eHealth and the Delivery of Person-Centred Care for Children with Life-Limiting Conditions: a Realist Evaluation

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Dedication

Writing this thesis would not have been possible without the support and encouragement of colleagues, family and friends over many years. In particular I would like to thank Drs Tim French and Louise Newbury who encouraged me to follow my heart into the field of children's palliative care, and (the late) Professor Margaret Fletcher who spurred my first tentative steps towards academia. More recently my supervisors Toity Deave, Antonia Beringer and Andy Gibson provided the academic guidance and support for this project from its embryonic stage, nurturing it, and me, through assorted life events along the way – I am so very grateful for your input over the last six years. Most crucially, this work would never have happened had the families of patients not been so generous with their time, their feedback, and their ongoing support since the earliest days of the MyQuality project ten years ago.

Maintaining momentum through multiple delays and interruptions to study has been difficult at times, but PhD life has been beautifully balanced by the encouragement of friends and family, in particular my cycling buddies, arty pals and music mates – thank you for listening ad infinitum and never doubting that I would finish eventually. I'm especially grateful to my PhD colleague Linda, who shared my discovery of realist methodology and provided valuable solace and laughter in the process.

Last but not least, I am indebted to my family for their unbending support over many years: my parents who always encouraged ambition and led by example, my children who never questioned the wisdom or sacrifices required to venture into a new career at this stage in life, the dog who sat by my feet patiently waiting for "the right time" to go for a walk and didn't pester when the writing was in full flow, and most especially my dear husband Andy, who has stood by me through all the ups and downs of the last six years. I can't thank you enough.

Abstract

Background: Children with life-limiting conditions have complex healthcare needs, creating associated “patient work” for their families and requiring multiple interactions with healthcare professionals (HCPs). Ehealth provides opportunities to enhance communication and support person-centred care, but when and for whom is this most useful, and why?

Method: a realist evaluation of use of a bespoke website (MyQuality) for patients with life-limiting conditions and their families, incorporating individualised outcome measurement with an interactive graphic interface accessible to HCPs. The evaluation considered the views of 15 patients/parents and 10 HCP teams about this approach, building on communications models by Brundage and Kujala to develop and refine theories. Self-Determination Theory framed the analysis of deeper mechanisms influencing the delivery of person-centred care.

Findings: For patients and their parents, MyQuality use supported life at home through efficient and meaningful documentation of daily life, facilitating reflection and improving understanding about the day-to-day variability in their child’s needs, increasing the parents’ sense of autonomy and competence. HCPs reported it helped to understand their patients’ needs and support these proactively, but only if adequately trained and resourced to meet the needs identified by patients. The patient-controlled content and access triggered concerns for some HCPs about the extent and remit of their role, and trustworthiness of data. Sharing information enabled more efficient prioritisation of needs during subsequent healthcare encounters, shared decision-making based on reliable information, and facilitated development of patient/HCP partnerships, thus supporting person-centred care.

Conclusion: This form of ehealth was welcomed by both individual patient/parent users and by many professionals, as it highlighted the perspective of the child and parents in healthcare dialogue. HCPs who struggled to engage with MyQuality described challenges to their professional autonomy, perceived limitations of their competencies, with subsequent difficulties maintaining supportive relationships with families. Future ehealth implementation needs to include recognition and support for the basic psychological needs of HCPs in order to improve communication and person-centred care, and simultaneously support workforce resilience.

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List of Abbreviations

ACT	Association for Children with life-limiting or life-Threatening conditions
CMOc	Context-Mechanism-Outcome Configuration
CPAP	Continuous positive airways pressure
CPC	Children’s palliative care
DLA	Disability Living Allowance
EHCP	Education, Health and Care Plan
GP	General Practitioner
HCP	Health Care Professional
HRQoL	Health-related Quality of Life
IOM	Individualised Outcome Measure
LLC	Life-limiting condition
LLI	Life-limiting illness
LTC	Life-threatening condition
MRT	Middle Range Theory
MyQuality	Measure Yourself Quality of Life Tool
PC	Palliative care
PCC	Person-centred care
PROM	Patient-reported outcome measure
PT	Programme Theory
TAC	Team Around the Child

Glossary of Terms

Children's Palliative Care &/or Service provision terminology – see also chapter 2

Child:	an individual under the age of 18 years
Young Person:	variably defined in clinical practice, from a lower limit of 12-16 years old to a higher limit of 18-25 years old. Services for young people may be provided by adult services from the age of 16 (hospital wards and much healthcare provision), 18 (social care), 19 (special needs education), or 21 to 25 (many hospice services).
Parent:	for the purposes of this thesis, I have defined all participants acting in a parental role as "parents", be they the biological parents, foster parents, adoptive parents, step-parents, grandparents or legal guardians of the child with the health condition.
Patient:	for the purposes of this thesis, the "patient" is the child or young person with a health condition who is receiving support from healthcare providers. When discussing communication, the "patient" may include the parents (defined as above) as those receiving healthcare support, in contrast to those whose professional role is to provide healthcare support.
Palliative Care:	Supportive holistic care where the focus is on improving the quality of life of an individual rather than to extend life at all costs. Palliative care is often considered synonymous with end-of-life care, or terminal care.
Children's Palliative Care:	a holistic approach to supportive care for the child and family, extending from the time of diagnosis of a LLC, to care

	as death approaches, and bereavement support for the family. It addresses physical, psychological, social, practical and existential issues.
ACT categories:	A classification devised in the 1990’s to indicate likely illness trajectory and palliative care support. It includes treatable conditions where cure is possible but might fail, conditions where treatment is exclusively palliative from diagnosis because cure is not possible, those where intensive treatment may be possible but the underlying condition is incurable, and static conditions where accumulations of complications result in an increasing likelihood of premature death (Chambers, 2015).
LLC:	Life-limiting conditions, where there is no reasonable hope of cure and from which children or young people will die. This includes many chronic illness or genetic conditions, or long-term sequelae of events such as trauma or premature birth. Many parents use this phrase in preference to LLI if their child has an underlying condition which is not curable but may be “well” rather than “ill”.
LLI:	Life limiting illness, where there is no reasonable hope of cure and from which children or young people may die. Many parents use this phrase in preference to LLC for acquired conditions, in the hope that their child will return to normal if cure or life-saving intervention becomes possible.
LTC:	Life-threatening condition, where curative treatment may be feasible but can fail, such as cancer treatment.
CPAP:	Continuous positive airways pressure, a form of support for those with breathing difficulties where air (+/- oxygen) is directed into the lungs at pressure to keep the airways open.

BiPAP:	Breath-initiated positive airways pressure, Intermittent positive airway pressure to support breathing in those whose respiratory muscles are weak.
Catheterise:	To pass a tube into the body – typically into the bladder to drain urine, but the word can also be used to refer to access blood vessels and other bodily spaces.
Gastrostomy/PEG:	A gastrostomy is an opening in the abdominal wall, directly into the stomach. A tube through this opening allows food, fluid and medicines to be given directly into the stomach, bypassing the mouth and throat for those with swallowing difficulties. PEG feeding refers to the use of the Percutaneous Enteral Gastrostomy to administer nutrition.
Hyperphagia:	insatiable appetite, always reporting hunger even when fed
Metabolic Disorder:	In children, these refer to genetic conditions resulting in abnormal metabolism. In many cases a defective gene results in an enzyme deficiency, resulting in faulty cellular processes in the body, or a build-up of toxic chemicals. This can cause a wide range of symptoms, with variable treatment and prognosis.
Neurodegenerative conditions:	a range of incurable, debilitating conditions that result in progressive loss of structure or function of nerve cells. This may lead to the loss of mobility, vision, cognitive function, or the development of new symptoms such as tremor, seizures, and difficulties with co-ordination. In children, previous developmental milestones may be lost.
Seizures:	Also referred to as convulsions or fits, these represent abnormal electrical activity in the brain which may result in loss of consciousness, abnormal movements, absent spells,

	atypical sensory experiences and loss of control of bodily functions. Can be difficult to differentiate from dystonia.
Dystonia:	Abnormal muscle contractions that produce repetitive involuntary twisting movements and abnormal posturing.
Suction:	clearance of mucus or other secretions from airways, by passing a narrow flexible tube attached to a suction pump into the mouth, nose or throat.
EHCP:	Education, Health and Care plan, a legal document from the Local Authority that sets out the education, healthcare and social needs of a child or young person with significant and complex special educational needs or disability, whose needs cannot be met by the usual support that is available to them in their school or setting.
DLA:	Disability Living Allowance, a UK benefit payment for the additional costs incurred when caring for a disabled child. The rate payable is dependent on the level of assistance required (Gov.uk website).
TAC meeting:	Team Around the Child, a multidisciplinary meeting to discuss a child’s progress and needs, bringing together input from parents and professionals in healthcare, social care and education to provide a comprehensive, best-interests consensus for support.
Panel:	Continuing Care Needs Panel – an assessment process for additional support from the NHS if children and young people have needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone (NHS website).

Realist Terminology – see also chapter 3

Programme Theory:	a hypothesis to explain how a specific intervention works.
Context:	In realist terms, the context may refer to aspects of the individual, interpersonal relationships, institution, or societal infrastructure that affect the functioning of a mechanism underpinning an intervention (Pawson, 2013).
Mechanism:	the underlying processes, entities or social structures that, when operating in particular contexts, lead to outcomes (Westhorp, 2014).
Outcome:	the intended or unintended consequences of an intervention or programme (Pawson, 2013)
CMOc:	Context-mechanism-outcome configuration; a heuristic in realist methodology to portray how the context and mechanism lead to an outcome, in a manner that explains how a programme works (Pawson, 1997).
Middle Range Theory:	Generic theories of human reasoning or activity that have relevance to the programme and facilitate understanding or explaining it. They are not specific to the intervention under study (Pawson, 2013).
Abduction:	The thinking process that brings together creativity and expertise to reconceptualise explanations for observations (Mingers, 2004)
Retroduction:	Building on abduction, this is the process of unearthing activated mechanisms in a theory-testing approach to gain a comprehensive causal view of the nature of projects and programmes (Jagosh, 2020)

eHealth Terminology – see also Chapter 2

eHealth:	an umbrella term for access to health information using electronic means. This includes one-way communication to patients who gain access to information via websites; interactive communication methods such as email, text messaging and telephone; social media and on-line support groups; and interactive websites which receive data from the patient and deliver advice on health management in return. Ehealth incorporates both mHealth and telehealth.
mHealth:	interactive management of a patient’s health, using electronic methods of data collection. These may include manual patient entry of data, and automatic data collection via wearable sensors such as “fitbits” and similar activity sensors, and sensors of metabolic data such as blood pressure and glucose levels. mHealth platforms may simply store relevant data for health care professionals to analyse and advise patients, or may use algorithms designed to improve patients’ health through manipulation of their activity, diet, or medication.
Telehealth:	the remote exchange of data between a patient and healthcare professional to assist in the diagnosis and management of health. It incorporates methods of communication such as telephone consultations, and skype or similar audio-visual consultations.
uHealth:	the ubiquitous use of technology for health purposes

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1 Prologue

Modern healthcare aims to prevent or treat conditions which deprive us of our maximal quality of life. Over recent centuries medicine and nursing have evolved from studies of healing to become science-based disciplines. However, by the early 20th century concerns were being raised about the emphasis on science as a basis for medical care (Miles 2011). The tension between a scientific approach to medicine and a holistic, person-centred approach has continued into the 21st century (Bensing 2000).

As a doctor, working in the fields of paediatric oncology and children's palliative care medicine, I was long aware of the importance of holistic care when dealing with patients and their families. I was trained under a system where the tremendous success of evidence-based medicine, particularly in paediatric oncology, was rightly lauded as progress in saving and improving lives (O'Leary et al., 2008; Saletta, Seng & Lau, 2014). As a palliative care clinician I also encountered many patients where evidence to guide best practice was inadequate or sorely lacking, where making best-interest decisions was extremely difficult, and where working closely with families to understand their priorities and wishes was essential to navigate treatment choices when facing uncertain outcomes (Hinds et al., 2005, 2009; Mack et al., 2005; Tomlinson et al., 2011). Over the past 25 years I have had the privilege of meeting and providing care for a considerable number of children living with, and sometimes dying from, significant illness. As poor health imposed challenges on their daily lives, the children and families reacted in ways reflecting their own individual, family or social circumstances. Professionals' interventions – be they medical, psychological or practical – needed to be flexibly and sensitively offered, as there was no "one-size-fits-all" recommendation in these circumstances.

I then had an unexpected opportunity to appreciate the patient's perspective on navigating uncertainty as I developed a malignancy of my own. An arduous treatment regime has (hopefully) cured me, but the experience shone a spotlight on the limitations of evidence-based medicine and the tensions and difficulties surrounding the provision of holistic care in practice. On reflection I was probably a challenging patient, resisting taking advice at face value, asking difficult questions, and struggling to agree to "obvious" treatment recommendations whilst wrestling with my own concerns and priorities for long-term implications of my decisions.

I tried to rationalise my experiences and simplify my decision-making process by using the historical principles of evidence-based medicine: observing and recording changes, looking for recurring patterns and seeking explanations to justify or inform decisions about my future care. Returning to work many months later, I had the opportunity to share my reflections with a number of my patients' families and was surprised at the volume and nature of the responses. Despite feeling that our service was trying to provide holistic care, recurrent themes emerged from patients and families about communicating effectively in the limited time allowed by health service encounters, and the challenges of combining being "a good patient" with being true to your own values and priorities. Many patients and their families had resorted to similar approaches of detailed recording of their health and daily lives in order to support decision-making in uncertain times. From these discussions MyQuality was born: a website to facilitate monitoring and communication of an individual's concerns, aiming to highlight the patient's voice and priorities for care within healthcare encounters. I had no expectation that a website would suit everyone, but it was my intention that it should be made available to those who might find it helpful, free of charge, as a contribution towards improving the quality of the care they needed.

MyQuality was developed in 2011 in a children's hospice setting, where the complexity of healthcare needs and the underlying deterioration in a child's condition meant that quality of life, rather than curative intent, was the driving force behind most medical decisions. The website (www.my-quality.net) allows personal users to identify issues relevant to the quality of their daily lives, and can be used by individual patients or by their families or carers on their behalf. Users are asked to quantify the impact of these chosen issues on a numerical scale (0-10) and describe them in their own words through free text, and monitor change on a daily (or less frequent) basis. This data entry is facilitated by a visual analogue scale to support rapid, sensitive, precise data entry. The numerical interface is accompanied by a free-text diary section for documentation of supplementary detail of daily life. As daily scores are entered, there is instantaneous production of a graph to illustrate change over time. The graphic outputs can be adjusted to show change over variable time periods and in a variety of formats. This output may be shared electronically with selected health and social care providers who have registered with MyQuality, and there is an optional facility to send an email alert to a healthcare professional should any numerical score exceed a predetermined limit. The content and access to the data contained in a user's MyQuality account is entirely controlled by them, not by the health or social care professionals involved in their care.

Over subsequent years MyQuality was introduced into clinical practice in the children's hospice and evaluated for impact (Harris, Beringer & Fletcher, 2015), but questions remained about ensuring a holistic view of the needs of the child and family. It is my intention in this PhD to explore how the use of modern technology and the approaches incorporated in the design of MyQuality may provide a voice for patients and their families in healthcare dialogue and support the delivery of person-centred care. In doing so, I recognise that this is a complex area where the perspectives of different individuals, organisations, and pressures from society as a whole bring a range of views on the processes and desired outcomes of this venture.

In order to accomplish this, I have been drawn to realist evaluation as a methodological approach, as it incorporates the flexibility and sensitivity that is entrenched in my personal approach to healthcare provision, and recognises the complexity inherent in bringing about change in the behaviour and attitudes of individuals and society. A realist asks not whether a social intervention works, but seeks to understand what works, for whom, under what circumstances and why (Pawson & Tilley, 1997). Realist enquiry acknowledges and incorporates variables associated with individuals' circumstances and their reasoning as key factors that determine how an intervention works for people. Further details of this approach are outlined in chapter 3.

In this quest I intend to use my years of professional and personal experience to illuminate the debate with an “insider’s view”. I also recognise that over recent years I have developed and steered the evolution of the website, investing time, energy and emotion into this project whilst doing so. The additional insights available from my involvement throughout this research need to be balanced against the potential risk of bias during this evaluation. I acknowledge this and I will explore the implications of this dual role fully in chapter 4.

In summary, the challenge of this PhD is to delve into the “black box” of factors that influence MyQuality’s contribution to patient care, in a manner that maximises insider knowledge, but retains objectivity, transparency, relevance and usefulness.

1.1 The flow of the thesis

The thesis is divided into 11 chapters. The next chapter summarises the key issues around children’s palliative care, person-centred care, and ehealth and communication in order to contextualise the research, followed by a more detailed assessment of the first MyQuality study to highlight what we know, the gaps in current knowledge, and the development of the research question.

Chapter three introduces the methodological basis for this work, Realist Evaluation, and chapter four details the design of this study and methods used. Following this I will discuss my programme theories and how they have been developed, tested and refined in chapters 5-9, bringing together findings from a realist-informed review of the literature and the data collected as part of the study. Chapter 10 will bring together all the programme theories and relevant middle range theories and discuss the wider implications of these findings. Chapter 11 is a reflection on the production of the thesis itself, and on the directions for future research.

2 Setting the scene

In order to set the scene for this thesis this chapter will introduce palliative care, person-centred care and ehealth to outline current knowledge and highlight areas requiring further clarity. Whilst all are broad topics, they are linked by the common thread of the primacy of the patient within healthcare. Although this concept sounds self-evident, conflicting pressures from society, public policy, economic constraints and technological advances can conspire to render the individual patient relatively invisible, inaudible, and insignificant (Currie & Szabo, 2019).

These topics and the way they inter-relate are key to understanding how I have addressed the question of how MyQuality may contribute to improved communication and a person-centred approach to care. This will lead on to a discussion of the research question and a framework to address this.

2.1 Palliative care for children and young people

Palliative care is “a total and active approach to caring for individuals with life-limiting or life-threatening illness, addressing the physical, emotional, psychological, social and spiritual impacts of facing the end of life. The care is holistic, and supports not just the affected individual, but the family, and continues beyond the individual’s death to incorporate bereavement support for surviving relatives.” (Goldman et al., 2006, p6). The healthcare professionals’ attention is focussed on maximising the quality of life, rather than its duration (Richards & Ramirez, 1997). It depends on effective communication and a multidisciplinary approach to caring for the whole family throughout the care continuum (Madhavan et al., 2011).

Facing the death of your child is a parent’s worst nightmare. Professionals who work with dying children and their families look to provide support despite knowing that death of the child, and bereavement for the family, will be inevitable. Although members of the public and many professionals may view palliative care as “giving up”, my experience confirms quite the opposite - there is always something that can be done to provide support for the child and family even if death remains the likely outcome.

This research will focus on children and families with chronic, life-limiting illness who receive supportive and palliative care in the UK. Modern health care can increasingly save and extend lives, and a significant effort is made to ensure that even the very sickest in our population have the opportunity to receive life-saving support. This means that children and young people who may previously have died early in life now survive (Fraser, Bluebond-Langner & Ling, 2020; Norman & Fraser, 2014). Unfortunately, this often comes at a price, as there may be a personal cost in the form of ongoing health issues or disability rather than a "cure" or return to full recovery (Hawley, 2014). It may also become a challenge to the child's family who live with ongoing demands of parenting a child with complex needs (Whiting, 2014; Spiers & Beresford, 2017; Koch & Jones, 2018; Page et al., 2020). There is also a cost to society in the form of health and social care and education provision which may extend into decades (Fraser, Bluebond-Langner & Ling, 2020). Individuals, families and society accept this as part of a civilised culture in which all individuals are valued as equal, and in which decisions are based on the best interests of the individual (Carnevale, 2012).

2.1.1 Children's palliative care - demographics

In modern western society, the death of a child or young person is an uncommon event (Chambers, 2018), but 2931 children and young people aged between 1 and 19 years died from medical conditions in England in 2017 (NHSDigital, 2017). For children and young people aged between 1 and 15 years, cancer, nervous system (including neuro-disabling conditions), respiratory, cardiovascular and congenital conditions (which tend to be chronic and progressive) accounted for about 60% of deaths (Patel, 2018). Approximately 40% of the deaths in children and young people under the age of 15 years occur in infancy. For young people aged 15 and over, external causes (such as accidents) are more common, accounting for 42% of deaths, and the proportion who die from chronic conditions falls to about 30% (Fraser et al., 2020a).

Although death in childhood can occur with little warning, for many of these conditions it is possible to predict the likelihood of premature death. Collectively these conditions are referred to as life-limiting conditions (LLC) or illnesses (LLI). In these circumstances, the children and their families may have the opportunity to consider appropriate therapeutic options, which may include palliative care. Life-threatening conditions (LTC) are those for which curative treatment may be feasible but can fail, such as cancer. Children in long-term remission or who have received successful curative treatment are not included in calculations of numbers of children requiring palliative care (Fraser, Bluebond-Langner & Ling, 2020).

Palliative care may be necessary for children of any age (Fraser et al., 2020a). The national prevalence of life-limiting conditions in children aged 0-19 in England has been increasing, rising from 26.7/10,000 in 2001/2 to 66.4/10,000 in 2017/18, equating to 86,625 children in England in 2017/18. The prevalence of life-limiting conditions was highest in those under 1 year old, at 226.5/10,000 in 2017/18 (n=15,489) (Fraser et al., 2020a).

Palliative care support may be appropriate for a wide variety of life-limiting conditions in children (Hain et al., 2013), which have been classified into four general groups. These include diagnoses of cancer or organ failure, where successful treatment is often possible but may fail, resulting in the premature death of the child or young person (ACT group 1). ACT group 2 includes children and young people with conditions such as cystic fibrosis or Duchenne's muscular dystrophy, where premature death in adulthood is likely, but in childhood treatment aims to maintain normal life as long as possible. There is a wide variety of metabolic, genetic or degenerative illnesses which can present in infancy, childhood or adolescence, where no cure is available so management is exclusively palliative in the face of inexorable progression and steadily deteriorating health (ACT group 3). In addition, palliative care may be required for those with static underlying conditions such as severe cerebral palsy or epilepsy where life-threatening complications mean that survival into adulthood is unlikely (ACT group 4). Statistically, the prevalence was highest for congenital abnormalities (mostly ACT group 3), which by 2017/18 was 27.2/10,000, more than twice the next most prevalent group, neurological disorders (10.8/10,000) (Fraser et al., 2020a).

In general, the aim is to support the children and their families to live as normal a life as is feasible, in their own homes where possible, as would be society's ideal for children without life-limiting conditions (Verberne et al., 2017; Winger et al., 2020). Children with major illness diagnosed antenatally or presenting from birth may be supported in hospital from the start of their lives. Others may be born healthy but later spend very significant amounts of time in hospital due to medical conditions or their complications. Many of these children have complex healthcare needs, requiring extensive support form a wide variety of professionals in a range of settings (Page et al., 2020; Winger et al., 2020). In either circumstance, the presumption is that the children and their families will aim to be based at home rather than in institutional care for any longer than absolutely necessary (Gibson-Smith, Jarvis & Fraser, 2021).

2.1.2 Children's palliative care – the child's and family's perspective.

Whilst all children will require support from parents or carers to develop from infancy to independence, the role of the parent for children with life-limiting illness changes significantly from the role they might have had supporting a child unencumbered by health issues (Spiers & Beresford, 2016; Yu et al., 2020; Page et al., 2020). Caring for a child with a life-limiting illness has an impact on the entire family. It is exhausting and can go on for many years (Steele & Davies, 2006; Donohue et al., 2018). Many report a "roller coaster life of intermittent crisis management" (Menezes, 2010) and can become socially isolated and highly stressed (Verberne et al., 2017). These tasks have a cost, with resulting detrimental effects on their own health (Fraser et al., 2020b), relationships, financial affairs, and the time available for care for their other children, partners or themselves (Verberne et al., 2017; Woodgate et al., 2015).

Corbin & Strauss (1985) identified the concept of "illness work" decades ago, encompassing the activities directly involved with managing an illness (eg following medication regimes), the "everyday life work" such as managing a household, and "biographical work" to articulate, plan and co-ordinate life around illness.

Woodgate et al. (2015)'s ethnographic study detailing the experiences of parenting children with complex care needs documents multiple roles within illness work, collectively described as "intense parenting". The parents in her study felt under great pressure to be a "good parent", not only ensuring their child's health and safety, but striving to ensure that their child had a good life. As well as being a parent, they took on multiple extended activities, described as being "much more than a nurse", including acting as a:

- healthcare provider: combining elements as required of nursing, physiotherapy, occupational therapy, managing equipment such as catheters and feeding tubes or ventilators, or adjusting medication.
- case manager: with a daily role to assess, prepare, implement, co-ordinate, monitor and evaluate their child's complex care routines and treatments. This involves extensive planning, scheduling and routines.
- student: in a continual learning process to educate themselves about their child and the condition, care and treatment options.
- teacher: as parents knew their child best, they became a key source of information, keen to provide guidance to respite workers and share knowledge with doctors and the healthcare team. They were often helping to educate extended family, friends, school and community about their child's condition and needs.
- Detective: figuring out various aspects of their child and child's care, such as how to make technology work best for their child, as everything was "a one-off" as their children's treatments and circumstances were unique. Interpreting non-specific signs and symptoms was difficult.
- Guard: watching over and protecting their children, monitoring their health status, and protecting their psychosocial wellbeing.
- Advocate: standing up for their children to make sure their needs are met and their interests and self-worth respected. (Woodgate et al., 2015 p 6-9)

Collectively, the work associated with caring for a child with complex needs has been estimated at an average of nine hours a day (Lazzarin et al., 2018). These activities were supplemented by a variety of services and supports, but parents reported that services offered usually fell short of what was required to help a child with complex needs (Woodgate et al., 2015).

One of the most important tasks for parents is to be a decision-maker, making healthcare-related decisions on behalf of their child, a particularly challenging role given the multiple uncertainties associated with managing life-limiting conditions (Feudtner, Schall & Hill, 2018; Yu et al., 2020). Parents may have to navigate through a world of medical complexity, making difficult choices or decisions regarding the care of their child based on infrequent, time-limited discussions with specialists, who may have an incomplete understanding of the issues pertaining to their child or circumstances (Feudtner, Schall & Hill, 2018). Decisions may be required when parents are confused, emotionally drained, exhausted, or disorientated by a healthcare system and medical language with which they may be unfamiliar. They need to learn both the speech and the body language of the nurses and doctors in order to understand the real messages hidden in words used by health professionals (Verberne et al., 2019). Layered on top of these complexities are social and cultural judgements in relation to parenting (Randall, 2019), so the decisions that parents confront are not only about their child, but also about themselves in how they will judge their own motives and actions as they fulfil their sense of duty as a parent (Feudtner, Schall & Hill, 2018).

In addition to the duties on parents relating to their child who has a life-limiting illness, parents must juggle these with “everyday life work” (Corbin & Strauss, 1985) as they adress the needs of any other children, maintain their own marriage or relationships, provide income and housing, and look after their own needs (Mooney-Doyle & Deatrick, 2016; Page et al., 2020). Sadly, many family units are put under great strain under these circumstances (Yu et al., 2020) and there is a high rate of marital breakdown (Sobsey, 2004), and a proportion of children with life-limiting illnesses are in the care of social services, fostered or adopted (McConnell et al., 2016).

