world is it...	
INTERVIEWER: yeah yeah	
14_F_51_RS: [laughs]	
INTERVIEWER: so you say it's just part of it, what do you mean by it?	

14_F_51_RS: oh the--the having a stroke...	
INTERVIEWER: yeah	
14_F_51_RS: it's er you know, it could be a lot worse...	Identity Others worse off
INTERVIEWER: yeah, so there's like a level of acceptance	
14_F_51_RS: yeah, oh gosh yeah	
INTERVIEWER: yeah, ok and do you find the pain affects your social life in any way?	Being part of the world
14_F_51_RS: um I don't think so, no [laughs]	
INTERVIEWER: ok, so it doesn't affect who you go to see or where you go?	
14_F_51_RS: no	
INTERVIEWER: no, ok that's fine. So kind of going back to the right side of your body and that lack of feeling that you mentioned...	Body changes Awareness of body
14_F_51_RS: mm	
INTERVIEWER: could you talk to me a little bit more about that sensation?	
14_F_51_RS: I can obviously move all my limbs, but I can't really feel them, it's like um...	
INTERVIEWER: mm	
14_F_51_RS: having um, novacaine the dentist's thing...	
INTERVIEWER: yeah yeah	
14_F_51_RS: that side feels, it feels bigger...	Body changes Body distortions
INTERVIEWER: mm	
14_F_51_RS: um it's like, I'd say monster-ish [laughs]...	Body in mind's eye
INTERVIEWER: mm	
14_F_51_RS: um, I'd say I feel something but I don't know what it is	Body changes Awareness of body It's not part of me
INTERVIEWER: yeah	
14_F_51_RS: if I move it, if somebody tugs my arm I'm aware of it...	
INTERVIEWER: mm	Objectified body
14_F_51_RS: but it's never re--it doesn't feel like me anymore [laughs]...	
INTERVIEWER: ok, no absolutely yeah, so it doesn't feel like it's part of you...	
14_F_51_RS: yeah	
INTERVIEWER: if you touch that side can you feel it?	Body changes Dulled sensation
14_F_51_RS: not really no	
INTERVIEWER: no ok, um and you describe it feeling monster-ish	
14_F_51_RS: [laughs]	
INTERVIEWER: could you describe a bit more about what that--what that means to you?	
14_F_51_RS: it--it looks, if I--it's like [pause] it's like--like a--a--um marshmallowey, come sort of like bloated...	Body in mind's eye Body distortions
INTERVIEWER: mm	
14_F_51_RS: not human	Can't describe it Objectified body Uncertainty
INTERVIEWER: mm	
14_F_51_RS: [laughs]	
INTERVIEWER: and is--is which part of your left side feels like that?	
14_F_51_RS: I'm sort of--it's--	
INTERVIEWER: right side, sorry	

14_F_51_RS: hands, big and feet I supposed those are the tw-yeah	Body distortions
INTERVIEWER: so your hands and feet feel much bigger and marshmallowey sort of, bloated...	
14_F_51_RS: : yeah	
INTERVIEWER: yeah and how about the right arm and the right leg, where are they?	
14_F_51_RS: don't understand	
INTERVIEWER: if the right hand and the right foot feel very bloated	Body distortions
14_F_51_RS: they're--they're the same, but not so much	
INTERVIEWER: not so much, ok	
14_F_51_RS: [laughs] I just sound so	It's weird Can't describe it
INTERVIEWER: no absolutely [laughs] so if you were to kind of close your eye and just imagine what the whole of the right side of your body looks like, not visually but through what it feels like...	
14_F_51_RS: yeah	
INTERVIEWER: um you've already painted quite a lot of a picture for me, is there anything else in that picture that you haven't described to me?	
14_F_51_RS: um, my--my feet and my hands get very very cold...	Body changes Cold
INTERVIEWER: mm	
14_F_51_RS: um and my lower leg gets aches...	It aches
INTERVIEWER: mm	
14_F_51_RS: when it's--it's--it's cold, it's...	
INTERVIEWER: mm	
14_F_51_RS: um, yeah	
INTERVIEWER: ok, so your hands and feet feel very cold on your right side only...	
14_F_51_RS: yeah	
INTERVIEWER: does that change at all through the course of the day or anything like that?	
14_F_51_RS: um, no just does it [laughs] not all the time, but...	Changes over time
INTERVIEWER: yeah, be a chunk of the time	
14_F_51_RS: I think because I had my stroke such a long time ago I just don't pay any attention of it...	Got used to it
INTERVIEWER: mm, yeah, what does it feel like when you do notice it or pay attention to it?	
14_F_51_RS: um, I tend to rub it...	What helps Coping - alleviate
INTERVIEWER: mm	
14_F_51_RS: um and make sure it's all wrapped up with arm things all... [points to knitted things on the table]	
INTERVIEWER: so it's what--those kind of--is that a mitteny type thing or?	
14_F_51_RS: fingerless	
INTERVIEWER: fingerless glove sort of	
14_F_51_RS: things yeah	
INTERVIEWER: yeah, yeah so you put on gloves to keep it warm, is there anything you do to the foot to kind of try and warm it up?	
14_F_51_RS: um, [laughs] [lifts foot to show slippers]	
INTERVIEWER: yeah big furry slippers [laughs] yeah	
14_F_51_RS: um yeah	

INTERVIEWER: yeah ok, um so that's a few things that help it make it better um, does it--how comfortable is that cold sensation?	
14_F_51_RS: um it's--it's--it--it can ache...	It aches Discomfort
INTERVIEWER: yeah, because of the cold feeling?	
14_F_51_RS: yeah	
INTERVIEWER: yeah	
14_F_51_RS: um, I have problem just sleeping with that side because I can't--I try to sort of put my arm or wherever so it doesn't get crunched at night...	Physical impact Muscle tension Discomfort
INTERVIEWER: mm	
14_F_51_RS: and--but 'cause I don't--if I--if it moves or it goes into the claw...	
INTERVIEWER: yeah	
14_F_51_RS: um, I can wake up and feel very--'cause I put it in a wrong place...	Physical impact Discomfort
INTERVIEWER: mm	
14_F_51_RS: it's uncomfortable	
INTERVIEWER: yeah, so it can be quite uncomfortable when sleeping	
14_F_51_RS: yeah	
INTERVIEWER: and you mentioned there your--your hand kind of going into a claw	
14_F_51_RS: yeah it does the old stroke thingy	
INTERVIEWER: the old stroke thingy	
14_F_51_RS: when I'm tired it comes up round like that if I don't think about it [does action]	Muscle tension Mind body interaction Changes over time
INTERVIEWER: so the arm kind of clamps up and the hand curls up when you're tired...	
14_F_51_RS: yeah, yeah	
INTERVIEWER: is there anything	
14_F_51_RS: or I'm nervous	
INTERVIEWER: ok, yeah	
14_F_51_RS: yeah	
INTERVIEWER: yeah, so tense and nervous then that kind of...	
14_F_51_RS: goes straight up [pulls arm up]	
INTERVIEWER: what does that feel like when that tense up?	
14_F_51_RS: um, I don't notice it...	
INTERVIEWER: mm	
14_F_51_RS: my husband will say he'll come out and push it down...	Being part of the world
INTERVIEWER: yeah ok, so you don't feel any change in that arm at all when it does it	
14_F_51_RS: no	
INTERVIEWER: ok, um when it does it when you're sleeping how does that feel?	
14_F_51_RS: it will wake me up sometimes, but not all the ti--depends if I in a deep sleep...	Physical impact
INTERVIEWER: mm	
14_F_51_RS: if I've moved and it's--it's gone underneath or--and I wake up, but that's all tight and really achey...	It aches
INTERVIEWER: ok	
14_F_51_RS: so just put some heat on it or something to	What helps

INTERVIEWER: so when it gets really tight, then it aches and you mentioned that putting heat on it to...	Coping - alleviate
14_F_51_RS: yeah	
INTERVIEWER: help it and how does the heat help?	
14_F_51_RS: um, just relaxes it I think	
INTERVIEWER: mm, how long does that take?	
14_F_51_RS: er, oh--if it's more--if I have a bath it will just sort of...	
INTERVIEWER: mm	
14_F_51_RS: ease it...	
INTERVIEWER: ok	
14_F_51_RS: or sort of do I squeeze it and [laughs] [does action]	
INTERVIEWER: yeah yeah, so you're kind of doing a sort of massage on it? Would that be right?	
14_F_51_RS: well I suppose so yeah...	
INTERVIEWER: yeah	
14_F_51_RS: sort of, yeah, just sort of...	
INTERVIEWER: a basic massage maybe	
14_F_51_RS: just trying to--also just checking that it's not in pain pain	
INTERVIEWER: mm ok, so you're kind of doing that thing you mentioned before where you're testing where the...	
14_F_51_RS: yeah yeah	
INTERVIEWER: pain is in the arm and how bad that pain is	
14_F_51_RS: yeah	
INTERVIEWER: ok, um and through touching the arm like that and squeezing it, does that have any other benefits for the arm at all?	
14_F_51_RS: don't think so	
INTERVIEWER: that's ok [laughs] um ok, we mentioned there about the hand clamping, um that affecting your sleep sometimes, are there any other body sensations that affect you when you're sleeping?	
14_F_51_RS: I do get the old um, I do get cramp now and again, but that's-- I've had that forever...	Other health problems
INTERVIEWER: mm	Strange sensations Crawling
14_F_51_RS: I get the old spiderey feeling now and again...	
INTERVIEWER: yep, talk to me about the spiderey feeling	
14_F_51_RS: er yeah, usually arms and feet sometimes...	
INTERVIEWER: mm and what does it feel like with the [laughs]--	
14_F_51_RS: [laughs] spiderseys	
INTERVIEWER: like spiderseys and you're kind of mimicking down, they're crawling down your leg	
14_F_51_RS: just--just--just yeah	
INTERVIEWER: is that what it feels like, that there's spiders crawling on your skin or?	
14_F_51_RS: yeah yeah yeah just like	
INTERVIEWER: and you get that in your foot is that right?	
14_F_51_RS: foot and arm and hand	
INTERVIEWER: yeah and that's normally when you're sleeping is that--	
14_F_51_RS: yeah	

INTERVIEWER: ok are you aware of anything that kind of triggers that sensation at all?	Changes over time
14_F_51_RS: no, anything could be [laughs]	
INTERVIEWER: [laughs] so it's kind of out of the blue a little bit	
14_F_51_RS: yeah	What helps Coping -
INTERVIEWER: and is there anything that helps it?	
14_F_51_RS: well I do the usual squeezing things and but yeah--but yeah	
INTERVIEWER: does that help it go away or?	
14_F_51_RS: I don't know I probably go back to sleep	
INTERVIEWER: ok ok, um so kind of it wakes you up but it's not something that keeps you awake, is that	
14_F_51_RS: um, not unless it carries on	
INTERVIEWER: mm	
14_F_51_RS: for longer than it wakes me up, then I can't go back to sleep	
INTERVIEWER: ok, um so something about waking up or touching the area helps that sensation to go away, is that correct?	
14_F_51_RS: um, I suppose so [laughs]	Identity Ignore it
INTERVIEWER: [laughs]	
14_F_51_RS: don't think about these things	Ignore it
INTERVIEWER: yeah yeah [laughs] you probably just deal with it at the time and don't	
14_F_51_RS: yeah	
INTERVIEWER: yeah, ok and has that sensation changed at all during your recovery?	Uncertainty
14_F_51_RS: um, [pause] I really wouldn't like to say...	
INTERVIEWER: mm	Health professionals
14_F_51_RS: I don't know	
INTERVIEWER: ok	
14_F_51_RS: [laughs]	
INTERVIEWER: is it anything you've ever mentioned to a doctor or a health professional at all, that sensation?	
14_F_51_RS: no [laughs]	
INTERVIEWER: [laughs]	
14_F_51_RS: what they going to do?	
INTERVIEWER: so the same sort of feeling that	
14_F_51_RS: yeah	
INTERVIEWER: it's a consequence of stroke but	Other health problems
14_F_51_RS: yeah	
INTERVIEWER: yeah ok and you mentioned also cramp in the right calf is that right	
14_F_51_RS: I've had cramp since I was little on and off...	
INTERVIEWER: mm	
14_F_51_RS: so, it--it--I wouldn't say [exhale]	
INTERVIEWER: so that might not be as a result of stroke or	
14_F_51_RS: no	
INTERVIEWER: ok that's just something you experience	
14_F_51_RS: yeah	

INTERVIEWER: yeah ok that's fine, um, you did mention some feelings of aches in the lower leg, can you talk to me a little bit about those?	Strange sensations It aches
14_F_51_RS: it's usually on the right side of the foot...	
INTERVIEWER: mm	
14_F_51_RS: not on the [points to foot]	
INTERVIEWER: not on the left side, mm	
14_F_51_RS: yeah, it's--it's--which is--I don't understand why that is, but it tends to be there and up to the ankle	
INTERVIEWER: so kind of all along the outer top area...	
14_F_51_RS: yeah	
INTERVIEWER: of your right foot up to the...	
14_F_51_RS: yeah	
INTERVIEWER: outer area of the right ankle	
14_F_51_RS: yeah, sometimes further up I would think	
INTERVIEWER: yeah yeah, so sort of half way up	
14_F_51_RS: I've never worked out what that was all about, that it's only half of it that aches most	
INTERVIEWER: mm, when do you notice those kind of aching feelings?	Changes over time Uncertainty
14_F_51_RS: whenever	
INTERVIEWER: whenever, just through the course of the day...	
14_F_51_RS: yeah, um, yeah yeah I think--trying to think is it when I wake up, or is it--I don't know	
INTERVIEWER: mm	
14_F_51_RS: don't know	
INTERVIEWER: ok, but at some point in the day you do notice those kind of feelings	Emotional effects Can't make sense of it Uncertainty Identity
14_F_51_RS: not all the time, but yeah	
INTERVIEWER: mm, ok and is there anything that helps with that sensation?	
14_F_51_RS: no it's, that irritates me, I don't know why, out of all the--one of the things that...	
INTERVIEWER: mm	
14_F_51_RS: I don't--don't know--I just--that's irritating, I can't do anything about that	
INTERVIEWER: ok, so there is anything at all that you've found...	
14_F_51_RS: doesn't seem to	
INTERVIEWER: that helps, ok, um so you mentioned feeling quite irritated by that, is there any thoughts that kind of go through your mind when that sensation comes along?	
14_F_51_RS: um it's just bit fed up I suppose, like "oh, here we go"...	
INTERVIEWER: mm and does it tend to last for a set period of time or?	Coping - distraction
14_F_51_RS: um, I just go and do something else to not think about it and you know	
INTERVIEWER: mm and kind of distract yourself from it then	
14_F_51_RS: yeah	
INTERVIEWER: yeah	
14_F_51_RS: yeah	
INTERVIEWER: and does it affect anything that you do in your day-to-day life?	
14_F_51_RS: no	

INTERVIEWER: ok, that's fine and again, is that anything you've spoken to doctors about that kind of--	Talking to health professionals
14_F_51_RS: no	
INTERVIEWER: no [laughs] I'm sensing a theme here	
14_F_51_RS: [laughs]	Coping
INTERVIEWER: ok, so that's something you just cope with on your own and	
14_F_51_RS: mm	Awareness of body Changes over time
INTERVIEWER: ok, that's fine, um so kind of thinking about that loss of feeling on the right side of the body...	
14_F_51_RS: mm	
INTERVIEWER: is that anytimes that that feels better or worse at all or?	
14_F_51_RS: no	
INTERVIEWER: no, it's a fairly consistent feeling	
14_F_51_RS: mm	
INTERVIEWER: how does that affect what you do in your day-to-day life?	Physical impact Compensating
14_F_51_RS: um, I'm lucky that I'm left handed...	
INTERVIEWER: mm	Coping
14_F_51_RS: so, that's um, I--if I'm doing something like vacuuming or cleaning or cooking...	
INTERVIEWER: mm	
14_F_51_RS: I check it when I'm doing things, that I'm not doing--somethings happening to it...	
INTERVIEWER: mm	
14_F_51_RS: um because with the half of the vision as well...	Safety
INTERVIEWER: mm	
14_F_51_RS: I try to be very careful	Conscious of body
INTERVIEWER: mm, so as you're doing your day-to-day task you check your right arm to check it's ok	
14_F_51_RS: where--where it's placed	
INTERVIEWER: where it's placed	
14_F_51_RS: um, support it or whatever	
INTERVIEWER: mm, how do you feel about your right arm?	
14_F_51_RS: um, I suppose that--that side just doesn't--it's--it's not me...	Body awareness It's not part of me
INTERVIEWER: mm	Emotional effects
14_F_51_RS: it's--it's like--like a um, [exhale] a parasite [laughs]	
INTERVIEWER: mm, so it feels like a parasite...	Identity
14_F_51_RS: yeah	
INTERVIEWER: tell me a bit more about that feeling	
14_F_51_RS: um, well it's like i--i--it's--it is part of me but it's not what it was...	
INTERVIEWER: mm, what is it now?	
14_F_51_RS: [pause] it's who I am now	
INTERVIEWER: mm	
14_F_51_RS: I don't hate it, it's just that that's what it is...	Coping - acceptance
INTERVIEWER: mm	
14_F_51_RS: I don't have to like it but [laughs]	

INTERVIEWER: yeah yeah, so it's somewhere between it's--it's not hate, but it's not like, it's somewhere in the middle	
14_F_51_RS: yes, it's what it is, that's	
INTERVIEWER: mm	
14_F_51_RS: yeah	
INTERVIEWER: it is what it is	
14_F_51_RS: yeah	
INTERVIEWER: yeah, do any thoughts run through your mind about your right arm at all?	
14_F_51_RS: um, not really no, no, it--I survived, I'm a hell of a lot better than a lot of other people, so I ca--can't moan, I cannot	Coping - Others worse off
INTERVIEWER: mm, is there anything that helped you that level of acceptance about your stroke and how it's affected you?	Identity Making sense of it
14_F_51_RS: I don't think I've ever really had a problem with that...	
INTERVIEWER: mm	
14_F_51_RS: I--I um, I don't know why	
INTERVIEWER: mm yeah [laugh]	
14_F_51_RS: things happen	
INTERVIEWER: yeah	
14_F_51_RS: you deal with it, you don't know do you	
INTERVIEWER: yeah yeah yeah, so	
14_F_51_RS: [laughs]	
INTERVIEWER: so just a natural level of acceptance about it	
14_F_51_RS: yeah, you don't--you just don't know you could get run over by a bus, you could--you just don't know...	Others worse off
INTERVIEWER: mm	
14_F_51_RS: you can't--no	
INTERVIEWER: ok, um, does your right arm affect your social life or going out or about in any way at all?	Being part of the world
14_F_51_RS: um, I don't think physically that I ha--have problems because of the aphasia more than physical problems	
INTERVIEWER: mm, so way the loss of feeling in the right arm isn't affecting your social life at all	
14_F_51_RS: no	
INTERVIEWER: no ok	
14_F_51_RS: I can still drink gin with that hand [laughs]	Identity
INTERVIEWER: [laughs] the most important remedy	
14_F_51_RS: [laughs] well yeah	
INTERVIEWER: fantastic, um ok, so I--I think I know the answer to the next question but [laughs]	
14_F_51_RS: [laughs]	
INTERVIEWER: have you spoken to a health professional at all about um the feelings that the arm isn't part of you, or that it's a parasite or anything like that?	Talking to health professionals
14_F_51_RS: no, no no no [laughs]	
INTERVIEWER: um and do you think--is there anything--do you feel you've needed any support about that at all?	
14_F_51_RS: I think it's been twenty years and it would have been nice to somebody to come back and see if I need some more physio, whether I need some more help...	