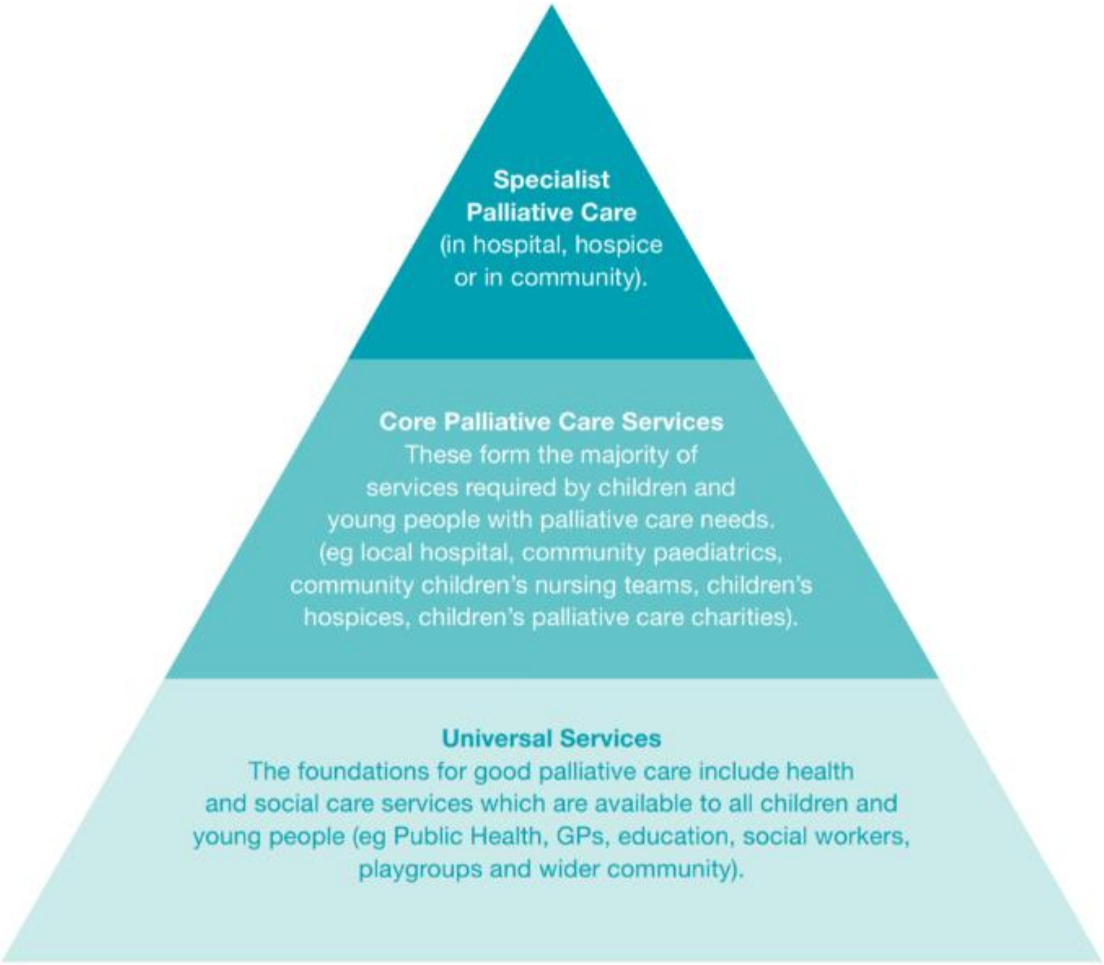
2.1.3 Services to support families.

Families of children with palliative care needs in the UK have a variety of sources of support, as portrayed in Fig 2-1 (Together for Short Lives, 2015).

For those based at home support is available from universal service providers, usually based in primary care settings such as GPs, health visitors, midwives etc. In addition to health-focussed services, universal services include professionals working in social work, education, early years support and the wider community (Chambers, 2018). These service providers often have very little experience of providing palliative care for children but have a key role in early detection of problems, appropriate referral to specialists in secondary care where relevant, and holistic care for all family members (Mitchell et al., 2021).

Core palliative care services consist of the typical professional support agencies required by children and young people with palliative care needs (Parker et al., 2011). These include secondary health care services such as general paediatricians in local hospitals, and community paediatricians working alongside other specialties allied to medicine such as physiotherapists, occupational therapists, speech and language therapists, dieticians, specialist community nursing teams, and child psychologists and mental health teams (Chambers, 2018). These services may provide outpatient clinics or outreach services (local clinics, or domiciliary assessments) for those in their catchment area, alongside admission to a local hospital if required. Some of the secondary care services may have experience of caring for dying children, and a few have specialist community services to support primary care teams as outreach from hospital provision (Eaton, 2000). Their responsibilities are mainly about identification and the day-to-day treatment of the ill child where possible, and recognition of the need for onward referral to more specialist care in tertiary centres for those with more complex conditions or where particular expertise is required for diagnosis or therapeutic intervention (Together for Short Lives, 2015).

Figure 2-1 Three levels of children's palliative care provision



Specialist children's palliative care services are often based around a regional children's hospital ("tertiary care"), and include teams providing highly specialist care for children with a range of medical conditions which are either too complex, or occur too rarely, for secondary care teams to acquire sufficient experience in their management to deliver safe and effective clinical support (Chambers, 2018). Many of these paediatric specialities (cardiology, oncology, neurology, respiratory teams etc) will have experience of supporting children whose conditions are so severe that they die from them. The disease-specialist teams may have variable experience of delivering palliative care, as their primary focus is controlling or curing disease, not maximising quality of life or providing end-of-life care (Kaye, Friebert & Baker, 2016; Wan, Weingarten & Rapoport, 2020; Vemuri et al, 2022).

Increasingly tertiary care services are developing specialist children's palliative care teams to work alongside disease-specialty teams (NICE Guideline, 2016), but these are variably resourced, variably experienced, and variably accepted by their disease-specialist colleagues (Kruser et al., 2020) or by parents of ill children (Mack et al., 2005).

Whilst many of these services are provided by the public sector, there are important supplementary contributions made by voluntary sector agencies for children and families living with life-limiting conditions (Together for Short Lives, 2018). These include a wide range of bespoke services such as residential children's hospices, hospice-at-home community nursing teams, bereavement support services, and voluntary groups allied to special schools or local communities (Chambers 2018). In many cases the services provided by the voluntary sector such as respite care, psychological support, peer groups for siblings and parents/carers, and 24/7 helplines are key aspects of holistic support for children and families, and the contribution of the voluntary sector is included in service planning and delivery at a statutory level (Together for Short Lives, 2015).

In the UK there is limited use of privately funded health or social care support to provide services for children with palliative care needs, and these tend to be organised on an ad-hoc basis by individual families. This may increase in the future with the use of personalised health budgets, which allow families to employ their own care and support staff, funded by local service commissioning groups (NHS England, n.d.). The roles and responsibilities of employed staff are determined by each family and will be unique to their particular circumstances, so this dimension of care provision will not be examined further in this work.

An ideal world would see a truly integrated system which enables universal, core and specialist providers from public, private and voluntary sectors to work together in a co-ordinated way that enables accessible local support and management of everyday problems, with access to specialist services when needed (Kuo et al., 2018). Integration of services is challenging, but the complexity of conditions and high level of care needs that many children live with, often over many years, means that services do need to use their combined workforce and resources effectively (Chambers, 2018).

2.1.4 Improving outcomes in palliative care

Outcomes are loosely defined as the results of an intervention, and in the healthcare context are defined as the change in a patient's current and future health status that can be attributed to preceding healthcare (APPM Outcomes Taskforce, 2015). Outcome measures may take the form of data generated by patients, caregivers, healthcare professionals, and the health system (Agar & Luckett, 2012). Over recent years, the development and use of outcome measures has been a research focus within the area of palliative care as a whole (Etkind et al., 2015; Bausewein et al., 2011; dos Santos Tavares et al., 2016; Agar & Luckett, 2012; Antunes et al., 2018), paediatric medicine (Huang, Revicki & Schwartz, 2014) and children's palliative care (Knapp & Madden, 2010; Friedel et al., 2019; Coombes et al., 2016; Harding, Chambers & Bluebond-Langner, 2019). Given the nature of palliative care, many of the outcome measures generated by health services data are not reflective of the quality of the service provided. For example, commonly used metrics such as the length of stay in hospital or death in the patient's preferred location may be determined primarily by the patient's stated preference, which may change as circumstances evolve. Many aspects of symptom control, emotional, psychological or spiritual support may be difficult to measure objectively and are monitored through feedback from those receiving care, or their caregivers.

2.1.4.1 Measuring quality of life as an outcome in palliative care

Given that the aim of palliative care is to focus on improving the quality of life (QoL) rather than extending life at all costs, it would seem logical that the most relevant outcome measure should reflect improvements in quality of life. In 1948 the World Health Organisation (WHO) defined QoL as not merely the absence of disease, but complete physical, psychological and social well-being. Health-related quality of life (HRQoL) is defined as the functional effect of a medical condition and/or its consequent therapy upon a patient (Ala'S & Mayo, 2017). This is generally understood as a latent, not directly observable construct, and contains the perceptions and evaluation of one's life from the subjective view of the individual, as well as the individual's subjective well-being and affective mood (Coombes et al., 2016). Calman (1984) defined quality of life as the gap between an individual's expectations and experience. It is a dynamic construct, as experiences constantly change expectations, so there is an inherent instability in its meaning for each individual (Carr, Gibson & Robinson, 2001).

The subjective nature of QoL means that measuring it must incorporate the perspective of the patient, or a proxy report on their behalf. Patient-reported outcome measures (PROMs) have been developed to address this, but there are particular challenges in integrating these into palliative care, despite the fact that research with PROMs in clinical practice has been going on for decades (Krawczyk et al., 2019; Antunes et al., 2018; dos Santos Tavares et al., 2016; Etkind et al., 2015). Although there is often enthusiasm to use them due to the potential for improvement in the care of individualised patients (Krawczyk et al., 2019; Bausewein et al., 2011) there may be organisational constraints for clinicians and health service providers that compromise implementation (Krawczyk et al., 2019; Schepers et al., 2016; Radionova et al., 2020).

Given the changeable nature of quality of life, the search for a standardised measure of HRQoL remains a challenge in palliative care, both for adult patients (Higginson & Carr, 2001) and for children (Knapp & Madden, 2010; Coombes et al., 2016; Friedel et al., 2019). Tools to assess HRQoL typically consist of a range of questions covering physical, psychological, social and spiritual aspects of an individual's life, with answers given a numerical score. Multiple tools are available, ranging from those that are very broad and generic to those that are specific for individual diseases (asthma, cancer, diabetes, or arthritis) or for individual symptoms such as pain or shortness of breath (Varni, Burwinkle & Lane, 2005). Coombes's review of HRQoL measures found that no measures that were developed specifically for use in CPC. Most that were in use were not tested for responsiveness to change (Coombes et al., 2016).

Furthermore, as many conditions requiring palliative care evolve over time with inexorable deterioration in health, expectations of what is "normal" or "acceptable" shift as people adapt to their changing circumstances. When monitoring HRQoL over time, this process is known as “response shift” (Carr, Gibson & Robinson, 2001) and means that a changing empirical score based on reporting of physical symptoms does not necessarily correlate with a subjective perception of one’s quality of life. In palliative care, changing expectations can signify a successful means of coping with increasing health-related disability (Carr, Gibson & Robinson, 2001; Westerman et al., 2007).

Much of the research into development of a QoL measure for CPC has been driven by the research community and based on the needs of healthcare providers (funders, managers or clinicians) to demonstrate the value of their interventions (Lhussier et al., 2005). Family-defined QoL has been a poorly researched area until recently. Gaab (2015) conducted qualitative research with primary caregivers in California to consider components of QoL for their children and found that the ability to communicate in a respectful, controlled, physically- and socially-comfortable environment underpinned the concept of QoL for families. Families spoke about the need to adapt to their children’s situations in order to maintain wellbeing, adjusting expectations to reflect “a different normal” for their child. Symptom control and “not suffering” was key to QoL for many families. Almost all caregivers wanted their child to be “heard” in whatever mode they communicated (even if non-verbal, by using other aural or behavioural cues), and valued their child being treated with sensitivity and respect. QoL was enhanced by social stimulation and being involved in social activities contributed to their state of wellbeing. The families’ emphases on communication, adaptation and social exchange to improve wellbeing is a contrast to the parameters more commonly identified by research driven by healthcare providers (Gaab, 2015).

In light of the challenges inherent in the measurement of outcomes of interventions in chronic illness, and in particular in children’s palliative care, there is potential for individualised outcome measurement (IOM) to allow the recipients of support to identify the outcomes that are the most significant for them. MyQuality adopts this philosophy by incorporating the technology to identify personal goals or priorities and to establish a scoring system that reflects the individual’s own perceptions of good or poor quality outcomes, and can monitor change over time. This enables the perspective of the patient (or the parents or carers reporting on their behalf) to rise in prominence. The literature review (chapter 5) will consider issues surrounding the use of IOMs in greater detail.

2.2 Evidence-based practice and person-centred care (PCC)

The practices and values of modern medicine have their foundation in the social and intellectual contexts of the mid-nineteenth century (Engel, 2008). Medicine built on foundations of empirical science, encouraging physicians to become objective observers of humans, a biophysical approach which involved distancing themselves from the lived experience of illness. Since the 1990's there has been a marked emphasis on evidence-based practice (Bensing, 2000), involving rigorous investigation of diseases or conditions and the evaluation of effectiveness of interventions in a positivistic manner. Whilst this trend towards evidence-based healthcare has been a constructive process to reduce variability and improve standards of healthcare, it focuses on the biomedical approach to the conditions in question and quantitative methodologies, ignoring many of the social, psychological and existential elements of illness, and the qualitative aspects of psychological, emotional and spiritual interventions. Outcomes of this research have a hierarchy that assumes that randomised trials, systematic reviews and meta-analyses are most valuable (Rycroft-Malone et al., 2004).

However, the original visions of evidence-based practice as outlined by Sackett et al. (1996) were not simply focussed on a more scientific approach, but on the integration of research with the expertise of the clinician and the patient's values in order to make decisions about the optimal approach for any healthcare intervention for an individual patient (Miles et al 2008). For rare conditions or situations where the goals of treatment differ from those of the general population, such as those found frequently in children's palliative care, research findings are often inadequate for use as the principal foundation for evidence based practice (Rycroft-Malone et al., 2004). On a practical level, research may guide clinicians to conclusions about what may happen in similar populations or situations but may not be appropriate for the circumstances faced by that particular person.

Sackett's second component, clinician experience and expertise, incorporates "practical know-how" and "professional craft". These are often tacit but are accrued through professional practice and life experiences (Rycroft-Malone et al., 2004). This facet of knowledge and understanding facilitates clinical judgement and is one key component of the integration of research evidence into the clinical situation that may be encountered.

In addition to the above, Sackett's concepts about evidence-based practice should incorporate the perspective of the patient in order to ensure the holistic nature of the decision process and optimise the outcomes of care. Integration of the patient's perspective within a healthcare encounter requires a focus on constructive relationships and effective communication. In practice this is not as easy as it sounds, and person-centred care is a concept that has evolved in response to evidence-based "processing" of patients in healthcare. This section of the chapter will explore these concepts and link them to the development of MyQuality and the rationale for this research question.

2.2.1 Interactions between professionals and patients

Professional relationships between clinicians and their patients they have been variably dominated by doctors/healers or patients (Kaba 2007), but recent trends have sought more mutual participation (Mead 2000; Epstein 2011; Scholl et al., 2014; Zill et al., 2015). Sociologists, political philosophers and ethicists have made important conceptual contributions to understanding doctor-patient relationships (Yedidia, 2007), describing the tensions inherent in an unequal partnership. Doctors (and healthcare professionals more generally) bring their specific knowledge of health and disease, accumulated through training and experience, whilst patients bring their own lived experience and personal concerns. The behaviour of professionals in these encounters is guided by institutional regulations and codes of conduct, whilst the behaviour of patients is guided by societal norms and values. Clinical relationships have been characterised as interactions between "those who know" and "those who are to be known" (Frank, 1998), with the physician cast in the role of the active knower and the patient as a passive recipient of healthcare (Engel, 2008).

The concept of person-centred care (PCC) has been evolving since the 1950's and is defined as care that "respects and responds to the individual patient's preferences, needs and values and ensures that clinical decision-making incorporates patients' values." (Institute of Medicine 2001 p3). PCC is not disease-focussed, nor is it clinician-driven. This model of care recognises the importance of the patient as a distinct individual, whose needs for information, empathy, control and engagement will be influenced by personal history, circumstances, preferences and fears.

This approach mirrors shifts in British society, which has changed from a culture where beneficence has been the dominant ethical principle to one in which autonomy is valued as highly (Taylor, 2009). PCC is part of a visible trend in the last 30 years of growing patient expectation to be treated as a whole person and engaged in decisions about their healthcare (Greenfield et al., 2014), an approach endorsed by influential think tanks such as the Health Foundation (2016), the Kings Fund (Foot, Goodwin & Sonola, 2012), and multiple pronouncements from the Department of Health in the UK.

2.2.2 Definitions of person-centred care

Person-centred care is frequently referred to as "patient-centred care" as an interchangeable phrase. Terms such as "child-centred care" or "family-centred care" have been used when discussing services for children (Shields, 2015) or the elderly, or "client-centric" when discussing social care, mental health and allied professions. Many of these phrases are used without being precisely defined (Shields, 2015) and represent very similar principles (De Silva, 2014). For the purposes of this thesis, I have chosen to use the phrase "person-centred care" (PCC), unless quoting from other sources. Patients are people first and foremost, the identity as a patient being variable in nature, perhaps transient, and not all-encompassing as a descriptor. A similar concept is "relationship-centred care", which broadens the model of PCC to include the role of practitioner as a person (Beach, 2006).

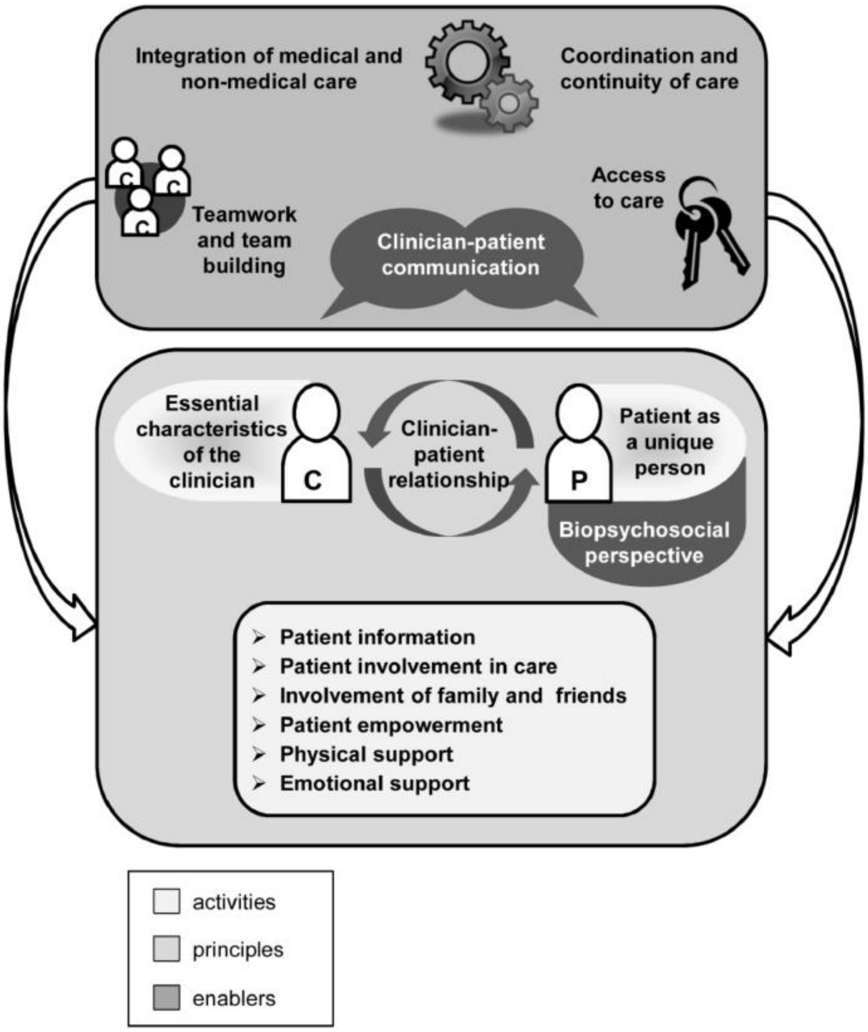
PCC can be considered "a fuzzy concept" (Pluut, 2016) with the lack of a globally agreed definition (Scholl et al., 2014; De Silva, 2014). Early contributions identified seven dimensions: respect for patients; co-ordination and integration of care;

information, communication and education; physical comfort; emotional comfort/alleviation of fear and anxiety; involvement of family and friends; and transition and continuity (Gerteis et al., 1993). Simplistically, PCC is all about putting patients first, at the centre of health and social care. It is respectful and responsive to individual patient preferences, needs and values (Greenfield et al., 2014). De Silva (2014) defines it as a philosophy that sees patients as equal partners in planning, developing and assessing care to make sure that it is most appropriate for their needs. This involves patients and their families being at the heart of all decisions. Services are reorientated to be user-focused, to promote control, independence and autonomy for the patient and the carers and family, to provide choice and be based on a collaborative team philosophy. It takes service users' needs and views into account and builds relationships with family members. Key components include compassion, dignity and respect.

Similar contributions from Mead & Bower (2000; 2003) focussed on defining PCC in primary care and nursing. Kitson's narrative review of the core elements of PCC found few common definitions across the literature but did identify three core themes: patient participation and involvement, the relationship between the patient and the healthcare professional, and the context where care is delivered (Kitson et al., 2013). Similarly, Harding, Wait & Scrutton (2015) described three conceptual pillars: an emphasis on personhood, on partnership, and on an overarching coherent holistic approach to care.

Scholl et al. (2014) performed a systematic review to consider the lack of conceptual clarity of definitions and developed a model with fifteen components. This was divided into the principles of PCC, enablers of PCC, and activities of PCC (Fig 2-2). The principles of PCC include the essential characteristics of the clinicians (such as being respectful, empathetic, compassionate and committed to the patient); a clinician-patient relationship characterized by constancy, trust, positive rapport and a mutual understanding of roles and responsibilities; understanding the patient as a unique person, eliciting each patient's individual needs, preferences, concerns and expectations; and using a biopsychosocial perspective to understand the whole person's life history, family and social support, cultural context, and focusing on the patient's quality of life. Enablers of PCC are sensitive clinician-patient communication, the integration of medical and non-medical care, teamwork, offering appropriate, preferred and timely access to care, and the importance of co-ordination and continuity of care. Scholl's activities of PCC included the provision of patient information, patient involvement in their care, active involvement of family and friends, patient empowerment, and physical and emotional support for patients in accordance with their needs. Scholl et al. (2014) describe these as being closely interrelated rather than independent components, but they may be present at differing levels of healthcare activity.

Figure 2-2 Integrative model of person-centredness (Scholl 2014)



The inner circle represents the micro level, the middle circle the meso level, and the outer circle the macro levels of care

Although the concepts of PCC are relevant at the level of health policy and organisations in addition to individual healthcare encounters, I have focussed on the meaning of person-centred care as it applies to interactions between individual professionals with their patients.   While Scholl's work is very comprehensive, it includes principles such as the essential characteristics of clinicians which are important but difficult to influence through an intervention such as MyQuality. The remaining principles, focussing on understanding the patient as a unique person, the clinician-patient relationships, and using a biopsychosocial approach rather than a more limited biomedical one, are more amenable to change given appropriate education or opportunity.

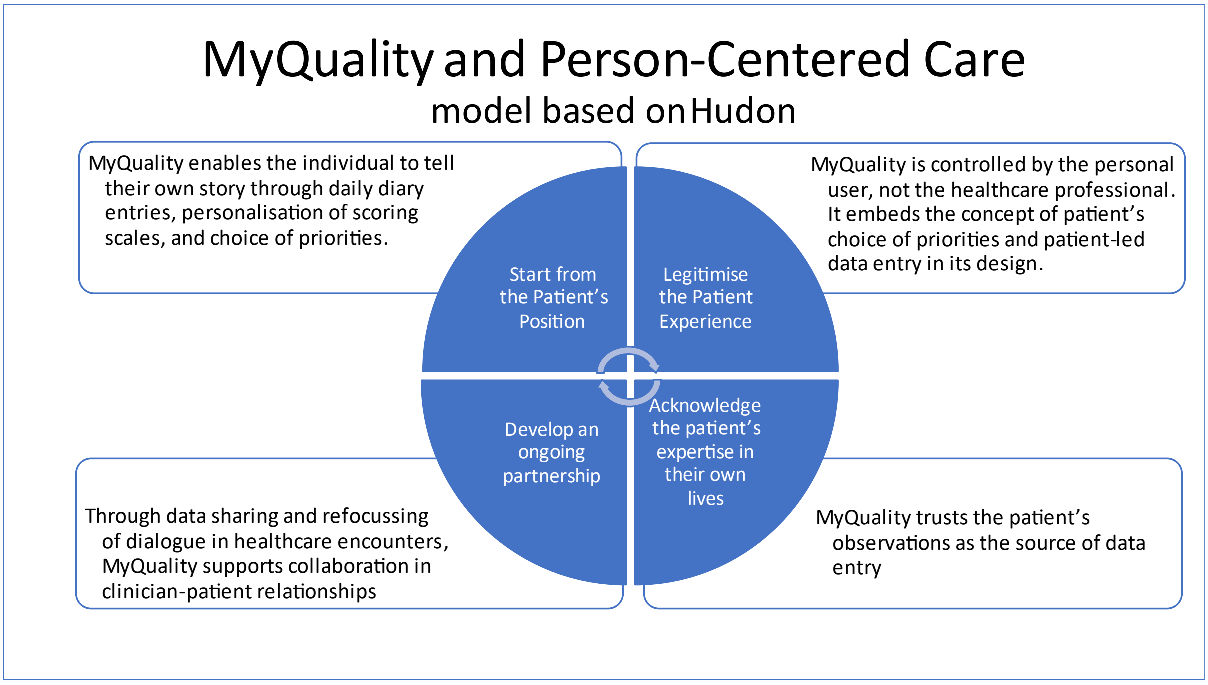
To add further clarity to the nature of these principles as they relate to clinical practice, I was drawn to Hudon's work which includes a thematic analysis of the literature about PCC in chronic disease management (Hudon et al., 2012). This provides a useful conceptualisation more closely aligned to the clinical situation faced by children and young people with long-term complex needs or life-limiting illness. Six major themes emerged in Hudon's work: starting from the patient's situation, legitimizing the illness experience, acknowledging the patient's expertise, developing an ongoing partnership, offering realistic hope, and providing advocacy for the patient in the healthcare system.

The first four of these align closely with Scholl's concepts of understanding the patient as a unique person and the importance of the clinician-patient relationship. PCC also entails offering realistic hope, often in the context of uncertainty or the inevitable decline of chronic conditions. The provision of hope is not specifically mentioned by Scholl, but maintaining appropriate hope is a key component of the provision of emotional support, identified by Scholl as an activity of PCC. Emotional support is encompassed in the "whole life" approach adopted in a biopsychosocial approach to care.

And finally, Hudon's work reminds us that PCC includes providing advocacy for the patient in the healthcare system, guiding them through and coordinating care. This category includes many of Scholl's enablers and activities of PCC.

By breaking down the components of PCC as they relate to clinical practice it is possible to identify where these map to the opportunities provided by MyQuality, to understand how this intervention may facilitate the delivery of person-centred care (Fig 2-3).

Figure 2-3 MyQuality and person-centred care



MyQuality enables the individual to tell their own story through daily diary entries, personalisation of scoring scales, and choice of priorities.

MyQuality is controlled by the personal user, not the healthcare professional. It embeds the concept of patient's choice of priorities and patient-led data entry in its design.

Through data sharing and refocussing of dialogue in healthcare encounters, MyQuality supports collaboration in clinician-patient relationships

MyQuality trusts the patient's observations as the source of data entry

2.2.3 Ethical justification for person-centred care

Although it is possible to understand the concepts behind PCC, it is also important to consider the nature of this approach within the context of healthcare delivery. Duggan et al. (2006) and colleagues have questioned the moral nature of PCC, asking "is it just the right thing to do?" They approached these concepts using three schools of ethical reasoning – consequentialist, deontological and virtues-based – and concluded that all three agreed that patient-centredness was morally valuable on the grounds that it could lead to improved outcomes for patients, reflected the ethical norms inherent in medicine such as respect and shared decision-making, and could positively influence physicians' behaviours toward their patients through physicians' moral capacity for self-reflection.

This concept is important because it supports the philosophical basis on which MyQuality has been developed. Further consideration of the specific ethical issues relating to this study are outlined in section 4.6, but all depend on the recognition that the pursuit of a person-centred approach to care is morally defensible in itself.

2.2.4 Measuring the outcomes of person-centred care

Whilst PCC may feel morally and ethically correct for the healing professions (Duggan et al., 2006; Epstein 2011), there is mixed evidence to show that it improves clinical outcomes for patients, or is cost-effective.

Two Cochrane systematic reviews (Lewin 2001, Dwamena 2012) concluded that the evidence on the effects of patient-centred interventions on patient healthcare behaviours or health status is mixed. Rathert, Wyrwich & Boren (2013) reviewed PCC and outcomes in a systematic review of the literature, focussing on the Institute of Medicine classification of elements of PCC. They found mixed evidence of beneficial outcomes arising following implementation of PCC, though there was stronger evidence for positive influences on patient self-satisfaction and self-management.

Street Jr (2017) reported that differences in conceptualisation of PCC meant that attempts to measure it were incoherent, a finding mirrored that mirrored De Silva‘s comprehensive review. Although there are increasing numbers of tools available to measure PCC, there is no agreement about which tools are most worthwhile, and no “best measure” that covers all aspects of PCC (De Silva, 2014).

2.2.5 Putting person-centred care into practice

There is a wide range of definitions and activities claiming to be person-centred, but it is often construed as an overall change in healthcare organisation and ethics, with less consideration for implications in practice (Naldemirci et al., 2020). Scholl’s and Hudon’s themes may illustrate the components of PCC, but do not instruct front-line providers about the practical aspects of their delivery.

Kitson et al. (2013) and her team examined the main themes that emerged from their review of PCC, to consider how to apply these concepts in practice. These included patient participation and involvement, and a focus on the relationship between the patient and the health professional.   Several attributes of the patient-centred professional were identified, including “being polite”, “good etiquette”, “good manners”, “being respectful”, “sensitive”, “welcoming” in the nursing literature, though none of these were acknowledged in the medical texts (Kitson et al., 2013). It was notable that nursing articles tended to accentuate respecting patients’ values and beliefs in promoting PCC, whilst more medical attention was devoted to understanding the nature of the informed decision-making process between the doctor and the patient. However, a key underpinning principle was that of effective communication.

Similarly, in Sweden a range of approaches have been explored with a variety of clinical teams, focussing on eliciting the patients’ narrative and nurturing a partnership between HCPs and patients to develop commonly-agreed goals (Britten et al., 2017).

Street Jr (2017) focussed on a conceptualisation based largely on the models of Mead and Bower (2000) and Epstein and Street (2011) when looking at the main driver of PCC delivery, communication. He suggested that communication to support PCC should:

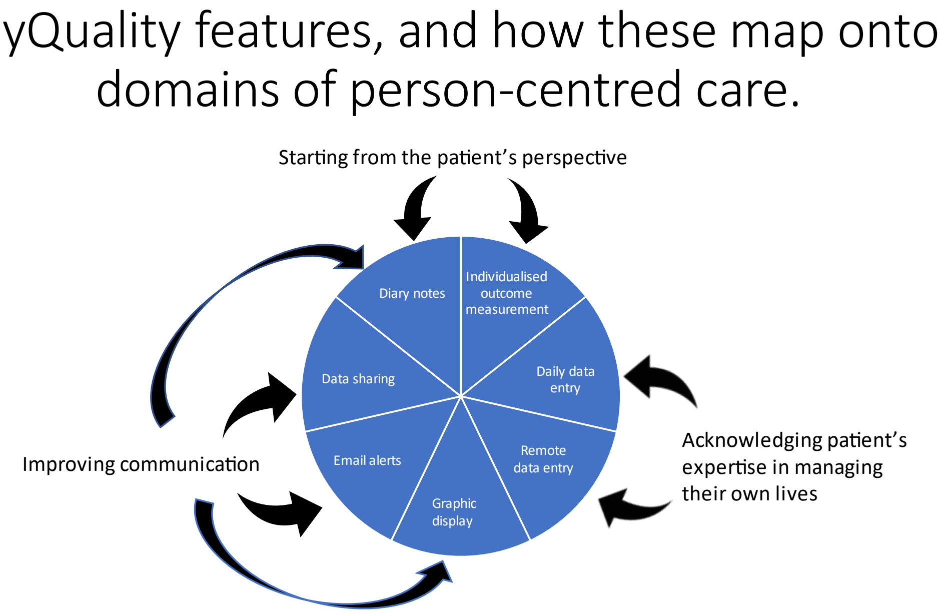
- Reveal the patient’s perspective (beliefs, preferences, concerns and needs)
- Explore the biopsychosocial context of the patient’s health and well-being
- Create or reinforce trust and mutual respect in the clinician-patient relationship
- Include explanations of disease and treatment options in ways the patient understands
- Has patients actively participating in the conversation and decision-making process
- Creates shared understanding of the problem and courses of action
- Produces decisions that are based on the evidence, consistent with patient values, and feasible to implement (Street, 2017).

The focus on effective communication as a mechanism to support the delivery of PCC will be instrumental to the exploration of MyQuality’s potential to influence the delivery of palliative care for children.

2.2.6 PCC and MyQuality

Scholl's principles of PCC and Hudon's categories provide a useful structure to consider the potential role for MyQuality to support delivery of PCC, as outlined in Fig 2-4. In particular, MyQuality aims to give a voice to the individual to aid understanding of each person's unique story (Scholl et al., 2014) as it "starts from the patient's situation" (Hudon et al., 2012), acknowledges the individual's expertise in their own lives, legitimises their concerns, and could be used to provide information and insights to provide realistic hope for the future. MyQuality could support individuals to self-manage, and healthcare professionals to advocate for their needs, and when used by healthcare professionals and patients together MyQuality could encourage them to develop an ongoing partnership. Understanding how, when and why this occurs (or doesn't occur), may shed light on the challenges of implementing PCC in practice.

Figure 2-4 Aspects of MyQuality design, mapped onto PCC domains



2.2.7 PCC and empowerment

The colloquial understanding of the word "empowerment" includes two meanings: firstly, to give power or authority to someone to do something, and secondly the process of becoming stronger or more confident, particularly relating to controlling one's life and claiming one's rights (Oxford English Dictionary, 2010). In an academic sense, the underlying philosophy views human beings as having a right and ability to choose by and for themselves, and is largely guided by the principles of self-determination (Aujoulat, d’ Hoore & Deccache, 2007).

Patient empowerment embraces the concept that individuals have the right to make their own choices about their health care and that they are equipped with the skills and abilities to act on issues that they define as important (Zimmerman, 1995). Whilst this is important across healthcare generally, it is particularly significant for those facing deteriorating health and an uncertain future, where personal priorities and control over one’s destiny are prominent concerns. Empowerment in healthcare includes dimensions such as access to education and knowledge, shared decision-making, self-determination, self-efficacy, and self-management (Skinstad & Farshchian, 2016). These are key components of PCC, and demand informed participants, who have access to required knowledge or information and are enabled to share this within dialogue between healthcare professionals (HCPs) and patients or their carers. In a health context the literature often includes discussions about control – either sharing control, or taking control, of heath related information and decision-making, but this is a simplistic approach which belies the complexity of the processes underlying empowerment as an individual, in the healthcare encounter, and within healthcare as a wider social setting (Godbold & Vaccarella, 2012; Bravo et al., 2015).

Patient empowerment can be viewed as a theory, a process, an intervention, an outcome, a feeling or a paradigm (Castro et al., 2016). The process of empowerment occurs when the purpose of an intervention is to increase the patient’s capacity to think critically and make autonomous, informed decisions about their healthcare (Cattaneo & Chapman, 2010). The outcome of empowerment occurs when there is a perceivable increase in the patient’s ability to perform such actions (Anderson & Funnell, 2010). However, the “empowered patient” is not a static entity, an informed, active decision-maker who wants to take a central role. Patient empowerment is a much more fluid concept and varies according to the circumstances in which the patient finds himself, the urgency of the decision, and the nature of the relationships between healthcare providers and healthcare recipients. An individual's ability to locate, absorb, retain and understand information is in a state of flux, and may be affected by emotions and fears, social and cultural factors, distractions or impediments (such as exhaustion or resource limitation). People may become confused, or chose to avoid information which challenges their beliefs, understanding, or coping mechanisms (Godbold & Vaccarella, 2012) .

The process of empowerment is not a passive process, as it involves "mutual participation, active listening and individualized knowledge acquisition" by both patients and HCPs (Holmström & Röing, 2010; Bravo et al., 2015). Furthermore, the nature of the relationships between patients and healthcare professionals is not a meeting of equals, but an unbalanced encounter between two participants – one of whom has extensive knowledge and a clear role definition in terms of diagnostic and therapeutic support, and another who brings the life context of the "whole patient", incorporating the worries, fears, anxieties, hopes, aspirations, stories, values, preferences, psychology, emotionality and spirituality of his or her circumstances (Miles, 2012). It is not simply a process of acquisition of information. Empowerment involves a reconfiguration of the relationships between healthcare professionals and patients (Anderson and Funnell 2010). Both parties need to support principles of empowerment to support a shift towards person-centred care.

Empowerment encompasses multiple components (Anderson & Funnell, 2010; Fumagalli et al., 2015). Patients require an awareness and willingness to actively engage in an empowered fashion, and to acquire knowledge, skills, autonomy and self-determination. Healthcare professionals need to support development of skills by patients, by developing positive patient-practitioner relationships (Rowland and Politi, 2016) and a therapeutic alliance to implement patient-centred care (Chatzimarkakis, 2010). These component processes include enablement (feeling confident in one's abilities) and activation (being willing to act, for which enablement is a prerequisite). Patients and HCPs need to engage in relationships with each other to co-produce and share decision-making, and ultimately support the development of autonomously able patients who can self-manage aspects of their care.

In CPC many families are exhausted by the demands of care delivery at home and may have become disempowered after years of encounters with health services. This process may also require a paradigm shift for HCPs trained in traditional models of care who see their role as the decision-maker or instructor (Kaba & Sooriakumaran, 2007). The potential to use eHealth to empower individuals is exciting, but as yet unproven in CPC.

2.3 eHealth

Having outlined the nature of children's palliative care and the concepts surrounding person-centred care in this chapter, I will now turn my focus to the role of technology and explore how the components of this could support delivery of communication in a person-centred manner.

2.3.1 eHealth – definitions

The advent of the internet in the 1990's has revolutionised society's approach to information and communication. Within the field of health care this has spawned a new vocabulary including ehealth, telehealth, mHealth and Health Improvement Technology (HIT).

eHealth is generally defined as any joined-up application of electronic or computer-based technology in a health care environment (Gaddi, Capello & Manca, 2013; Schreiweis et al., 2019). This umbrella term includes electronic storage and sharing of health care records, mobile technologies for monitoring or communicating information between individuals and their healthcare professionals such as SMS messaging and other communication apps, clinical decision-support software, and websites for the delivery of healthcare information or educational purposes (Wilson et al., 2014). eHealth also incorporates the use of telehealth (using visual or audio technology such as telephone or skype) in clinical interventions, or for education and training for staff, and mHealth which refers to the use of wearable (mobile) devices or remote monitoring of biological parameters such as BP or blood glucose measurement. Recent developments include virtual reality applications (eg to simulate exercise), applications of game theory to increase motivation, home automation (domotics) sensor technology for independent living and remote monitoring, and robotics, the development of robots to assist people with tasks (van Gemert-Pijnen et al., 2011). These developments have been collectively described as uhealth, when technology appears ubiquitous.

In its broadest sense, ehealth can be considered as

> ‘‘not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology.” (Knapp, 2010, p1).

These ehealth definitions are very wide. This study will be restricted to the role of ehealth as an interactive process involving health care professionals and their patients and families, encompassing interpersonal relationships, communication and sharing of information, and shared decision-making. These areas have been recognised as dimensions of ehealth with the potential to improve healthcare outcomes of children and families (Knapp, 2010).

2.3.2 eHealth – overview of use in palliative care

A systematic literature review of the effectiveness of ehealth interventions and information needs in palliative care services for adults (Capurro et al., 2014) found limited evidence of the effectiveness of ehealth interventions for either palliative care patients, caregivers, or health care professionals. Some studies reported some improvement on quality of care, documentation effort, cost, and efficiency of communications, but in general the studies did not describe patient-relevant clinical outcomes such as feeling connected, empowered or supported, or improvements in symptom management outcomes. The use of telehealth in paediatric palliative care was the subject of a systematic review (Bradford et al., 2013) which found that there were some benefits to levels of parental anxiety, but no consistent benefits to quality of life of children or parents, and many barriers to effective implementation. A second systematic review was conducted into the use of ehealth in home-based paediatric palliative care (Holmen, Riiser & Winger, 2020) and looked specifically at ehealth systems as facilitators of improved care and communication with two-way ehealth communication as the major intervention of interest. Only seven studies met their criteria and the authors concluded that ehealth could be both a support at home, and seen as an intrusion, and that professionals demonstrated considerable reluctance to use it.

Searches of the literature on ehealth and palliative care demonstrate exploration of the potential of this technology to improve patient outcomes in a variety of circumstances. A review of developments in ehealth in end-of-life care services for adults found a range of ehealth formats in use, but little evaluation of outcomes of these, and suggested that the impact of these technologies would be best understood when studied in relation to other aspects of human communication (Ostherr et al., 2016). Knapp's review found many services which explored the use of on-line resources, point of service documentation, web-based peer support discussion groups, and shared access to health care records (Knapp, 2010). Improvements in paediatric palliative care communication were found that might be possible due to ehealth, but Knapp emphasised that these interventions should supplement, not supplant, the provider-family relationship. However, the interventions described in her paper are quite unlike the patient/professional interactive nature of the MyQuality website, which aims to facilitate two-way dialogue between children and families and their health and social care professionals as an adjunct to existing routes of communication.

In addition to the lack of evidence of benefit, ehealth needs to be implemented and used in clinical practice in order to be effective - this is not without its own challenges. These relate to the design and function of the ehealth intervention so that it is acceptable to users and fit for purpose; addressing the motivation for use by patients, professionals, and provider organisations; and consideration of the greater impact of technology on daily life. There are potential risks to the privacy and confidentiality of patient information which might have previously been shared within a private encounter between a professional and a patient, whereas ehealth involves transmission of data which may now be seen by "third agencies" such as IT support staff who may not regard confidentiality in the same manner as health and social care professionals (Demiris, Oliver & Courtney, 2006). The use of ehealth may create a sense of greater dependence on healthcare professionals rather than independence and autonomy when outside a healthcare setting, and may medicalise the home environment and activities of daily living (Bradford et al., 2013; Johnston, 2014). The lack of "human touch" may depersonalise working relationships and inhibit the development of trust between professional staff and the children and families (Heckemann et al., 2016). Although development of internet-based communications has been rapid over the past ten years, access to the latest technology may be limited by infrastructure (such as rural broadband), costs of equipment, or levels of computer literacy which may create a "digital divide" between those who have the means and willingness to benefit from these technologies, and those who cannot (Johnston, 2014). Staff have expressed concerns about resource and workload implications, particularly when interventions require additional training and a change in routine (Johnston et al., 2012).

Although the potential benefits of ehealth are significant, there are challenges and risks associated with this development. The outputs of research in this area struggle to keep up with the pace of evolution in ehealth. As this technology advances in its complexity, and its role in society evolves, we need to ensure that ehealth developments are used to enhance healthcare responsibly.

2.3.3 MyQuality as an example of an ehealth intervention

MyQuality was developed in 2011 in a children's hospice setting, aiming to address the needs of patients and families using the hospice and other NHS services by providing a platform to document and share information about the ill child in an easily accessible format, and support continuity of care, co-ordinated care, and shared communication between families and healthcare providers. It was developed with input at the design stage from a variety of stakeholders, including patients with LLC and their families, front line nursing and medical staff, hospice senior managers, funders and executive staff. Although MyQuality was developed a decade ago, more recent research has highlighted the design recommendations for digital health tools for families of children with complex healthcare needs, highlighting the reduction in the need for physical documentation of care, timely access to information for those who need to see it, flexibility and customisation of data entry and access, and ensuring that interaction with the communication technology interface is simple and intuitive and does not create additional demands for families (Tennant et al., 2022).

MyQuality is a website that incorporates multiple features that address these specific requirements. These include the provision for individualised health-related outcome measurement by patient and family; the use of the programme's technology to transform digital scoring into an interactive graphic display; the opportunity for healthcare professionals and patients to communicate with each other electronically via the daily diary; the facility for healthcare professionals to view the input of their patient's health concerns remotely; and the ability to generate emails automatically in response to abnormal data values entered by the patient or family. Further exploration of the components of MyQuality and how these contribute to the provision of PCC will be explored in chapter 5.

2.3.3.1 MyQuality – background and initial evaluation

Preliminary evaluation of the use of MyQuality took place in 2013/14 (Harris, Beringer & Fletcher, 2015). Families of children with life-limiting conditions who used the hospice were given a demonstration about MyQuality and invited to use it as much or as little as they wished. At the start and after three months of use semi-structured interviews were conducted to seek user feedback, and participants were asked to complete a validated empowerment questionnaire. Standard levels of hospice support were available throughout the study in addition to the use of MyQuality. Qualitative analysis of the interviews with families were combined with descriptive analysis of website use and measurement of empowerment. Thirty-two families took part in the study, from 3 different hospice sites.

Analysis of website use confirmed that 72% of invited families registered on the site and proceeded to enter data, for a mean period of 106 days (range 2-301). Most families identified 2 or 3 priorities (mean 2.4, range 1-15), and 81% of families chose to share their data with at least one member of their healthcare team (median 2.1, range 1-8).

Empowerment of participants was measured using Family Empowerment Scales (Koren, DeChillo & Friesen, 1992), which showed an increase in all domains (family, interactions with health professionals, and community) after using MyQuality for 3 months.

Themes that emerged from analysis of interviews included:

- the practical benefits of recording information in a simple manner
- the value to families of being able to tell their story and demand the attention of their clinical staff
- having a record of events over time
- a greater understanding of relationships between various symptoms or patterns of behaviour, or the effects of interventions for these, in their children
- a sense of active engagement in their child's care and decisions about care
- a sense of empowerment when dealing with healthcare professionals.

These results reflect many of the key domains of patient-centred care identified by Scholl et al. (2014). Whilst the findings from the initial MyQuality study were encouraging, there remains insufficient information to understand the impact of this approach on the interactions between healthcare providers and their patients/families.

Informal discussions with professionals have given some preliminary insights into their perceptions of this approach, but professional feedback was not sought as part of the initial evaluation of MyQuality. This warranted further exploration in order to understand the development of this approach in future.

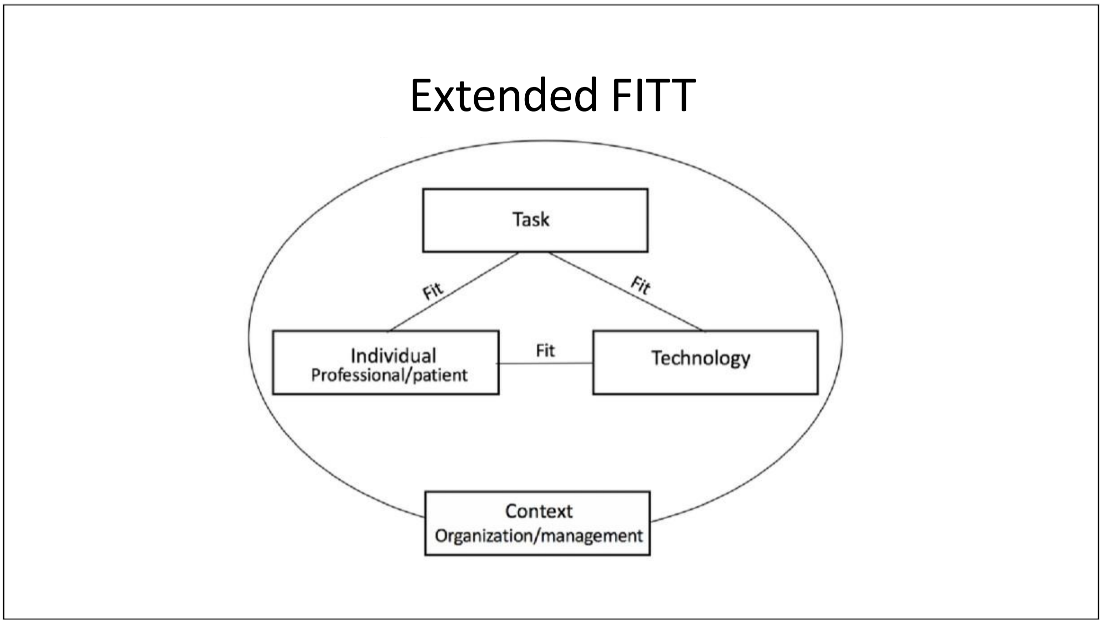
It was also notable that even though participants for this study were a self-selected group, not all families chose to use MyQuality, and some of those who had used it stopped much earlier than others. This finding is also worthy of further study in order to know who would be most likely to benefit from this intervention, and how to improve MyQuality to attract and engage those who would not use it.

2.4 eHealth and PCC – putting these together

There are many theories that can illuminate aspects of the implementation of ehealth (Heinsch et al., 2021), but it would be simplistic to assume that the impact of MyQuality was solely related to its effective implementation in clinical practice.

The FITT framework (Fit between Individuals, Task and Technology) is based on the idea that IT adoption in a clinical environment depends on the fit between the attributes of the users (eg computer anxiety, motivation), the attributes of the technology (usability, performance) and the attributes of the clinical tasks and processes such as their organisation and complexity (Ammenwerth, Iller & Mahler, 2006). A subsequent revision of the FITT identified the different needs of patients and professional staff for interventions for self-management and the influence of wider contextual factors in the healthcare environment, and this enhanced model (Fig 2-5) will be used to more fully explore the implementation of MyQuality (Kujala et al., 2020).

Figure 2-5 Extended FITT (Kujala 2020)



An "individual" in the FITT framework can be a single user or a user group. In the case of MyQuality, this can refer to the use of the website by individuals in their capacity as patients or the main carers about managing their own health, and to the use of the website by healthcare professionals involved in providing clinical support for their patients. At a higher level, the framework can be applied to consider IT use by the team or organisation (eg as part of their standard policies and practice). "Technology" can include the hardware, software and connectivity required to accomplish the given task. It not only comprises computer-based tools, but all tools used by individuals to execute the tasks, including paper-based tools. The "Task" comprises the wholeness of the tasks and working processes that have to be completed by the user and that are supported by the given technology (Ammenwerth, Iller & Mahler, 2006). The objective of the IT management can be defined as reaching an optimal fit between technology, user and task.

The quality of the fit depends on attributes of each category, so that for individuals the level of IT knowledge, motivation, flexibility and openness to new ways of working may have an impact on their decision to use IT as proposed by managers (Gagnon et al., 2012; Ross et al., 2016). Team factors such as the politics and culture, organisational context and level of co-operation can determine the adoption of an IT process (Lluch M, 2011). External factors such as staff recruitment and retention, changes in workload, or team strategy can all influence the ongoing fit (Ross et al., 2016). On a task level, the organisation of the tasks to be completed, activities and their interdependence, scheduling and sequence of task components, and complexity, can all have a bearing on the use of IT for that task. These may vary due to reorganisation of task and working processes, reallocation of responsibilities within a team, and changing complexity of the task in response to external influences such as organisational targets or legal requirements (McGinn et al., 2011). And at a technological level, the stability and usability of a software or hardware tool, its costs, functionality, infrastructure and support, the compatibility of a new program with existing IT systems, and issues about access and availability when needed can all be decisive factors in the decision to adopt an IT approach to the task in hand (Gagnon et al., 2012). Repeated software updates or redesigns or new technological standards for information systems can all have an impact on the persistence of an optimal fit (Ammenwerth, Iller & Mahler, 2006).

Whilst Ammenwerth's team originally described this framework to understand IT adoption in a hospital clinical setting (Ammenwerth, Iller & Mahler, 2006), the FITT lends itself to a structured approach to the introduction of IT in other clinical environments, as demonstrated with the Extended FITT modified model (Kujala, 2020). In addition to providing a framework for exploring how the implementation of an IT system was successful, it also provides a structure to enquire about the causes for lack of uptake. Other theoretical frameworks have also been used in research in this area, and these have been reviewed comprehensively by Jacob, Sanchez-Vazquez & Ivory (2020b) and Heinsch et al. (2021). However, the focus for many of these is on the introduction of technology to clinical teams, without considering the nature of the task to which that technology refers.

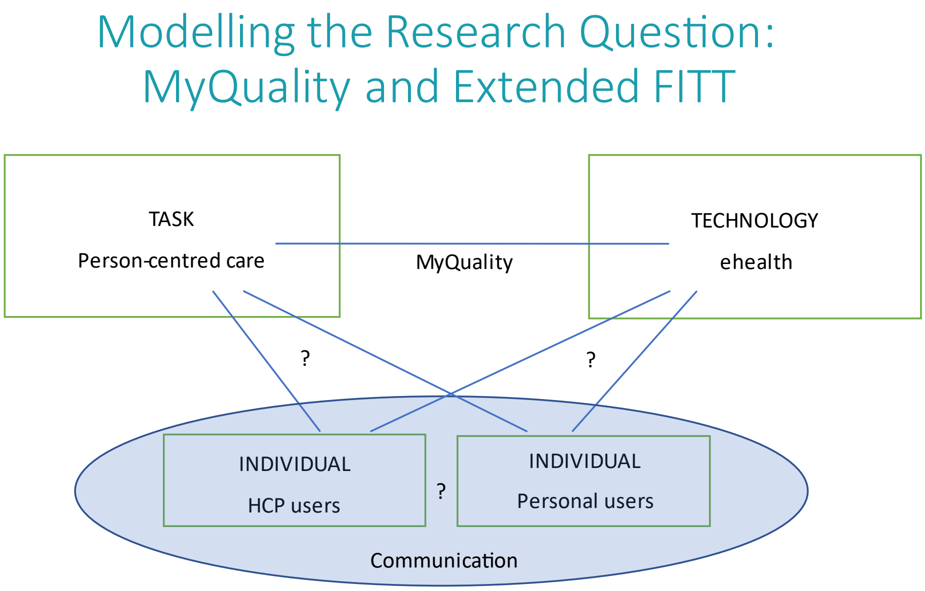
2.5 Summary and research question

This chapter has provided an overview of concepts fundamental to this area of research, namely the nature of children's palliative care, person-centred care, and ehealth, and includes a summary of the background and existing knowledge about MyQuality as an intervention to contribute improvements to the delivery of person-centred care. Gaps in knowledge about how to deliver PCC in practice, and incomplete understanding of the use and effects of MyQuality on staff and the dynamics of patient-professional interactions, suggest that further study is warranted. The aim of this research is to understand how MyQuality, as an example of an ehealth intervention, may affect communication and the delivery of person-centred care for children receiving palliative care services and their families.