INTERVIEWER: mm	Uncertainty
14_F_51_RS: you're sort of floundering around--for I know, I could have made it worse...	
INTERVIEWER: mm	
14_F_51_RS: I do what I think it--I should be doing...	
INTERVIEWER: mm	
14_F_51_RS: I don't remember my physio or what I did now...	
INTERVIEWER: mm, whens the last time you had any physio	
14_F_51_RS: [exhales] probably about eighteen years	
INTERVIEWER: mm and do you feel that um, any of your problems would have benefited from further physio since then?	
14_F_51_RS: yes, yeah	Body changes
INTERVIEWER: what sort of things?	
14_F_51_RS: I know my posture is not [pause] as good as it should be	Using aids Coping - alleviate
INTERVIEWER: mm	
14_F_51_RS: I have problems finding a walking stick...	Emotional affects
INTERVIEWER: mm	
14_F_51_RS: because I'm short, the adult ones are too big...	
INTERVIEWER: ok, yeah yeah	
14_F_51_RS: [laughs] um yeah	
INTERVIEWER: yeah so, what do you do about that?	
14_F_51_RS: um, I wear higher shoes [laughs]	
INTERVIEWER: ok right	
14_F_51_RS: yeah I've got some that are shorter but they're not, I need a white one, but yeah	
INTERVIEWER: ok, so you can't find quite the right stick to use	
14_F_51_RS: yeah	
INTERVIEWER: ok and how does that make you feel?	
14_F_51_RS: irritated	
INTERVIEWER: yeah, yeah and who supplies the stick that you use?	
14_F_51_RS: um, the RNIB gave em one initially, but it was one of the rolling ones but I need one with more su--support so I buy my own	
INTERVIEWER: ok, where do you buy them from?	
14_F_51_RS: that's been the problem...	
INTERVIEWER: mm	
14_F_51_RS: finding one, yes, so just one of the ones on the web	
INTERVIEWER: ok and how comfortable is it using a--a walking stick for you?	Body changes Physical impact Discomfort
14_F_51_RS: um, the problem I ha--have--'cause I do have problems with my shoulder and my elbow, I've had to get ones that got the squeegey things at the bottom...	
INTERVIEWER: yep	
14_F_51_RS: can't think what they're called	
INTERVIEWER: I don't know either [laughs] but that kind of cushions it a bit does it?	
14_F_51_RS: yeah	
INTERVIEWER: um, so that makes it a bit more comfortable with the pain in the shoulder...	

14_F_51_RS: mm, yeah	
INTERVIEWER: shoulder and the elbow on the left side	
14_F_51_RS: yeah	
INTERVIEWER: and is there any other difficulties with using a stick that you've found?	
14_F_51_RS: um, [pause]no I don't think so	
INTERVIEWER: ok and you use a stick all the time when you go outside, is that	
14_F_51_RS: I--I do because I'm not particularly stable, I can walk, I'm fine, but if it's uneven um and it keeps people not knocking me over 'cause I don't feel that side...	Safety Body awareness Feel unstable Being part of the world
INTERVIEWER: mm	
14_F_51_RS: I often bump into things and people	
INTERVIEWER: mm, talk to me a little bit about those experiences	
14_F_51_RS: um, I think it affects my husband more than me 'cause he wants to kill people...	
INTERVIEWER: oh really yeah	
14_F_51_RS: [laughs] he gets quite cross...	
INTERVIEWER: yeah	
14_F_51_RS: um, because I can't feel it it doesn't bother me, but I do bruise, I--I go into lamp posts and all sorts...	
INTERVIEWER: mm	
14_F_51_RS: it does affect me if it's a place I don't know...	Safety
INTERVIEWER: Mm	
14_F_51_RS: I get a bit um, [pause] er rabbit--like a squared rabbit--no	Emotional effects
INTERVIEWER: rabbit in the headlights or?	
14_F_51_RS: that's right, um, [pause] yeah	
INTERVIEWER: so if it's somewhere you don't know you feel like a rabbit in the headlights	
14_F_51_RS: I don't know, 'cause I can't see quite as well...	Body changes Vison
INTERVIEWER: mm	
14_F_51_RS: and um, it takes me s--some time to work out where I am where the even is right, whether it's--it	
INTERVIEWER: mm so there's a lot of effect there	
14_F_51_RS: mm	
INTERVIEWER: yeah, ok, um and you mentioned there not feeling stable...	
14_F_51_RS: mm	
INTERVIEWER: can you talk to me a little bit about that feeling?	
14_F_51_RS: 'cause I can't feel my foot or my right side, I don't know how hard the pressure...	Body awareness Dulled sensation Feeling unstable Safety
INTERVIEWER: mm	
14_F_51_RS: so if I--if it's--I might slip...	
INTERVIEWER: mm	
14_F_51_RS: or trip...	
INTERVIEWER: mm	
14_F_51_RS: um, yeah	
INTERVIEWER: so it's hard to sense the sole of your right foot...	
14_F_51_RS: yeah	

INTERVIEWER: which means you don't feel what the--the ground is like underneath that foot...	
14_F_51_RS: yeah	
INTERVIEWER: ok, is there any places that feel more safe to you	
14_F_51_RS: what places or?	
INTERVIEWER: er, could be--interpret it as you like	
14_F_51_RS: [laughs]	
INTERVIEWER: [laughs]	
14_F_51_RS: what was the question again?	
INTERVIEWER: is there any--any environments or places that feel safer?	Safety
14_F_51_RS: um, places that I know well	Discomfort
INTERVIEWER: mm	
14_F_51_RS: anything new is, mm...	
INTERVIEWER: Yeah	
14_F_51_RS: it's not stressful but it's not comfortable either...	
INTERVIEWER: Mm	
14_F_51_RS: certainly if I'm on my own	
INTERVIEWER: mm, ok, er and how comfortable do you feel going out on your own?	Safety
14_F_51_RS: again, places I know well fine, others no I don't--I'd rather go to--somebody with me the first time so I know where everything is and...	Being part of the world
INTERVIEWER: mm	Discomfort
14_F_51_RS: do a bit of a risk-assessment [laughs]	Physical impact
INTERVIEWER: yeah yeah absolutely, um so does that feeling affect where you go in any way?	
14_F_51_RS: um, because I can't drive I can only do places that are really by the bus...	
INTERVIEWER: Mm	
14_F_51_RS: because of the sight I find it's got to be in the day, not in the evening or night...	
INTERVIEWER: mm	
14_F_51_RS: um, yeah	
INTERVIEWER: ok, so there are some limitations on what makes you feel comfortable going out	
14_F_51_RS: mm	
INTERVIEWER: yeah, ok, um and you mentioned before about your stick and it not being quite the right one, um is--what's stopped you going to the doctor and talking about that stick?	Talking to professionals
14_F_51_RS: well what's the doctor going to do? [laughs]	Coping
INTERVIEWER: [laughs]	
14_F_51_RS: never--no, never even thought of it...	
INTERVIEWER: oh ok, yeah	
14_F_51_RS: never!	
INTERVIEWER: [laughs] ok, that's fine, so you've mentioned a few times about your vision...	
14_F_51_RS: mm	
INTERVIEWER: and the affect that's having on you, could you talk to me about what it feels like to have that change in your vision?	Body changes
14_F_51_RS: I think it--it--it has been hard...	Vision

INTERVIEWER: mm	Being part of the world Physical impact
14_F_51_RS: one because I can't drive and that really does limit you...	
INTERVIEWER: Mm	Got used to it
14_F_51_RS: um, [pause] yeah you do get used to it, but I do miss--like going to the cinema I can only see--I can't see the whole screen...	
INTERVIEWER: Mm	
14_F_51_RS: so if it's one of the really big ones then I just see...	
INTERVIEWER: yeah	
14_F_51_RS: yeah um yeah it doe--it does, yeah I don't like that	
INTERVIEWER: mm, how does that make you feel?	
14_F_51_RS: um, second class citizen	
INTERVIEWER: mm, tell me a little bit about that feeling	Identity Emotional effects
14_F_51_RS: um, it's um, I can't go where I want to go when I want...	
INTERVIEWER: mm	
14_F_51_RS: um, yeah	
INTERVIEWER: is there any um instances of that that you can describe to me?	
14_F_51_RS: I do--I think it--it--it's all the time I think...	
INTERVIEWER: mm	
14_F_51_RS: um, your--my independence has been curtailed...	
INTERVIEWER: mm	
14_F_51_RS: um, certain things people have to pick me up and that--I hate that, absolutely hate that...	
INTERVIEWER: mm, what is it about that that you hate?	
14_F_51_RS: um because that's what I used to--I would be the one that was doing that...	
INTERVIEWER: mm	Coping - acceptance
14_F_51_RS: so you just um, yeah you got to accept it and that's--life is slower...	
INTERVIEWER: mm, in what way?	
14_F_51_RS: you can't rush around, which is probably a good thing	
INTERVIEWER: mm, so what does it feel like having that change and not being the person who picks people up, but being picked up by people?	
14_F_51_RS: in what way?	
INTERVIEWER: what does it feel like emotionally?	
14_F_51_RS: um [pause] it--it--I think it's a gradual thing, I mean it irks now and again but it doesn't bother me...	
INTERVIEWER: mm	Emotional effects
14_F_51_RS: it's this old 'accept' [laughs]	
INTERVIEWER: yep yep, so you've kind of made your peace with that	Coping -acceptance
14_F_51_RS: ah a long long time ago yeah	
INTERVIEWER: mm, ok, um what other sort of daily activities does your eyesight affect?	Physical impact Got used to it
14_F_51_RS: um, I don't know as I say, it's such a long time now, I wouldn't like to say	
INTERVIEWER: can you describe to me what your world looks like when you're looking out?	
14_F_51_RS: it's half what it was before, lit--literally it's half...	
INTERVIEWER: mm	Body changes Vision

14_F_51_RS: um, it's I just miss fifty percent that everyone else does...	
INTERVIEWER: mm and the half that you can't see what does that look like?	
14_F_51_RS: it's not there	
INTERVIEWER: is it a er a colour or is it--	
14_F_51_RS: nope, nothing it's just bumpf	
INTERVIEWER: mm, so do you see--you keep putting your hand like a straight line in front of your eye...	
14_F_51_RS: yeah it is--it is--it's from there to there...	
INTERVIEWER: yeah	
14_F_51_RS: and I can't see anything, it's just normal--it--normal?--yeah--seems like, same as--shrunked	
INTERVIEWER: so the--the image that you see is shrunk	
14_F_51_RS: it's just not--not--this side is exactly the same as it was before...	
INTERVIEWER: so your left eye is completely the same	
14_F_51_RS: absolutely the same, there is just nothing, it's just...	
INTERVIEWER: mm yeah	
14_F_51_RS: can't explain it	
INTERVIEWER: yeah it's a difficult thing to explain, yeah, um and you kind of were pulling your hand down in a straight line, is that how it feels that it is a straight line?	
14_F_51_RS: that--it doesn't feel--doesn't feel anything...	
INTERVIEWER: mm	
14_F_51_RS: it's just not there...	
INTERVIEWER: yeah	
14_F_51_RS: my vision just stops there...	
INTERVIEWER: yeah	
14_F_51_RS: [laughs]	
INTERVIEWER: [laughs] it's a tricky thing to explain understandably...	
14_F_51_RS: yeah yeah	
INTERVIEWER: um yeah, it's just interesting for me to really try to understand it	
14_F_51_RS: ah [exhales] yeah 'cause I've lost fifty percent of both eyes...	
INTERVIEWER: mm	
14_F_51_RS: which is really weird trying to tell other people 'cause they don't understand it either so...	It's weird Can't describe it Being part of the world
INTERVIEWER: mm, so it's fifty percent on this side [gestures to right side] of both eyes	Can't describe it
14_F_51_RS: yeah	
INTERVIEWER: yeah, absolutely yeah	
14_F_51_RS: [laughs] you can explain me now	
INTERVIEWER: [laughs] that makes sense yeah, um and how does that make you feel in yourself, dealing with that everyday?	
14_F_51_RS: um, the fact that it--it stops me--I can't drive, um I wouldn't say it's--I not say it's funny, but it's just so weird it's just, bizarre...	It's weird Emotional effects
INTERVIEWER: mm	
14_F_51_RS: um, it doesn't hurt, I'm not in pain, it just um and it does--I--I've worried, I don't want to lose anymore sight, that--that...	Emotional effects

INTERVIEWER: mm	
14_F_51_RS: yeah	
INTERVIEWER: mm, absolutely, is there anything you do to cope with having lost that half of you sight	Coping
14_F_51_RS: um, use a kindle	
INTERVIEWER: mm, how does that help	
14_F_51_RS: bigger font and make it brighter...	
INTERVIEWER: yeah	
14_F_51_RS: er yeah, don't think there's much else I can do	
INTERVIEWER: ok, um and you mentioned sort of socially because you can't drive...	Being part of the world
14_F_51_RS: mm	
INTERVIEWER: that's an--an effect on where you go, has your vision had any other effects on your relationships with friends and family at all?	
14_F_51_RS: don't think so	
INTERVIEWER: how have your friends and family responded to you um having a stroke and dealing with the changes to your body?	
14_F_51_RS: er I think it's harder from--for them to me--they saw all the nasty stuff, I was drugged up to the eyeballs...	
INTERVIEWER: mm	Identity
14_F_51_RS: very protective--probably too protective, um yeah and I rebel now and again and just go out on my own [laughs]	
INTERVIEWER: [laughs]	
14_F_51_RS: "I'm going anyway" you know	Being part of the world
INTERVIEWER: yeah, how does it feel when they're being too protective?	
14_F_51_RS: [exhale] it worries that they--it affects them...	
INTERVIEWER: mm	
14_F_51_RS: um, certainly my husband you know, he shouldn't have to and he worries and he shouldn't...	
INTERVIEWER: mm	
14_F_51_RS: and it affects him...	Identity Emotional effects
INTERVIEWER: mm, why shouldn't he worry?	
14_F_51_RS: 'cause I'm an adult, I--I--ok I'm a bit slow but I've--I can deal with as much as anybody else...	
INTERVIEWER: mm	
14_F_51_RS: I may need to do things a bit differently and it takes me a little bit longer...	
INTERVIEWER: mm	
14_F_51_RS: but you know	
INTERVIEWER: how does it make you feel when he worries?	
14_F_51_RS: um well I worry for him	
INTERVIEWER: [laughs] yeah	
14_F_51_RS: [laughs]	
INTERVIEWER: yeah	
14_F_51_RS: yeah	
INTERVIEWER: and what do you worry about?	
14_F_51_RS: um, I try not worry, I do worry but not necessarily strokey things...	
INTERVIEWER: mm	

14_F_51_RS: yeah	
INTERVIEWER: ok, do you feel like other people understand the changes--	Being part of the world Identity Emotional effects
14_F_51_RS: no	
INTERVIEWER: talk to me about that--a bit about that	
14_F_51_RS: no I don't think anybody can, they can't understand unless you've had a stroke	
INTERVIEWER: mm and how does that make you feel?	
14_F_51_RS: um it gets me cross when we're talking about benefits and things like that...	
INTERVIEWER: mm	
14_F_51_RS: because people are judging on something they can't understand...	
INTERVIEWER: mm yeah, so that makes you feel cross	
14_F_51_RS: mm yeah	
INTERVIEWER: what kind of thoughts go through your mind?	
14_F_51_RS: you get--you --you get cross and then you think is there anything I can actually do and there isn't...	
INTERVIEWER: mm	
14_F_51_RS: so, the best thing I can do is support other people that have got the same problem...	
INTERVIEWER: yeah absolutely	
14_F_51_RS: [laughs]	
INTERVIEWER: yeah [laughs] um so you feel that people who haven't had a stroke can't understand the changes	Being part of the world
14_F_51_RS: not really no	
INTERVIEWER: and is it important to you that the people could understand those kind of changes to your body?	
14_F_51_RS: yeah	
INTERVIEWER: why would that be?	
14_F_51_RS: um, [pause] th--th--they just can't understand it can they?	
INTERVIEWER: mm	
14_F_51_RS: um [laughs]	
INTERVIEWER: yeah ok, that's fine, um just going back to the description you gave of er how your body looks to you now...	
14_F_51_RS: mm	
INTERVIEWER: how does it feel, um living with that changed image to your body, how does that make you feel emotionally?	Emotional effects Coping - acceptance
14_F_51_RS: th--the change--can you	
INTERVIEWER: so you mentioned that your body sometimes feel bloated or marshmallowey or er not part of you...	
14_F_51_RS: yeah	
INTERVIEWER: what does it feel like emotionally living with a body that feels like that?	
14_F_51_RS: um, yeah, it's what it is...	
INTERVIEWER: mm	
14_F_51_RS: yeah, I don't	
INTERVIEWER: do any thoughts go through your mind about um, how your body feels in that sense?	
14_F_51_RS: no, it's fine	

INTERVIEWER: no, ok and does having a body that sometimes feels bigger um or more bloated does that affect you in any way in your day-to-day life?	Body changes Body distortions	
14_F_51_RS: I don't think so, I thi--thing if I do feel any changes then I check--I visually check...	Physical impact Coping	
INTERVIEWER: mm		
14_F_51_RS: and feel if--if it there's something that's not quite right		
INTERVIEWER: and does it affect your movement at all, that feeling of having a bigger body area?		
14_F_51_RS: I notice it if I'm walking...		
INTERVIEWER: mm		
14_F_51_RS: if it's not then I--or I see it in a mirror if I'm out and about and think "oh that's not quite right" and I'll try		
INTERVIEWER: so in what way does it affect you walking?		
14_F_51_RS: what generally?		
INTERVIEWER: er how it--when the body feels bigger on that side how does that affect you walking?		
14_F_51_RS: oh the--the lurching gets more, I get quite lopsided...		
INTERVIEWER: mm		
14_F_51_RS: um, if I'm tired it gets worse...		Changes over time
INTERVIEWER: mm		Uncertainty
14_F_51_RS: as the day gets long--as the day grows on, it--it gets worse		
INTERVIEWER: and 'it' is the feeling of the body feeling bigger or?		
14_F_51_RS: just generally the whole--that side gets worse		
INTERVIEWER: what sensation in that side feels worse, or what ac--what movement?		
14_F_51_RS: I think it--it's--it aches more as the day goes on, um and it--my shoulder droops...		
INTERVIEWER: mm		
14_F_51_RS: and comes in I think		
INTERVIEWER: yep, ok, so would it be fair to say that all of the sensations you've described on that side start feeling worse as the day goes on		
14_F_51_RS: yeah		
INTERVIEWER: yeah, ok and just when you mention feeling lopsided...	Body changes Lopsided Emotional effects	
14_F_51_RS: mm		
INTERVIEWER: is that a visual change to your body or is that something that you're feeling?		
14_F_51_RS: um it's--it's a--I can see it in the mirror and I can feel it...		
INTERVIEWER: mm		
14_F_51_RS: it--it--it's like dead		
INTERVIEWER: mm, what can you see in the mirror		
14_F_51_RS: um, an old woman [laughs] crone		
INTERVIEWER: oh		
14_F_51_RS: it just [laughs]--Quadi--Quasio--modo		
INTERVIEWER: Quasimodo		
14_F_51_RS: it's definitely not--yeah yeah		
INTERVIEWER: um and you mentioned the right shoulder drops...		
14_F_51_RS: yeah		
INTERVIEWER: is that something that makes it feel like Quasimodo or?		

14_F_51_RS: um, yeah postures not good anyway--intially they made me a brace thing...	Using aids
INTERVIEWER: mm	
14_F_51_RS: but it didn't do anything...	
INTERVIEWER: mm	
14_F_51_RS: they tried taping it and all sorts of things and it--it never worked so	Body changes
INTERVIEWER: so, which aspects of your body make you feel like an old crone or feel like Quasimodo?	
14_F_51_RS: I think the shoulder	
INTERVIEWER: mm	
14_F_51_RS: definitely yeah	
INTERVIEWER: with it dropping on the right side	
14_F_51_RS: it--it drops--it goes down and forwards...	
INTERVIEWER: forwards	
14_F_51_RS: so it's sort of	
INTERVIEWER: mm, ok, so when you feel lopsided um, is that because the right shoulders dropped, or is there any other aspects of your body that's affecting that feeling?	
14_F_51_RS: it's probably that	
INTERVIEWER: yeah	
14_F_51_RS: yeah	
INTERVIEWER: and you mentioned a few times about your posture...	
14_F_51_RS: yeah	
INTERVIEWER: can you tell me a little bit about that?	
14_F_51_RS: um it's not good [laughs]	
INTERVIEWER: it's not good [laughs] in what area?	
14_F_51_RS: um, well 'cause of the back--'cause of these there [gestures to breasts] [laughs]	
INTERVIEWER: [laughs]	
14_F_51_RS: um yeah, I don't sit up well...	Can't describe it Body tired
INTERVIEWER: yeah	
14_F_51_RS: but I think [pause] [exhale] I'm very aware of what the stroke has done, um--forgotten what I was going to say now, um, but when I'm tired it--it just all go [makes body flopping noise and gesture]	
INTERVIEWER: mm, so when you're tired, you're kind of motioning there that your body kind of flops down...	
14_F_51_RS: yeah	
INTERVIEWER: and forward a little bit	
14_F_51_RS: yeah	
INTERVIEWER: um does that mean that it's harder to kind of keep it up	
14_F_51_RS: yeah	
INTERVIEWER: yeah, just talk to me a little bit about how it feels when you're tired and you're trying to keep your body up	
14_F_51_RS: um, [exhale] I--I--I've done it for as long as I can--I've had the stroke that I'm--I'm aware of doing it and I will try and sit up...	Conscious of body
INTERVIEWER: mm	
14_F_51_RS: and walk properly and yeah	
INTERVIEWER: yeah, so you're trying very hard to kind of...	