Research Question: How does an ehealth intervention such as MyQuality affect communication and the delivery of person-centred care for children with life-limiting conditions?

In this thesis I will explore aspects of the task (delivery of PCC), the users (children and families with LLC and healthcare staff who support them), and the technology (MyQuality) in order to understand the complexity of this intervention, its impact on communication, and to consider how, why, and for whom MyQuality may make a useful contribution. Figure 2-6, a diagram of the inverted FITT model, outlines the research question in visual form.

Figure 2-6 Research question model



The design of MyQuality offers opportunities for technology to support the task of PCC, but the impact of MyQuality on other dimensions in this framework are unknown.

Thus, the specific objectives of this project are:

- to explore the influence of MyQuality, as an example of an ehealth intervention, on the dynamics of patient/family-professional communication.
- to identify the circumstances under which MyQuality may support, or hinder, communication and the delivery of person-centred care
- to explore how MyQuality, as an example of an ehealth intervention, may support a person-centred focus within healthcare encounters.

These objectives involve understanding the dynamics of interpersonal interaction in patient-professional relationships, and the role of these interactions in determining the focus of healthcare encounters, decisions and outcomes. These questions do not easily lend themselves to a quick analysis, but a deeper investigation into the subtleties of the needs, hopes, fears and expectations of the individuals involved, which will influence the mode of investigation. As Datta (1994 p55) states:

> *Neither the quantitative hook set for the big fish nor the qualitative net*
> *scaled for the little fish adequately captures life in most seas.*
> *We need a paradigm to help us become scuba divers.*

The next chapter will describe my methodological approach to this work, outline how and why this was chosen, and lead into the details of the methods for this study.

3 Methodology and realist methods

Having considered the background concepts of children's palliative care, person-centred care and ehealth in chapter 2, this chapter will summarise the decisions about the design of the study. I will start with an overview of research approaches and my reasons for considering realist evaluation as an appropriate choice to address the research question.

3.1 Identification of an appropriate methodology

The MyQuality website was designed to facilitate the sharing of information and provide a vehicle to amplify the observations or concerns of the patients within healthcare dialogue. As such, the aim of the intervention was to support communication to deliver a person-centred model of care, as outlined by Scholl, Hudon and many others. Investigating how this occurred could have explored a number of options, and some were ruled out for purely pragmatic reasons: whilst an obvious approach might have been to measure some attribute of the communication process, or the person-centeredness of care, there is no consensus on the best way to do this (De Silva, 2014) and the circumstances for the delivery or receipt of palliative care services would have made this very challenging. More fundamentally however, this research was not about whether or not people use a website, or whether the outputs of the website improve patient outcomes. It was about gaining an understanding about how people are influenced by the process of using the website, be this within individuals, or between individuals or families and their healthcare professional teams. This type of knowledge demanded an alternative approach.

Having explored a variety of options at the start of this project I was drawn to realist methodology for a number of reasons. One of the first steps in addressing the research question was to map out the connections and interactions between the various concepts outlined in the background – person-centred care, ehealth, and what is already understood about MyQuality, and to frame these within the environment of children's palliative care. The knotty complexity of the interactions was immediately obvious. Rather than shying away from this, realist approaches recognise the complexity inherent in the introduction of innovations into real life and identify these from the outset (Pawson, 2013a) using the VICTORE framework (Volitions, Implementation, Context, Time, Outcomes, Rivalry and Emergence) to untangle different elements of the intervention in practice. More details on complexity and what this means for this study are in section 3.5.

The second reason was the nature of the research question, which sought to understand the detail of what it was about MyQuality that might have produced the findings seen in the first study. One of the observations noted during the first evaluation was the variable extent of engagement with MyQuality by families, suggesting that not all families responded to the website in the same way. The strapline for realist enquiry is “What works, for whom, under what circumstances, how and why?” (Wong, 2018a), recognising the variety of settings, choices, decisions, behaviours, actions and outcomes when participants interact with a complex intervention. An observational approach might have identified “what” people do but would not provide depth of understanding to address “how and why” MyQuality could be useful, nor the detail to explain what worked for different individuals, or in varying circumstances. The opportunity to dig deeply for explanatory reasoning would enhance understanding of how MyQuality might exert its effects. Further discussion of the concept of ontological depth is in section 3.3.1.

The third reason was the nature of theory-driven evaluation. The intervention (or programme, as a realist might describe it) is not the focus of realist enquiry, rather it is the theories that underpin those interventions (Pawson & Tilley, 1997). By looking beyond MyQuality itself, an understanding of the underlying drivers (or mechanisms) of change and how these are related to and affected by circumstances (or contexts) supports the development of theories to account for the outcomes of the intervention. These explanatory theories provide knowledge that is transferable to interventions in different circumstances, as well as enhancing the ability to introduce, implement and develop similar interventions in the future (Gilmore et al., 2019; Kislov et al., 2019). There is further discussion of mechanisms and theories in section 3.4.

Alternative approaches to this research question were explored, including a descriptive case-study approach which was rejected as it might not provide the depth of explanatory detail I sought. Direct observation of healthcare interactions or analysis of discourse might have given a different perspective on communication processes. This was ruled out for pragmatic reasons related to the nature of healthcare delivery in children's palliative care, and concerns about the sensitivity, privacy and confidentiality of professional-patient interactions within a children's palliative care setting. In practice, patient-HCP encounters may involve a diverse range of professionals, with discussions occurring when appropriate opportunities arise rather than taking place at fixed times or settings.

Getting to grips with realist evaluation has been challenging at times, particularly as I arrived at this PhD with a solidly positivist mindset. Realist methodology has a different philosophy and analytical approach which will be explained in this chapter. This will be followed by more detailed description of the study methods and processes in chapter 4.

3.2 Ontology and epistemology

The choice of methodology is driven by the research question, but also by theoretical assumptions about the nature of the knowledge being sought, and how to recognise the validity of that knowledge – in other words, the epistemological and ontological framework necessary to underpin the chosen methodology. Ontology, the study of "being", questions the nature of reality by asking "what is real"? Epistemology refers to the nature of the knowledge: how do we know that something is "real"?

A positivist ontology considers reality as that which can be objectively known, independent of us, while constructivists attest that reality is subjective, constructed through and within human knowledge or discourse (Robinson & Groves, 1999). Although these views are not absolute and there is a spectrum of philosophical approaches in-between (for instance, post-positivists recognise that some elements of reality do not readily lend themselves to empirical measurement), realism deviates from both positivism and constructivism in its understanding that both the material (people and things) and social worlds (politics, religion, class, gender, feelings etc) are real, and human knowledge captures only a small part of a deeper reality (Westhorp et al., 2011) .

Critical realism is a philosophical movement that emerged in the 1970's in the wake of Bhaskar's *A Realist Theory of Science* (1975), following the positivist/constructivist "paradigm wars" (Fletcher, 2017). The ontology of critical realism is based on the concept that the nature of the world is largely independent of an observer's ideas about it (Ellaway, Kehoe & Illing, 2020), i.e. a "mind-independent reality", but it recognises that we may never be able to view the whole of that reality. Critical realism recognises the limitations of partial truth, reflecting the differing and limited perspectives on reality constructed from our position of observation or engagement (Mukumbang, 2021), and our understanding that all social systems are open systems that are fluid in nature (Danermark et al., 2001).

These social systems have porous boundaries (Westhorp, 2014); people, ideas, information and resources flow in and out of social systems. They are not static but will change over time, in complex and interactive ways. Westhorp (2014) gives examples of families and schools, economic systems and politics; for this study examples would include the specific health and social care needs of the child and family, the remit of teams providing their care, broader policy issues regarding place of care and the personalisation agenda in healthcare, and cultural positions about rights and responsibilities in society, to name but a few.

Epistemologically, critical realism focusses on exploring and understanding the mechanisms that drive social reality. By focussing on mechanisms, the knowledge that critical realism generates goes beyond description to seek out explanations (Ellaway, Kehoe & Illing, 2020). Knowledge in critical realism is produced through the process of abduction, defined by Tavory & Timmermans (2014) as "pragmatic theorizing with a focus on creativity as a logic of inference". Creativity and re-conceptualization are key concepts for abduction. It is the point where novelty, innovation and creativity enter the scientific method (Mingers, 2004) and can be described as "being able to understand something in a new way by observing and interpreting this something in a new conceptual framework" (Danermark et al., 2001). Abduction is a gut feeling, hunch, or informed imagination that leads to new ideas for generating theories and testing possible mechanisms (Jagosh, 2020). The creativity is derived from expertise and common sense to infer causal explanation and associations, and to generate theories to explain observations. Critical realism, therefore, combines a realist ontology with a constructivist epistemology (Ellaway, Kehoe & Illing, 2020).

3.2.1 Critical realism and scientific realism

The methodology chosen to address this research question, Realist Evaluation, draws on the principles of critical realism and abductive reasoning (Pawson 2013). Developed by Pawson and Tilley in the latter half of the 20th century, they have based this on a distinctive philosophical stance they have previously described as "Scientific Realism" (Pawson 2013, Pawson and Tilley 1997). This term is now falling out of favour because of the emerging understanding that both critical realism and scientific realism are closely related and represent points on a continuum between positivist and constructionist approaches (Westhorp, Rameses discussion group, Feb 2021).

There are differences between the paradigms of Scientific Realism and Critical Realism. While both differ from purely positivist or constructionist positions, they share an understanding that the world consists of a mind-independent reality, the totality of which is unknown to us, and both develop theories to explain the world around us. Critical realism addresses this ontology to issues of societal activity and has a broad philosophical approach, such as exploring large-scale social movements, where empirical testing is not possible (Jagosh, Rameses discussion group, Feb 2021). Pawson and Tilley's scientific realism (sometimes referred to as empirical realism) is a more strategic or pragmatic approach directed at smaller areas of societal interaction or tangible programmes. It is a theory-driven methodology and builds on the work of Popper and Campbell (Pawson, 2013b, pp8-11).

There will always be a chasm that exists between the manifested reality that we see, and our ideas about that reality, as we can never be aware of the whole of that reality. Thus a key concept for scientific realism is the accumulation of evidence that reflects what happens across a range of circumstances or results in a variety of outcomes (Pawson, 2013b). Unlike a positivist paradigm, in realist enquiry the strength of evidence is not related to the number of times an event occurs, but to the explanatory power of the mechanisms that can be observed to account for that outcome (Pawson, 2006). As mechanisms may not be empirically measurable, they can only be postulated and approximated, thus the theories about causation need to accumulate over time (Popper, cited in Pawson, 2013b, p9). Repeated efforts to explore mechanisms and test and retest theories in different contexts will lead us to a more general understanding of causative mechanisms that may apply to a variety of interventions and circumstances. This can lead to the development of more generalised theory, abstract enough to underpin the development of a range of programme types yet concrete enough to withstand testing in the details of programme implementation.

One of the criticisms of a realist approach relates to this incomplete understanding of reality. As Ray Pawson has put it:

> "even when undertaken well, it promises no certitude in terms of findings or recommendations, provides no verdicts, eschews rankings. It offers enlightenment on what are the key choices and how those options have fared in the past. It can offer reasons for preferring theory A over theory B, and back theory A over theory C. But it leaves open the possibility that a further set of ideas D might lead to more improvement. Even at best, its findings are tentative and fallible." (Pawson et al. 2004 p38).

Despite this caveat, a realist evaluation that reveals at least some of the theoretical underpinnings about how an ehealth approach such as MyQuality works would provide valuable information towards future refinement and implementation of that specific model of ehealth, and guide the evolution of other ehealth developments in other settings in the future.

3.3 Key concepts in realist methodology

3.3.1 Stratified reality and ontological depth

Realist methodology is firmly rooted in a belief in the stratified nature of social reality, in that all human actions are embedded within a wider range of social processes (Dalkin et al., 2018; Westhorp et al., 2011). Human actions are only understandable because they contain innate assumptions about social rules and institutions, and reasoning is understood in terms of its locations within different layers of social reality (Pawson, 2013b).

Bhaskar described stratified reality, visualising layers referred to as the empirical, the actual, and the real (Bhaskar, 1975). The "empirical" layer of reality can be observed, perceived, and often measured or scientifically tested. The domain of the "actual" refers to those mechanisms exercised that result in events, whether these are observed empirically or not. The "real" layer consists of all entities that exist, including all causal mechanisms, both exercised and latent. Latent mechanisms may be theorised but are not visible or testable until activated. Activated mechanisms may evade empirical capture, but unearthing these, or at least proxy equivalents, means that inquirers can use empirical methods to confirm their quality and existence (Jagosh, 2020). If these concepts are illustrated as if pertaining to MyQuality, the empirical reality might be reflected in the presence of the website or the number of individuals who used it. The actual reality would be the thought processes undertaken by users when deciding what to record when entering data – a deeper understanding of what it means to use the website. The real issues would include all the above, but also societal attitudes to privacy, control over personal information, or power and responsibilities in healthcare relationships – a more profound appreciation of the social influences on the reasoning of the individuals using the website.

A realist methodological approach requires consideration of both observable and hidden aspects of reality to be brought into view as abstract concepts in order to understand complex problems (Mukumbang 2021). Retroduction is the process of unearthing activated mechanisms in a theory-testing approach. Through the scientific realist process, retroduction can reveal and resolve things that appear to be paradoxical through an understanding of the configuration and association among elements in the empirical and actual realms (Jagosh, 2020). The role of retroduction is to gain a comprehensive causal view on the nature of projects and programmes, and to capture programme outcomes in an ontologically deep sense (Jagosh, 2020). Retroduction is an iterative process, continually reviewing observations and revising theories in order to better understand underlying causative mechanisms.

3.3.2 Mechanisms of change

Understanding causation is the critical question in realist enquiry (Westhorp, 2014). In realism, the powers or processes which generate events, or patterns of events, can be seen as causal mechanisms. These operate at all levels of reality and the outcomes of any mechanism are usually at a different level from the mechanism itself. Mechanisms often cannot be directly observed; they need to be hypothesised and tested (Westhorp et al., 2011). They may not “fire” in all situations, only in particular contexts. A realist evaluation tries to identify the mechanism that “fired” and to understand what caused (or, given multiple causation, at least contributed to) the outcomes (Westhorp et al., 2011).

Within a realist evaluation, multiple causative explanations for events are described and visualised through the development of Context-Mechanism-Outcome configurations (CMOcs). These are developed to explain “what works, for whom, in what circumstances” (Pawson & Tilley, 1997). The key to this configuration is the interdependence between context and mechanism. According Marchal et al. (2012) “change occurs when interventions, combined with the right contextual factors, release the generative mechanisms”.

Contexts may be material circumstances or social, psychological, organisational, economic, technical conditions etc and may operate at many levels from personal to societal (Coldwell, 2019). Pawson (2013) identified “the 4 I’s” to structure these: Individuals, Interpersonal relations, Institutional settings and Infrastructure (the cultural, economic and social aspects of the setting). Greenhalgh & Manzano (2021) reiterated the central role of context as a trigger for the firing of mechanisms. Rather than being a neutral factor in the background describing the circumstances in which an intervention works or doesn’t (such as a list of facilitators and barriers), the role of context is relational and dynamic. Contextual forces shape the mechanisms through which an intervention works and are intrinsic in causal processes. Understanding *how* a context influences a mechanism can illustrate what it is about the intervention in question that generates an outcome. Realist evaluation aims to explore the range of contexts and the interactions between contexts and mechanisms to produce a variety of outcomes (Westhorp, 2014).

In realist philosophy, a mechanism is the underlying causal process that contributes to an outcome. Realist evaluators do not assume the successionist view that interventions directly cause outcomes, but understand that interventions may offer a range of resources to participants. Rather than asking the question “does X cause Y?” (successional causation), retroduction asks “What is it about X that results in Y?” otherwise known as generative causation (Williams, 2018). Mechanisms involve an interaction between the resources (which may be material, social, emotional, political etc) and the responses these prompt from participants (Dalkin et al., 2015). Outcomes may arise when *resources enable* existing reasoning (e.g. for MyQuality users, a website provides a simple route to communicate information) or by *changing reasoning* (e.g. MyQuality users can now understand the importance of sharing this information) (Westhorp, 2014). Interventions may trigger outcomes via a wide range of mechanisms for any one participant, and many social interventions involve multiple participants, thus increasing the complex nature of understanding how an intervention produces an outcome.

The quest for deeper generative causal mechanisms is what makes realist evaluation distinct from other theory-driven forms of evaluation. The contemporary evaluation landscape is littered with an array of similar terms such as “theory-based evaluation”, “programme theory”, “logic models”, “theory of change”, “intervention logic”, “outcomes hierarchies”, “theory-anchored”, “theory-oriented” and more (Astbury & Leeuw, 2010; Rogers & Weiss, 2007). Although many of these are used interchangeably, there are important conceptual differences as some are used to identify and describe the way in which a programme fits together, and others build an explanatory account of how a programme works. Central to this process is the identification of theories to account for the outcomes of social interventions. Weiss (1997) argues that it is crucial for evaluators to distinguish between what she calls “implementation theory” (or logic models), which provide operational details about how the programme is carried out, and programme theory which:

> “deals with the *mechanisms* that intervene between the delivery of programme service and the occurrence of outcomes of interest. It focuses on participants’ responses to programme service. The mechanism of change is not the programme service per se but the response that the activities generate” (p46, emphasis in original)

Logic models or Theory of Change may identify successionist causal mechanisms but these are not supported by deeper ontological exploration and hypothesis testing as part of the investigative process. Models based on “Theory of Change” may be viewed as too focussed on implementation rather than underlying causal theory, and are often seen as too descriptive, linear and non-critical (Blamey & Mackenzie, 2007).

Mechanisms can be activated and thus become apparent in the “actual” or “empirical” world, in certain circumstances or contexts, so realist enquiry can use empirical methods to confirm their quality and existence. The activation means they are always entangled within particular contexts of manifestation, so the context is relevant to theory-building about how and why interventions may produce the outcomes that were intended (Westhorp et al., 2011).

3.4 Explanatory theories

Programme theory, the specific idea about how an intervention causes the intended or observed outcomes, should be the central aspect of any realist evaluation or synthesis (Shearn et al., 2017; Pawson, 2013b).

A programme theory (PT) is a set of assumptions which explain how and why the intervention is expected to work, and in which conditions (Marchal et al., 2018). Programmes are “theories incarnate” (Pawson & Tilley, 1997). Theories can be conceptualised at a very narrow sense where a specific intervention is theorised to lead to a goal, or at a more abstract level highlighting key concepts or relationships that might be influential for other, similar interventions. For the purposes of this work, I will refer to PTs as referring to specific aspects of the intervention under study, and more abstract theories as "middle range programme theories" (MRPT) (Kislov et al., 2019). MRPTs are testable but sufficiently general to be scientifically interesting and may contain a theory of action for a specific context (Punton, Vogel & Lloyd, 2016).

Formal middle-range theories (MRT) are more substantive ideas about human behaviour which often provide a bridge to a wealth of existing research and knowledge about a topic (Kislov et al., 2019). They are more abstract than PTs or MRPTs. Pawson and Tilley have adopted Merton's definition of a middle-range theory: "theories that are between the minor but necessary working hypotheses […] and the all-inclusive systematic efforts to develop a unified theory that will explain all the observed uniformities of social behaviour, social organisation, and social change (Merton 1968, p38). A PT may test a MRT; a MRT may direct investigation into a specific PT. Merton puts forward the idea that MRTs should produce explanations that are sufficiently abstract to deal with different spheres of social behaviour and social structures, so that they transcend sheer description (Pawson, 2013a). However, this theory classification merely points to a spectrum between the highly specific programme theory and the very abstract or "grand" theory, which could broadly apply to a wide range of circumstances and not simply to the intervention or social behaviour in question (Punton et al., 2020).

Westhorp (2012) reflects on the use of theory to understand policy processes and outcomes and points out that using substantive theories is of particular value in understanding the processes of change in complex adaptive systems. Substantive theories encourage researchers to draw boundaries around systems within which an evaluator will work, identify which interactions matter for generating outcomes, and explore the details of the "local rules" that govern social interactions (Westhorp, 2012). Theories may be layered and predict outcomes at different layers of systems. On a practical level, the use of theory in this way may support explanations for expected outcomes or may explain the failure to achieve anticipated outcomes, either due to implementation failure of the intervention, or theory failure (Punton, Vogel & Lloyd, 2016).

3.5 Embracing complexity

The realist argument is that solutions to complex problems require us to bring abstract concepts into concrete form, and observable and hidden aspects of reality into view, by theorising and theory testing. Although defining “complex problems” is difficult, these generally involve multiple influences on the decisions and behaviour of individuals, organisations, or social policy and political programmes.

Glouberman and Zimmerman set out to distinguish between problems that are simple, complicated, and complex. Simple problems are those which, once mastered, are easily solved by following the examples of previous successes, with a good assurance of a positive outcome (the example given is “following a recipe”). Complicated problems are those which may contain subsets of simple problems but are not merely reducible to them as solving them will also require co-ordination or specialised expertise (the example given is “flying a rocket to the moon”). Complex problems can encompass both complicated and simple problems but are not reduceable to either as they also incorporate aspects of interdependency, unique local conditions or influences, and a capacity to adapt as conditions change (the example given is “raising a child”). Complicated problems can be resolved with a high degree of certainty given sufficient resource, expertise, and commitment. Complex problems are more challenging as formulae from previous situations have more limited application, and although expertise can contribute to the process in valuable ways it provides neither necessary nor sufficient conditions to assure success. There is always some uncertainty of outcome (Glouberman & Zimmerman, 2002).

Rogers (2008) suggests that complicated interventions are those with multiple strands – multiple sites, multiple stakeholders, multiple ambitions, whereas complex interventions develop “a life of their own”, with feedback loops, endogenous change, emergent properties, disproportionate relationships (where at critical levels, a small change can make a big difference and act as a tipping point) and unintended consequences. Rogers suggests that evaluation of complicated interventions is possible if they can be broken down to their component parts or combinations, but that for complex interventions this is much more challenging as it may not be possible to determine specific measures for evaluation in advance of an intervention as emergent outcomes may be unpredictable, making pre- and post-comparisons difficult.

Realist enquiry recognises complexity at its core, and embraces the idea that complexity is inherent in social systems. Social interventions are influenced by multiple contextual features at different social levels (individual demographics, interpersonal relationships, political and economic structures), and these act like a web of causal processes which in combination, generate the outcomes (Shearn et al., 2017). Realist evaluation visualises these as the contents of the “black box”. The “black box problem” refers to the practice of viewing social programmes primarily in terms of outcomes or effects, with little attention paid to how those effects are produced (Astbury & Leeuw, 2010). Unpacking the black box so that the inner components or logic of a programme can be inspected allows researchers to develop an understanding of how and why an intervention works (or doesn’t). This is important because if social interventions or programmes are based on faulty logic or theories of action, they will not bring about the desired changes, irrespective of how well they are implemented (Astbury & Leeuw, 2010).

Healthcare is often viewed as a complex system and interventions in healthcare may act and interact at many levels, from focussing on behavioural change at an individual level, to changes in the health service, public health or social policy. Various parts of the intervention may not be complex in themselves, but the whole of the intervention can be seen as distinct from the parts and have more or different powers than the aggregate powers of the parts (Elder-Vass, 2013). Complex interventions cause change when parts of the intervention come together under particular circumstances to generate changes in outcomes. Even small changes in one part of an intervention may lead to marked larger changes in the outcomes of the complex intervention. These generative causal powers are prone to temporal changes, as causation is not necessarily static over time. New and potentially powerful aspects of an intervention may emerge from parts of complex interventions, such as elements of its content, design, providers or recipients (Clark, 2013).

Exploring the use of MyQuality and its potential impact on communication between healthcare professionals and their patients and families, and as a route towards a more patient-centred focus in healthcare interactions is, by the definitions above, a complex intervention. There are multiple participants, multiple options for decisions at multiple stages, and the intervention will be used in a wide variety of environments with differing policies, social expectations, and desired outcomes. The potential for unanticipated emergent outcomes even at small scale use is high, and with upscaling or broadening of the intervention this would grow and be increasingly affected by potential feedback loops at individual, organisational and policy level. Realist approaches are particularly focused on uncovering causal processes rather than simply outcomes and may be most effective when dealing with issues of complexity where many causal factors interact. Hence this project lends itself to investigation using realist methodology.

Realist methodology uses a practical approach to unpick potential aspects of complexity that need consideration during evaluation. Pawson (2013a) explored this area through the VICTORE framework to consider complexity regarding social interventions, as outlined in Table 3-1.

Table 3-1 VICTORE Framework (Pawson, 2013a)

Dimension of complexity	Example	Implications for MyQuality
Volitions	what motivates potential participants to join in a programme of change, or to use a new intervention? What choices do subjects have to make to achieve the ambitions of the programme?	Range of participants, range of motivations
Implementation	What processes, strategies or tactics are involved to influence the uptake or engagement with the intervention in question? Which measures facilitate or block involvement?	Range of participants and settings, variable extent of support for website itself, and integration with other records and practices
Contexts	Consider the pre-existing contexts in which a programme is embedded. These may be individual factors or interactions, organisational settings or policy or societal influences, and these may be subject to change over time.	Which users? Which settings? Pre-existing inclinations regarding data use and data sharing, communication style
Time	consider how previous experience with similar programmes, or in similar environments, may influence decisions about the current intervention	Changing tech environment, changing views on autonomy, rights and responsibilities over time.
Outcomes	what outcomes are sought, and how will they be measured? Will the process of identifying outcomes or monitoring them have an impact on the intervention programme itself?	Short-term vs long-term, whose perspective?
Rivalry	Other pre-existing services, policies or activities may share or oppose the current intervention and may influence the actions of those involved in this intervention or programme. Consider how these may continue to have an impact on delivery of your intervention over time.	Increasing emphasis on data privacy, increasing emphasis on potential of big data, and new tech innovations appearing regularly
Emergence	Potential outcomes of your programme may have unintended or unanticipated consequences, or unforeseen long-term or societal implications. How will these influence the wider significance of the intervention in question and contribute to the success of the programme in question?	Consider wider implications for workload, resilience, privacy and accountability

3.6 The realist evaluation process

Realist Evaluation involves four core steps: Articulating the programme theories to be tested, collecting data to test hypotheses, testing the hypotheses, and interpreting and refining them (Brousselle & Buregeya, 2018). These proceed in an iterative manner as illustrated in Fig 3-1 (p57).