14_F_51_RS: yeah	
INTERVIEWER: keep it up and things like that	
14_F_51_RS: yeah	
INTERVIEWER: and when you do manage to keep your posture up how does that affect your body?	Uncertainty Making sense of it
14_F_51_RS: um well I'm assuming it's going to be better [laughs]	
INTERVIEWER: does it feel better?	
14_F_51_RS: in my head yes, whether it's true yeah	
INTERVIEWER: yeah ok, um so we've descr--we've talked about quite a lot of different sensations on the right-hand side, is there any other experiences or changes to your body since your stroke that we haven't talked about yet?	
14_F_51_RS: don't think so	
INTERVIEWER: ok, um and on your left hand side, you mentioned aching in your elbow and your knee and your shoulder...	
14_F_51_RS: mm	
INTERVIEWER: um because of the overcompensating that side is doing	
14_F_51_RS: yeah	
INTERVIEWER: apart from those sensations, does the left side feel as it did before your stroke	
14_F_51_RS: yeah yeah	
INTERVIEWER: yeah ok, um how much of an impact on your life would you say the changes to your body are having on you?	
14_F_51_RS: er, I'm not as fit I would have been...	Fatigue
INTERVIEWER: mm	
14_F_51_RS: um I get tired quickly, um, just generally I need to rest more...	
INTERVIEWER: mm	
14_F_51_RS: I'm not as active as I was...	Physical impact
INTERVIEWER: ok	
14_F_51_RS: I was never one for going to the gym and things but I was...	
INTERVIEWER: mm	
14_F_51_RS: reasonably fit...	
INTERVIEWER: yeah	
14_F_51_RS: um, I wouldn't consider myself being fit now	
INTERVIEWER: mm, so it's had an effect on your fitness then, ok and out of the changes to your right side of your body, which of those are having the biggest effect on you on your day-to-day life?	
14_F_51_RS: I wouldn't like to say to be honest...	Changes over time
INTERVIEWER: mm	
14_F_51_RS: it's just it--it's part of the whole...	
INTERVIEWER: Mm	
14_F_51_RS: um and it would vary day-to-day	
INTERVIEWER: yeah, ok, if treatment existed for any--	
14_F_51_RS: [laughs]	
INTERVIEWER: [laughs]	
14_F_51_RS: yeah alright	
INTERVIEWER: burst out laughing there you go...	
14_F_51_RS: sorry	

INTERVIEWER: no no that's fine, if treatment existed for any of the problems on your right side that you've described, which thing would you get treated first?	What to treat	
14_F_51_RS: um, well obviously I'd like the sight to [laughs]...		
INTERVIEWER: mm		
14_F_51_RS: come back, [pause] I--do you know what, I've never really thought about it		
INTERVIEWER: [laughs]		
14_F_51_RS: yeah		
INTERVIEWER: so your sight would be something that you would--		
14_F_51_RS: that's the thing that affects a lot, the aphasia is very well hidden but it stops me from...		
INTERVIEWER: mm		
14_F_51_RS: I would say working, but actual aches and pains and [makes noise that's dismissive] so		
INTERVIEWER: mm ok, so it sounds like it's more of a whole-body sort of thing...		
14_F_51_RS: mm		
INTERVIEWER: yeah ok and how comfortable would you say you are um thinking about those changes to your right side?		Discomfort
14_F_51_RS: what emotionally or?		
INTERVIEWER: any way you like		
14_F_51_RS: say the question again		
INTERVIEWER: how comfortable that you are with everything on your right side		
14_F_51_RS: it--it is--it never feels comfortable...		
INTERVIEWER: mm		
14_F_51_RS: but it doesn't bother me...		
INTERVIEWER: mm, ok and which areas are the most uncomfortable?		
14_F_51_RS: probably shoulder and arm, wrist		
INTERVIEWER: ok and is that related to the pain that we talked about in those areas?		
14_F_51_RS: probably yes		
INTERVIEWER: yeah		
14_F_51_RS: yeah		
INTERVIEWER: ok, is there anything that we haven't talked about that you think would be helpful for me to know?	Strange sensations Heavy	
14_F_51_RS: um, sometimes feels very heavy		
INTERVIEWER: yeah		
14_F_51_RS: don't know whether I mentioned that		
INTERVIEWER: heaviness and that's in the right arm?		
14_F_51_RS: yeah		
INTERVIEWER: is there any heaviness in the leg at all?		
14_F_51_RS: I'm always assumed that it does the same, but I couldn't		
INTERVIEWER: mm		Uncertainty
14_F_51_RS: yeah, could be but I don't know		
INTERVIEWER: um and is there--any thing that affects how heavy it feels?		
14_F_51_RS: no		
INTERVIEWER: does it feel the same heaviness throughout the day?		Changes over time
14_F_51_RS: no		

INTERVIEWER: what makes it feel--	
14_F_51_RS: I don't know	Uncertainty
INTERVIEWER: [laughs]	
14_F_51_RS: no it just--it's not everyday it just--some--sometimes it just feels heavy	Can't describe it
INTERVIEWER: yeah and is there anything that helps with that	Coping - ignore it
14_F_51_RS: no	
INTERVIEWER: no [laughs] and does the heaviness affect what you do?	
14_F_51_RS: no	
INTERVIEWER: no [laughs] you carry on	
14_F_51_RS: just yeah [laughs]	
INTERVIEWER: [laughs] just deal with it	
14_F_51_RS: yeah	
INTERVIEWER: are you able to um give me an idea of how heavy it feels? Is there anything that it's like?	Strange sensations Heavy
14_F_51_RS: well 'cause I feel it's bloated anyway it li--it sort of [pause] heavy I don't know [pause] like--like when you--you've um you've got your baby [makes gesture like cradling a baby] on your	
INTERVIEWER: mm	
14_F_51_RS: sort of "ah heavy"	
INTERVIEWER: so as if you're carrying a baby	
14_F_51_RS: that sort of weight sort of	
INTERVIEWER: yeah yeah	
14_F_51_RS: yeah	Can't describe it Emotional effects
INTERVIEWER: that level of extra weight	
14_F_51_RS: just ignore that that's just	
INTERVIEWER: no no that makes sense	
14_F_51_RS: [laughs]	
INTERVIEWER: is that how it feels	
14_F_51_RS: [laughs] heavy	
INTERVIEWER: ok that's fine yeah	
14_F_51_RS: [laughs] I do--	
INTERVIEWER: no that absolutely makes sense [laughs] so it feels extra heaviness in that right arm	
14_F_51_RS: yeah	
INTERVIEWER: sometimes, not all the time	
14_F_51_RS: no	
INTERVIEWER: nothing really helps with it, you just potter on and carry on as normal	
14_F_51_RS: yeah	
INTERVIEWER: yeah, is there any other changes to that right side that you've noticed at all that we haven't talked about yet?	
14_F_51_RS: it gets--it does--I've said it's cold haven't I...	
INTERVIEWER: mm	
14_F_51_RS: and that yeah, that's probably about it	
INTERVIEWER: so cold, heavy, talked about spiderey sensations and obviously the aches and pains er and er was there anything else--oh and the loss of feeling and	

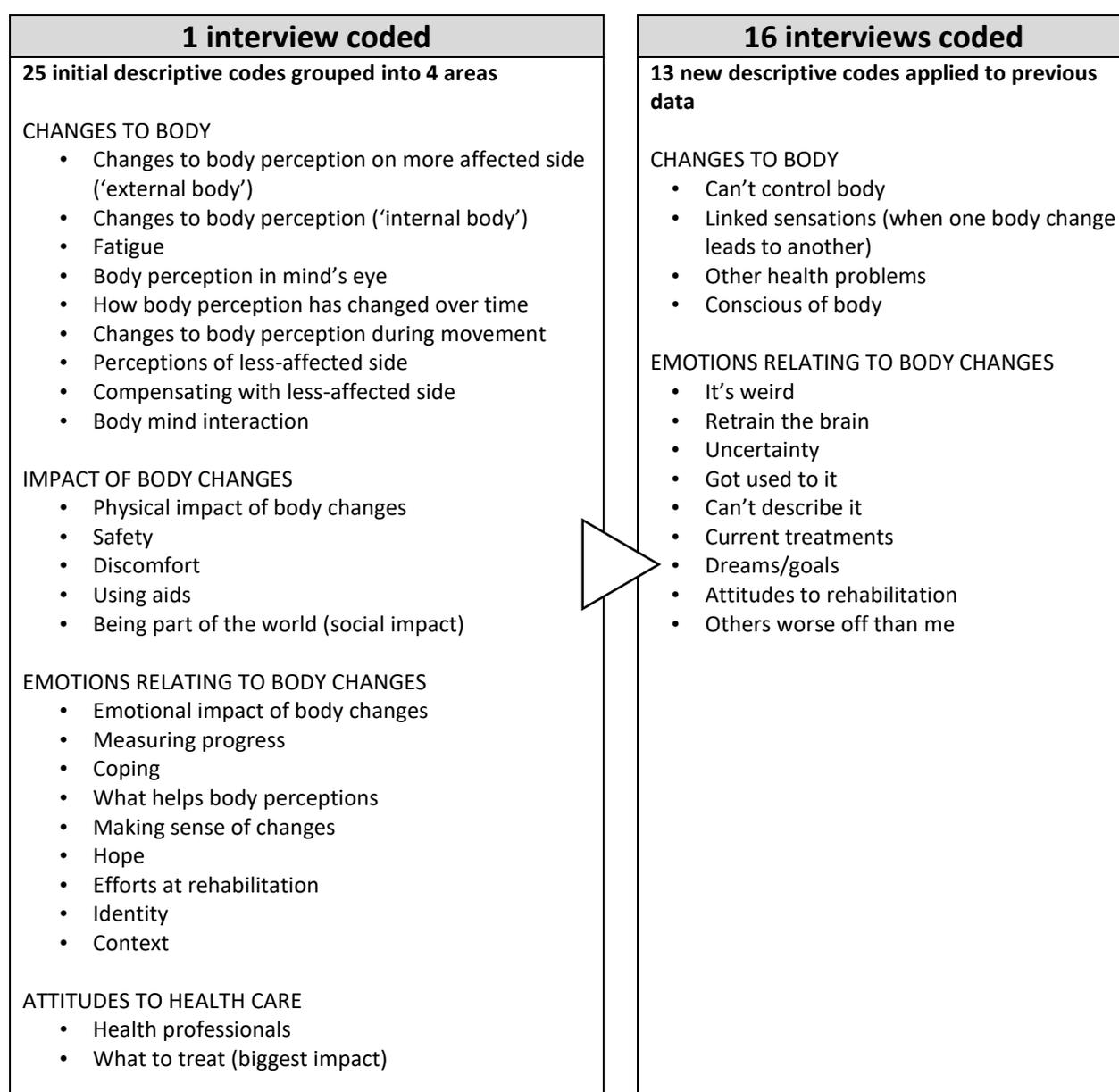
things and feeling lopsided are the main things we've talked about, is there anything else at all? The main things	
14_F_51_RS: I think so [laughs]	
INTERVIEWER: yeah that's fine, lovely	

B.11. Transparency in the analytic process

Phase 1 and 2: Coding all interviews in broad descriptive terms

Initial coding of interview one (Toby, 46) used objective language to code the data into broad descriptive categories which are identified in the left column of Figure 29, below. As new interviews were coded, new descriptive categories emerged, which are identified in the column to the right. The benefit of starting with large descriptive codes, was that the majority of data were selected for further analysis, meaning there was little researcher bias in which items were selected for further consideration.

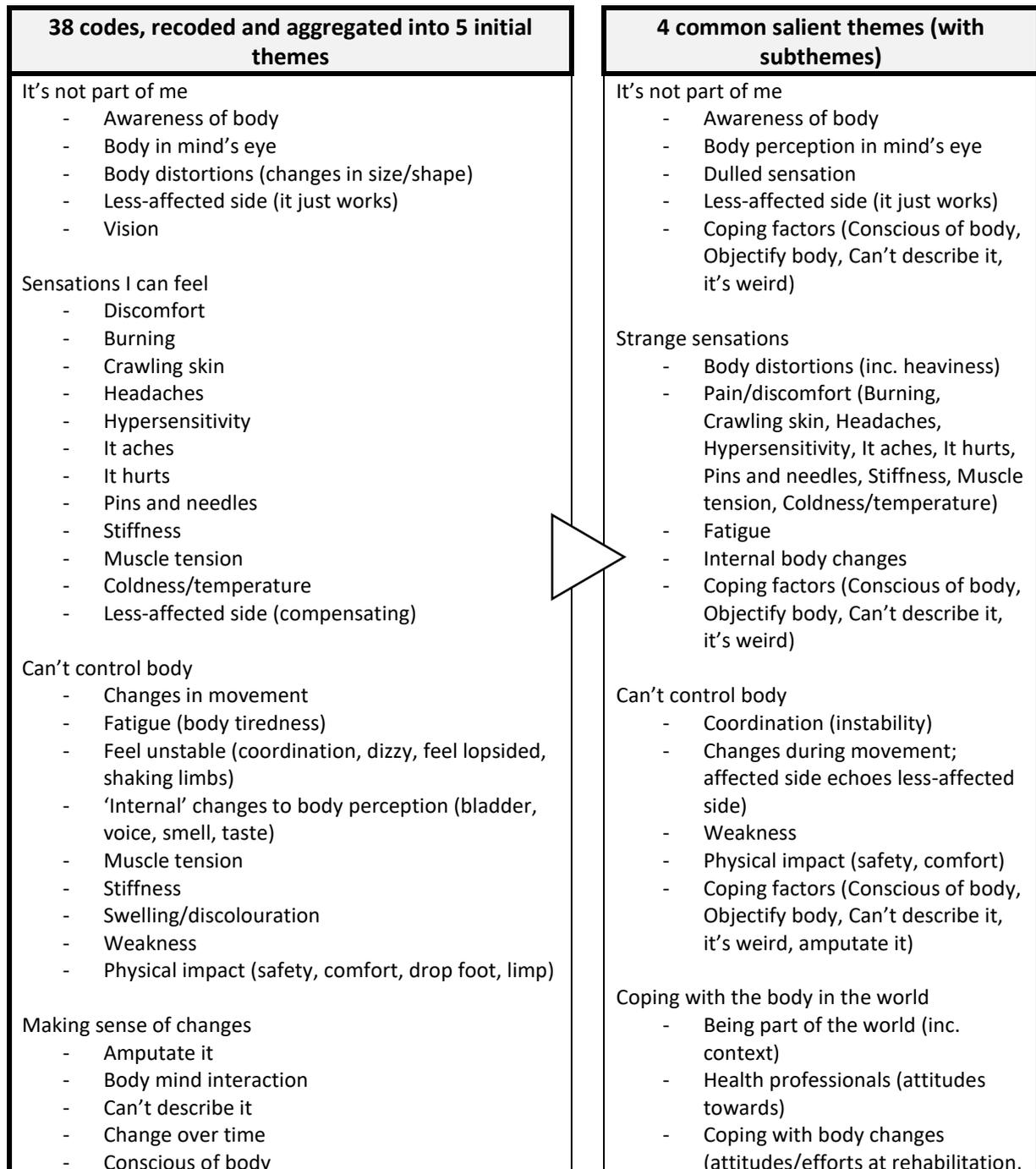
Figure 29. Coding all interviews in broad descriptive terms



Phase 3: Aggregating similar themes and recoding them to reflect more shared experiences

Once the data were categorised into broad themes, it was recoded into aggregated, more detailed themes (left hand column below). These were then regrouped into the most salient themes (right hand column below) were then selected to reflect similarities most prominent in the data.

Figure 30. Aggregating similar themes

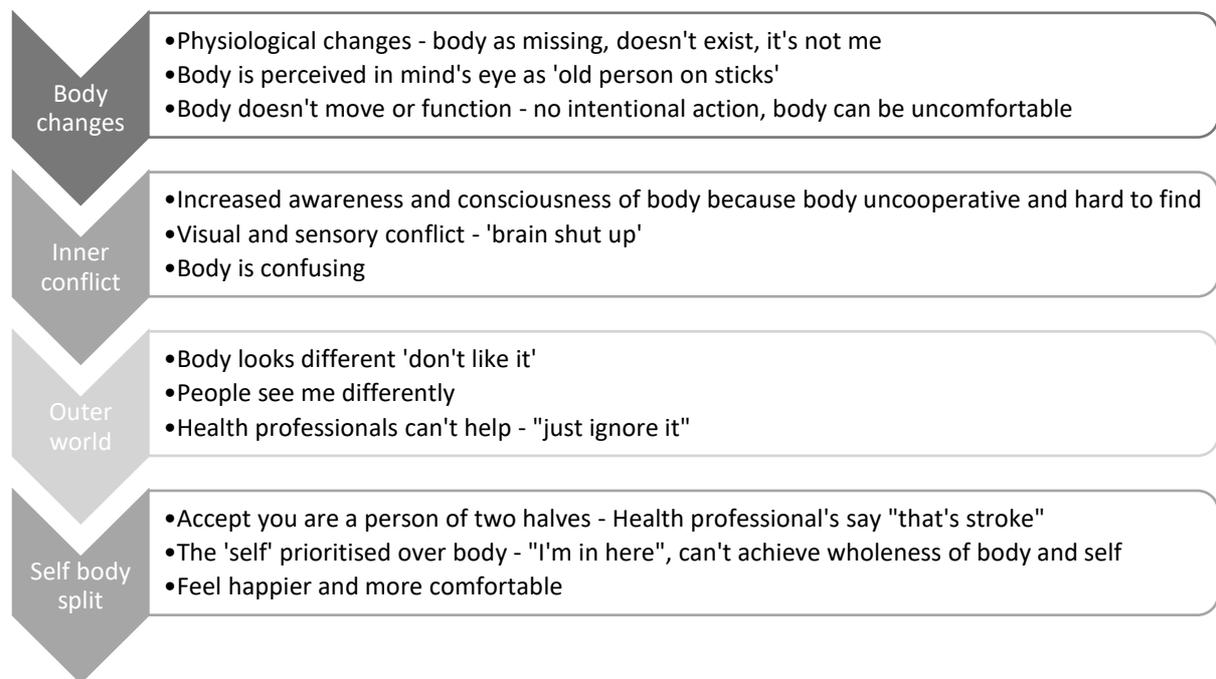


<ul style="list-style-type: none"> - Body in 1st/3rd person (Objectify body) - Got used to it - It's weird - Linked sensations - Uncertainty - Coping - Being part of the world <p>Recovery</p> <ul style="list-style-type: none"> - Health professionals - Hope - Efforts at rehabilitation - Identity (inc. dream/goals) - Measuring progress (inc. worm feelings) - Retrain the brain - What helps (inc. using aids) - What to treat and What has biggest impact 	<p>measuring progress, identity, hope, dreams, Thoughts about the future – what to treat)</p>
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Phase 4 (part 1): Exploration of themes using one case-study example

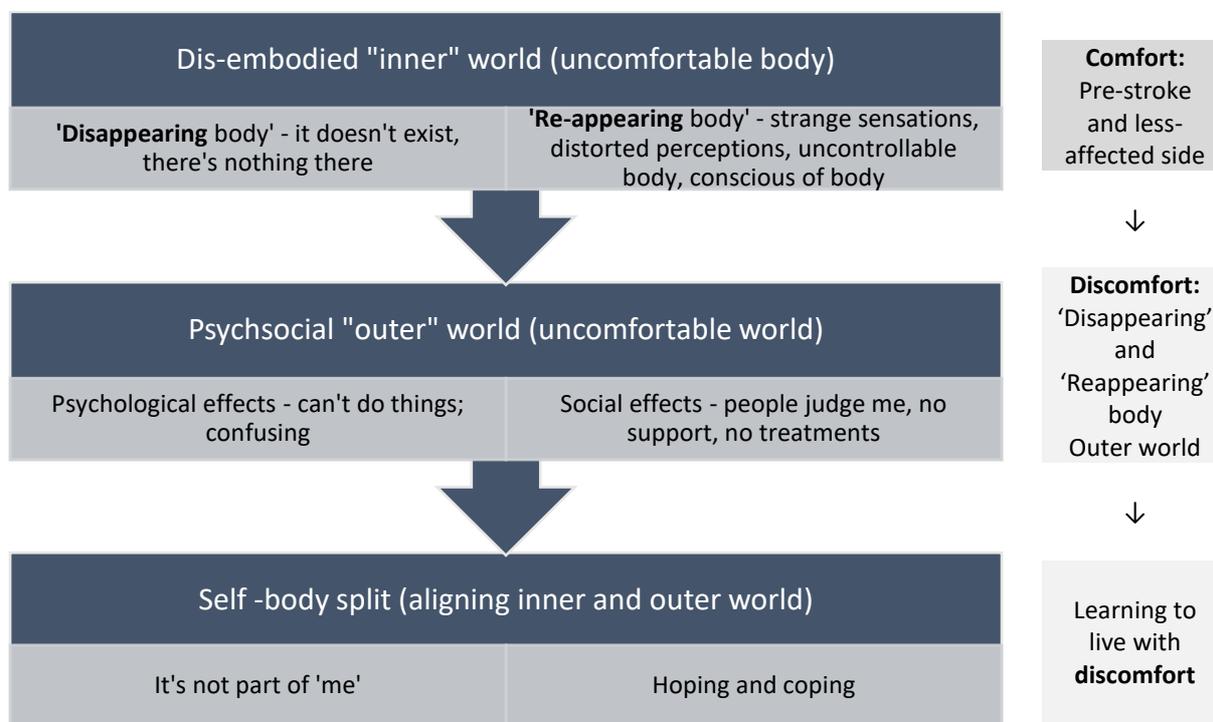
The links between salient themes were explored in one case-study (Becky, 58) which was selected for further linguistic and interpretive analysis (Figure 31).

Figure 31. Exploration of themes using one case-study



Phase 4 (part 2): First exploration using thematic diagram

Figure 32. First exploration using thematic diagram



Phase 5: Final themes with examples of how they relate to quotes

The final groupings of themes are included in Chapter 4, Table 8 and illustrated by quotes throughout that chapter. The groupings moved on from the thematic diagram illustrated above in order to more fully integrate the experience of discomfort into the bodily and psychosocial experience of altered perceptions. Adding focus to body comfort added an embodied focus to the data, ingraining psychosocial consequences in bodily changes. However, once the concept of comfort was more integrated into the interpretation this phrase could be responded to in both physical and psychological ways. This provided dual focus highlighting that the affected limb was no longer part of the body as perceptually it was not integrated into the bodily whole whilst at the same time it was psychologically problematic and not part of 'me' or my 'self'. This comfort 'lens' served to root complex holistic perceptions into bodily terms; reflection on the body experience allowed this to be explored as the source of the discomfort.

For example, the complexity of the embodied experience showed how participants described the body as 'not me'; 'parasitic'; in the third person and lost and forgotten. Participants described a sense of detachment from the affected limbs which generally did not enter into their conscious attention. When participants did give the body attention it was from an observer (or parental) standpoint, in which they consciously focused their attention to maintain the 'detached' body area. In the 'reappearing body', participants described instances in which the body was perceived as unpleasant, alien and unusual and

demanded conscious attention. In this theme uncomfortable altered perceptions such as pain or body distortions demanded alleviation or distraction, forcing participants to separate their sense of self to remedy a body which was obviously problematic. The 'uncontrollable body', described a body and self divided, as one tried to regain control of the other. The body was 'remote controlled', the self 'schizophrenic'. When static and unresponsive, the body was abnormal and surprising, which emphasised its separation from the bodily whole. The 'weirdness' of this experience, capturing the embodied emotional discomfort. In movement (intentional action) the 'uncontrollable' body became frustrating and a battle, the emotional discomfort worsening as the body became experienced as unnavigable. The loss of intentional action, was potentially the most damaging altered body perception for the sense of self - causing participants to describe feelings of frustration and worthlessness.

Researcher reflections

Throughout the interpretation stage I was aware of my own perspective and how this interacted with the analytic process. Two instances in which my own viewpoint may have had a role in the interpretation are reflected on below.

Throughout Chapter 4 participants described a sense of having to take care of the separate and objectified body. The body which was lost, uncontrollable and needed consciously looking after was consistently described. Many participants responded to this bodily demand with a calm and detached response, they made light of their disobedient bodies, they cared for their sore and problematic limbs and tried not to let these changes affect their sense of self. As a mother of a six-year-old boy, participants' descriptions resonated, as they reminded me of a parent caring for a child. The objectification of their body parts made those limbs seem almost like they were another person, who they felt a responsibility to care for. At times those limbs were annoying, frustrating and hard work, but despite this, like a parent to a child, participants maintained an attitude of conscious care and forgiveness. I found this separation between the body and the complexity of the psychological response fascinating.

A further moment in which I noticed a resonance in the data with my own personal experience was when Michelle described her extended wait for services to improve her walking. Her description made me feel angry on her behalf that she had been so let down by services and I felt inspired by her attitude to coping with her difficulties. I compared it to my own short waiting time and excellent physiotherapy services referral to manage back pain. I felt the NHS system was unfair in that I had received speedy and efficient care, yet my condition was comparatively minor and my condition did not impact my daily activities. Yet, the stroke pathway was slow, inefficient and inconsistent between patients, despite them needing input to cope with basic activities-of-daily-living. I felt passionate to make sure these narratives were conveyed in the themes of the research. The data easily and inductively drove the construction of the 'isolated body' theme in which this topic is touched on. Yet the formulation of the construct was likely influenced by mine and my participants sense that there is inequality in health care provision for those who require significant input.

B.12. Participants' understanding of the meaning of comfort

The ambiguity of the term comfort meant that participants interpreted it in subjective ways. For example, Marc used the term to relate to a loss of movement – a perceptual loss which may not otherwise be perceived as physically uncomfortable.

"I'm not in discomfort if you see what I mean... I'm only in discomfort when I can't move it..." (Marc, 64, 2 years post-stroke)

His reference to discomfort here may relate to multiple factors – loss of bodily response, loss of utility and psychological factors associated with this – yet it is unlikely that in this instance he is using the term to refer to painful sensations. For some, using the term comfort was useful as it allowed description of their perceptions beyond the binary constructs of the presence and absence of pain. It shed light on alternate physical discomforts such as being conscious of the body during movement, whilst facilitating reflections on the psychological consequences of living in a distorted or unresponsive body.

Contrastingly, another participant emphasised feeling inhibited using the term explicitly, seemingly because he didn't want to exaggerate the effect of his altered perceptions.

"[Interviewer: you mentioned that on your right side you have quite a lot of discomfort, in the form of stiffness, or things not working in the way they should?] I wouldn't call it discomfort... I would just say, well discomfort to me implies a bit of you know, a bit of pain or something...and it's not that" (Stuart, 60, 20 months post-stroke)

Appendix C.

A feasibility study of the acceptability of assessment tools to communicate altered body perception and comfort after stroke

C.1. Ethics approval



Faculty of Health & Applied
Sciences
Glenside Campus
Blackberry Hill
Stapleton
Bristol BS16 1DD
|
Tel: 0117 328 1170

UWE REC REF No: HAS.17.10.028

27th October 2017

Hannah Stott
Faculty of Health and Applied Sciences
University of the West of England
Glenside Campus, Blue Lodge
Blackberry Hill, Stapleton
Bristol
BS16 1DD

Dear Hannah

Application title: Exploring the acceptability of assessment tools to communicate altered body perception and comfort after stroke: a pilot study

Your ethics application was considered by the Faculty Research Ethics Committee and, based on the information provided, has been given ethical approval to proceed.

On the participant information sheet a couple of the picture symbols did seem a little obscure, and although there is no condition attached to this I wonder if the researcher could think about whether the symbol relating to anonymity could be substituted with another image more directly relevant.

You must notify the committee in advance if you wish to make any significant amendments to the original application using the amendment form at <http://www1.uwe.ac.uk/research/researchethics/applyingforapproval.aspx>

Please note that any information sheets and consent forms should have the UWE logo. Further guidance is available on the web: <https://intranet.uwe.ac.uk/tasks-guides/Guide/writing-and-creating-documents-in-the-uwe-bristol-brand>

The following standard conditions also apply to all research given ethical approval by a UWE Research Ethics Committee:

1. You must notify the relevant UWE Research Ethics Committee in advance if you wish to make significant amendments to the original application: these include any changes to the study protocol which have an ethical dimension. Please note that any changes approved by an external research ethics committee must also be communicated to the relevant UWE committee.

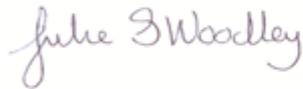
2. You must notify the University Research Ethics Committee if you terminate your research before completion;
3. You must notify the University Research Ethics Committee if there are any serious events or developments in the research that have an ethical dimension.

Please note: The UREC is required to monitor and audit the ethical conduct of research involving human participants, data and tissue conducted by academic staff, students and researchers. Your project may be selected for audit from the research projects submitted to and approved by the UREC and its committees.

Please remember to populate the HAS Research Governance Record with your ethics outcome via the following link: <https://teams.uwe.ac.uk/sites/HASgovernance>.

We wish you well with your research.

Yours sincerely



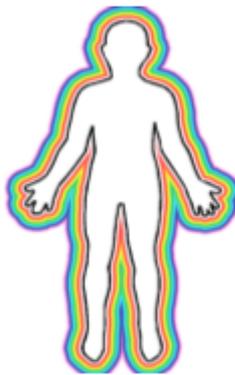
Dr Julie Woodley
Chair
Faculty Research Ethics Committee

[c.c.](#) Dr Mary Cramp

C.2. Flyer

UWE Bristol | University of the West of England

Take part in research to show what your body feels like after stroke
For people with or without aphasia

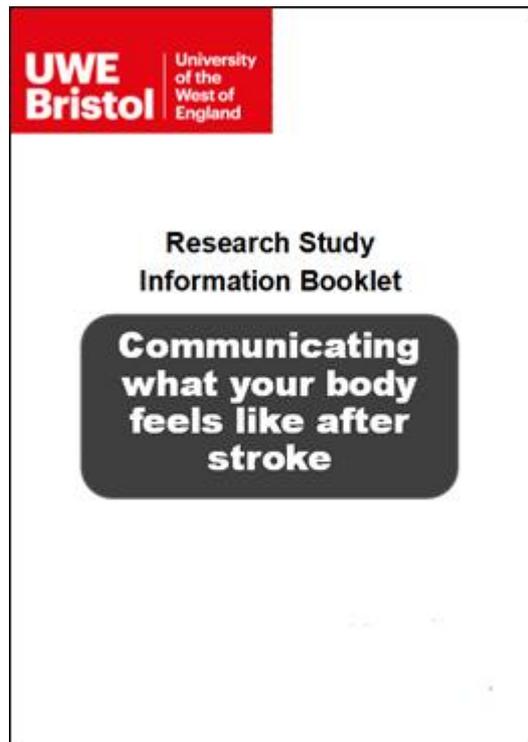


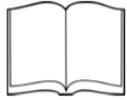
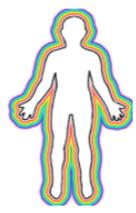
- To take part you must experience **changes to the sensation or awareness** of your body
- It must be at least **6 months since** your stroke
- You must take part in **1 interview**

I would like to hear more about the research (**please tick**)
Yes No

If you **tick Yes**, Hannah will come and talk to you to **arrange a time to talk** more about taking part

C.3. Participant information booklet



	About the project
<p>About this booklet</p>  <ul style="list-style-type: none"> I am Hannah Stott I am a Researcher working at the University of the West of England  <ul style="list-style-type: none"> This booklet includes details about the study and what it would involve if you decide to take part  <ul style="list-style-type: none"> Please read this information carefully and show it to anyone you think may help you make your decision  <ul style="list-style-type: none"> If you choose to be contacted, Hannah will go through the booklet with you and answer any questions you may 	<p>About the project</p>  <p>The study is about communicating what the body feels like after stroke</p> <p>I would like to talk to people who have:</p> <ul style="list-style-type: none"> had a stroke at least 6 months ago who are currently experiencing changes to sensation or awareness in their bodies If you have aphasia you can take part  

<h3 style="text-align: center;">What do I have to do?</h3> <div style="margin-bottom: 20px;">  <p>Have a short meeting with Hannah to see if you are suitable to take part in the research</p> </div> <div>  <p>Meet with Hannah again to do 3 questionnaires and make a computer image about how your body feels</p> <ul style="list-style-type: none"> • This meeting will take 30-60 minutes • This meeting can take place at your home, or at another location if you would prefer • Any transport costs will be paid for by the University </div>	<h3 style="text-align: center;">What are the benefits?</h3> <div style="margin-bottom: 20px;">  <ul style="list-style-type: none"> • The research will not benefit you directly • The research hopes to improve the lives of those affected by stroke </div> <h3 style="text-align: center;">What are the downsides?</h3> <div>  <ul style="list-style-type: none"> • There aren't any known risks to taking part in this study • You may feel emotional if talking about stroke experiences that have been difficult for you • If you feel distressed Hannah will be able to refer you to further support if needed </div>
---	--

<h3 style="text-align: center;">Do I have to take part?</h3> <div style="margin-bottom: 20px;">  <ul style="list-style-type: none"> • You do not have to take part in this study, Hannah will respect any decision you make • You can withdraw from the study at any time, and you can withdraw your information up to two weeks after taking part • If you choose to take part Hannah will go through this information booklet with you and then ask you to sign a consent form </div> <div style="margin-bottom: 20px;">  </div> <div>  <ul style="list-style-type: none"> • You can discuss the study with people close to you. You can choose to have someone with you during the meeting </div>	<h3 style="text-align: center;">What will happen to my information?</h3> <div style="margin-bottom: 20px;">  <ul style="list-style-type: none"> • Your interview will be made anonymous so you cannot be identified </div> <div style="margin-bottom: 20px;">  <ul style="list-style-type: none"> • All information will be kept confidential • Your personal details will not be shared with anyone outside of the research team </div> <div style="margin-bottom: 20px;">  <ul style="list-style-type: none"> • Your interview will be audio recorded on a Dictaphone • It will be stored on a secure password-protected electronic file on the University server with your personal details </div>
--	---

<p>Who will see the findings of this study?</p>  <ul style="list-style-type: none"> • Hannah will send you a copy of the findings • The findings may be reported in professional publications or meetings • If you agree, your anonymous interview information will be kept for use in future research   <p>Is this study approved?</p>  <ul style="list-style-type: none"> • A panel of experts at the University of the West of England Research Ethics Committee have 	<p>What if something goes wrong?</p>  <ul style="list-style-type: none"> • If you have any concerns about this study, contact Hannah whose details are at the end of this booklet • It is extremely unlikely that anything would go wrong, but if something did happen during the study and you were harmed due to someone's negligence you may have grounds for legal action against the University of the West of England to claim compensation. You may have to pay your own legal costs. • If, after you have spoken to Hannah, you wish to make a formal complaint, you can contact: <table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="padding: 5px;"> <p>Dr Mary Cramp Research Supervisor</p> <p>UWE Glenside Campus Blackberry Hill Stapleton Bristol, BS16 1DD</p> </td> <td style="padding: 5px;"> <p>The Complaints and Appeals Team</p> <p>Academic Services UWE Frenchay Campus Coldharbour Lane Bristol, BS16 1QY</p> </td> </tr> </table>	<p>Dr Mary Cramp Research Supervisor</p> <p>UWE Glenside Campus Blackberry Hill Stapleton Bristol, BS16 1DD</p>	<p>The Complaints and Appeals Team</p> <p>Academic Services UWE Frenchay Campus Coldharbour Lane Bristol, BS16 1QY</p>
<p>Dr Mary Cramp Research Supervisor</p> <p>UWE Glenside Campus Blackberry Hill Stapleton Bristol, BS16 1DD</p>	<p>The Complaints and Appeals Team</p> <p>Academic Services UWE Frenchay Campus Coldharbour Lane Bristol, BS16 1QY</p>		

How do I take part?



- Tell Hannah now



- **Call or text** Hannah
Stott on: 07342 894802



- **Email** Hannah Stott on:
hannah3.stott@uwe.ac.uk



- **Post** your details to:
Hannah Stott
UWE Glenside Campus
Blue Lodge
Blackberry Hill
Stapleton
Bristol
BS16 1DD

C.4. Consent forms

Standard consent form

**Consent Form****Communicating how your body feels after stroke**

Please tick the appropriate boxes Yes No

Taking Part

I have understood the information booklet

I have been given the chance to ask questions about the project

I agree to take part in the project

I understand that:

- taking part is voluntary
- I can withdraw from the study at any time (up to 2 weeks after interview)
- I do not have to give any reasons for why I no longer want to take part

What will happen to the information I provide

I understand that my interview data and personal details will be stored separately in electronic files on the secure UWE computer system

I understand my personal details such as name, phone number and address will not be revealed to people outside the project

If you have any questions then please contact **Hannah Stott** via [Tel: 07342 894802](tel:07342894802) or Email: Hannah3.stott@uwe.ac.uk

Consent Form



I understand that my anonymous words and any images I create may be used in publications, reports and online

I agree for my words and images I create to be stored for future research

I understand that other researchers will have access to my anonymous words and images

I understand that other researchers may use my words or images in other research publications, reports and online

Using the information you provide legally

I agree to give the rights I hold over any words or images I create in this project to Hannah Stott

.....
Name of participant [printed] Signature Date

.....
Name of researcher [printed] Signature Date

If you have any questions then please contact **Hannah Stott**
via [Tel: 07342 894802](tel:07342894802) or Email: Hannah3.stott@uwe.ac.uk

'Aphasia friendly' Consent form



University of the West of England

Consent Form

Communicating how your body feels after stroke

Please tick the appropriate boxes

Yes No

Taking Part



I have understood the information booklet

I have been given the chance to ask questions about the project



I understand that:

- I don't have to take part
- I do not have to give any reasons why
- I can take back any of my information for up to 2 weeks after interview

Consent Form



University of the West of England

<u>What happens to my information?</u>		Yes	No
	<p>I understand that UWE will keep information about me:</p> <ul style="list-style-type: none"> - Personal details (name, phone number and address) - Voice recording and notes from the interview <p>This information will be kept safely on UWE's secure computer</p> <p>Only people involved in this study will know my name</p>	<input type="checkbox"/>	<input type="checkbox"/>
	<p>I understand words and pictures from the interview will be made anonymous</p> <p>I understand that my anonymous words and pictures may be used in publications, reports and online</p>	<input type="checkbox"/>	<input type="checkbox"/>

Consent Form



University of the West of England

Sharing my information?

Yes No



I agree for my anonymous words and pictures to be stored for future research



- other researchers will have access to this
- they may use my words or pictures in other research publications, reports and online
- I agree to give the rights I hold over any words or pictures I create in this project to Hannah Stott

I agree
 I disagree



I agree to take part in the project

.....
Name of participant

.....
Signature

.....
Date

.....
Name of researcher

.....
Signature

.....
Date

C.5. Selection of measures

Diverse questionnaires relating to multiple perspectives of body perception were identified through the search process. This was useful to provide context for the development of a measure to assess body perception and comfort after stroke. The tools identified below were excluded for several reasons. They were focused on interoceptive or autonomic body perception issues (such as increased heart rate in anxiety); they focused on body image (attitudes to how the body looks or is perceived); they were related to single body areas which wouldn't relate to the 'whole-body' stroke experience (e.g. Fremantle back and knee questionnaires) or they focused on the emotional response to body perception changes. Terms such as body consciousness, awareness, perception and image were used often and exploring their use in different disciplines created clarity around how best to use these terms in stroke literature. Questionnaires exploring comfort specifically were not broad enough to capture the experience of comfort without using prescribed categories to explore it, such as ability to engage in activities-of-daily-living or focusing on comfort in hospital. The questionnaires and reasons for exclusion are tabulated below (Table 13).