As the programme theory, rather than the intervention itself, should be the "evaluand" in realist evaluation (Pawson, 2013b), it is important to consider which theories might be relevant when planning a realist evaluation. It may be possible to identify these in the documentation and design of interventions, but these may be difficult to discern when interventions are not well defined, or if implemented without clear boundaries. Theory development is an iterative process, and may involve cycles of hypothesising, theory testing, theory selection and shedding, or developing additional lines of enquiry as an evaluation proceeds. It is also a multi-layered process, as theories may be significant at different levels of social strata: micro level (relating to the individual), meso level (relating to interpersonal) and macro level (relating to institutional, infrastructural, and cultural factors) (Westhorp, 2012). When developing theories, it is critical to define concepts and the fundamental character of the intervention, and to develop an interim or propositional programme theory based on a conceptual framework that considers the multiple layers of social structures and interactions.

3.6.1 Identifying Theories

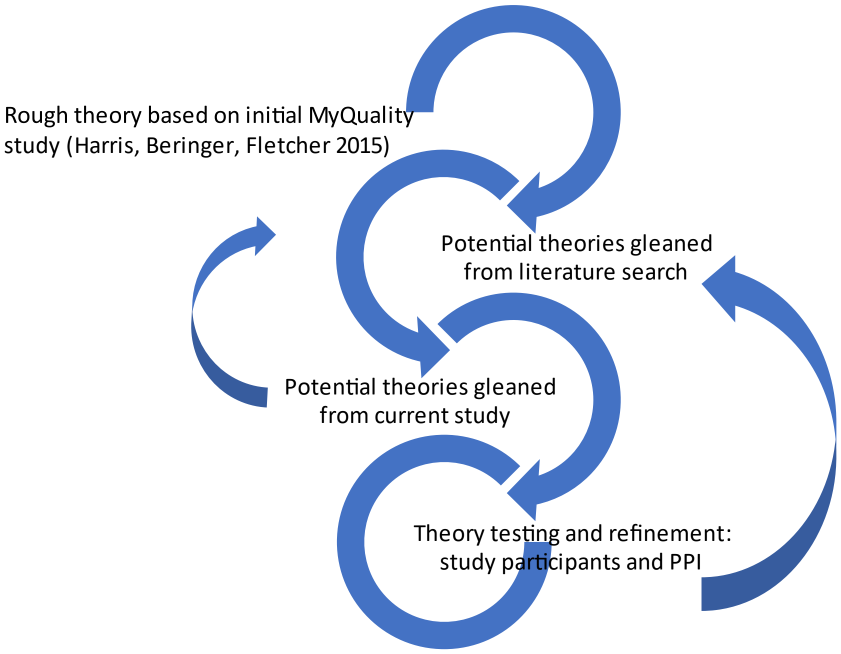
Shearn et al. (2017) outline the challenges of building programme theories when there is no explicit theory written in policy or service documents, and recommend four approaches: using concepts from abstract theories which were used to inform comparable interventions; using concepts from abstract theory selected purposively for the research evaluation but which have not been referenced in the programme literature; extracting tacit theories about what is working and why from interventions on similar topics reported in the literature; and extracting tacit theories directly from stakeholders and or developed by the research team who may be embedded in the intervention or use their own experiential or professional knowledge.

When extracting tacit theories that have not been previously articulated, a range of techniques can ensure that key concepts such as context, mechanism and outcome are elucidated (Punton et al., 2020). Using if-then-because statements to describe specific features of a programme supports a retroductive approach and provides explanatory, rather than just descriptive, links between context and outcome (Astbury & Leeuw, 2010). These if-then-because statements may in themselves highlight partial links between context and outcome, context and mechanism, and mechanism and outcome. They must be sufficiently detailed to provide explanatory power relating to the intervention under investigation. Preliminary, provisional or partial programme theories may evolve over time as theories are tested as part of an evaluation process (Astbury, 2018).

Unlike empirical paradigms, observing a variety of outcomes does not signal programme "failure", even if the results may not be the desired effects produced by the intervention. Unexpected, unwanted or infrequent results may be valuable in highlighting how contextual influences may trigger the dominance of alternative mechanisms to that proposed in the initial programme theory (Westhorp, 2014). Practices such as the development of rival theories which incorporate a range of potential context-outcome, context-mechanism or mechanism-outcome combinations may shed light on the mechanisms activated at different social levels (Shearn et al., 2017). Rival theories can emerge with granular exploration of theories. "Granularity" refers to the idea that delving in detail into vague concepts in a theory to operationalise or gain specificity in causal claims will help to clarify a range of potential contexts, mechanisms and outcomes that can be hypothesised as rival theories, to be explored as theories are tested (De Weger et al., 2020). Juxtaposing highly granular rival theories can expose contextual elements that matter but can be difficult to detect otherwise, thus supporting a deeper understanding of generative causation of the outcome in question (Pawson & Tilley, 1997).

There was no clearly articulated detailed programme theory for MyQuality in the first study (Harris, Beringer & Fletcher, 2015). Instead, successionist thinking followed a logic that the introduction of a new resource (MyQuality) would lead to an outcome of improved communication in the short-term, and improvements in patient and family outcomes in the longer term. This rough theoretical model did not provide explanations of how or why these outcomes might arise as it was lacking in ontological depth and granularity. Whilst the initial MyQuality study was not designed to elicit mechanisms to underpin this process, the findings led to speculation that the combination of empowered patients and families, and greater information provision for healthcare professionals, would lead to the desired outcomes. These speculative ideas equate to the “black box” containing mechanisms, the nature of which remained unclear. Further theory exploration and development was warranted using a multi-pronged approach to extract tacit theories from the literature and this research study, as illustrated in Fig 3.1.

Figure 3-1 Iterative design of MyQuality study



3.6.2 Theory Development using existing sources – searching the literature

A conventional approach to a systematic literature review to address this research question would involve identifying key words and their synonyms, interrogation of relevant databases, and a structured, systematic evaluation of the quality of evidence and its findings. A good systematic review should be thorough, replicable, current, and provide a comprehensive summary of the state of knowledge on a specific question (Booth, Briscoe & Wright, 2020). However, a systematic literature review may not contain the sort of information that will support the realist quest for causative mechanisms to explain observed outcomes, so the search needs to be broader and the strategy more flexible in order to find the required data (Booth, 2018). When seeking this in literature, relevance, richness and rigour are key factors (Hunter et al., 2022).

Data are relevant in a realist enquiry when they support the development of theories, or the testing or refinement of aspects of a realist programme theory (Wong, 2018b). This means that searches should not necessarily be restricted to academic literature, driven by the content of databases of published material, nor influenced by hierarchies of evidence (Wong et al., 2013, Hunter et al., 2022). Meta-analyses and randomised controlled trials may obscure many explanatory details about how interventions may work by focussing on quantitative outcomes, and publication bias may limit the range of available sources. Relevant information may be found in policy documents, case histories, or discussions with stakeholders with experience relevant to the field in question, so a much broader search strategy is required (Booth, 2018). As Pawson and others recommend (Pawson et al., 2004), this may start with a background search of the published research to explore the range of relevant data, but may evolve to incorporate more sources in an iterative manner, as potential programme theories are found or evolve.

These search approaches may produce overwhelming amounts of data, much of which is very wide-ranging. The challenge then becomes managing to focus on what is relevant, and this may involve refining the scope of enquiry and adopting a pragmatic approach to limiting data sources. The concept of data saturation may be relevant, as the search for evidence should aim for a point at which additional evidence does not add to, or contradict, evidence already identified (Booth, 2018). Rather than a conventional systematic review where the aim is to retrieve an exhaustive body of literature on a specific review question, it is more appropriate to privilege the specific over the comprehensive in the search for relevant data to support theory development (Pawson et al., 2004).

Rich data sources will not only describe the intervention, but should also include details about the context in which it took place, and a degree of theoretical and conceptual development that explains how an intervention is expected to work (Booth et al., 2013). Contextual richness does not simply mean a description of the participants or setting as a simple reporting of facts, independent of intentions or the circumstances that surround an action. Contextual richness should include sufficient detail to establish what exactly is going on, both associated with the intervention and the wider environment, to enable the reader to infer whether the findings can be transferred to other people, places, situations or environments. This information may be found in qualitative papers, but word counts and journal publication rules may encourage much richness to be buried or hidden from academic papers. Other publication formats, such as grey literature, blogs, or book chapters may include details or perspectives that are not found in academic databases (Booth, Briscoe & Wright, 2020).

Rigour refers to an assessment of the quality of evidence found (Wong, 2018b). This is not dependent on an appraisal of where the study in question sits in a research hierarchy (where qualitative case studies may be seen as less rigorous than randomised controlled trials for instance) but on the value of the evidence to support theory development. Thus the unit of evaluation of rigour is the fragment within a paper or report that provides explanatory power, be it direct quotations from participants, or articulation of theory, not the paper as a whole (Pawson, 2006). The aim is to provide a subtle portrait of intervention success and failure, and a comprehensive explanation of the subjects, circumstances and respects in which a programme theory works, and in which it fails. The quality of the data gathered is determined by its explanatory power of the mechanisms at work, rather than the size of the effect. The data needs to be trustworthy, and plausible (Wong, 2018b). Trustworthy data will have been collected empirically and may often be echoed in more than one source. Plausible data will be coherent, explanatory, simple, and fit with what we currently know, and/or substantive theory. Decisions about the selection of relevant data should be transparently documented and justified (Berg & Nanavati, 2016). This approach to exploring the data should support theory development in a robust and rigorous manner.

Data from the literature is configured using context-mechanism-outcome configurations (CMOc's). This approach applies whether the data comes from academic literature, interview or focus group transcripts, blog analysis, grey literature documents or other sources, and should take place throughout the theory development process in an iterative manner (Manzano, 2016).

The extraction of information to support programme theory development for this study is outlined in more detail in chapter 5.

3.6.3 Theory Development from the study of the Intervention

As Shearn (2017) and Flynn et al. (2020) report, theories may be developed with input from stakeholders or those embedded in the delivery of an intervention, who contribute professional or experiential knowledge. The details of the study design to enable primary data collection about MyQuality in practice have been articulated in Chapter 4, but some general principles are outlined below. This abductive process is closely entwined with use of sources in the literature as theories develop and are confirmed, refined, refuted or discarded, and in this study the literature searching and primary source interrogation took place in an iterative manner with repeated cycles of testing and exploration over a period of two years.

Realist methodology is not prescriptive in the types of methods used to gather evidence (Greenhalgh T., 2017; Punton, Vogel & Lloyd, 2016; Pawson 2013) and may involve the use of a range of qualitative and quantitative approaches. The use of multiple methods is encouraged (Bergeron & Gaboury, 2020; Greenhalgh T., 2017). In addition, a realist enquiry is designed to explore what works, but also what doesn't work, and thus needs flexibility to investigate unexpected or unintended outcomes (Dalkin et al., 2020b).

Qualitative data collection frequently involves interviews with participants or stakeholders, as individuals or in groups. Much qualitative interviewing focuses on the desire to explore concepts or experiences, and interview techniques range from the open-ended question, to the use of semi-structured conversations or the structured prompts and guides to direct the discussion (Roulston, 2010). In contrast, the aim of the interviews in realist enquiry is the exploration of theories about how and why an intervention works, which necessitates a theory-driven design of interviews to encourage participants to explore and validate, falsify, or modify the programme theories presented to them (Manzano, 2016; Pawson, 1996). This does not mean that open exploration is not welcome, as this may be the source of valuable insights leading to new theories about the intervention that had not been previously articulated, but the interviews should include discussion of theory in a more systematic and explicit manner than in many other forms of qualitative interviewing.

When reviewing raw data such as interview or discussion transcripts, the focus is not on the thematic analysis of the interview, but on theory-relevant data extraction (Pawson, 2006). Transcripts are initially scanned for causal insights, the “golden nuggets” that will support theory development. Coding for insights into the provisional programme theories or suggestions for new theories allows the emphasis of data analysis to remain the theory, not the intervention. The data can then be reorganised and catalogued according to lists of contexts, mechanisms and outcomes (Bergeron & Gaboury, 2020). This process can help to define and clarify these key elements and this in turn may help to revise initial programme theories. These are then assembled into CMO configurations to demonstrate the generative association between mechanism and context that leads to the outcome (Jackson & Kolla, 2012; Flynn et al., 2020).

3.6.4 Theory testing and refinement

The goal of a realist evaluation is to question programme theory to ascertain if it is sound, to adjudicate between rival programme theories, and to consider the same theory in comparative settings, in order to better understand what works, for whom, in what circumstances and why. Testing the programme theories can incorporate a range of methods, and it is recommended practice to incorporate both qualitative and quantitative data to support both outcome assessment (especially what works, or not) and to understand underpinning mechanisms to explain why (Wong et al., 2017). Realist evaluation is not method-specific, but some methods can be made particularly relevant for realist enquiry by ensuring that the focus remains on the theory development and testing, rather than a more generalised review of empirical outcomes, or participant experiences.

As theory development, testing and refinement is an iterative process, concepts such as sample size, interview content and data saturation need to reflect the methodological underpinnings of realist enquiry. Sample size considerations should be designed to discover whether a programme succeeds or not across a whole spectrum of sites, population groups, and circumstances such as implementation barriers (Manzano, 2016). Sample size for interviews will be theory-based, guided by the variability of contexts and outcomes to be explored, and sampling may be purposive to address a range of factors present in the intervention population (Rameses II project, nd). The significance of an outcome is not related to its frequency in the test population: an outcome may be caused by an individual set of contextual circumstances activating mechanisms in a unique manner, so exploring the mechanisms that may be driving a wide range of outcomes, common or not, may reveal a number of contextual triggers that might otherwise have remained hidden (Pawson 2013; Pawson & Tilley, 1997).

Interviews should be sufficiently structured to address discussion of proposed theories, but flexible enough to adapt to theory evolution over time (Pawson, 1996). Rather than having prescribed interview guides, the researchers may need to adapt the interview content to allow the exploration of new insights into contexts, mechanisms and outcomes, to discuss rival theories that emerge as the theory process develops, and to delve into the particular details that may refine the specifics of theory (Manzano, 2016; Pawson, 1996). Ideally, the ability to collect data in a longitudinal manner allows time for reflection and theory development as the evaluators become more knowledgeable over time.

Data saturation for realist enquiry differs from the same concept in other forms of qualitative research, as realist theories are not confirmed or abandoned through saturation obtained in a set number of interviews but through the relevance and rigour of data collected from a range of resources, including a wide variety of literature and other mixed method sources (Pawson, 2006).

3.7 Realist evaluation and MyQuality – chapter summary

The research question for this thesis asks how an ehealth approach, such as MyQuality, may affect communication and the delivery of person-centred care within the field of children's palliative care. Although the scope of this exploration is tightly constrained by the intervention and the population exposed to it, the question is important because an understanding of the underlying responses or reasoning by users may illustrate concepts about the behaviour of patients, families and healthcare professionals that may have more generalised implications for ehealth and for patient-professional interaction.

This chapter has outlined the philosophical underpinnings of realist evaluation and described the methodological processes that will support this investigation. By asking what works, for whom, under what circumstances and why, a theoretical framework can be developed that explores the range of contextual circumstances that may influence the mechanisms that drive the thoughts or behaviour of the users of MyQuality. Rather than ignoring the diversity of forces and circumstances affecting the various agents involved, realist evaluation recognises and embraces these dimensions of complexity and is thus an appropriate approach to address the research question.

The following chapters will build on the rationale described above. Chapter 4 outlines the methods used for theory development, including the specifics of the data collection processes designed to uncover and test theories for this realist evaluation. Chapter 5 will expand on the processes of data extraction from existing literature sources, followed by the preliminary development of theories.

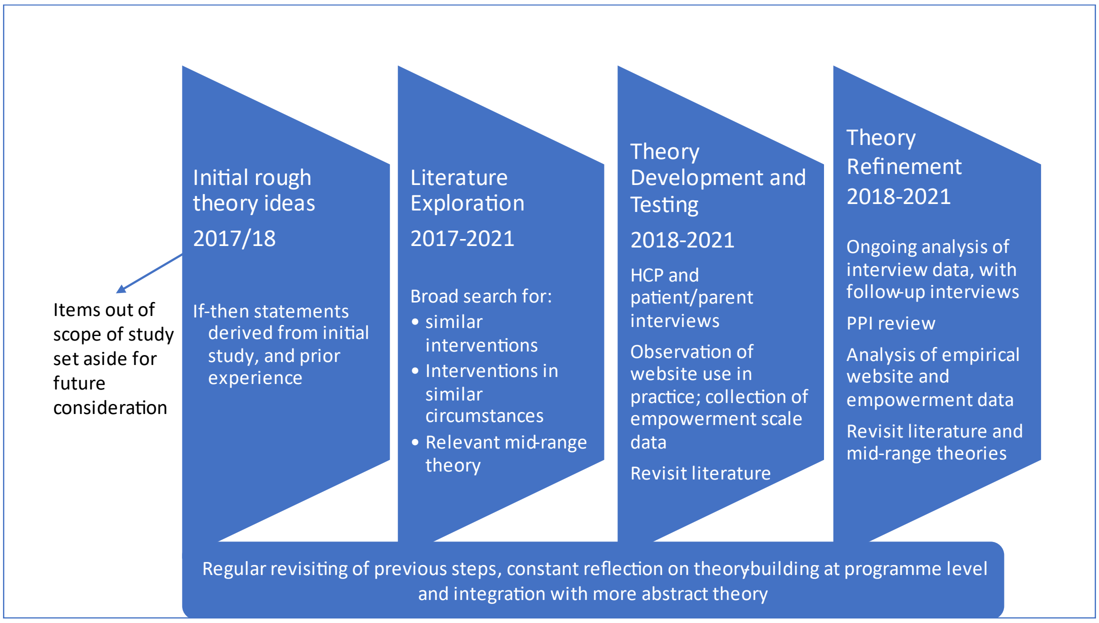
4 Methods

This chapter reports the design of activities undertaken to address the research question. The study involved a range of processes in order to define and refine explanatory theories.

- A retroductive exercise to identify an initial range of concepts that might be relevant to theory development, based on the initial MyQuality study.
- Literature exploration (in the widest sense, including non-academic sources).
- Interrogation of key stakeholders, those who have been involved with using the intervention.

The iterative nature of realist research meant that many of these processes ran in parallel, as visualised in Fig 4-1.

Figure 4-1 MyQuality Study Overview

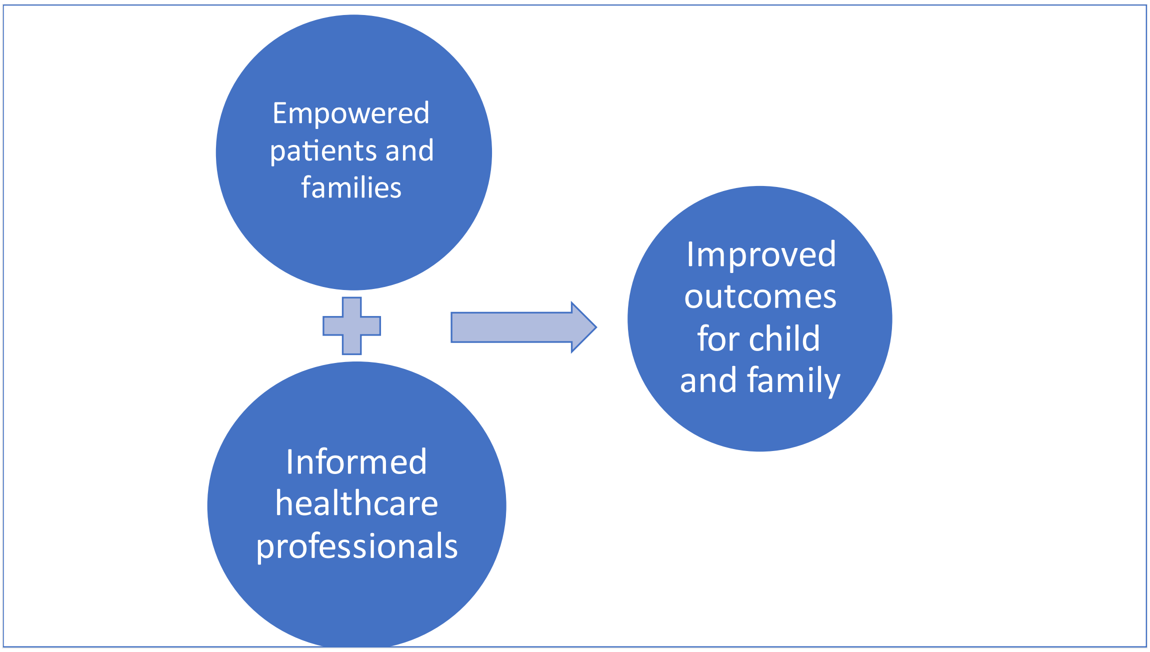


4.1 First steps in theory development: an exercise in retroduction

MyQuality was evaluated in 2013/14 (Harris, Beringer & Fletcher, 2015), as described in section 2.3.3.1. This was a mixed methods study to explore the feasibility of website use and was not designed to elicit underlying mechanisms of action. The initial evaluation of MyQuality suggested a rough programme theory as illustrated in Fig 4-2, but this was not clearly articulated in causal terms. However, the knowledge gleaned in the processes of developing, using and testing the intervention in clinical practice gave this researcher insights into a range of mediating factors, facilitators and barriers to its use which were felt to contain potential causal insights, variously referred to as “pearls of wisdom” or “golden nuggets” (Pawson, 2006).

These were extracted through a retroductive brainstorming exercise where the possible contexts, outcomes and mechanisms were listed and catalogued. They were developed using “if-then-because” sentences, as these facilitated the contemplation of different contexts (individuals, interpersonal relationships, institutions or infrastructure) and differing outcomes, with “because” suggesting potential explanatory mechanisms. This became a lengthy exercise as the combinations and possible explanations were extensive, and eventually was curtailed for pragmatic reasons once the list exceeded 200 if-then-because statements. These were then coded to identify possible contexts, mechanisms, outcomes, and to differentiate these from the nature of the intervention itself. An example of one page is included in Appendix L.

Figure 4-2 Rough MyQuality programme theory based on Harris, Beringer, Fletcher 2015



This process provided some key information for the subsequent data extraction processes. Firstly, by visualising the scope of hypothetical theory areas, it emphasised the need to restrict the focus of this evaluation to the "micro" interactions between healthcare professional and the patients/families, rather than extending this to explore meso-level issues for teams of service providers, or macro-level policy and organisational issues. These remain important considerations but are beyond the remit of this project. Secondly, it highlighted several key concepts where there was blurring of categorisation, such as empowerment: this could be a context (the already-empowered user), a mechanism (empowered reasoning) or an outcome (becoming empowered as a result of the intervention). This lack of clarity suggested a need to focus on deeper exploration of this area. The third benefit was that the creative thinking involved in the retroductive process identified many rival theories which exposed conflicting underlying themes such as the tensions between privacy and openness, or the delegation of responsibilities between HCPs and those under their care, which suggested further areas of enquiry for potential deeper mechanisms. A final additional benefit of the first exercise was a clearer understanding of the architecture of the intervention itself, which helped to structure the literature search (see chapter 5 for details).

The if-then-because statements were revisited at intervals over the course of the study. The reflections based on this exercise served as a reference point for decisions about the scope of the literature review and theory development process, and a reminder that "a realist enquiry is never 'done', but it is important to know when to stop" (paraphrased from Ray Pawson lecture, August 2020).

4.2 Parallel steps in theory development: from the literature and stakeholders

The literature review process started in 2017 and continued throughout the study, contributing to theory development for the programme itself and through the identification of relevant middle range theories. At the same time, theory development and testing took place with key stakeholders involved with children's palliative care services, those who were either providing or receiving support. Data collection was focussed on three sources: interviews with study participants, analysis of patterns of interaction with the MyQuality website, and assessment of empowerment using a questionnaire. The details of the exploration of the literature are outlined in the narrative report in chapter 5. This chapter describes the processes involved to collect and analyse data about the use of MyQuality in practice. Figure 4-3 illustrates the study activities as a flow diagram.

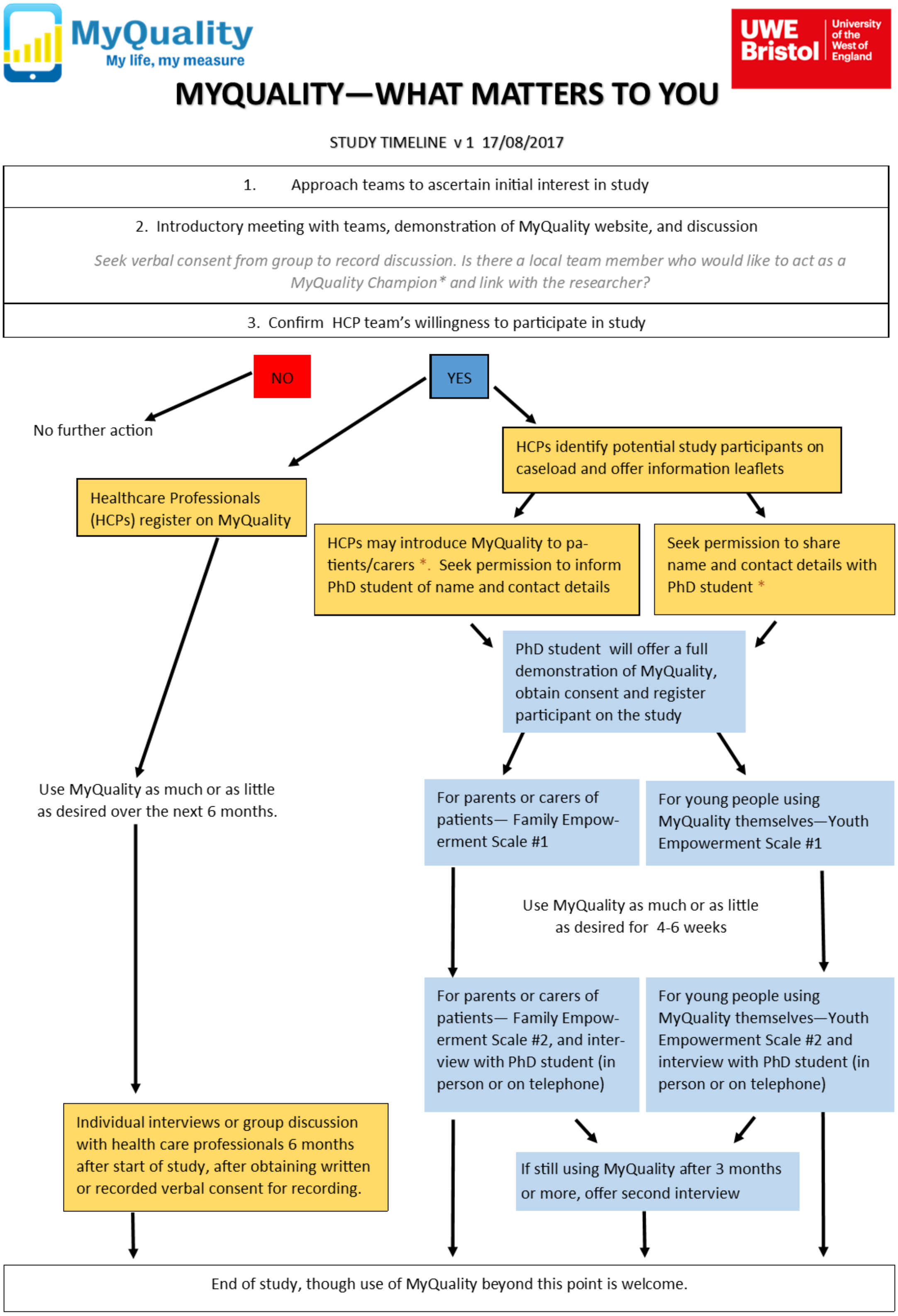
4.3 Study sample

4.3.1 Site selection

Recruitment of study participants was aided by the presence of the South-West Children's Palliative Care Network. The lead researcher was a founder member of the network, which had been in existence since 2002. It provides training meetings for interested healthcare professionals across the region three times a year, along with time for networking with peers and the opportunity to share best practice. These meetings provided the ideal opportunity to sound out interested healthcare professionals and arrange to meet with their palliative care teams at their base, at a time of their choosing, for an initial introduction to the study and information about the MyQuality website. For logistical reasons related to research governance requirements, the number of organisations participating was limited to five.