Table 13. Body perception measures

Name of measure	Focus	Reason for exclusion
Fremantle back awareness questionnaire (Wand et al., 2014)	Body perception	Developed to assess back pain. Relevant in terms of body perception, but questions related to back perception
Fremantle Knee awareness questionnaire (Nishigami et al., 2017)	Body perception	Developed to assess knee problems in osteoarthritis, as such questions related to knee perception
Scale of body connection (Price and Thompson, 2007)	Body perception and comfort	Developed to assess body connection and disassociation. Contains interesting bits about comfort and feeling separated from body, but overly focused on emotions
Multidimensional interoceptive assessment inventory (Mehling et al., 2012)	Interoceptive body perception, body awareness, comfort	Developed to assess awareness of body. Parts of questionnaire relevant, some focus on body perception related to somatic perceptions e.g. anxiety
Arthritis body experience scale (Hider et al, 2002)	Comfort, body image	Developed to assess self-consciousness in arthritis. Focused on body image
Body awareness rating questionnaire (Dragesund et al., 2010)	Comfort, body awareness, body perception	Developed to assess long-lasting musculoskeletal and psychosomatic disorders – focus more on psychosomatic awareness of bodily changes
Body image disturbance scale (Cash et al., 2004)	Body image	Developed to assess body image concerns, not focused on body perception
Body image scale (Cancer) (Hopwood et al., 2001)	Body image	Developed to assess body image concerns in cancer patients
Body awareness scale (Shields, Mallory and Simon, 1989)	Body awareness	Developed to assess awareness of the body, related to general body changes, not post-stroke
Body awareness scale health (Roxendal, 1985)	Body perception	Developed to assess quality of movement – does not assess other aspects of body perception
Autonomic perception questionnaire (Mandler, Mandler and Uviller, 1958)	Autonomic body perception	Developed to assess autonomic perception during anxiety – does not assess other aspects of body perception
Body cathexis scale (Jourard and Secord, 1955)	Body image	Developed to assess body image – not related to body perception
Body consciousness questionnaire (Miller and Murphy, 1981)	Body image and autonomic body perception	Developed to assess body image and autonomic perception – not related to body perception issues after stroke
Objectified body consciousness scale (McKinley and Hyde, 1996)	Body image	Developed to assess sense of objectification in body consciousness – not about body perception
Body satisfaction scale (Slade et al., 1990)	Body image	Developed to assess satisfaction with 16 body areas – not about body perception
Body sensations interpretation questionnaire (Clark et al., 1997)	Autonomic body perception	Developed to assess misattributing body sensations in panic disorder, not about body perception issues post-stroke
Phenomenology of consciousness (Pekala, Steinberg and Kumar, 1986)	Body awareness	Developed to assess consciousness in response to stimulus, not related to body perception issues post-stroke
Pilot scale comfort stroke – (Rogeau et al., 2014)	Comfort	Developed to assess comfort in terms of activities-of-daily-living – very specific and functional interpretation of term comfort
General comfort questionnaire (Kolcaba, 1992)	Comfort	Developed to assess holistic comfort. Hospital focused and not enough about physical comfort

C.6. PainQuILT™

First a body area is selected via the body map in (Figure 1). Second the pain perception is selected and the level of pain experienced is rated (Figure 2). There is then the option to make a note about this pain type and add another pain (Figure 3). Once all pains are recorded, participants are asked to consider the impact on the quality of life over the previous 24 hours which is rated on a Visual analogue scale from 0 to 10. The final screen which presents a summary of all information then appears (Figure 4).

Figures 33 – 36: Copyright® (2014) McMaster University, Hamilton, Ontario, Canada. All images used with permission. Any further use or copying of these images must be granted by McMaster Industry Liaison Office – MILO.

Figure 33. Body map (PainQuILT™, 2017)

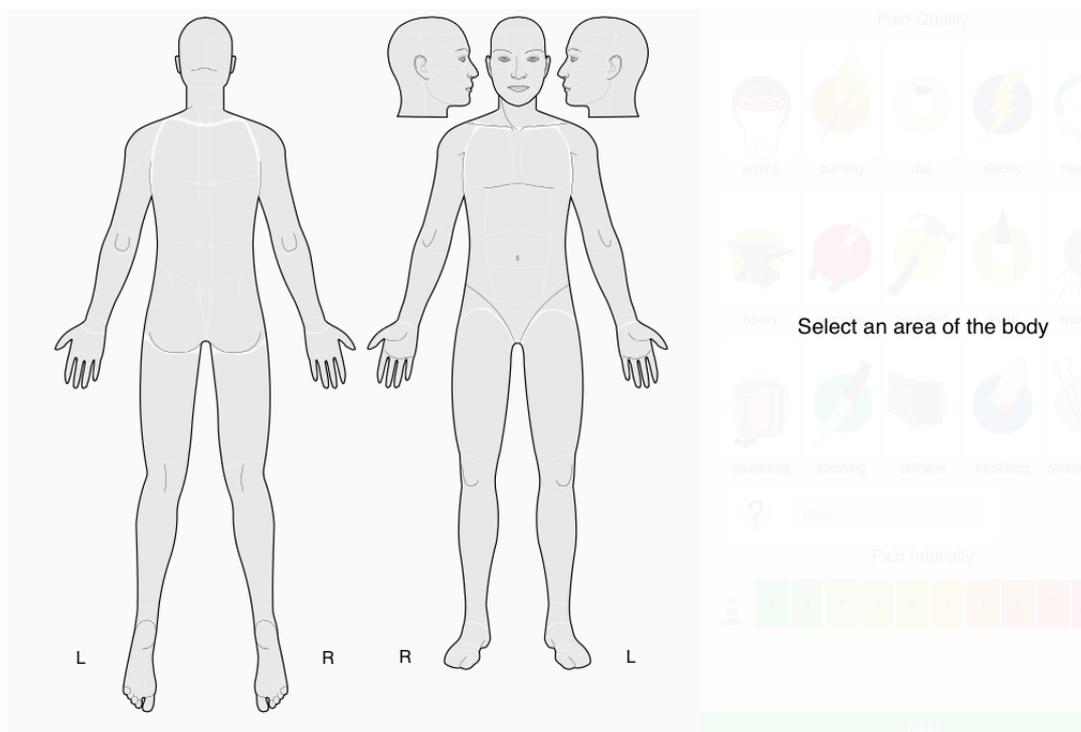


Figure 34. Pain identification and severity rating (PainQuILT™, 2017)

Pain Quality

aching	burning	dull	electric	freezing
heavy	pinching	pounding	sharp	shooting
squeezing	stabbing	stiffness	throbbing	pins/needles

Pain Intensity

0 no pain	1	2	3	4	5	6	7	8	9	10 worst pain
-----------------	---	---	---	---	---	---	---	---	---	---------------------

Figure 35. Note area (PainQuILT™, 2017)

Confirm Selection

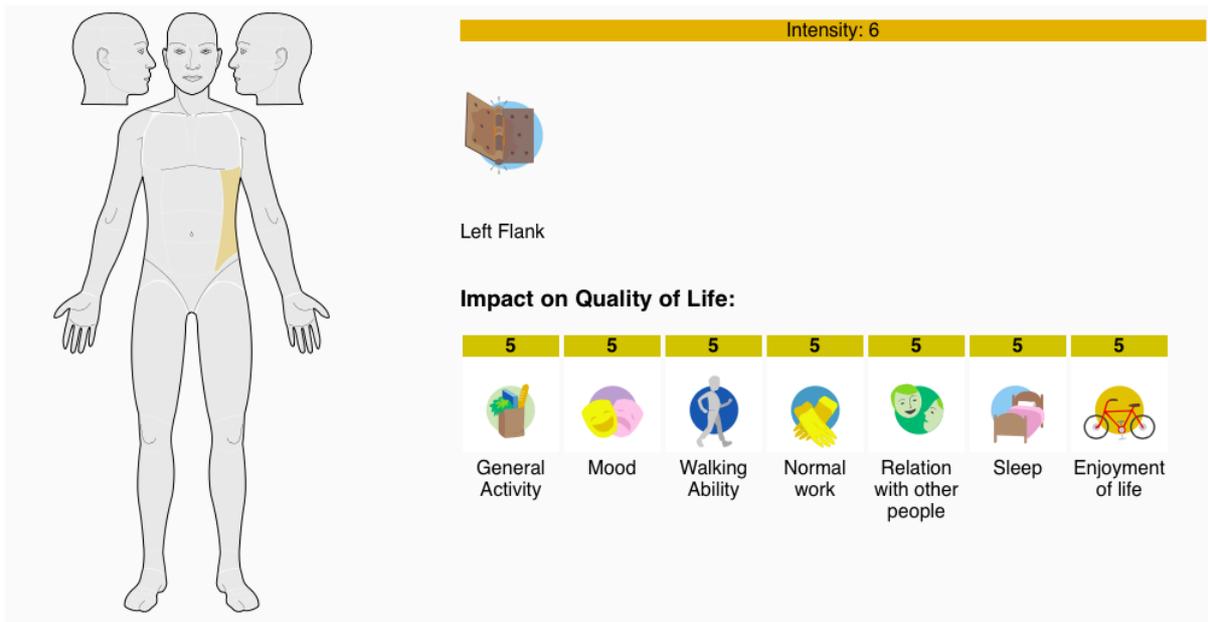
Selected areas marked as 5/10 and stiffness

Provide a note about this pain (*optional*)

Add Another Pain

Confirm

Figure 36. Summary screen including impact of pain (PainQuILT™, 2017)



C.7. Email



Tue 14/11/2017, 2:43 PM
Hannah Stott



Download Save to OneDrive - UWE Bristol (Staff)

Hi Hannah

Thanks!

The data are stored on a server at our software developer in Ontario. However, the app does not collect or store any PHI (personal health information) - users sign up using an email address and their pain data are linked to that email address rather than to a name, location, etc.

The icons were developed through an iterative process during my graduate work. I conducted qualitative semi-structured interviews with adolescents and adults with different types of chronic pain to develop and refine the icon library. Some of this content validation work is described in the attached paper. The icons were not chosen based on the McGill, however, based on patient feedback, there is some overlap between PQ and MPQ in terms of the pain qualities that were identified as important. I actually did a direct comparison study between the PainQuILT, MPQ, and Brief Pain Inventory in terms of patient preferences – available [here](#).

Chitra

Chitra Lalloo, BHSc, PhD
Research Associate

C.8. Bath Body perception disturbance scale[©]

Developed by Lewis, J.S. (2008) The Royal National Hospital for Rheumatic Diseases Bath, England. v2. All rights reserved. Content reproduced with permission.

Bath Body Perception Disturbance Scale

Participant name: _____ Date: _____

Diagnosis: _____ Date of symptom onset: _____

Body part affected: 1. _____

2. _____

3. _____

1. On a scale of 0-10 how much a part of your body does the affected part feel?
Very much a part = 0__1__2__3__4__5__6__7__8__9__10 = Completely detached

2. On a scale of 0-10 how aware are you of the physical position of your limb?
Very aware = 0__1__2__3__4__5__6__7__8__9__10 = Completely unaware

3. On a scale of 0-10 how much attention do you pay to your limb in terms of looking at it and thinking about it?
Full attention = 0__1__2__3__4__5__6__7__8__9__10 = No attention

4. On a scale of 0-10 how strong are the emotional feelings that you have about your limb?
Strongly positive = 0__1__2__3__4__5__6__7__8__9__10 = Strongly negative

5. Is there a difference between how your affected limb looks or is on touch compared to how it feels to you in terms of the following:

Size Yes No _____

Temperature Yes No _____

Pressure Yes No _____

Weight Yes No _____

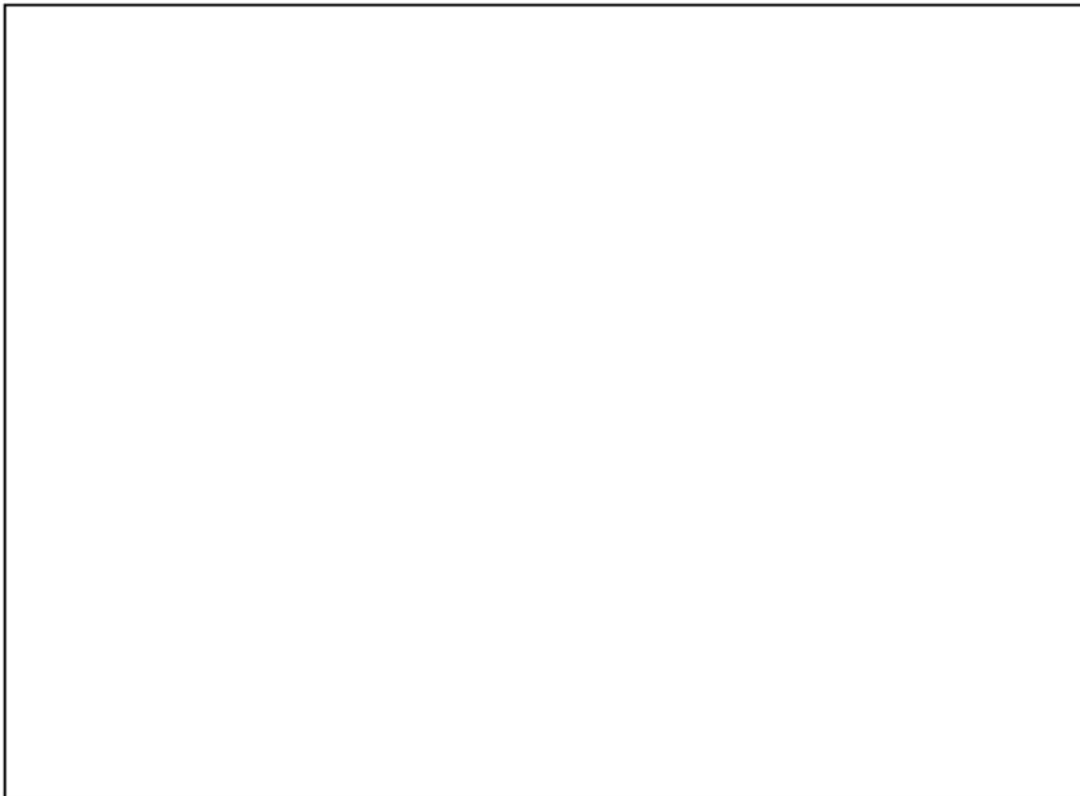
6. A. Have you ever had a desire to amputate the limb? Yes No

B. If yes, how strong is that desire now?

Not at all = 0__1__2__3__4__5__6__7__8__9__10 = Very strong

Desired amputation site: _____

7. With eyes closed describe a mental image of your affected and unaffected body parts (drawn by assessor during patient description then verified by the patient)



This is an accurate account of my image of my affected body part.

Signature _____ Date _____

C.9. Body Perception Tool

The Body perception tool was developed at University of the West of England by Turton, Palmer et al. (2013). Any further use or copying of these images must be granted by University of the West of England (UWE). All images used with permission.

The functions of the body perceptions tool are outlined below via Figures 37 to 42.

Figure 37. Home screen with functions

Body sections can be selected and altered perceptions applied. Body areas are hand, lower and upper arm, chest (left and right), head (left and right), stomach, pelvis/groin, thigh, knee, lower leg, foot. Functions to change position, scale, appearance and sensation can be applied.

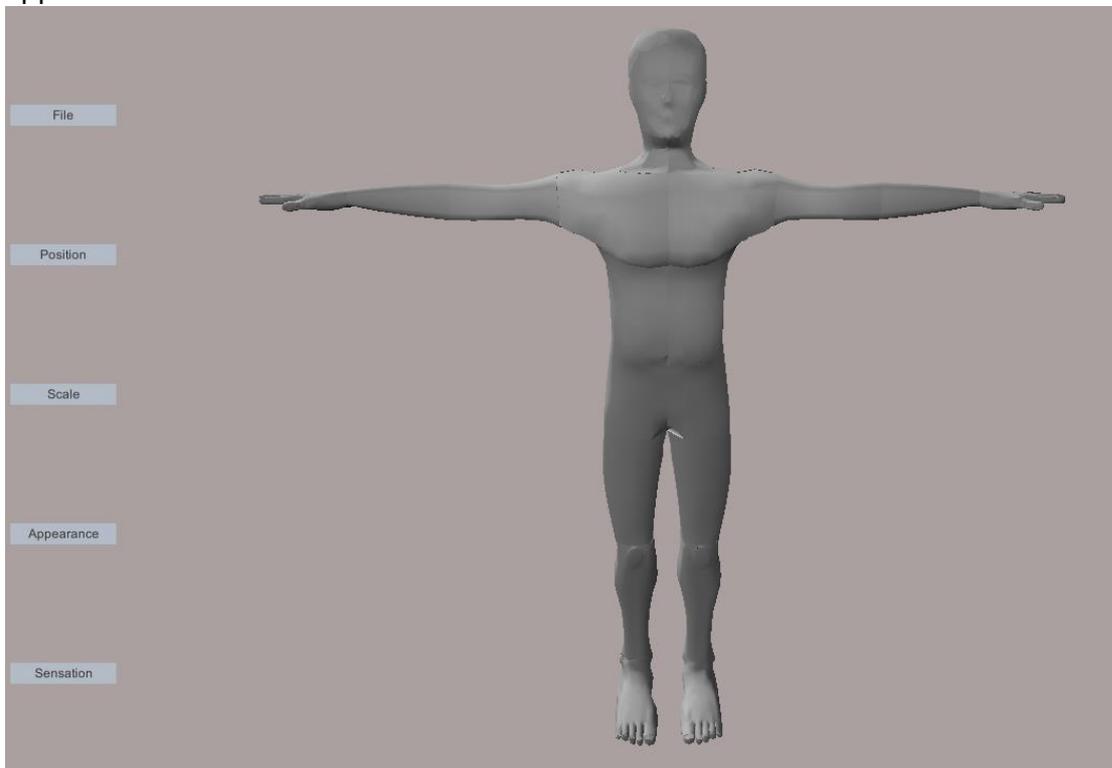


Figure 38. Body rotation

The avatar can be rotated 360 degrees and tilted back and forward

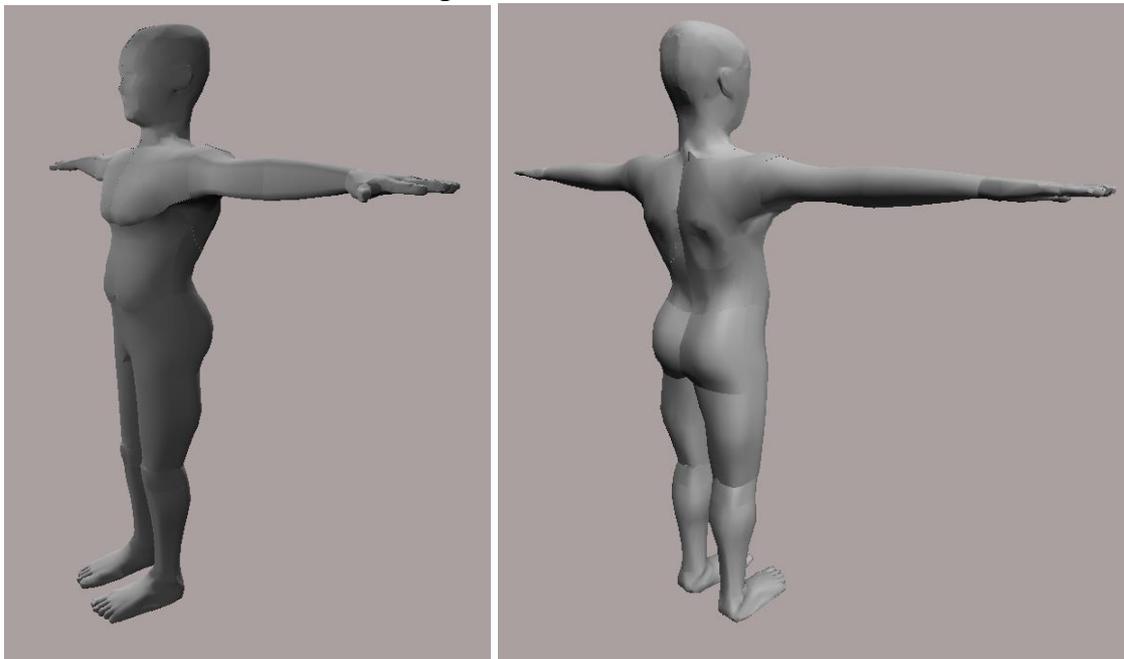


Figure 39. Scale

Limbs can be selected and made thicker, thinner, longer, larger all over via selecting the body area and using the slider functions

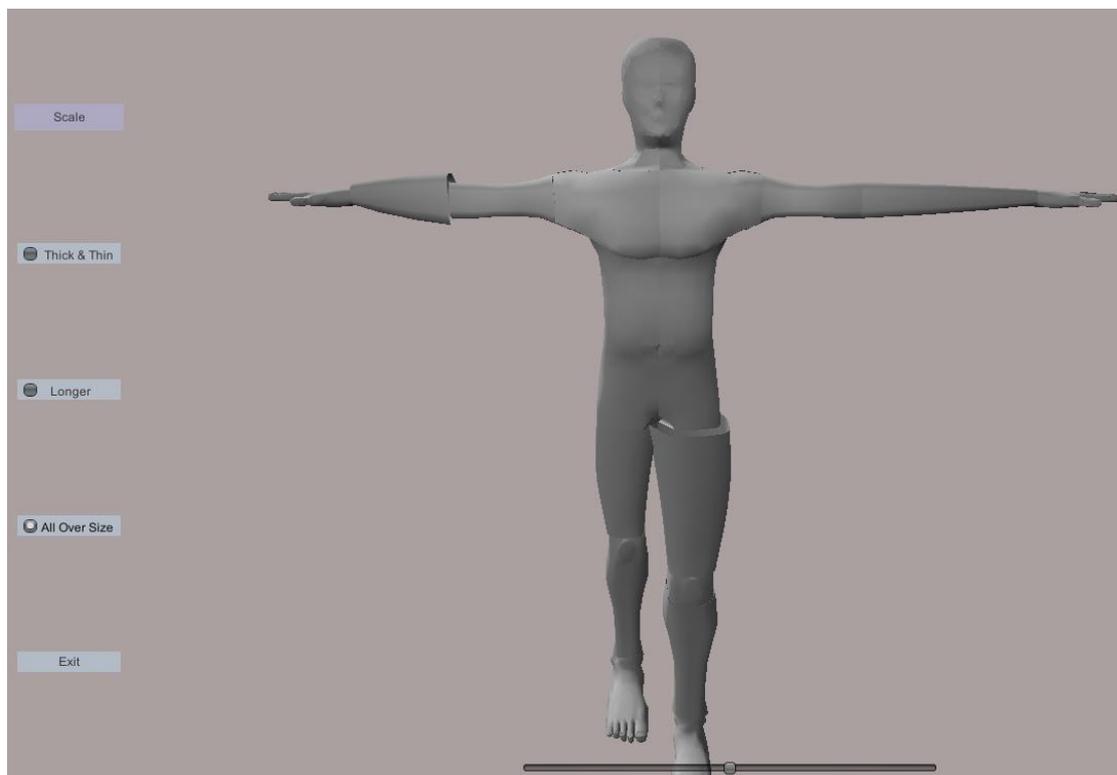
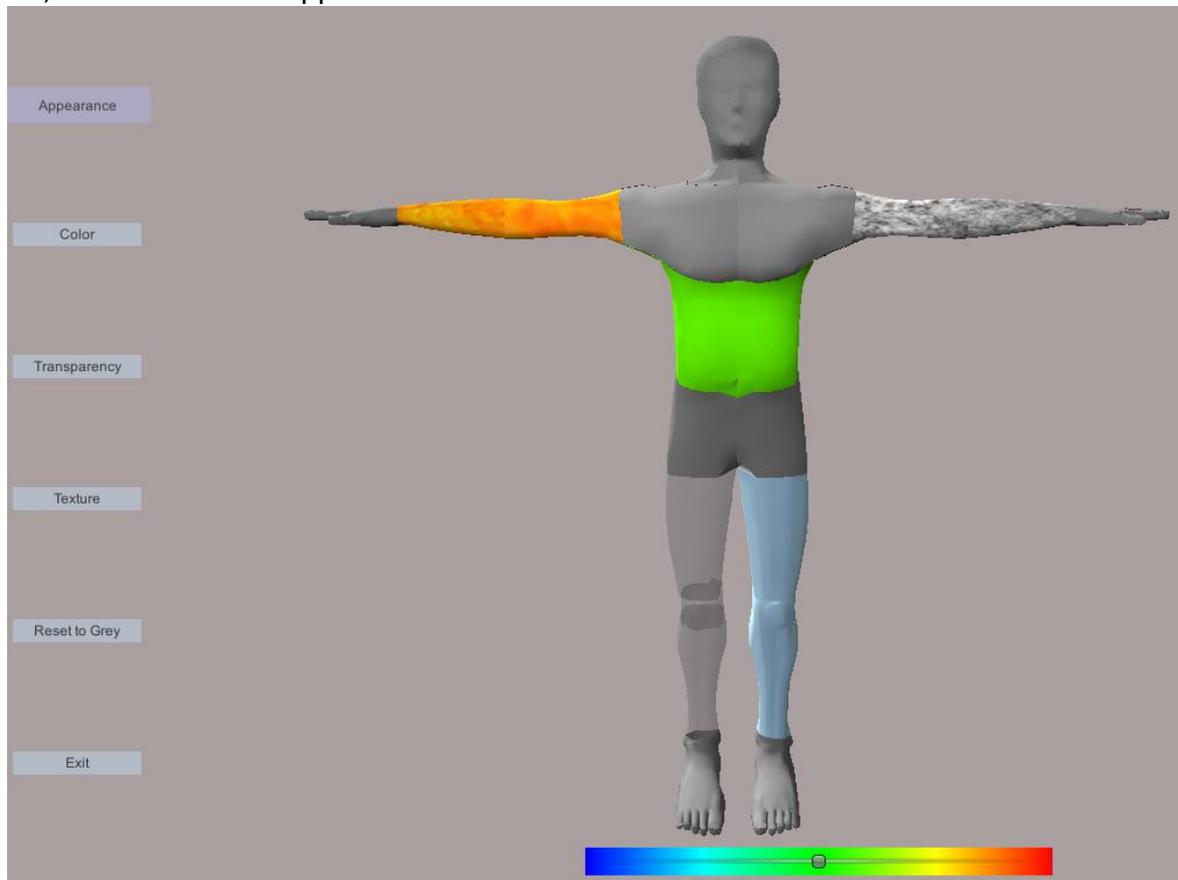


Figure 40. Appearance

Body areas can be selected and colour, transparency and 'textures' including perceptions of ice, stone fire can be applied



Visual icons to alter 'texture'



Figure 41. Position

Limb position can be altered as follows: 'up and down', 'side to side', 'depth' and 'rotation'

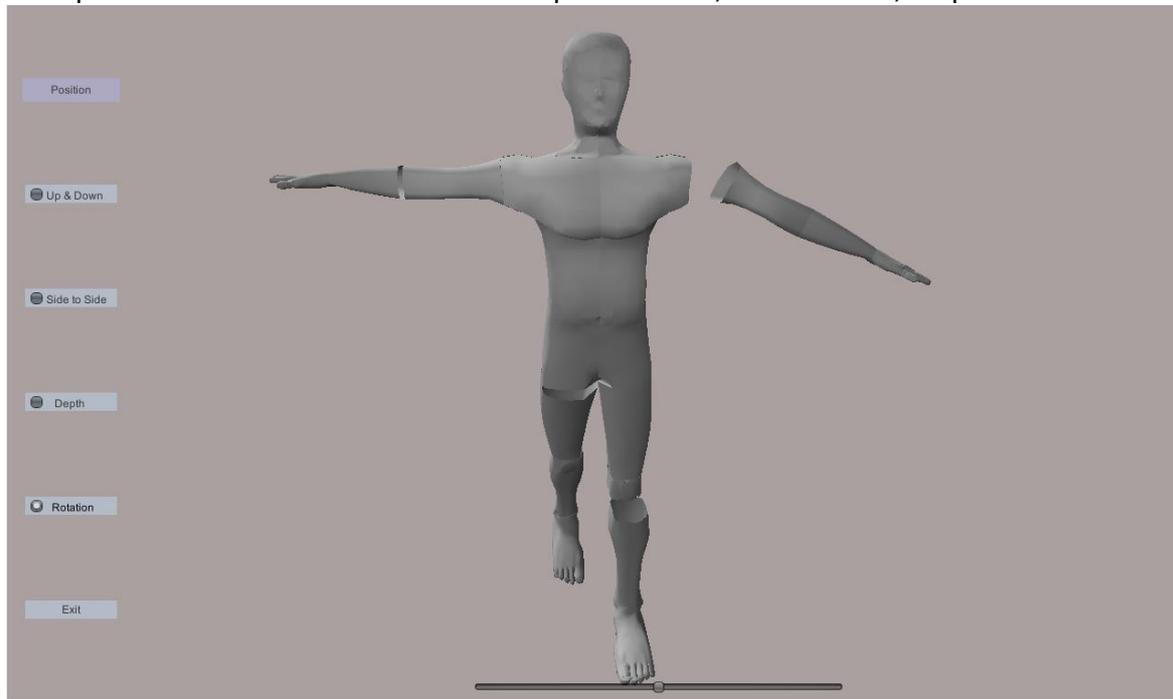
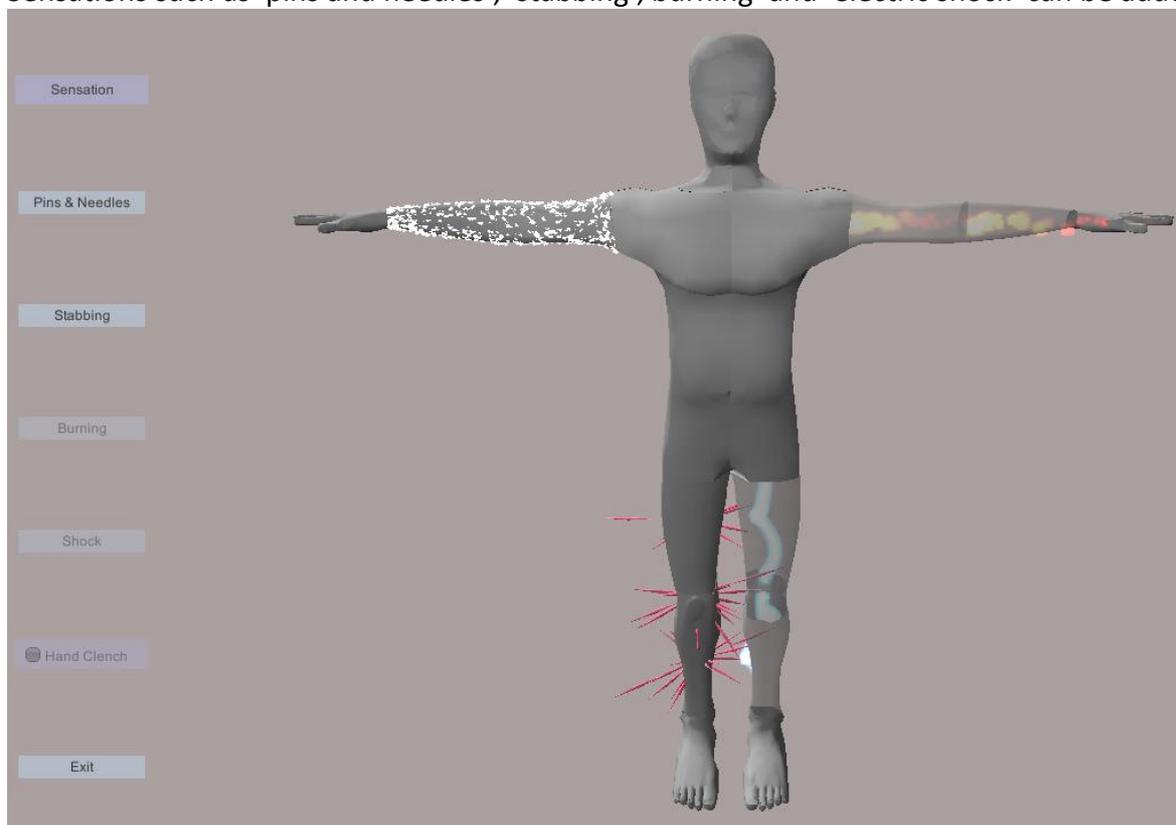


Figure 42. Sensation

Sensations such as 'pins and needles', 'stabbing', burning' and 'electric shock' can be added

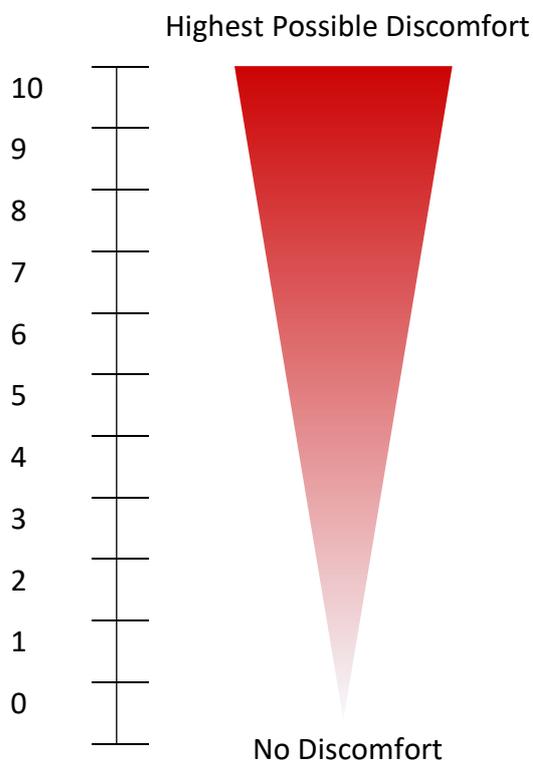


C.10. Visual Discomfort Rating Scale

This concept of using a visual analogue scale to measure discomfort has been explored by Kolcaba and Steiner (2000). A version of an unreferenced visual tool was identified via Kolcaba's website: Comfort Line (2010) and was used as the basis for the scale below which was created independently by the author.

The scale was used in conjunction with the Body perception tool described in Appendix C.9.

Figure 43. Visual Discomfort Rating Scale



C.11. Devising the acceptability questionnaires

The two acceptability questionnaires were mapped from the criteria outlined below in Sekhon et al.'s (2017) acceptability framework to assess participant responses to healthcare interventions (Figure 44). These criteria ensured that a broad and holistic understanding of patient acceptability was explored. Figure 45 underneath, shows how the criteria map to the actual questions used in the acceptability questionnaires.

Figure 44. Acceptability framework

Theoretical framework of acceptability developed by Sekhon et al. (2017). Image used with permission.

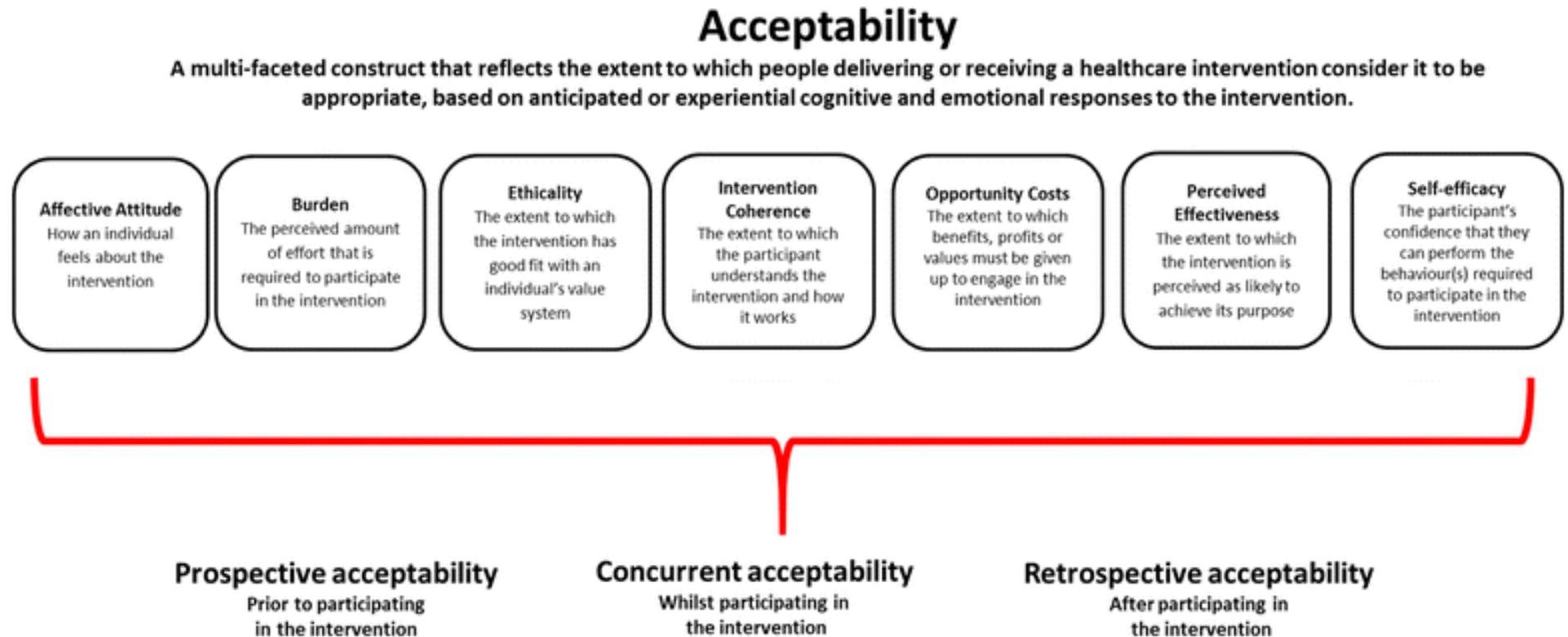


Figure 45. Mapping acceptability questions to fit criteria

Acceptability criteria (Sekhon et al., 2017)	Questions used in the acceptability questionnaires
1. Affective attitude (How you feel about tool)	Q. Did the tool capture your experience of your body/your comfort after stroke? (A. Yes/no) (Meets: 6)
2. Burden (How much effort is it?)	Q. Was there anything else you would like the tool to capture? (A. Open) (Meets: 6)
3. Ethicality (Do you have any worries/consequences of tool?)	Q. How satisfied were you overall with the tool? (A. Scale: satisfied to not at all satisfied) (Meets: 1)
4. Intervention coherence (Understanding what to do/how it works)	Q. What did you like/dislike? (A. Open) (Meets: 1)
5. Opportunity costs (Were there any downsides to using tool?)	Q. How easy was the tool to use? (A. Scale: easy to very difficult) (Meets: 2, 3, 7)
6. Perceived effectiveness (Was it effective?)	Q. What did you find easy/difficult? (A. Open) (Meets: 2, 3, 7)
7. Self efficacy (Can you do it?)	Q. Were you able to understand the tool? (A. Yes/no; If no, expand) (Meets: 4, 7)
	Q. Was the time the tool took acceptable? (A. Scale: acceptable to unacceptable) (Meets: 2, 5)
	Q. Did the tool make you feel worse about your body changes or comfort? (A. Scale: Worse to better) (Meets: 2, 3, 5)
	Q. Is there anything that would improve the tool? (A. open) (Meets: 6)
	Q. Would the tool help you communicate your body changes/comfort more easily? (A. Yes/no) (Meets: 6)

C.12. Acceptability questionnaire

Figure 46. Acceptability questionnaire for single tool

1. How much of how your body feels was captured by the tool?

None Some Most All Don't know

2. How much of your discomfort was captured by the tool?

None Some Most All Don't know

3. How much of the tool were you able to understand?

None Some Most All Don't know

• What was difficult to understand?

.....

.....

.....

4. How easy was the tool to use?

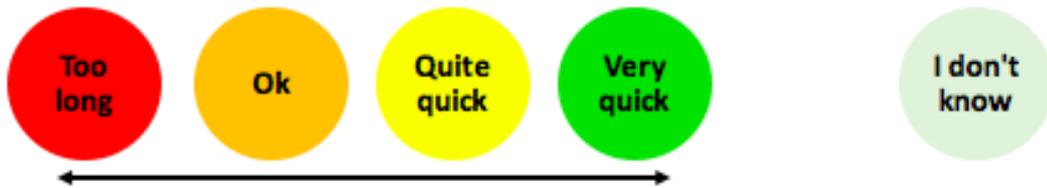
Couldn't do it Difficult Okay Easy I don't know

- What did you find easy or difficult?

.....

.....

5. How acceptable was the time the tool took to complete?



6. How satisfied were you with the tool overall?



- What did you like or dislike about it?

.....

.....

.....

- Is there anything that would make it better?