Once an appropriate date was agreed, the introductory meetings with clinical teams took place over the course of approximately one hour. Teams were informed about the need to audio-record the meetings, and verbal consent was sought before proceeding with the recording. These introductory meetings followed a fixed format based around a Powerpoint presentation to ensure consistency of information delivery and to guide discussion. This presentation included an introduction to the MyQuality website and a summary of the previous evaluation, an outline of the proposed study, and time for questions and discussion about how it might work within their own teams and organisations. Time was included for those listening to use the opportunity to log on and explore MyQuality themselves and become familiar with its use. Multidisciplinary input was encouraged, as healthcare professionals working with children and families have a variety of roles and approaches to communication with their patients. There was

Figure 4-3 Flow diagram of study processes



MyQuality
My life, my measure

UWE Bristol University of the West of England

MYQUALITY—WHAT MATTERS TO YOU

STUDY TIMELINE v 1 17/08/2017

1. Approach teams to ascertain initial interest in study

2. Introductory meeting with teams, demonstration of MyQuality website, and discussion

Seek verbal consent from group to record discussion. Is there a local team member who would like to act as a MyQuality Champion and link with the researcher?*

3. Confirm HCP team's willingness to participate in study

NO

No further action

YES

HCPs identify potential study participants on caseload and offer information leaflets

Healthcare Professionals (HCPs) register on MyQuality

HCPs may introduce MyQuality to patients/carers *. Seek permission to inform PhD student of name and contact details

Seek permission to share name and contact details with PhD student *

PhD student will offer a full demonstration of MyQuality, obtain consent and register participant on the study

Use MyQuality as much or as little as desired over the next 6 months.

For parents or carers of patients— Family Empowerment Scale #1

For young people using MyQuality themselves—Youth Empowerment Scale #1

Use MyQuality as much or as little as desired for 4-6 weeks

For parents or carers of patients— Family Empowerment Scale #2, and interview with PhD student (in person or on telephone)

For young people using MyQuality themselves—Youth Empowerment Scale #2 and interview with PhD student (in person or on telephone)

Individual interviews or group discussion with health care professionals 6 months after start of study, after obtaining written or recorded verbal consent for recording.

If still using MyQuality after 3 months or more, offer second interview

End of study, though use of MyQuality beyond this point is welcome.

no obligation for teams to take further part in this project, and free and frank discussion about the potential challenges as well as benefits of participation was encouraged at this point. If teams felt they were happy to continue with the proposed study, they were offered the opportunity to sign a consent form to allow monitoring of their website activity during the study.

Recruitment aimed at a mixture of hospital-based teams, hospice teams, and community-based services in order to reflect the range of service providers likely to be encountered by families with children with LLCs (Chambers, 2018). Hospital teams that were not primarily offering a palliative care service were approached based on the likelihood that they would support care for children with palliative care needs at some point over the next year outside hospital. The speciality with the largest numbers of deaths in children is neonatology, but the overwhelming number of neonatal deaths occur in hospital (Gibson-Smith, Jarvis & Fraser, 2021) and it would be highly unlikely that a parent would be recording data about their children under these circumstances, so neonatal teams were not approached. However, oncology services and neurology services were approached, as cancer is the second largest cause of death in children aged 1-15, after congenital or genetic conditions (Wolfe et al., 2014; Ward, Wolfe & Viner, 2020) and many genetic conditions are associated with neurological abnormality or symptoms such as seizures or developmental delay (Hoell et al., 2019; Pawliuk et al., 2020).

4.3.2 Identification and recruitment of patient/family participants (personal users)

Teams who agreed to continued participation in this study were to act as participant identification centres (PIC) in line with recommended research practice in NHS/HSC organisations (IRAS 2018). All were given an information pack about the study containing a list of inclusion and exclusion criteria (see Appendix A).

Teams were asked to identify at least one patient under the age of 25 years with a life-limiting condition who was under their care and might find MyQuality of use. There were no specific diagnoses or conditions named as eligibility criteria, and the information sheets for patients and parents described this as “living with a significant health condition”. In accordance with requirements from the NHS Research Ethics Committee, the child’s anticipated life expectancy needed to be greater than three months in order to protect families whose children were rapidly approaching the end of their lives from the potential distraction or distress of research participation at a critical time. The age limit of 25 was chosen for pragmatic reasons: although many NHS paediatric services only support adolescents until their late teens before transferring them to adult service providers, the local children and young people's hospices' age limit was 25 and we did not want to refuse participation for young people at the upper limits of the hospice caseload. For practical purposes, participant families needed to have a good command of English to participate in interviews and complete the questionnaires, they needed to live in the southwest region of the UK to allow for home visits as part of the data collection process, and they needed to have access to the internet via a computer, tablet or phone to enable them to access the website.

Patients (or their parents, where relevant) who fitted those criteria were approached by staff from participating teams to ascertain their interest in this project and to seek their permission to share their contact details with the researcher. This information was transferred either via personal discussion (face to face or on the telephone) or by using a secure email service such as nhs.net, which is sufficiently encrypted to be used for sending confidential patient information within or around NHS and voluntary sector providers and is the "industry standard" practice. The patients or their parents or guardians (those with authority to give parental consent) were then contacted by telephone, text or email by the researcher with further study details. Study participants were given information sheets designed for children or young people, or parents of younger children or those not able to use the website themselves (see Appendix B) and were made aware that there was no obligation to participate. Those who did not want to proceed were thanked and there was no further contact from the researcher.

If participants were still keen to take part, a meeting was arranged at an appropriate time and place of their choosing, the details of the study were discussed, and written consent was sought in order to proceed. Those over the age of 16 or "Gillick competent" could provide their own written consent (All England

Law Reports, 1984; Hein et al., 2015; Lambert & Glacken, 2011), but younger children or those lacking capacity were offered appropriate information and their assent to continue was sought, alongside formal consent from the parent or guardian as per national guidelines (HRA, 2021).

Demographic details were collected about the child participants, including their names, ages, addresses, diagnosis and date of diagnosis. Participants were asked to identify the household members who might expect to use MyQuality, and to estimate their level of confidence using IT. There were no specific recruitment targets about the range of ages, health conditions, gender or racial distribution, economic or educational attributes of participants. For practical purposes a total of twenty patient participants was considered to be the maximum to allow adequate time for data processing by the researcher within the remits of time allowed by the university for completion the study.

4.3.3 Study activities

The researcher then conducted a semi-structured interview with the patient and family who were prospective MyQuality users, and participants were asked to complete a questionnaire for baseline evaluation of empowerment (see section 4.4.2).

4.3.3.1 Initial interview with patients/parents

Interviews were conducted in person or over the telephone by the researcher, according to the preference expressed by interviewees. Face-to-face interviews took place in private, with children present with their parents, and young people interviewed individually or with company, at their request. The expected interview duration was 30-45 minutes. This format was intended to allow the participants and the researcher to develop an understanding of the unique circumstances of each family, to develop a trusting relationship, and support enquiries and future communication over the course of the study. Unless participants had already registered on MyQuality, this visit also allowed a demonstration of the use of MyQuality in person, and an opportunity to discuss its use and concepts from the outset. There was a structured format for the discussion about MyQuality to ensure that all aspects of the utility of the website were covered, but otherwise this meeting was informal in nature to encourage free and open dialogue. Details of the data collection from interview processes are outlined in section 4.4.3.

4.3.3.2 Website use

Children and young people (CYP) over the age of 12 were then invited to use the MyQuality website. Children who were unable to use the website due to young age, cognitive or neurodevelopmental limitations, or the effects of ill health could have their data entered by their parents or guardians as proxy reporters on their behalf. Whilst it might have been possible for cognitively-able children under the age of 12 to access a website, the researcher respected parental views that using MyQuality for the purposes of improving health care was a parental responsibility, not only a child's. In addition, evidence suggests that younger children have more difficulties with numerical and visual analogue scales (Shields et al., 2003), which were an integral part of the website design. It was therefore recommended that children under the age of 12 participated either with a parent alongside, or that their priorities and scoring were recorded by a parent on their behalf.

4.3.3.3 Training for participants

Both professional and personal users received demonstrations of how the website worked, using a PowerPoint demonstration initially, followed by a live demonstration of how to register, log in, set up and personalise priorities (for patient/family users only), make diary entries, look at graphs and manipulate their presentation, and discussion of the email alert function. The website contains FAQs about its use, and How-To guides. Healthcare professionals were also given advice about issues to consider about contact arrangements within their teams, such as the consideration of providing a team email contact rather than contacts for individual clinicians. Healthcare professionals were given a series of samples of data outputs, to familiarise themselves with receiving and interpreting visual information via MyQuality.

All participants had access to the researcher via email for any subsequent queries about website functionality.

4.3.3.4 Participant engagement – personal users

Following the initial home visit to patient/parent participants, a follow-up email was sent a few days later to confirm that they were able to use MyQuality and see if they had any additional questions. There was no ongoing contact for the next month or so, to allow IT behaviour habits to develop and become established. During this time participants could use the website as much or as little as they wished.

About six weeks later participants were contacted again to consider arranging a convenient time for a follow-up visit. This second meeting involved a further interview about their experiences of using MyQuality that was anticipated to last less than an hour, and a second completion of the empowerment questionnaire.

There was no further expectation of feedback from personal users of MyQuality beyond this point, and they were thanked for their contributions. Those who were keen to continue to use the website were welcome to do so.

Participants who felt unwilling to have a second meeting after six weeks, or requested a delay and further opportunity to use MyQuality were given additional time and approached again another 4-6 weeks later. Those who did not respond were sent a reminder email after one month, and another 6 weeks after that, offering to book a visit or to give them the opportunity to withdraw from the study if that is what they chose to do. Although they did not have to give a reason for withdrawal, any reason that was mentioned was recorded in the study files.

4.3.3.5 Participant engagement – professionals

All the participating healthcare teams were sent a communal update email about study progress every month whilst participant recruitment was underway. In addition, specific individual email updates kept them informed them of the results of contact with the participants that they identified, so that they were aware of who had agreed to participate, had declined, or had withdrawn from the study in order to prevent repeated or unnecessary approaches to families. Once 6 months had elapsed HCPs were invited for a follow-up interview at a time of their convenience, to reflect on their experience of using MyQuality from a professional perspective.

Professionals were welcome to introduce MyQuality to children and families on their caseload during and beyond the duration of the study, regardless of continued participation in this research.

4.4 Data collection

There were three types of data for collection, as outlined below.

4.4.1 Website use

Study participants who consented to enrol in the MyQuality project as personal users were given a study number and entered this when registering on the website. This generated a unique, randomly-generated computer code as an identification available to the researcher when downloading activity information about their website use. Access to the master copy linking individual study numbers to the website codes was limited to the lead researcher, with the list kept securely away from the main data storage. The researcher could see when the website was accessed, and what activity took place at that time – entering data, making comments on the daily diary, adding or amending priorities, viewing graphs, adding or deleting healthcare professionals from their list of those entitled to see their data, or the triggering of email alerts. The researcher was able to see their graphic display, but unable to alter any data.

Professionals registered on the study were also allocated a study number, distinct from any reference to their name or location of work, and a randomly generated computer code which allowed the researcher to track how often they accessed the website, and which elements were viewed (graphic display, daily diary) or triggered (email alerts).

The data from both of the above were formatted as .csv files on Excel spreadsheets for analysis. Descriptive statistical analysis was used, partly as the small numbers of participants precluded inferential statistical evaluation, but primarily because the value of the website data was to add contextual depth to the qualitative data collected at interview, in line with realist approaches to the use of mixed data sources during theory testing and refinement (Maxwell & Mittapalli, 2010).

4.4.2 Empowerment scales

The empowerment scales used in this study were chosen to allow age and culturally sensitive assessment of empowerment at baseline and after using MyQuality. One of the challenges is measuring empowerment (Barr et al., 2015) as a construct that is separate from shared decision-making, enablement, activation or patient-centred care. The lack of clarity, and limited psychometric quality of some of the questionnaires (Barr et al., 2015) and the need for generic rather than disease-specific measures has hampered the evaluation of patient empowerment in palliative care, and this difficulty is magnified when seeking questionnaires relating to empowerment of children and young people (Grealish, 2013). A number of options were explored, including the Family Empowerment Scale (FES), the Psychological Empowerment Scale (PES), and the Youth Empowerment Scale (YES).

The Family Empowerment Scale (Koren, DeChillo & Friesen, 1992) is a 34-part questionnaire designed to explore the level of empowerment, and the way that it is expressed (see Appendix C). The level of empowerment references the work of Gutierrez and Ortega (1991) who classified empowerment in three tiers: the Personal, concerned with the individuals feelings of personal power and self-efficacy; the Interpersonal level, concerned with an individual's ability to influence others; and Political empowerment, concerned with social action, social change and the transfer of power between groups in society (Koren, DeChillo & Friesen, 1992) . This is combined with a second dimension of empowerment which considers how it is expressed in terms of Attitudes, Knowledge, and Behaviours. Each of these expressions can occur at any of the three levels of empowerment.

The FES was designed in the early 1990s and analysed for validity and reliability by Koren, DeChillo & Friesen (1992). It was initially tested with a population of American families whose children had emotional, behavioural or mental disorders, and many had multiple disabilities. Subsequently it has been translated into multiple languages (Vuorenmaa et al., 2014) and used with families whose children had a variety of health conditions, ranging from emotional and behavioural disorders (Singh et al., 1995) to chronic conditions (Segers et al., 2019). Content validity when the FES was used to measure empowerment in families whose children had a chronic condition scored 0.88 on the scale-content validity index, considered sufficient (Segers et al., 2019).

As it was designed for use in America, the authors were contacted to gain permission to modify a few words so that it would make sense to British readers – for instance replacing "I get in touch with my legislators when important bills or issues concerning children are pending" for "I get in touch with my MP when important legislation or policy issues concerning children are pending". Each of the 24 questions was marked on a five point scale from "never" to "very often", with an area for free text comments at the end.

The Psychological Empowerment Scale (Akey, Marquis & Ross, 2000) is based on Zimmerman's theory of psychological empowerment (Zimmerman, 1990, 1995) and consists of three sets of items that were developed to assess the three dimensions of psychological empowerment: attitudes of control and competence; critical skills and knowledge; and formal and informal participatory behaviours. It was developed in America and validated with a population of families attending family support programmes for children with disability. Akey, Marquis & Ross (2000) compared this scale to the Family Empowerment Scale and found good correlation between the two. This questionnaire had 32 questions with five choices for each (from strongly disagree to strongly agree). Many of the questions used the word "disability", which was a concern as in my experience many British families would not choose to describe their ill children as disabled.

The Family Empowerment Scale was used in the initial evaluation of MyQuality (Harris, Beringer & Fletcher, 2015) and experience proved it to be easy to understand by the British families who were completing it and straightforward to score. In the initial evaluation, despite fairly high scores at baseline it measured a statistically significant increase in parental empowerment over three months of use of MyQuality, which was matched by interview comments by participants. It seemed appropriate to continue to use a familiar method which used language that was very acceptable to our study population in order to measure empowerment in this realist evaluation.

The Youth Empowerment Scale was developed in the UK to measure empowerment in young people with mental health conditions (Grealish, 2014). This was specifically designed to measure empowerment from the perspective of young people. Previous attempts to measure empowerment in this population had included constructs that measured it from the perspective of adults with mental health issues or used adapted carer tools such as the family empowerment scale. Although this scale had not been used for young people with physical rather than mental health issues, the young people in our PPI group unanimously favoured this over an adapted version of the FES. Therefore this study used both scales – the YES for young people aged over 12 who were intellectually capable of filling in a questionnaire (bearing in mind predictions that a large proportion of study participants would have some degree of learning difficulties) and the FES for the parents of those who could not complete the YES. The details of the scales themselves, and the permissions from the authors, are in Appendix C.

The scales were presented to participants for self-completion at the first meeting, and again at the follow-up meeting. Both were scored according to the instructions provided by the authors of the scales and scores were recorded on Excel and analysed using SPSS software.

4.4.3 Interviews

Interviews with personal and professional users of MyQuality were a key source of data about how and why individuals used the website. The interviews had multiple functions: supporting the development of a trusting engagement with the research process; providing an avenue to learn about the circumstances of the participant directly; and providing an opportunity for those using MyQuality to share their experiences in their own words.

The initial interviews began with an opening such as “Tell me about your child or circumstances”, and then focussed on understanding the perspectives of MyQuality users about communication between patients and healthcare professionals, and their views and confidence about the use of technology. In realist evaluation data collection by interview should allow an iterative, reflective component, so the interview questions evolved as concepts around theory development emerged throughout the process (Wong et al., 2017). The initial semi-structured interview guide for the patient/parent interviews (see Appendix D) was developed by the researcher to guide discussion about potential theories to explain how and why MyQuality could be of use. This included exploring contextual features relating to the child and family's particular circumstances, their motivations for exploring the use of MyQuality, and their perceptions of desirable outcomes of its use. This approach supported understandings of elements of complexity outlined in VICTORE (volitions, context, outcomes) and potential rivalry with other pre-existing practices about recording and sharing information about themselves or their child with healthcare professionals, as an understanding of the complexity could guide exploration of causal explanation (King et al., 2016; Pawson 2013). This semi-structured interview guide was reviewed by the research supervisory team when reflecting on progress after the first two uses but not substantially modified. It continued to be used to direct the remainder of the first interviews.

The interval between the first interview and invitation for the second interview was approximately six weeks, although if requested there was additional delay in order to arrange a mutually convenient time to meet. These meetings were more structured than the initial interviews, trying to ensure a balance between open-ended exploration of families' experiences of using MyQuality, and the opportunity to explore potential theory areas about MyQuality use in order to understand what worked, in what circumstances, and why (Manzano, 2016). Before every follow-up interview the website data for that user were downloaded and reviewed. The graphic display was printed out as a visual prompt for discussion, a form of photo-elicitation used in qualitative interviewing (Harper, 2002; Mukumbang and van Wyk, 2020). The researcher included prompts about evolving programme theories in the discussion to encourage individuals to share insights which might confirm or refute some of the theories around MyQuality use. Interviewees were encouraged to supplement their thoughts on theories with personal examples where possible.

The iterative nature of realist theory refinement and testing meant that no two interviews followed exactly the same pattern but were guided by the semi-structured interview plan which was supplemented by the relevant theory areas for exploration. An example of a second interview semi-structured guide is shown in appendix E.

Professional users of the website were contacted for interview at least 6 months after they recruited their first participant, to allow plenty of opportunity for any personal users to have provided data that may have been relevant to a subsequent review by that healthcare provider. Prior to these interviews the researcher reviewed the website data of the personal users who had agreed to share their information electronically with that healthcare professional. A copy of selected printouts was also given to the professional to use as a visual prompt, as with the interviews with families. This aimed to focus reflection on the value of the information provided, and the impact it may or may not have had on healthcare encounters with those individuals, and more broadly on professional activity within their provider role. As with the second interviews with personal users, these interviews were semi-structured and aimed to provide a balance of free discussion of their experience and reflection, and a more focused review of programme theories which they might confirm or refute. The iterative nature of realist enquiry required bespoke interview guides for each professional interview in order to tailor the theory testing process appropriately. An example is shown in appendix F.

4.4.3.1 Interview processing

All interviews were audio-recorded where possible but if not, extensive notes were taken throughout the discussion. After each interview, reflective notes were written by the researcher as soon as practicable (usually within an hour of the interview taking place). The interviews were transcribed verbatim prior to analysis, linked with the reflective notes, and both were anonymised using the personal identification code. Names and identifying comments or characteristics were removed. Given the potential number of individuals with rare conditions, these identifiable characteristics included any reference to age, diagnosis, location of home or supportive care, their healthcare professionals, or details of dates of involvement in the study.

After completion of the interviews a summary of comments and key quotes was sent to participants to confirm that they agreed with the accuracy of recording and my interpretation of their responses, and to request their agreement to use these when writing up the results. These summaries did not include the full transcript but pulled out themes and quotes that related to how MyQuality made a difference to them, their child, or their healthcare professionals. Allowance was made for comments or corrections made by respondents to be incorporated into the transcripts.

4.4.3.2 Interview analysis

Interview analysis was a protracted iterative process, guided by realist principles as outlined in chapter 3. Anonymised transcripts and reflective notes were read multiple times, and analysed repeatedly as theory concepts were confirmed, refined, amalgamated or discarded. The first two pairs of transcripts of family interviews were shared with the researcher's supervisors, who coded a sample set for comparison with the lead researcher to confirm the concordance of coding decisions. The remainder of the family interviews and all the HCP interviews were analysed by the researcher alone.

NVivo was used for some aspects of the analysis, as is common in realist research (Dalkin et al., 2020a; Gilmore et al., 2019; Jackson & Kolla, 2012). Anonymised transcripts were uploaded onto NVivo 12 for analysis. The first read-through enabled the reader to become familiar with the transcript. The second read-through focused on a holistic overview of the content to identify overarching themes in the data, and these were linked to provisional theories that had been derived from the literature review and early stages of theorising. The third read-through emphasised identification of potential contexts, mechanisms and outcomes associated with provisional theories. Subsequent re-reading focused on the specific links with particular features of MyQuality, or were loosely based on the principles of thematic analysis as outlined by Braun & Clarke (2006), looked for potential themes that had not been included in provisional theories, in order to ensure that any missing gaps in theory areas or modifications of existing theories could be addressed. The repeated immersion in the data as theories were refined meant that analytic lens evolved as theories matured, so different analytic techniques were applied at different times (Gläser & Laudel, 2013).

The transcripts were coded using NVivo against the provisional theories, the function of MyQuality that was being used, the sphere of influence, and contexts, mechanisms and outcomes that were derived from the initial programme theories. NVivo was particularly helpful when undertaking "direct coding" identifying contexts, mechanisms or outcomes within the transcripts, and cross-tabulating to identify links or couplings between contexts and mechanisms, mechanisms and outcomes, or contexts and outcomes (Bergeron & Gaboury, 2020). It was also possible to highlight larger areas of text where there was less explicit articulation of C's, M's or O's but where theory articulation was evident when examining a larger segment of text using "indirect coding" or through more holistic analysis of reflective notes. These areas were linked to theory codes, and cross-tabulated with individual C, M, O, or linked codes, and the evolution of theory documented in Memo notes as the process evolved (Gilmore et al., 2019).

The codebook is attached as Appendix M.

4.5 Public and Patient Involvement (PPI)

Stakeholders are those individuals, organisations or communities that have a direct interest in the process and outcomes of a project, research or policy endeavour (Boaz et al., 2018). Within health research this includes patients and members of the public, healthcare providers, funders, and those with strategic oversight of healthcare policy. Stakeholders are not necessarily part of the research project itself (although they can be if they are participants in a study) but their involvement in the design and oversight of the process can add support and critical insight and improve the value and relevance of research outputs (NIHR INVOLVE Standards, 2021).

Whilst research projects can have multiple stakeholder groups, a key dimension gaining critical importance is the involvement of public and patient input (PPI).

Whilst PPI has increased recently (Staniszewska & Denegri, 2013), and demonstration of PPI is often required by ethics committees, funders, publishers and research institutions, there is considerable debate about the best ways to involve patients and public in research, and how to demonstrate the added value that follows (Boaz et al., 2018).

There are multiple points at which engagement with research can happen, including the very early preparatory stages of study design, when defining the research question and seeking funding (NIHR, 2021). Once research has been planned in outline, there are opportunities for PPI with study design and procedures, recruitment, data collection and data analysis as the work proceeds. Key to the impact of research is translating the research outputs into action, so involvement in dissemination of results, implementation of roll-out of interventions and evaluating at scale are also critical to producing research with impact (Garces et al., 2012). A systematic review of PPI in patient-centred outcomes research demonstrated the way in which thinking about PPI in study design needed to evolve from one of research about patients, to research with patients, and ultimately to patient-led research (Garces et al, 2012).

PPI involvement in research is not without its difficulties. These include finding PPI contributors who have the “right” level of experience of the condition in question, ensuring an appropriate level of engagement which neither belittles nor overwhelms those who do not normally work in research in the field in question, recognition of time and expenses of contributors and the duration of their involvement (particularly difficult in conditions with high morbidity and mortality), and overcoming resistance from clinicians and research professionals about the value of input from lay people (Crocker et al., 2019).

4.5.1 PPI and the MyQuality project

The principles underlying PPI and stakeholder engagement have been implemented throughout the development and evaluation of the website. MyQuality was developed in 2011, based on discussions with parents of children in the hospice about their needs for adequate time to make their contribution to the medical discussions about the care of their children, and with hospice staff who shared their concerns about having adequate resources to incorporate the knowledge from patients and parents into healthcare encounters. There were also contributions from hospice management about using this approach to incorporate quality improvement measures for their service and improve patient safety. Thus, patients, staff and management were stakeholders in developing the website from the start.

After MyQuality was introduced and used at the hospice, preliminary evaluation and improvements took place with input from a Teenage and Young Adult PPI reference group, resulting in significant modification of the user interface to reflect their priorities in the subsequent upgrade of the website.

During this PhD study PPI input was sought prior to application for ethical approval from the Young People's Advisory Group and subsequently from parents of children with life-limiting illnesses during theory development, as outlined below.

4.5.1.1 Young People's Advisory Group (YPAG)

In April 2017 the YPAG met to discuss the outline for this study. The group consisted of 15 students aged 11-17 (mostly 15-17) who spent an hour considering this work. Although none of the participants had a life-limiting illness, one of the criteria for participant recruitment, the views of young people were considered highly valuable as a young person with a life-limiting illness needs to be seen primarily as a young person, not an ill person. The meeting included an initial overview of the research area and question, followed by an introduction to the website and the theory surrounding its use. Those attending were given an opportunity to explore the "sample patient" account and use MyQuality for themselves on their own smartphones. This was followed by distribution of the drafts of the consent forms and information leaflets about the study, and the questionnaires being considered to assess empowerment as part of the study. The discussions were informal, and attempts were made to seek input from all participants including the younger and quieter members of the group.

As a result of the discussion with YPAG the consent forms for adolescents were re-worded and the participant information sheets reformatted, as there was a strong preference for a leaflet for young people rather than an A4 page. The young people recommended production of two distinct information sheets for parents, who could either give consent *for* their children to use MyQuality or give consent for using MyQuality *about* their children in situations where the parents would be entering the data rather than the young person themselves. There were further discussions about the vocabulary in use in the information sheets, to ensure that these were at an appropriate reading level for a lay audience. Of the empowerment scales shown, the young people expressed a very strong preference for the Youth Empowerment Scale over the Family Empowerment Scale, so both were included in the study protocol in the final project submission for ethical approval.