.....

.....

.....

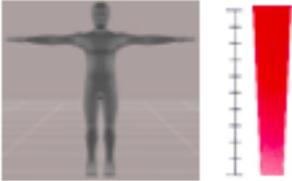
.....

.....

C.13. Overall acceptability questionnaire

Figure 47. Acceptability questionnaire for tools overall

1. Which of the tools was the best at capturing your body changes and comfort?

<p>Body perception tool</p> 	<p>Body disturbance questionnaire</p> 	<p>Pain-QuILT</p> 
---	---	---

2. Did any of the tools make you feel worse about your body changes or comfort?

Yes
 No
 Don't know

- If you felt worse, which tool affected you and what changed?

.....

.....

.....

- Would that feeling put you off using a tool like this again?

Yes
 No
 Don't know

3. Would your favourite tool help you talk about how your body feels to doctors?

Yes
 No
 Don't know

4. After stroke is it important for professionals to assess: (circle as necessary)



- Why is it important to assess what your body feels like and your comfort?

.....
.....

- Why is it important to assess your emotions?

.....
.....

5. When would you like how your body feels to be assessed? (Circle as many as needed)



6. When would you like your emotions to be assessed? (Circle as many as needed)

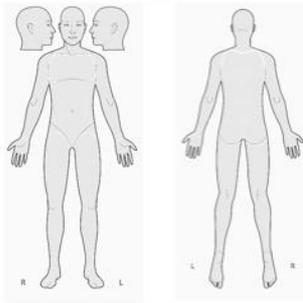
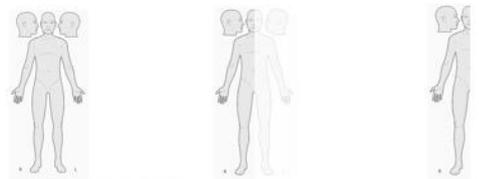
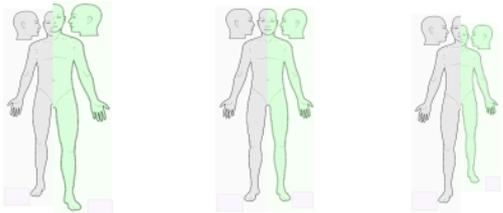


7. Anything else?

.....
.....
.....

C.14. Visual communication aids

Figure 48. Visual communication aids

<p>Body parts</p> 	<p>Sensations</p> 
<p>How do your muscles feel?</p>  <p>WEAKER THE SAME STRONGER</p>	<p>Can you feel the body? Is it part of you?</p>  <p>I can feel everything I can feel it a bit I can't feel anything</p>
<p>Does the more affected side feel a different size or shape?</p>  <p>Bigger The same Smaller</p>	<p>I notice the sensation when...</p>  <p>My body is moving My body is still</p>
 <p>I don't understand Say it again I understand</p>	 <p>I need the bathroom I'm tired I need a break I want to stop</p>



I can't explain it I want to tell you something else I've finished

9



0 1 2 3 4 5 6 7 8 9 10

10

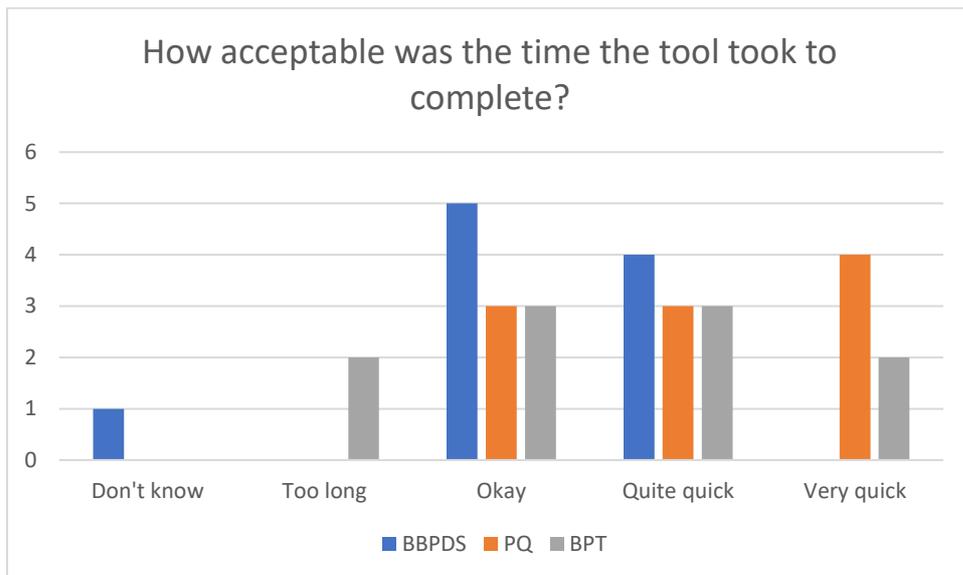
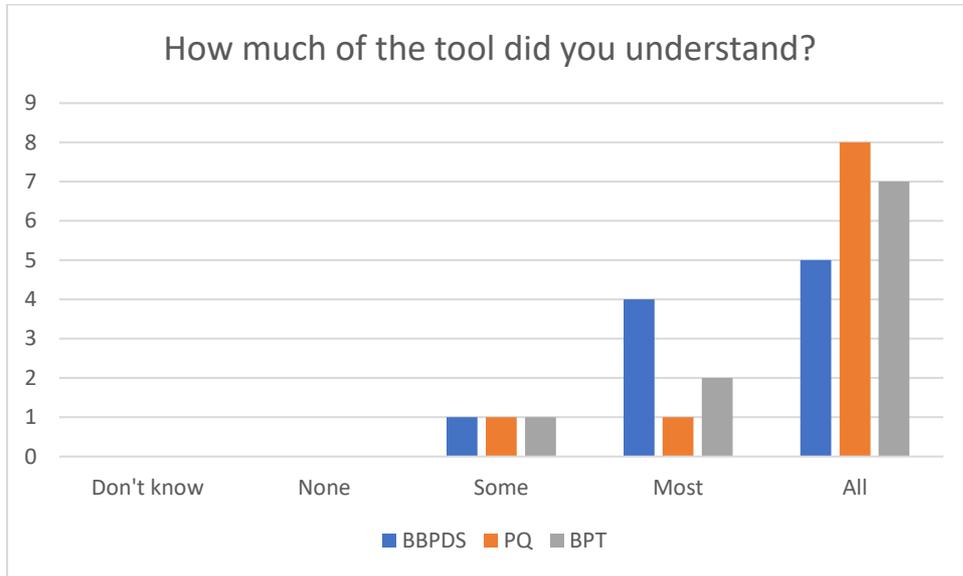


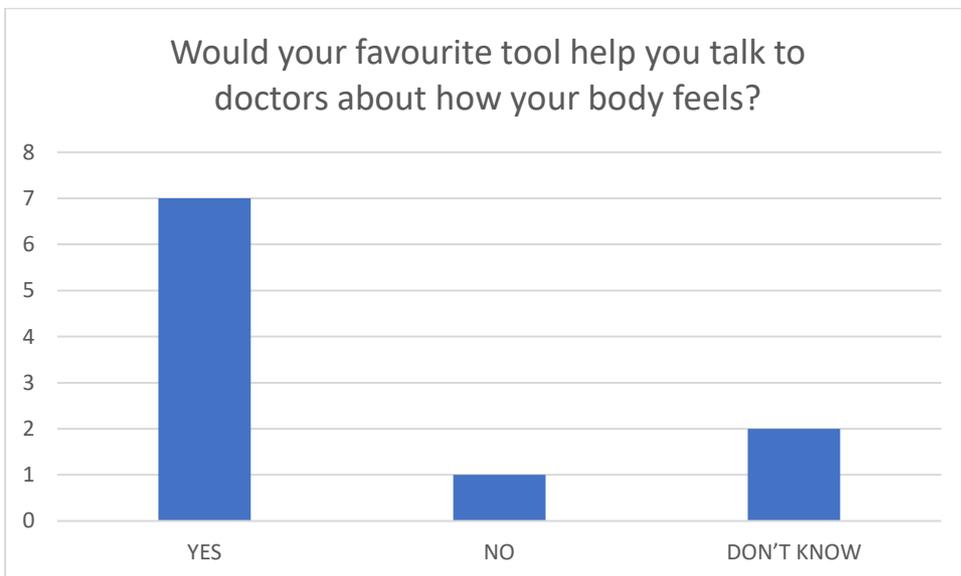
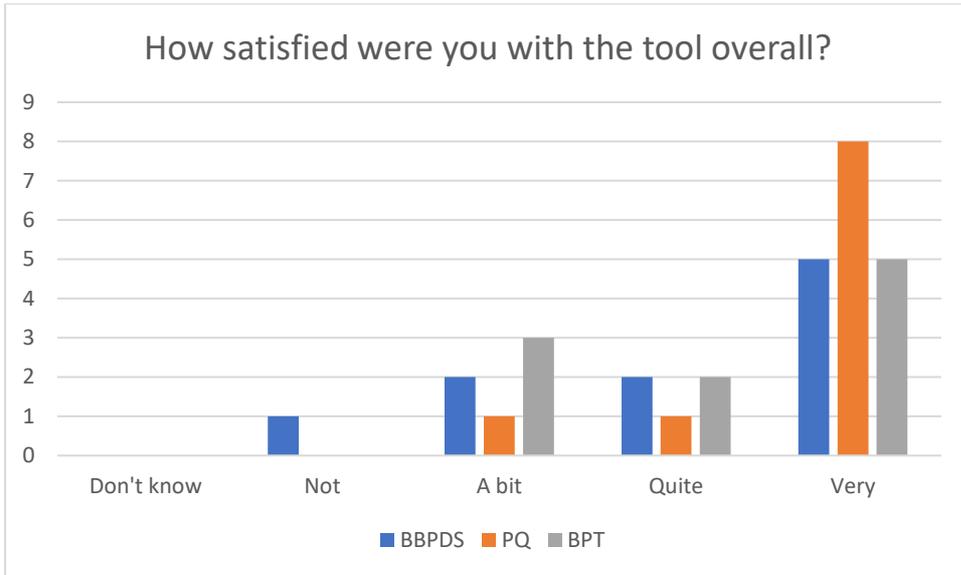
YES NO

11

C.15. Acceptability data

Figure 49. Charts showing overall acceptability of tools





C.16. PainQuILT™ images

One image has been included below to further exemplify the PainQuILT™. This image has been cut and pasted to fit onto one screen – on the tool these ratings appear on multiple screens in list format. The other images were not included because they do not effectively illustrate anything further about individuals' experiences of altered body perception when using this tool.

Figure 50. Example PainQuILT™ image

Janet (59, 9 years post-stroke). Image cut and paste in analysis onto one screen (PainQuILT™, 2017).

The screenshot displays the PainQuILT™ interface for Janet, a 59-year-old patient 9 years post-stroke. The interface is organized into several sections:

- Central Figure:** A human figure with green highlights on the right side of the body, indicating the affected area.
- Intensity 1:** A card with a question mark icon and a list of symptoms: Right Heel, Right TMFirstToe, Right MTFirstToe, Right IPFirstToe, Right TMSecondToe, Right MTSecondToe, Right IPSecondToe, Right TMThirdToe, Right MTThirdToe, Right IPThirdToe, Right TMFourthToe, Right MTFourthToe, Right IPFourthToe, Right TMFifthToe, Right MTFifthToe, and Right IPFifthToe. Note: no pain.
- Intensity 3:** A card with a hand icon and a note: "Note: its a sensation not a pain". Symptoms listed: Right Hip, Left Hip, Pelvis.
- Intensity 3:** A card with a hand icon and a note: "Note: cold to touch but not feeling cold. sensation feels dull." Symptoms listed: Right Knee, Right Hip.
- Intensity 1:** A card with a hand icon and a note: "Note: can't feel stiffness, its not a pain elbow just stops where it is". Symptom listed: Right Elbow Crook.
- Intensity 1:** A card with a hand icon and a note: "Note: reduced sensation all down right side. its annoying not painful". Symptoms listed: Right Shoulder, Right Upper Arm, Right Elbow Crook, Right Forearm.
- Intensity 1:** A card with a hand icon and a note: "Note: dull annoying not painful". Symptoms listed: Right Thigh, Right Knee, Right Calf, Right Ankle.
- Intensity 1:** A card with a hand icon and a note: "Note: cold to touch, jelly feeling - like having hand in jelly. its a sensation rather than a feeling". Symptom listed: Right Wrist.
- Intensity 1:** A card with a hand icon and a note: "Note: cold to touch, jelly feeling - like having hand in jelly. its a sensation rather than a feeling". Symptoms listed: Right Knee, Right Calf, Right Ankle.
- Intensity 1:** A card with a hand icon and a note: "Note: cold to touch, jelly feeling - like having hand in jelly. its a sensation rather than a feeling". Symptom listed: Right Palm.
- Impact on Quality of Life:** A chart showing scores for various life domains:

Domain	Score
General Activity	2
Mood	10
Walking Ability	0
Normal work	10
Relation with other people	10
Sleep	10
Enjoyment of life	5

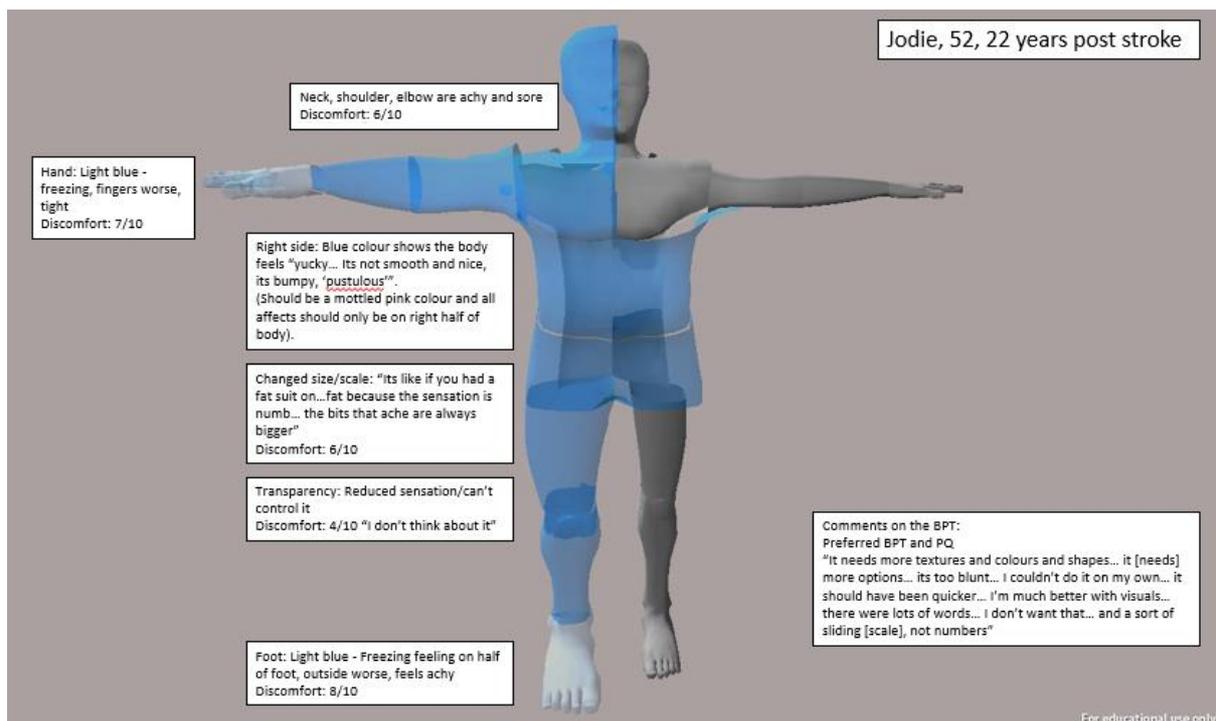
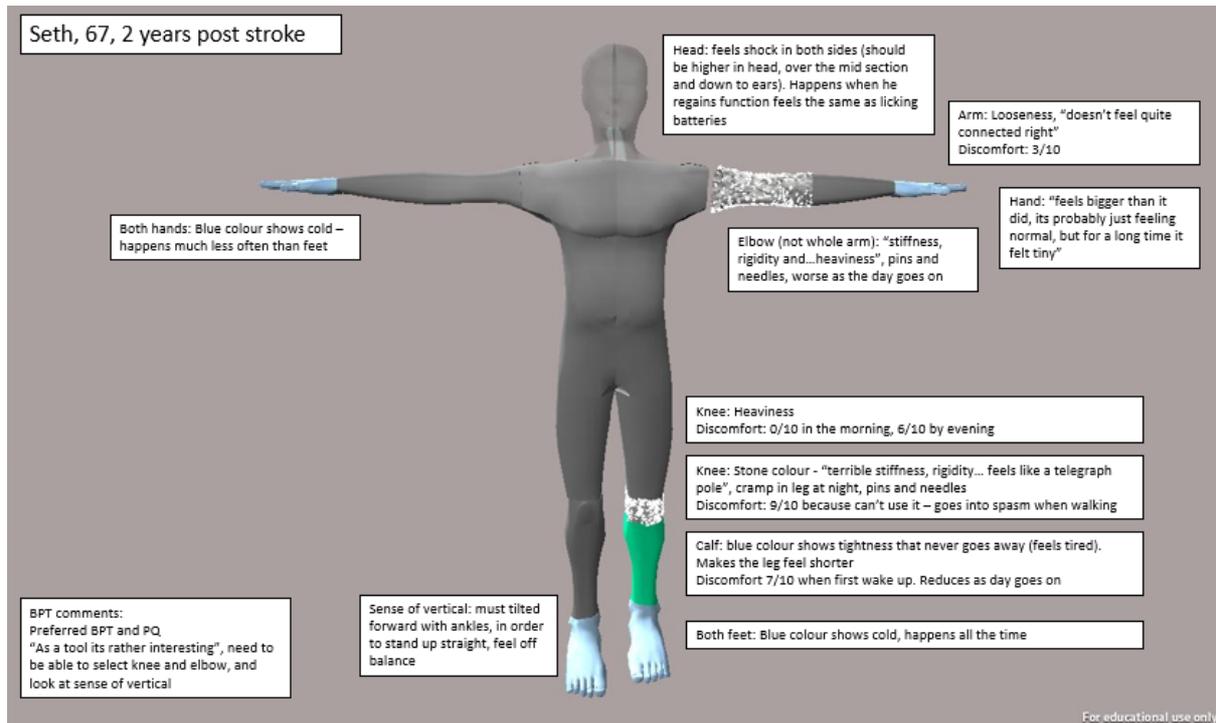
Copyright© (2014) McMaster University, Hamilton, Ontario, Canada. Used with permission. Any further use or copying of this image must be granted by McMaster Industry Liaison Office – MILO.