4.5.1.2 PPI meeting about theory development.

By March 2020 there had been several iterative cycles of programme theory development, drawing on input from literature, feedback from patient/family users of MyQuality, and from health care professionals. At this point, further PPI input was sought to ensure that the evolving theories did realistically reflect the experiences and priorities of parents of children with life-limiting illness. This was more complicated than initially anticipated as coronavirus shut down opportunities to meet with parents in groups as initially planned. Instead, a lay summary was shared with two bereaved parents who have been involved with the university and teach about life-limiting illness. Neither parent had used MyQuality on behalf of their children. The lay summary (see appendix H) included the background to the work, the theory development process, initial theories, and feedback from the data collection from parents. Discussion took place via a video-conference meeting two weeks later to allow time to digest the information and consider it in detail.

The key points that were raised concerned the need to maintain a child-central focus to see a more holistic and positive side of parenting and reduce any suggestions of “parental burden” or “parental vulnerability”, even though both participants commented frequently on the totally immersive and complex experience that is inherent in caring for a life-limited child. They wanted to emphasise that they were trying to create normal life as much as was possible given the needs of their children, including time to enjoy activities and make memories of the good aspects of their lives, and not focus on the medical complexity or uncertainty.

The initial five programme theories that related to individual users were all accepted, with minor modification of vocabulary to recognise the points mentioned above. In addition, two further theories about time-efficient parenting, and the endorsement of parental contributions were explored.

4.6 Ethical issues

Researchers and clinicians are bound by ethical codes of conduct, as outlined by their professional bodies (e.g. Nursing and Midwifery Council, or General Medical Council), and by responsibilities towards research participants as spelled out in the Declaration of Helsinki (World Medical Association, 2001) and overseen by research ethics committees. Both stipulate the duty to act in accordance with the patients' best interests, and to put patient wellbeing at the forefront of research.

This academic endeavour was potentially compromised by the fact that the intervention being used to test the research question was developed by the researcher, is now owned by the researcher, and was initially tested by the researcher when in a clinical role. This produced several possible conflicts of interest which needed to be scrutinised to ensure that the research outputs were credible and trustworthy. This section describes the steps taken to ensure that scrutiny throughout this PhD, incorporating reflective practice, critical review within the research team, and external inspection from lay members and the NHS ethics committee.

There were several ethical considerations to be addressed concerning this study. These related to five main areas:

a) clarity about the purpose and ownership of the MyQuality website;
b) the ethical challenges inherent in using a website to augment communication in healthcare;
c) ethical issues relating to the design and conduct of the study itself;

d) the need to be mindful of requirements for future management of data, in line with current developments for data repositories and trends towards more open access to existing research resources;
e) the conflicts that could arise related to the multiple roles of inventor/developer, researcher, clinician and colleague.

4.6.1 MyQuality website and the role of the researcher

The MyQuality website was developed in 2011, building on earlier work about patient-generated outcome measures by Dr Charlotte Paterson (Paterson & Britten, 2000), and integrating these concepts with interactive computer technology and a social media model of communications. As outlined in chapter 1, the spur for this development was in some part related to my personal experience of being a patient. On my return to work, discussions with other patients confirmed resonance with their own experiences, and I resolved to explore mechanisms to support the development and visibility of patient-generated outcomes as part of a drive towards patient-centred care.

The website development was funded by the Department of Health (UK) as part of a scheme to innovate and improve the provision of children’s palliative care services, and funding was administered via Children’s Hospice South West, who employed me at the time. Subsequent revisions and enhancements were financially supported by Marie Curie (2012), the Health Foundation (2013) and NHS England (2015). When I left the hospice, the management team did not feel they could support the development of the website further but acknowledged that it was my intellectual property, so a limited company (MyQuality Ltd.) was created to protect this and facilitate cost management. MyQuality has always been freely available and does not generate any income. My role as Director of MyQuality Ltd should not be considered a financial conflict of interest in this context as there will be no commercial gain from this project.

Although there may have been no financial incentive threatening the impartiality of this work, there has been a significant emotional investment in this venture for several years. This has had several advantages, in that it has helped to maintain motivation for the evolution and development of the concept over time, but it also had the disadvantage of introducing potential bias in the interpretation of data, particularly where interviews included negative feedback, or findings suggested that there were significant problems or oversights with the website or the principles underlying this concept. To protect against this, the research supervision team encouraged active reflection throughout the study period and regular discussion of any concerns during supervision meetings. The guiding principle has been "first do no harm" and we agreed that should the study findings suggest that this development did not support improved care for children and families with life-limiting conditions, the website would be taken off-line.

4.6.2 Use of MyQuality website as part of health and social support

The purpose of the MyQuality website was to improve communication and facilitate patient-centred care. Although this intention was honourable, the process of using the MyQuality website could incur risks such as an increased burden of "patient-work" (Valdez et al., 2014; Porter et al., 2011) or put confidentiality at risk should the site be insufficiently secure. If the website were to replace other forms of storage of information which are vital to ongoing care (paper diaries for instance) it had to be simple, convenient, reliable and accessible when needed, so there was an ethical obligation to maintain it in good working order and minimise any additional burden on website users.

These issues were addressed through considerate website design and a rigorous, vigilant approach to the security of internet-based communication systems. Data security was safeguarded by ensuring the server was backed up daily, protected by firewalls and up-to-date virus protection, data was encrypted, and access tightly controlled through the use of passwords and navigation limits.

Using any website to record personal health data will inevitably involve an active contribution from the user, at a minimum involving a registration process and taking the opportunity to learn about the website itself, which could be viewed as additional "patient work". Unlike many ehealth devices that record activity automatically (such as wearable step counters) MyQuality asked users to record their perceptions of symptom burden and events on a regular basis. Should potential MyQuality users have raised concerns about this additional workload, I would reassure them that this has been considered throughout the development and testing of MyQuality thus far. Although participants in the first study reported that they did change their usual habits when recording data, on-line data entry was quicker and simpler than using paper-based system (Harris, Beringer & Fletcher, 2015).

4.6.3 Design and conduct of the proposed study

The design of the study required patients (or their carers) and the professionals providing them with support to use the website, complete questionnaires and participate in interviews or discussions. Qualitative research in the health services raises ethical issues about the risks to participants, including causing anxiety and distress, the potential for exploitation, misrepresentation, and breaching confidentiality (Richards & Schwartz, 2002). These were considered using the framework for ethical research in healthcare (Beachamp and Childress, 2001), emphasising autonomy, beneficence, non-maleficence, and justice. Details of the ethical challenges and mitigations relating to the design and conduct of this study are outlined in Appendix G.

NHS ethical approval for the study was granted following full Research Ethics Committee review in May 2018 (IRAS ID 213423, REC reference 17/SW/0208).

4.6.4 Future use of research data

There is an ethical imperative to make the best use of available research data. Sharing data from one study for secondary use by other researchers may encourage further enquiry, debate and innovation in directions that are currently unknown. It also increases transparency and accountability by encouraging scrutiny of the findings, which should improve the quality and validation of research. Sharing data may have practical benefits by reducing the costs of duplicating research and increasing the impact and visibility of this work, which is particularly important when public funding is supporting research. This process may also provide important resources for education and training, and an opportunity for participants in research to project and defend their perspectives on the research question being studied (Van den Eynden et al., 2011; Bishop & Kuula-Luumi, 2017; Bishop, 2009).

Until recently it has not been standard practice to gain consent for future, unknown uses of data (Bishop, 2014). If it was not practical to obtain consent, alternatives such as anonymization of data, or control of access to it, could permit some use of data in the future without compromising the confidentiality of research participants (Morrow 2014).

There is an inherent tension between the autonomy of research participants, the justice implicit in the sharing of research resources as outlined above, and conflicting potential benefits and harms to privacy (which may become especially acute in the context of bereavement).   Respect for the privacy and autonomy of children and families with life-limiting conditions is the crucial foundation of relationships built on trust, and without trust both health care and future research will be in jeopardy (Yardley 2014).   Further work is needed to clarify the views of patients and families about the long-term storage and use of their data, and their views on anonymity or de-identification of data and the potential loss of quality that may ensue as a result (Manhas 2016).   This will require separate work beyond the remit of this PhD study, but would be important in order to sustain research within the field of children’s palliative care in the future (Harris et al., 2020).

In recognition of these issues, specific consent for long-term storage or re-use of data was sought on the consent form, separate from participation in the proposed study. If individuals wanted to participate but were not happy to consent to secondary use of the data, they could still take part in the study but their data would be stored separately and deleted after seven years in line with standard recommendations for data preservation for research studies (UWE, 2017).

4.6.5 Multiple Roles - challenges for clinician/researcher

The issues raised by being the developer and owner of the website have been explored in the section above, but there are also ethical challenges related to being a clinician and a researcher (Richards & Schwartz, 2002). A clinician-researcher is an individual who has been involved with the provision of direct patient care and who conducts research, though these two activities do not need to take place on the same patients, at the same time, or for the same organisation. Expectations and competing obligations mean that clinician-researchers may face situations in which their sense of clinical duty conflicts with the requirements of research, which can trigger role confusion (Hay-Smith et al., 2016). Researchers may have ingrained values, skills and knowledge from their clinical backgrounds which are difficult to set aside when meeting patients in a research setting rather than in a clinical relationship. Patient participants in research may be comfortable with, and bring expectations of, establishing a patient-clinical relationship in a research setting.

McNair has outlined the benefits of clinician researchers to the qualitative research process (McNair, Taft & Hegarty, 2008). She pointed out that clinician researchers may select research questions that are clinically relevant, they may have access to practical necessities such as research settings and colleagues in the field, and with the addition of tacit clinical knowledge in the analysis would be able to report research findings in a clinically applicable way. Clinicians may share at least some of the understanding of the clinical environment and values shared by their colleagues, bringing a depth of understanding to analysis that might not otherwise have been present. In some circumstances, clinicians may be placed in a position of greater trust by participants by virtue of their experience in the field leading to greater research participation and openness in the exploration of sensitive issues.

McNair also reminded us of the potential pitfalls to being a clinician researcher. As an “insider” with colleagues, it was important to consider whether the researcher was the most appropriate person to research their own community or domain. Participants could feel that boundaries between patients/colleagues/researchers were blurred. The rigour of the research could be compromised if clinician researchers fail to recognise shared “conceptual blindness” with clinician participants, or failed to fully report compromising findings (McNair, Taft & Hegarty, 2008).

Hay-Smith’s comprehensive review of dual role experiences in clinician-researchers identified two overarching themes – behaviour patterns by researchers that were more typical of a clinical role, and developing connections with research participants that started to resemble a clinician-patient relationship (Hay-Smith et al., 2016). The review concluded that clinician-researchers could not adopt a wholly non-clinical research identity. This was not necessarily a bad thing – Gardner (1996) reflected that this could be advantageous, enabling patient-participants to “talk with freedom and comfort” giving data that was “full rich, and thickly described”. Hay-Smith et al. (2016) suggested that the dual role might best be understood as a coherent moral identity that recognised both sets of obligations, rather than oscillating between the two roles of clinician and researcher. They highlighted recognition of the potential for clinician-researchers to experience tensions arising from their dual roles, the need to incorporate these issues at the research planning stage, and the provision of appropriate support and supervision during research, particularly for new or young researchers.

In this study I have never hidden the fact that I am a doctor, with the information sheets clearly stating that the researcher had prior experience of providing medical care to this population of children and families. Although no longer in clinical practice, there was a risk that both patients/families, and the researcher, could find it difficult to ignore the “dual role” of clinician and researcher, resulting in the potential for discussions concerning medical advice or opinion (Houghton et al 2010). This separation of the research role and the clinical role was important for both parties to understand. It was clearly not my role to provide clinical management or advice to patients and families as part of this study. A process of “bracketing” any such enquiries, and directing patients or their families to appropriate resources, was applied. At the end of each interview reflective diary notes were kept and areas of concern shared with supervisors.

In this research project participation involved not only patients, but other healthcare practitioners. This added a further level of complexity to the conflicting roles experienced by the researcher, particularly as many of the involved healthcare practitioners were former work colleagues or trainees (Coar & Sim, 2006). As such there was the potential for previous experiences of work relationships (such as being their line manager) to influence participation and response (Chew-Graham, May & Perry, 2002; Richards & Emslie, 2000). Many of them had worked alongside me during the first MyQuality study and were aware of my personal interest and emotional investment in this approach over several years. I have been dependent on them as gatekeepers to identify potential participants for my study, and on their honesty during staff interviews; in return they have relied on me not to be judgemental or take offense at poor recruitment levels or negative feedback, and not to be critical of their decisions about the use of MyQuality. All of these interactions could have had an impact on the study processes from recruitment to data collection and analysis (Coar & Sim, 2006).

Jennifer Heath (2018) has written eloquently about the challenges of multiple roles, and the changing positionality of the researcher, in her account of sensitive research with children with burns (Clift, Hatchard & Gore, 2018). She was not an “insider” (someone with a child with burns), but not an outsider either, as her previous work as a psychologist in a burns unit meant that she had experiential knowledge of many families dealing with issues around children who had experienced burns. She noted that Deutsch (1981) suggested that a researcher’s position is not simply ascribed to them in a binary fashion but is a process of ongoing evolution, as we are all multiple insiders and outsiders. Heath described herself as shifting between three distinct selves: the “student” (learning from her research participants, and a PhD student), the “equal” (an informed listener who could help participants share their experiences in the hope that together they could improve the life of future burns patients) and the “expert” (recognising the impact of burns, understanding the challenges, and with the ability to adapt interview technique when required to provide support). She reported that these shifting positions influenced her conduct within the research process and were associated with risks to the researcher that are often unacknowledged (Heath, 2018).

Many authors have pointed out that the way to mitigate the risks of dual role contamination of qualitative research and to ensure transparency throughout the process is to ensure that reflexivity is embedded throughout (Hiller & Vears, 2016; McNair, Taft & Hegarty, 2008; Råheim et al., 2016). In this study, there are multiple sources of role conflict: I have been a patient, a clinician, a researcher, and the developer of the MyQuality website which is the intervention under focus in this project. Whilst many writers confirm the importance of reflexivity, the model provided by Rae & Green (2016) provided a framework for reflection from a variety of positions throughout the research process, from the design phase to data collection to analysis. This was modified for this project (see Appendix J) and applied at an early stage to identify areas with a risk of role conflict as outlined above and continued to be used as a framework as the project progresses. An example of the reflective notes during the project is included in Appendix K.

4.7 Chapter summary

This chapter has described the methods used to address the research question, including exploration with stakeholders in their capacity as patients or family members or as HCPs to test and refine provisional theories that were identified in earlier work, and through inspection of literature. The study design has incorporated qualitative feedback, consistent with a realist approach to elicit underpinning causal mechanisms, and empirical assessment of the extent of website use and the possible impact on user empowerment, enabling synthesis of data from a variety of sources. This mixed method approach aims to illuminate underlying contexts and mechanisms, thus providing greater ontological depth to the understanding of how MyQuality may affect communication and the delivery of PCC.

Overall, this study has addressed the ethical issues associated with this research in a robust manner. Beneficence is evident through the aims and design of the study, which seeks to improve communication, understanding and empowerment in a way that respects the confidentiality and autonomy of individuals. Risks have been minimised through the use of a fully informed consent process, rigorous attention to IT security, simple user interfaces, and as low a burden of questionnaire and interview time as possible. The potential conflicts associated with multiple roles of the researcher have been addressed by ensuring that transparency and reflection are built into every stage of the research process, and efforts have been made to address the future use of data in an ethically responsible manner.

Having outlined the study methods, the next chapter will start to address the research question by interrogating the literature to build provisional programme theories.

5 Literature Review

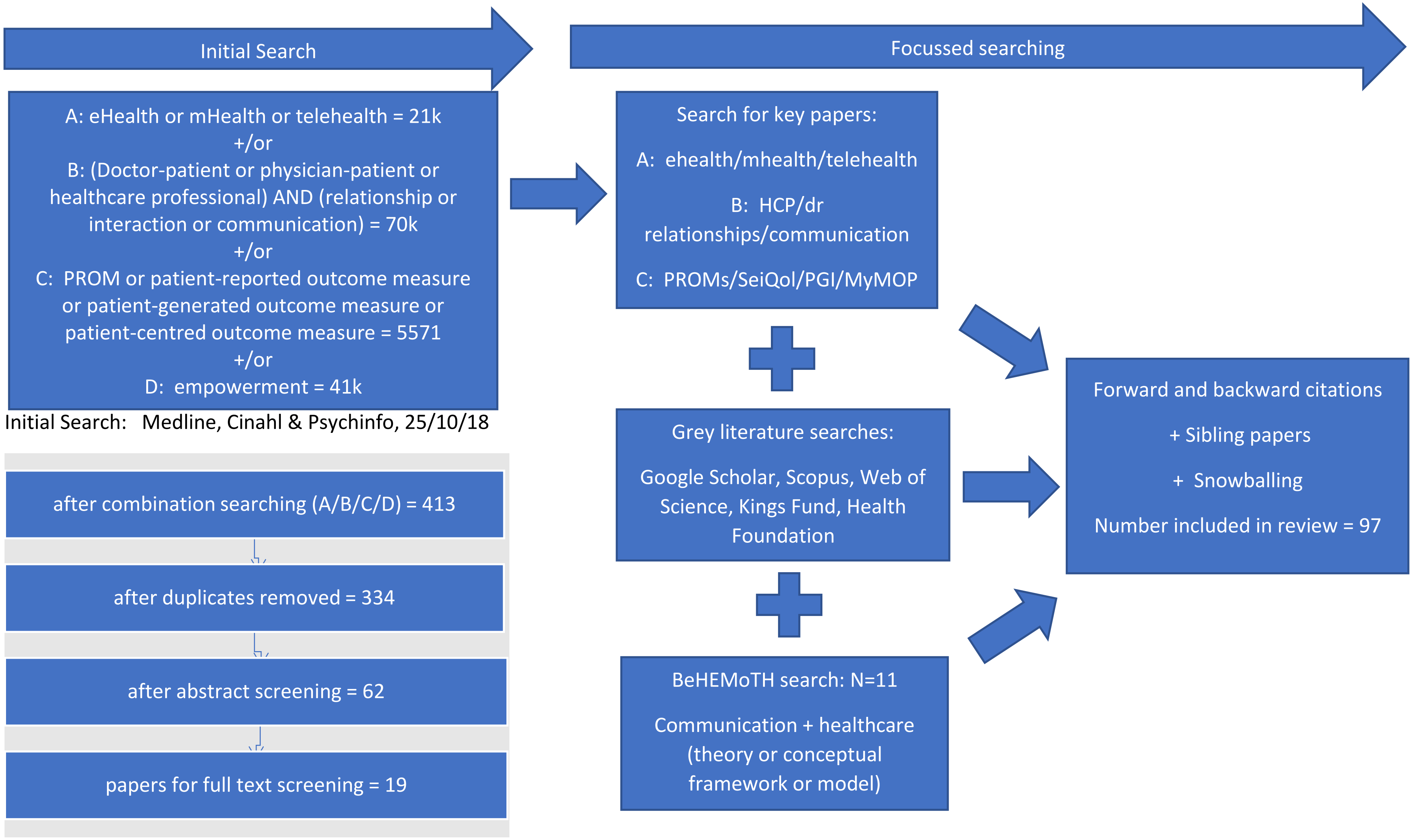
The aim of this realist-informed literature review is the development of initial programme theories (PTs) to provide insights into how an ehealth approach may (or may not) affect communication and support the delivery of person-centred care. This chapter reviews the literature and structures this within the FITT framework to consider the interactions between the task (person-centred care), the technology (ehealth), and the individuals involved.

The intervention being studied in this work is the MyQuality website, an example of ehealth which brings together multiple component parts. These include aspects of technology that support alternatives to face-to-face communication, including remote access via website data entry or email, shared access to a common portal for information, the ability to store and retrieve information in a format that facilitates interpretation of large volumes of data, and the ability of users to personalise information to suit their own needs. Central to the function of MyQuality is the concept of personalised outcome measurement. MyQuality is a tool to support communication, and the nature of relationships between patients and their healthcare professionals is integral to this process. The literature review explores individualised outcome measurement, various facets of technology, and communication theories in healthcare relationships in order to identify potential explanatory theories consistent with realist approaches. Key concepts extracted from the literature are itemised at the end of each section and brought together as rough PTs at the end of the chapter.

During this study the literature was revisited repeatedly as part of an iterative process, with the focus changing over time as theories emerged, developed and were refined. Thus it is not possible to give a clear timeline of when all the papers were identified, but the overall process is outlined in Fig 5-1.

See Appendix N for an illustrated example of the details of data extraction.

Fig 5-1 Search techniques for literature review



5.1 Outcome Measurement and Patient-Provider Communication

One of the key concepts around MyQuality use was its potential as a personal outcome measure. MyQuality incorporates monitoring of identified priorities at its core. This section examines the issues around outcome measurement in general and in the context of palliative care looking, in particular, at the impact on communication between patients and health care professionals.

In order to explore potential programme theories I drew on recommendations from Shearn et al. (2017) and Flynn et al. (2020) about how they used existing literature and began with a review of similar outcome measurement processes. This subject area is extensive, and I have not attempted a comprehensive review of the literature, but rather an exploration that may guide theory development. This started with a literature search of Medline and Cinahl (Cumulative Index to Nursing and Allied Health Literature) for patient reported outcome measures and similar terms, combining this with palliative care or long-term conditions or life-limiting illness. In addition, there were specific searches for three specific similar individualised outcome measures: SEIQoL, PGI and MYMOP. Subsequent searching followed an exploratory pattern chasing forward and backward citations, sibling papers and author tracking, foraging for the literature in an iterative manner to find examples of similar approaches to outcome measurement. The results are reported as a narrative review of findings (Ferrari, 2015), building on outputs from systematic reviews about the effects of outcome measurement on clinical practice and searching for hints within qualitative literature about the experience of outcome measurement on communication.

5.1.1 Patient Reported Outcome Measurement (PROMs)

The national PROMs programme was introduced in the NHS in 2009 (Department of Health). Much of these data were collated and aggregated prior to feedback to providers, with the intention to support provider accountability and benchmarking, support patient choice, and thus improve patient care (Greenhalgh et al., 2017). In addition to aggregated feedback, there has been an increase in interest in the use of PROMs to improve the care of individual patients (Greenhalgh et al., 2017).

Many PROMs take the form of a questionnaire, standardised for the condition for which the patient seeks intervention, be it an interventional procedure such as a hip replacement, or a chronic condition such as asthma or depression. The aim of the use of a PROM during individual clinical encounters between patients and clinicians is to improve the detection of patient problems, to support clinical decision-making about treatment through ongoing monitoring, and to empower patients to become more involved in their care (Greenhalgh et al., 2017; Chen, Ou & Hollis, 2013; Santana & Feeny, 2014). These arise from improvements in communication between patients and healthcare professionals (Velikova et al., 2004). Greenhalgh's review found that standardised PROMs were useful for those patients who preferred not to talk about personal or sensitive issues, helping them to share information (Greenhalgh et al., 2017), and theorised that the PROMs completion process could prompt patients to raise issues with clinicians through a process of self-reflection and empowerment to support dialogue and tell their story (Greenhalgh et al., 2018). A review of the use of PROMs in oncology found very strong evidence in supporting the notion that routine collection of PROMs with timely feedback enhanced patient-provider communication (Chen, Ou & Hollis, 2013), a finding consistent with previous reviews conducted in cancer and non-cancer settings (Valderas et al., 2008).

In some settings such as mental health or palliative care, clinicians perceived that standardised PROMs constrained the patient-clinician relationship because they trivialised patient's emotions or did not capture the complex and dynamic nature of patient's problems. The nature of the care setting (e.g., mental health compared to oncology) may change expectations (Salmon & Young, 2017), and the purpose of care and nature of communication can change over time during a patient's journey (Greenhalgh et al., 2018), from the initial encounter to active treatment or end-of-life care.

Greenhalgh et al. (2018) found evidence that across all contexts PROMs completion prompted patients to engage in self-reflection, enabled them to identify what is important to them and develop a deeper understanding of how their condition had affected their life. However, in the context of palliative care this could be an emotional experience, and patients who used denial as a coping strategy might disengage with PROMs or not report honestly.

5.1.1.1 PROMs use – the professionals' perspective

A review of qualitative research of the experiences of professionals using PROMs to improve healthcare (Boyce, Browne & Greenhalgh, 2014) offers more detail on the facilitators and barriers to PROMs use by clinicians, categorising them into four themes relating to practical, attitudinal, methodological and impact-related issues. Practical issues related to the additional time and workload associated with PROMs administration, collation and analysis (Valderas et al., 2008; Greenhalgh et al., 2017). These issues were helped by having managerial support, consensus guidelines on the data collection process, and training on how to correctly analyse and interpret the results. The use of technology could be a barrier when it slowed established clinical processes, or act as a facilitator if it made collection and dissemination of the findings more efficient (Boyce, Browne & Greenhalgh, 2014). Many questioned the value of collecting PROMs data when professionals were not open to receiving feedback or changing their clinical practice (Greenhalgh, 2009; Valderas et al., 2008). Methodological problems occurred when the validity of the measures was compromised, either by patients not completing the measures accurately, or when it was not clear how to interpret the results (Boyce, Browne & Greenhalgh, 2014). The sensitivity of the measures to detect meaningful change accurately was questioned (Bausewein et al., 2011; Hughes et al., 2003). Professionals and patients valued the presentation of results as simple line graphs (Brundage et al., 2015) but professionals also identified the need for more sophisticated feedback (Bausewein et al., 2011; Antunes et al., 2014; Hsiao et al., 2019). And finally, PROMs data collection was valued when it was seen as a tool to complement rather than to replace the clinical judgement of professionals, but negative effects included the intrusive nature of collection on the patient's privacy, the doctor-patient interaction (Easpaig et al., 2020) and the opportunity costs for what were perceived to be more important aspects of care. PROMs were felt to be more valuable to clinicians when they produced data that could be linked to individual patient care, but were viewed less positively when producing performance data about the care delivered by professionals to groups of patients (Boyce, Browne & Greenhalgh, 2014).

Easpaig et al. (2020) specifically considered the attitudes of healthcare professionals regarding PROMs in their synthesis of qualitative evidence on the use of PROMs in oncology practice. They identified benefits and challenges related to identifying patient needs and discussing sensitive issues. Trust was identified as a key factor, with clinicians either regarding PROMs data as valuable if they trusted the patient to be honest in their reporting, or not finding it valuable if they felt that patients were overstating their symptoms, preferring more objective, valid and reliable information in preference to patient feedback. There were mixed views about whether PROMs would inform the practice of HCPs, as some found the information useful to focus and streamline consultations and adopt a more holistic approach, while others noted that PROMs could be difficult to interpret and might identify problems where no adequate response existed. Practical considerations influenced the embedding of PROMs into clinical practice, such as the feasibility of integrating PROMs into existing medical systems and records, the impact on workflow, and clarity about the roles and responsibilities of those involved in responding to issues identified by the use of PROMs. Barriers to their use included concerns that the use of PROMS would be viewed as an additional task on top of other competing demands, perceptions that the PROMs information would not add value to the clinical encounter, and that the capacity for HCPs to respond to patient concerns was limited (Espaig et al, 2020).