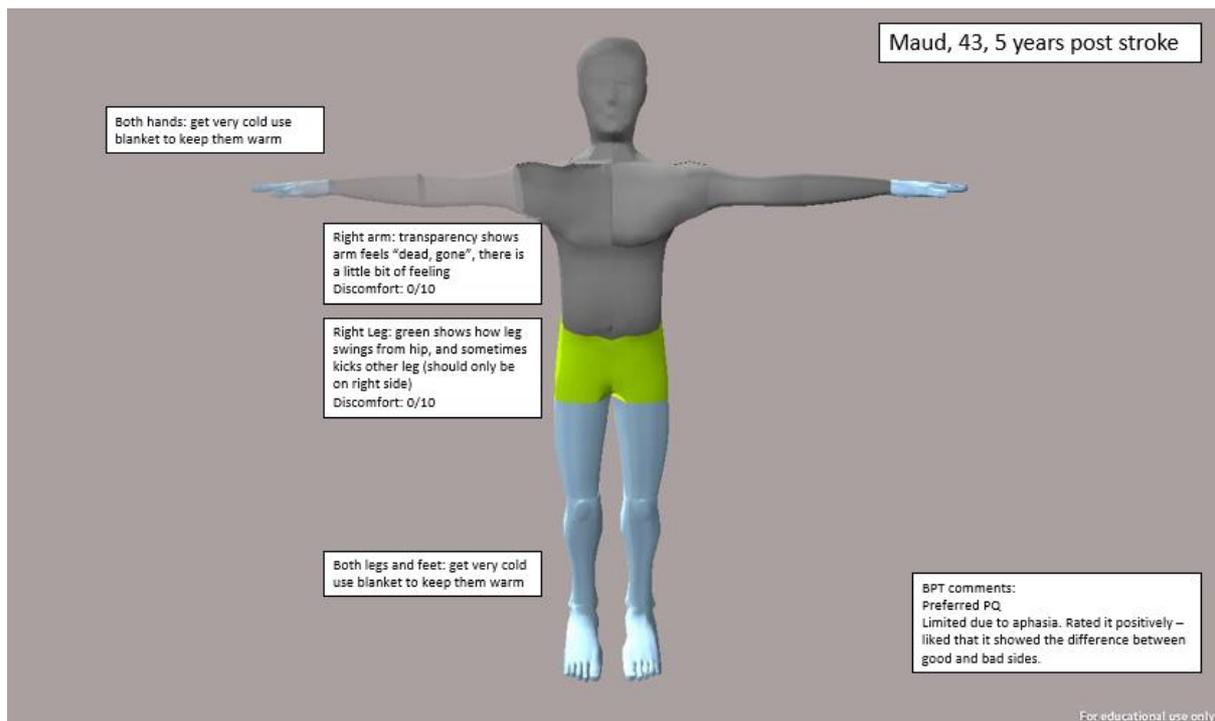
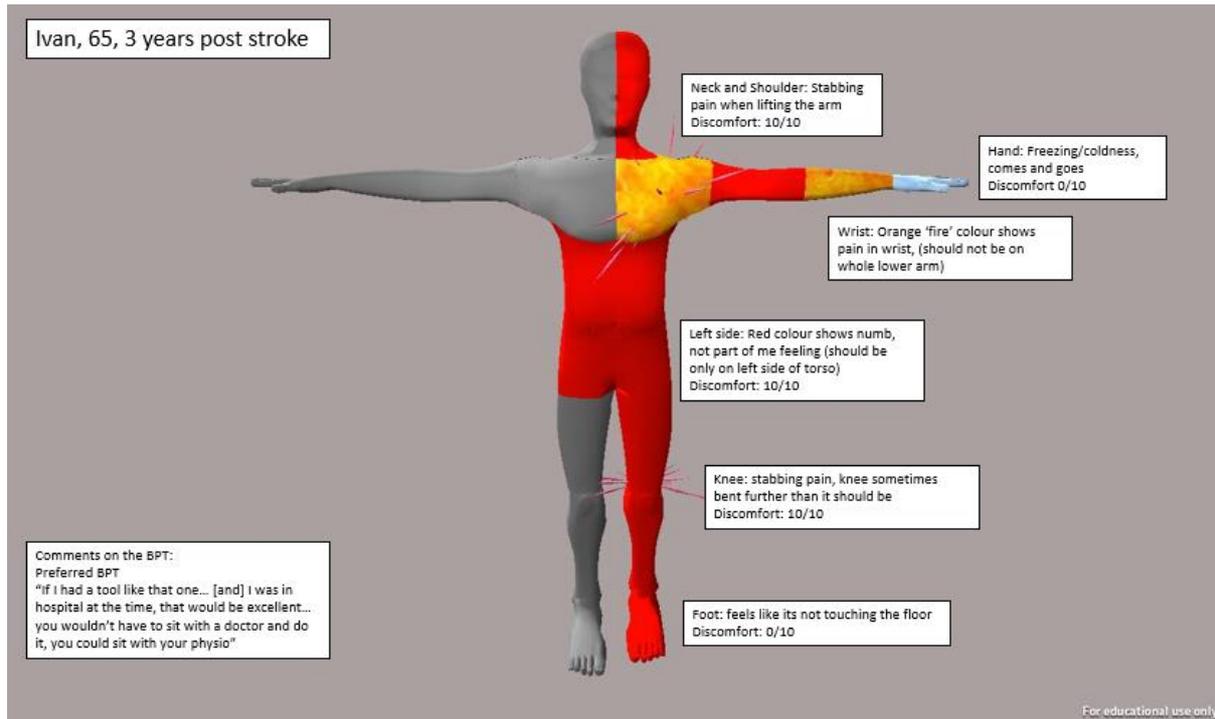
C.17. Body Perception Tool images

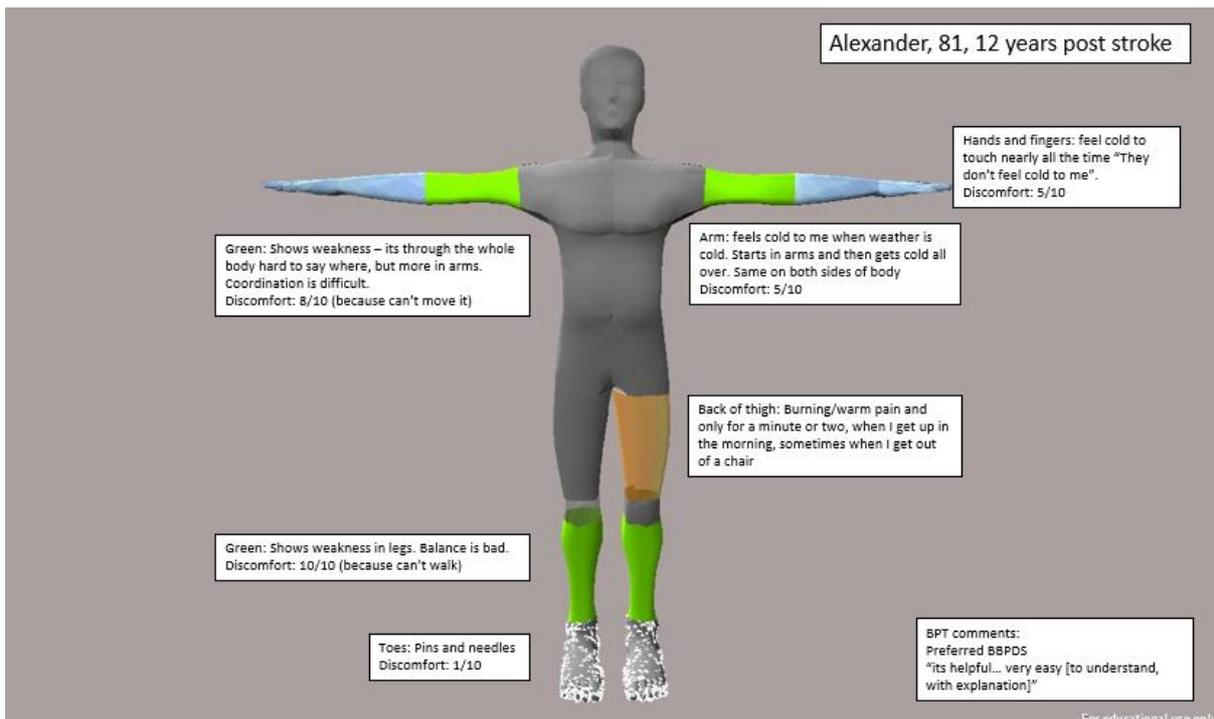
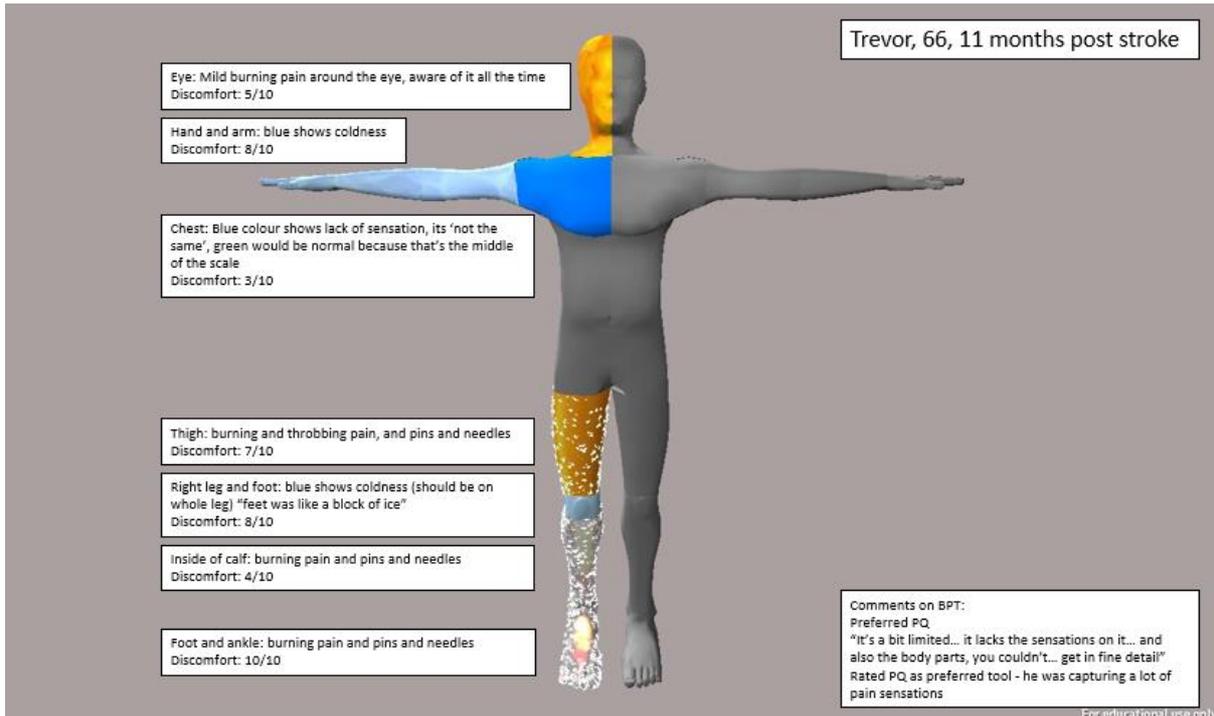
Any further use or copying of these images must be granted by University of the West of England (UWE). All images used with permission. (Turton and Palmer et al., 2013).

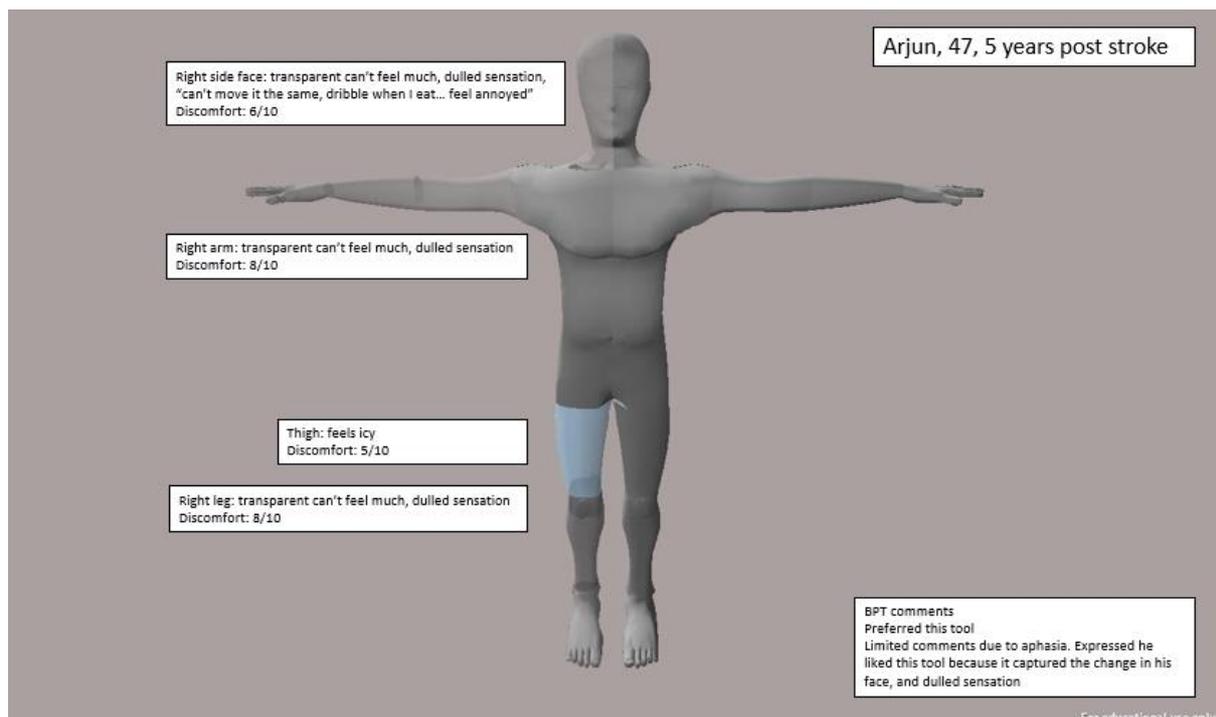
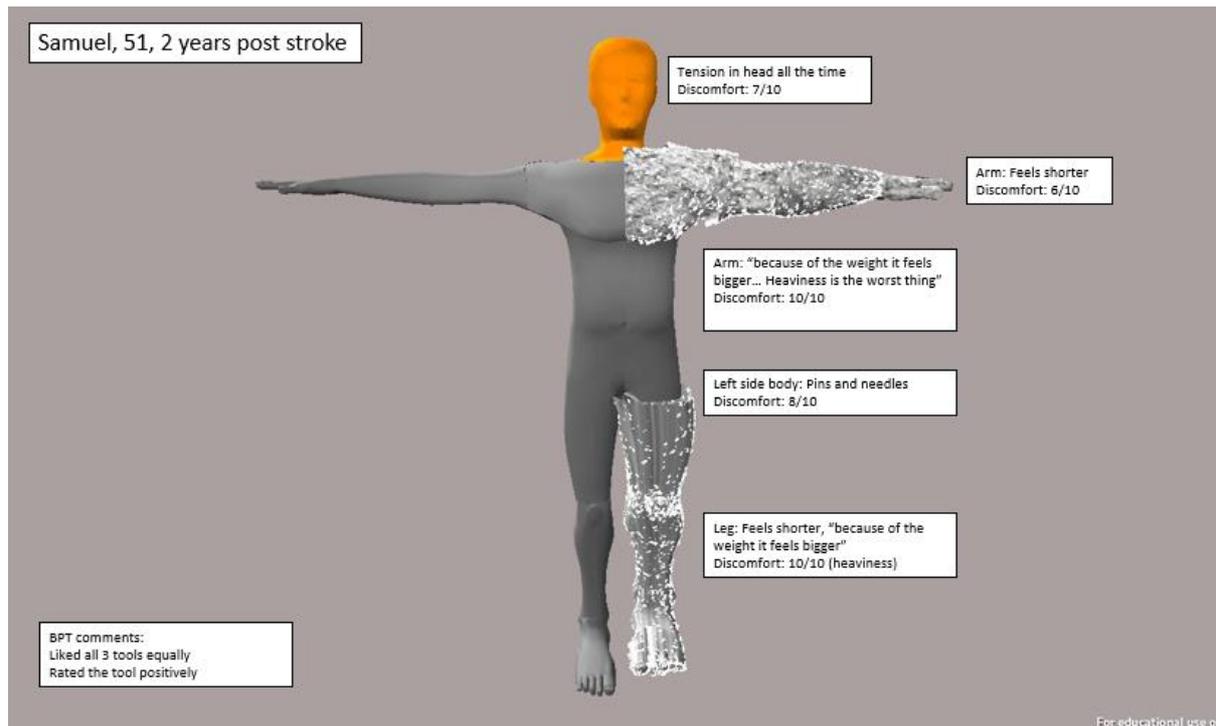
Figure 51. Body Perception Tool images for eight participants

Ten images were created in total. Eight are included here and the remaining two images are included in thesis text (Chapter 6, Figure 15).









C.18. Bath Body perception disturbance scale[®] images

Three images of participants' descriptions of the body with their eyes closed and drawn by the interviewer, are included below. These are derived from the Bath body perception disturbance scale devised by Lewis and McCabe (2010). These images were selected for inclusion because they show the diversity of experiences participants tried to capture and which images were more successfully translated in terms of reflecting patient experience and providing useful information for how the body schema is being represented without visual input. Participants were less satisfied with the interviewers' drawings as a means of reflecting their experience of altered body perceptions, unless they were capturing more simplistic changes such as those in Figure 54. Not all participants' images were included because they did not effectively represent the experience of altered body perception.

Figure 52. Bath Body perception disturbance scale[®] image: Seth

Seth (67, 2 years post-stroke) described multiple altered body perceptions with his eyes closed which were difficult to capture in this format and did not reflect the altered body schema in the way the image is intended to be used. He added the stick man drawing to the right to describe his altered perception of balance.

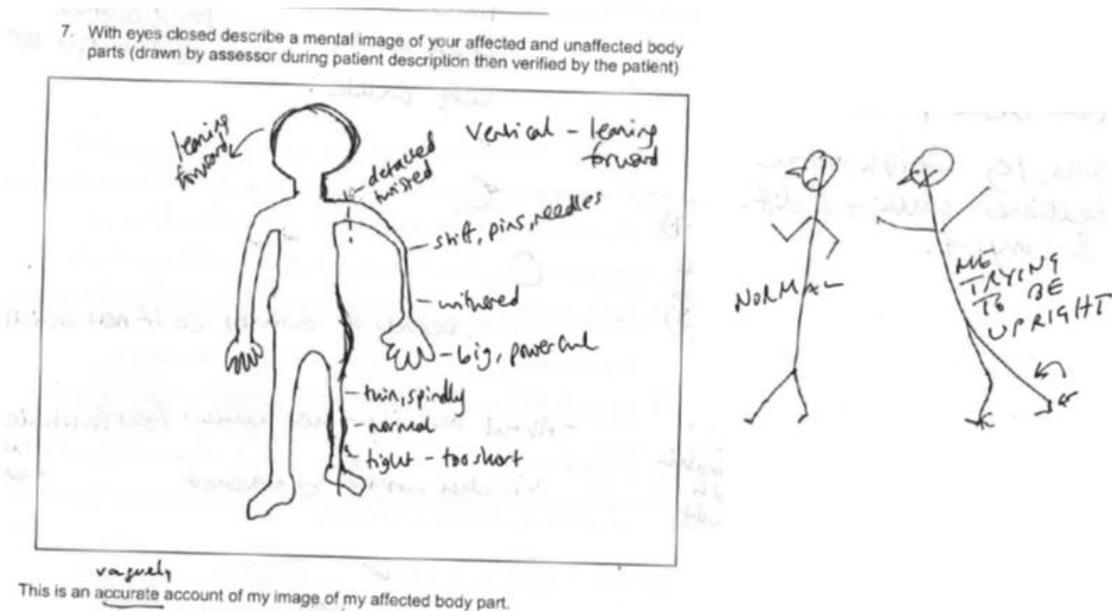


Figure 53. Bath Body perception disturbance scale[®] image: Samuel

Samuel (51, 2 years post-stroke) predominantly described altered perception of limb size and weight which was more easily captured via drawing by the interviewer.

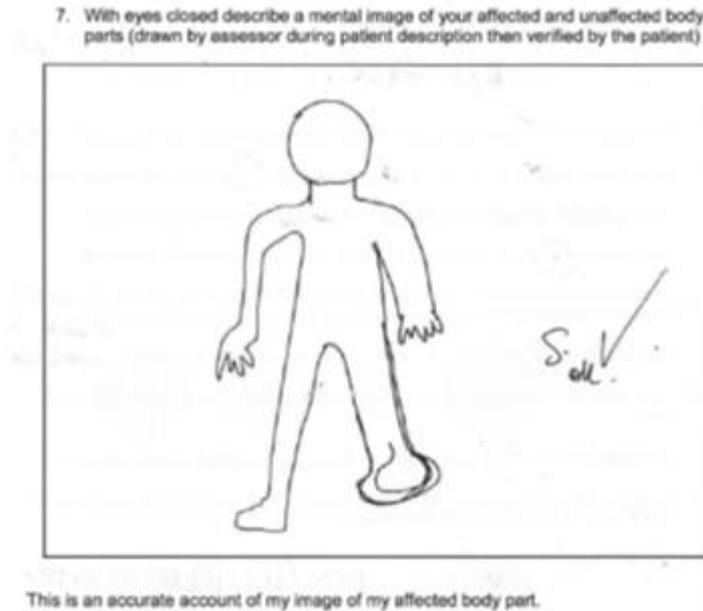


Figure 54. Bath Body perception disturbance scale[®] image: Arjun

Arjun (47, 5 years post-stroke) only described perceptual loss on his right side which was easily captured via interviewer drawing and reflected the type of altered mental image which is intended to be captured by this process – reflecting the changed body schema without visual input.