Whilst Easpaig's work related to oncology, Wheat et al. (2018) examined the use of PROMs to enhance person-centred care in practice, interviewing a range of practitioners, managers and commissioners or directors of service. Like the papers reported above, there were mixed views about PROMs use. Whilst PROMs were felt to enhance communication, Wheat's paper added insights into how that occurred, supporting Greenhalgh's conclusion that the use of PROMs enhanced communication by supporting patients to express their concerns more succinctly. The use of PROMs assisted focus in consultations, reflective thinking, holistic questioning, and the elicitation of the patient narrative (Wheat et al., 2018).

However, although PROMs could enhance practitioner-patient communication, several significant barriers to their effective use were identified relating to issues concerning the people using the PROMs, the design of the PROMs themselves, and access and interpretation of the data produced. Clinicians' skills in using PROMs, their approach to their work burden, and the emotional burden on staff were all identified as areas where additional support structures (such as training, financial incentives, or more efficient work patterns) would support wider PROMs use and enhance opportunities for a more person-centred approach to care (Wheat et al., 2018; Krawczyk et al., 2019; Stover et al., 2020).

Although the works cited above have provided a useful basis for the exploration of MyQuality with clues about potential mechanisms driving the desired outcomes, there are important differences which may limit the ability to extrapolate from these findings. MyQuality has incorporated an individualised outcome measure rather than a standard PROM, as outlined below.

5.1.2 Individualised outcome measurement (IOM)

As an alternative to standardised PROMs created by professionals and healthcare researchers, Person-Centred Outcome Measures (PCOM) focussed on assessing priorities defined by patients (De Silva, 2014). These were often standardised using feedback from relevant patient groups to identify the outcomes considered to be most relevant to their circumstances. However, some tools had the facility to be personalised by each individual respondent, known as individualised outcome measures (IOM), individualised PROMs (I-PROMs), patient-determined outcome measures (PDOM) or patient-generated outcome measures (PGOM). For the purposes of this thesis, I will refer to this group collectively as individualised outcome measures (IOM), and PROMs will refer to standardised outcome measures (whether developed by healthcare professionals, researchers or patient input) that are completed by individual patients themselves, as opposed to proxy reports by health care professionals.

In addition to PROMs, many organisations collect measures of the experience of receiving care, known as Patient Report Experience Measures (PREMs), which differ from outcome measures as they seek feedback on the individual's experiences of the processes rather than outcomes of care (De Silva, 2014).

5.1.2.1 IOMs in long-term conditions and chronic disease management

IOMs are not a new idea, and although not used in CPC settings it is useful to examine these in further detail as understanding their use in practice could highlight areas of significance regarding theories about the use of MyQuality. The most widely used IOMs are SEIQoL, PGI, and MYMOP, but there are a multitude of others, often designed for use by specific teams or circumstances.

5.1.2.2 SEIQoL

SEIQoL (Schedule for the Individual Quality of Life) is a generic quality of life measure that operationalises quality of life as "what the person tells him/herself it is" (Joyce et al., 2003). Completion of the SEIQoL is generally undertaken as an interview, where the respondent identifies elements (cues) that contribute to his own QoL. Ideally these will fall into each of the generally agreed QoL domains – Cognitive, Affective, Social, Physical, Ecological and Religious – and as few as three or as many as eight could be accommodated in the original version, later modified to five cues (Wettergren et al., 2009). For each cue, the respondent rates his satisfaction with its current functioning on a visual analogue scale of 0 (worst possible) to 10 (best possible). The five cues are then weighted by the individual in terms of their relative importance and allocated a proportion of a total of 100 points. A score is calculated by summing the products of each cue's rating and weighting. Each individual's score is unique and there is no external criterion for comparison.

SEIQoL was developed in the 1980s (O'Boyle et al., 1993) and validated for use in a variety of settings (Moons et al., 2004; Wettergren, Bjornholm & Langius-Eklof, 2005). It has since been used by individuals with a wide range of conditions including cancer (Wettergren et al., 2009; Ala'S & Mayo, 2017; Becker et al., 2014; Westerman et al., 2006), neurological diseases (Lee et al., 2006), those who are severely ill (Lhussier et al., 2005; Wettergren et al., 2009), and young people with diabetes and mental health conditions (Farrand & Woodford, 2013; Lhussier et al., 2005; Joyce et al., 2003; Ala'S & Mayo, 2017; Wettergren et al., 2009).

Farquhar et al. (2010) reported qualitative analysis of the experience of using SEIQoL in patients with advanced lung disease, considering its feasibility, acceptability and appropriateness from the perspectives of patients and researchers. The administration of the tool involved identification of cues, the instructions for which overwhelmed some respondents. Some respondents were reluctant to nominate certain cues, particularly those they felt powerless to change (such as long-term complaints of breathlessness), regardless of their importance in limiting daily life. Some found it difficult to identify the recommended five cues, either wanting to focus on fewer or more issues. The researchers reported feeling a need, even pressure, to help patients identify exactly five cues, with the risk of unintentional prompting of the patient by the researcher or the patient's carer rather than accepting the cues identified by the patient. The second step involved weighting the cues on a scale of 0 (worst possible) to 10 (best possible) in terms of function. However, this step was difficult as some patients found the concepts difficult to interpret, particularly with negatively worded cues such as “inability” or “helplessness”, and many found precise scoring difficult. The third step involved an estimation of the importance of the cue, either by allocating a score or manipulating a proportion of a pie chart, a process many found confusing. These issues raised the question of just how much measures such as SEIQoL incorporate the respondent's perspective, arguing that they actually manifest token consultation within a very restrictive, imposed qualitative framework (Farquhar et al., 2010).

Others (Becker et al., 2014) found disadvantages with the practical administration of the SEIQoL from the perspective of healthcare professionals, with the need for semi-structured interviews being a time consuming constraint making them impractical for clinical work in oncology or palliative care units. Wettergren's review found that the time for completing interviews ranged from <5 to 50 minutes, and that missing data was present in 10/39 studies, ranging from 8 to 83% of participants failing to complete the procedure (Wettergren et al., 2009). There was debate about the extent to which the scoring process changes over time and how to interpret responsiveness, test-retest reliability, and response shift

(Westerman et al., 2007). Nevertheless, SEIQoL has been used in a variety of settings, for a variety of health conditions, across a wide variety of age groups and cognitive levels, and has a well-established place amongst the options for individualised quality of life assessment.

5.1.2.3 PGI

The Patient Generated Index (PGI) was developed by Ruta et al. (1994) and initially used and evaluated in UK patients with low back pain. Like the SEIQoL, use of PGI involved three stages: self-identification of the most important areas or activities of their lives affected by their condition, coming up with these "ingredients" themselves or selecting them from a list of areas of life that are most frequently mentioned by patients with the disease in question; scoring the degree to which each is affected; and allocating points among the items listed to represent the amount in which they would like each area improved using a fixed number of hypothetical points. When considering the choice of ingredients, the PGI invited patients to consider the most important parts of their lives affected by their condition, and included examples of family, work, relationships, and friends in a list of general prompts. Five items should be identified, along with a sixth question which covered "all other areas of life affected by your condition" (de Achaval et al., 2013; Tang et al., 2014). PGI has been used in situations as varied as menorrhagia, varicose veins, dermatitis, stress incontinence and peptic ulcers (Tang et al., 2014).

The PGI required the patient to imagine that all the identified areas could be improved, but patients may differ in their acknowledgement of the limits to what may be medically possible and have unrealistic expectations. Like SEIQoL, the weighting system has been described as complex (Lindblad et al., 2002) as patients needed to consider how important they perceived the different areas to be, and to take into account how badly they were functioning in the respective areas. Recent improvements have resulted in improved completion rates across a range of conditions (Garratt, 2015) by simplifying the scoring and weighting stages.

PGI allowed patients to formulate and voice their own responses in an open-ended format. This element could contribute to some challenges. de Achaval et al. (2013) reported that the use of the PGI in Systemic Sclerosis in a specialist clinic setting yielded 54% of responses in the areas of social health, 28% in physical health, and 19% in mental health. Addressing this range of issues within a traditional healthcare setting would be difficult. Tang's review of the use of patient-generated measures in oncology settings reported a diverse range of patient concerns, from work to social life to sports or relationship issues in addition to physical symptoms, but this was felt to be important as it added an extra dimension to the understanding of patients' values (Tang et al., 2014). Although there were important benefits to the open-ended answers as they provided essential insights that were not captured through other measures, the lack of structure to categorise free-form answers created some difficulties for professionals. Tang recommended that it may prove more beneficial for patients and clinicians alike to administer the PGI as a complementary tool rather than as a replacement to more traditional methods of exploring a patient's quality of life. The PGI would require more extensive resources for developing and training personnel to score answers, but she concluded that the potential benefits and implications of allowing patients to characterise their quality of life in their own terms could be remarkable (Tang et al., 2014).

5.1.2.4 MYMOP

The concept of patient-generated quality of life measures was furthered by the development of MYMOP (Measure Your own Medical Outcome Profile) in 1996 (Paterson & Britten, 2000). This built on Ruta's work with PGI (Ruta et al., 1994) but was designed to be quick and simple for use within general practice consultation. MYMOP focused on the aspects and effects of illness that the patient decided were most important. The patient was asked to choose one or two symptoms (physical or mental) which bothered them the most and to rate these on a seven-point Likert scale. They were then asked to identify and score an activity that had been affected by their symptoms, and then to rate their general feeling of wellbeing on a seven-point scale. It was designed as a before-and-after health status assessment, with the follow-up version administered at reattendance after an intervention. This system allowed the patient to self-report change and share this information with the clinician during the consultation to support discussion and ongoing management.

Over time MYMOP has evolved to include reflections on medication use (MYMOP 2), and been modified for mental health (PSYCHLOPS – Psychological Outcomes Profiles) (Ashworth et al., 2004), complementary medicine (MYCAW, Measure Yourself Concerns and Wellbeing) (Paterson et al., 2007), translated into other languages (Hermann et al., 2014; Ishaque, Johnson & Vohra, 2019), and adapted for those who are illiterate, or those whose first language is not English, through the use of pictures (MYMOP-P – pictorial) (Day, 2004).

Much research has taken place to demonstrate how MYMOP compares to scales such as the SF-36 and to assess its reliability, validity and responsiveness to change. A recent review of the MYMOP class of measures looked at the format, content and evidence of measurement properties and concluded that MYMOP and its adaptations had an excellent fit with individualised patient-centred approaches and could provide robust data about the patients' perspectives (Ishaque, Johnson & Vohra, 2019). They recommended that they be used as a starting point for domain-specific measurement of symptoms like pain, nausea, anxiety etc, but that further work should be done to consider the validation of MYMOP against external measures and explore its construct validity and responsiveness.

Whilst a literature search of MYMOP and its descendants found 183 papers, the majority of these reported its use as an outcome measure in clinical studies and provided little detail pertinent to the research question here, namely the wish to understand how and why using this type of tool can support the provision of person-centred care by improving communication.

One of the advantages of using MYMOP is that it is conceptually in tune with holistic care, where interventions are individualised and participants are encouraged, where appropriate, to take an active role in considering their health needs (Paterson et al., 2007). The nature of children's palliative care, and the complexity of roles played by parents, means that using this model of individualised outcome measurement can provide the sensitivity and flexibility to personal need and circumstances required. In settings providing holistic support for adult cancer patients, MYCAW was found to be acceptable to patients, and assessors and practitioners were enthusiastic about the process of using it as well as the results (Paterson et al., 2007). One healthcare professional reported that it was “numerically affirming (for patients) when they see how far they have come, and qualitatively affirming when they articulate what it is that has been particularly important to them”. The sensitivity to change was valuable to clinicians, as it added value to the joint decision-making process. The MYCAW was felt to support additional insights for patients – “It can be such a useful tool to enable people to see that they are ready for discharge, often a tricky thing to negotiate with a patient who has tendencies towards dependence on a therapy” (Paterson et al., 2007) . Staff reported that it was difficult to find staff time to monitor the data collection process, especially the follow-up questionnaires, and for data input and analysis. Users also noted the limitations of descriptive outcome data in attributing benefit to any one intervention as many patients had multiple dimensions of medical and social support. However, Paterson’s study did identify sensitivity to change, suggesting that the MYCAW is responsive and that it had value in supporting shared decision-making between patients and healthcare professionals.

Murphy, Hollinghurst & Salisbury (2018) explored patient understanding of MYMOP in primary care.   She reported that 8/17 participants reported some difficulty comprehending the MYMOP, with symptoms misunderstood as conditions or difficulty choosing or sticking to a single “problem”, and 6/17 reported some confusion on how to interpret the scale or interpreted this inconsistently. A Likert scale that is labelled “as good as it can be” at one end and “as bad as it could be” at the other meant that patients differed in their interpretation of the top endpoint, with some interpreting it as asymptomatic and others meaning as good as possible, given their knowledge of their own health condition. Similar problems arose regarding the lower end of the scale, and these processes may lend themselves to response shift as patients recalibrate their expectations, particularly with long term conditions (Murphy, Hollinghurst & Salisbury, 2018). Despite these limitations, the individualised nature of MYMOP appealed to those completing it, though it was recommended to be administered in interview rather than self-completed.

Paterson & Britten (2000) reported qualitative analysis of MYMOP in primary care and complementary therapies in a study involving 176 patients and 12 practitioners, stating that from the health care professional's perspective it was useful for symptomatic conditions because it was problem-specific but flexible, and useful when the study population had a variety of problems, as is seen in general practice. In particular, its brevity makes it useful for repeated use in chronic problems when the profile of scores can be displayed graphically over time. It was also relevant in multidisciplinary clinical settings where basing measurement on the patient's values and concerns avoided interdisciplinary conflict over diagnosis or treatment aims. Patterson and Britten found that seeing the reduction of symptoms was welcomed by patients, alongside the facility to score a reduction in disability via the "affected activity" question. Many patients reported gaining control and coping skills, not directly measured by MYMOP (though possibly detected via improved well-being) and securing support and hope through the patient-practitioner relationship.

Paterson & Britten (2000)'s qualitative analysis found that there were other variable outcomes important to patients that were not easily documented using MYMOP. Case study analysis also demonstrated a group of the patients that was looking for a way forward, not necessarily depending upon symptom improvement. They valued aspects of their therapy such as gaining control and coping skills, keeping hopeful, or feeling supported. The patient-therapist relationship was often central to this. This suggests the possibility of a component of the therapeutic relationship that provides an additional dimension to the provision of holistic care, not easily captured even on an individualised outcome measurement.

PSYCHLOPS (Psychological Outcome Profiles) (Ashworth et al., 2004) is a modification of MYMOP designed for mental health practitioners, revising wording to be more appropriate for those living with, or treating, those with psychological distress – thus "symptoms that bother you most" became "problems that trouble you most". MYMOP's concise answers (ideally one or two words to describe a symptom) became larger free-text boxes to better capture the voice of the patient. However, even at the design stage the therapists raised concerns about the potential for the follow-up questionnaire to identify new problems for which they were ill-equipped, and which had the potential to extend therapy and undermine attempts to complete a course of treatment. This generated an ethical dilemma for therapists, the result being to omit this question in the follow-up questionnaire (Ashworth et al., 2004). This suggests that although the original aim of PSYCHLOPS was to hear the patient's voice, this aim conflicted with the therapists' concerns about the boundaries of their roles and responsibilities.

5.1.2.5 IOMs and MyQuality development

MyQuality contains an individualised outcome measure at its core, designed to follow the principles established by MYMOP, SEIQoL and PGI and to develop these into the digital era. It was never designed to provide aggregate information but to act as an adjunct to normal clinical discussions between healthcare professionals and families whose children have life-limiting illnesses. It has tried to circumvent some of the challenges identified in previous work by incorporating technology to ensure it is quick and simple to use, does not require the time or assistance of a professional to enter data, and results are readily accessible and easy to interpret. The website incorporates training material for patients and professionals and sample cases to familiarise them with its potential. It is free to use and readily accessible. However, website design alone cannot change the essence of individualised outcome measurement, which in itself raises practical, professional and personal challenges for clinicians.

5.1.2.6 IOMs and patient-clinician communication

Greenhalgh et al. (2017) reported that when used in first assessments, IOMs supported relationship-building because they enabled the patient to "tell their story". IOM feedback could increase discussion of symptoms during the consultation, as patients felt more comfortable raising physical, psychosocial and non-medical issues with their doctors. Furthermore, the process could provide a framework for discussion, and signal that the clinician was interested in their views (Greenhalgh et al., 2018). However, consultations still focused on symptoms rather than psychosocial issues, and clinicians did not substantially change their communication practices as a result of IOM use. Further exploration confirmed that in practice the impact on patient-clinician interactions was complex and dependent on the patients' and clinicians' circumstances (Greenhalgh et al., 2018). Patients and clinicians found difficulties incorporating outcome measurement into routine care, sometimes feeling that this was detrimental to a therapeutic alliance, adding to patient burden, and emotionally challenging (Greenhalgh et al., 2018; Krawczyk et al., 2019). Across all care contexts clinicians and patients felt that having a trusting relationship was necessary to support the sharing of concerns and problems, and clinicians adapted their use of PROMs to support ongoing management of patient relationships (Greenhalgh et al., 2018). In contrast to standardised PROMs, IOMs mimicked the more open structure that clinicians would normally use in their interactions.

In addition, there were practical challenges with the use of IOMs as these were felt to be more time-consuming to complete and interpret (Greenhalgh et al., 2018; Macduff, 2000; Boyce, Browne & Greenhalgh, 2014), and less useful as an outcome measure to judge change over time owing to differences in the way that cues were defined by patients and over time (Greenhalgh et al., 2017). Macduff (2000) suggests that these differences, described as intrasubject construct dynamism, reflect that what is important for people changes over time, a key concept in response shift in palliative care. By using IOMs to identify areas and quantifying them, it may be that IOMs do more to highlight individual adaptation than standard needs measures. Facilitating adaptation to adverse circumstances remains a key component in the provision of holistic palliative care.

5.1.3 Provisional PTs about IOMs and communication within the clinician-patient relationship

Greenhalgh et al. (2018)'s realist synthesis proposed two programme theories to illuminate the impact of PROMs on clinician-patient communication. The first: PROMs support patients to raise issues with clinicians; and secondly, PROMs raise clinician's awareness of patients' problems. The authors point out that future research needs to consider how and why patients use PROMs in the ways that they do, and how clinicians and patients interpret them and the impact that this has on developing and maintaining their therapeutic relationships. This thesis intends to focus on IOMs only, and to delve more deeply into the mechanisms driving the responses of patients and healthcare professionals to their use. Based on the literature discussed above, the following rough PTs (Table 5-1, p. 111) may shed light on the effects of this approach on communication between families and healthcare professionals and will be explored during data collection with MyQuality users.

5.2 eHealth Technology

In addition to individualised outcome measurement, MyQuality incorporates several facets of ehealth design as outlined below (Table 5-2, p.113) which will be considered in this section. Many interventions contain combinations of various aspects of ehealth.

In a similar approach to the section above, this foray into the literature began with a search for relevant review papers on ehealth (and related terms) and communication, followed by an iterative approach which involved chasing references and citations, identifying highly cited papers, and following leads from key authors and research groups. The field of ehealth is vast and this is not an attempt at a comprehensive synthesis of literature findings. This review is presented in a narrative manner, including reviews and papers with qualitative findings from the perspectives of both patients and service providers in order to illuminate potential resources and behavioural reasoning that drive the use of ehealth interventions. I have focussed on papers with particular relevance to facets of MyQuality function, and contextual similarities to the care requirement for children and families living with complex health care needs, and to HCPs working in palliative care or paediatrics or chronic illness.

Table 5-1 Initial theory concepts based on use of IOMs

Over-Arching Provisional PT
The process of individualised outcome measurement supports patients to identify key issues in their lives and gives permission to share this information with their HCPs, which improves HCP's ability to understand the patient's perspective and facilitates holistic, person-centred care.
Potential Contexts and Mechanisms: Communication processes
Prioritisation: If patients reflect on their own situation, they will identify and prioritise what is important to them and what they want to share or raise with clinicians
A Reminder: The process of completing an outcome measure will remind patients to mention or raise issues with their clinicians.
Enhancing and Valuing Discussion: The process of discussing the changes in the outcome measures increases the focus on issues relevant to the patient, which may in turn influence clinical decisions about patient management and improve patients' well-being though agreement about goals of treatment or changes to management of their care.
Changing patterns of communication: The focus on an outcome measure may distract or hinder the flow of conversation that would naturally take place in the clinic, which may change or hamper the development of the clinician-patient relationship.

Potential Contexts and Mechanisms: Patients, Professionals and Relationships
Trust: Patients will be more likely to share their concerns openly if they have a trusting relationship with their healthcare provider
Permission: If clinicians show an interest in the results of personalised outcome measurement, it signals to the patient that their perspective is valued, and this gives patients permission to share or raise issues with their clinicians.
Respect: If patients share their outcome data but this is not viewed or valued by the healthcare professional, patients may feel disempowered and disengage with healthcare support, or feel increasingly isolated and unsupported.
Potential Contexts and Mechanisms: Values, Beliefs and Emotions
Over-medicalisation: The process of contemplation about key issues and priorities for care may promote an excessive self-awareness, leading to increased anxiety and over-medicalisation of life, and an increased burden on patients and their carers.
Honesty: HCPs need to trust that patients are recording data honestly and not overstating their symptoms
Potential Contexts and Mechanisms: Practicalities, adapting to change
Overload: Clinicians may be overwhelmed by patient-generated issues that they feel are outside their remit, or where they do not have the resources to provide appropriate support. This can lead to negative feelings about their ability to support their patients, and an unwillingness to use IOMs.
Support for clinicians: Clinicians may lack the time, training, or enthusiasm to incorporate IOMs into their clinical practice

Table 5-2 Facets of eHealth incorporated into the design of MyQuality

Ehealth dimension	**Definition**	**Examples in general**	**MyQuality examples**
Remote contact	communication when individuals are not in the same physical space	Telephone consultation Video/skype consultation Email discussion	shared electronic access to graphs and daily diary notes
Real-time data collection	Regular and continuous updating of feedback	Daily data entry Continuous biometric feedback	daily data entry
Data management	Transformation of raw data into a format to simplify analysis and interpretation	Numerical outputs displayed as graphs Display of trendlines and normal ranges	graphs
Data sharing	Permissions to access data from multiple sources	Shared data accounts Multiple sources of data entry	Patient-controlled access to graphs and diary
Email alerts	Triggers for electronic sharing of data if pre-defined limits are exceeded	Automated email warnings	Optional automated email alert facility

5.2.1 Review papers about ehealth and communication in healthcare

Matusitz & Breen (2007) have reviewed the effects of telemedicine on health communication. From its earliest known use in 1959, in the form of a two-way closed-circuit microwave television system used in telepsychiatry (Perednia and Allen, cited in Matusitz & Breen, 2007), telemedicine has now expanded to include remote synchronous consultations via telephone link, or teleconferencing with skype and similar audio-visual approaches, and asynchronous communication via email or internet-based information resources. The potential health communication benefits that may follow the introduction of ehealth include the ability to transcend geographical and temporal boundaries, reduce cost, to increase patient comfort, security and satisfaction, and to digitise health communication via web-based services (Matusitz & Breen, 2007). The ability to access disadvantaged, secluded, and restricted communities and individuals improves equitable access to healthcare resources, and alleviates some of the time constraints imposed by the health service system. Matusitz and Breen speculated that some patients appreciated being the focus of several medical practitioners concurrently, a process that may reflect "media richness theory (Daft and Lengel 1986), due to the *enriched social presence"* (their italics) from multiple collaborating physicians which can relieve or diminish the uncertainty and fear by the patient regarding his/her disease. They also identified several key challenges to telemedicine, specifically around patient privacy and the control of access to information, issues around accountability and responsibility in healthcare, and the requirement for telecompetence in healthcare practitioners. Their biggest concern surrounded the deleterious effects on practitioner-patient communication, with telemedicine dehumanizing, dissocialising, and depersonalising human behaviour and contact. The negative impact was noted by other professionals too – Bloom (1996) conducted a study of telemedicine among nurses and found that they viewed this as dissocializing because they missed the physical contact of touching patients.

Christine Dedding and colleagues reviewed the literature on ehealth and its effect on relationships between professionals and patients (Dedding et al., 2011). They summarised the changes in relationships resulting from the use of ehealth with five potential results: the replacement of face-to-face encounters with alternatives; supplementing existing relationships and forms of care; strengthening favourable circumstances for improvements in communication; disturbing relationships; or demanding more intense and more frequent patient participation, with a shift in the burden of responsibility toward the patient.

The first of these, replacement of face-to-face encounters, was most appropriate for information-seeking on-line, or situations where physical contact is not necessary for diagnosis and treatment such as mental health care of for addiction, and where supported self-management may be appropriate. This was never the intended use of MyQuality.

The second category described situations where ehealth could supplement rather than supplant existing relationships, providing personalised, more rapid responses, and an interactive transaction model for communication – more closely resembling the role envisaged for MyQuality.   Active, two-way communication depends on a transaction between the sender and the receiver, who must understand the message and respond to it (Dedding et al., 2011). Thus it is the recipient of the message that drives the communication forward, and thereby continues the relationship. This interactivity is increasingly a component in ehealth developments such as health trackers, remote monitors, and discussion pages on websites. In order for these to supplement the patient/family – provider relationship, the relative roles of the individuals contributing to the process must be considered.

Dedding's third category discussed how ehealth could create favourable circumstances for improvements in patient participation. This may occur through empowering patients by the creation of a mechanism for interaction that supports choices, a decentralised decision structure, and stimulates self-disclosure communication – akin to MyQuality's aim to amplify the patient's voice. However, she also described the potential for the ehealth to disturb relations between healthcare providers and their patients. As Neuhauser & Kreps (2010) reported, the discourse of communication meant that at times "dominant" communication stimulated "submissive" behaviour in the receiver, as opposed to the empowerment that was sought. As McMullan found, health professionals could feel threatened by the information brought by the patients and respond defensively by asserting their "expert opinion", setting up a dominance conflict rather than a collaborative encounter (McMullan, 2006).

Dedding et al. (2011)'s final category recognised the potential for ehealth to demand increased patient participation and impose the burden of responsibility onto them. Whilst self-care and personal responsibility may be welcomed by many, the amount of "sick work" and the medicalisation of normal life may create obligations and burdens that cannot be supported, resulting in greater harm than benefit for the patient.

Vassilev's realist review of the implementability of telehealth interventions for self-management for adult patients with COPD, heart failure or diabetes covers similar ground (Vassilev et al., 2015). They identified three concepts which suggested how telehealth worked to engage and support health-related work: the enabling of relationships, the fit of the telehealth into everyday life, and the visibility of symptoms and feedback which had the capacity to improve knowledge, motivation and empowerment. In findings that echo Dedding's work, Vassilev's team reported a reshaping of relationships in a variety of ways, relating to their impact on the division of labour between users and professionals. In some cases, patients felt more anxious at the prospect of being required to exercise greater responsibility in engaging with the intervention, and others reported that they liked being telemonitored because they felt reassurance arising from what was perceived as the provision of continuous practitioner surveillance and support. Telehealth interventions that did not involve professional input were more likely to be successful if they were individually tailored for the recipient.

These reviews shed some light on the theories around the impact of ehealth on communication and relationships in healthcare, and on the underlying importance of having sensitive, flexible technology that will meet the needs of users and appropriate support for implementation of this intervention, including training, recognition of changing time pressures on workloads, and the need to reconfigure expectations and working relationships to accommodate it. Many of the themes identified in these reviews are similar to those identified in the section above concerning outcome measurement and may reflect the complex processes involved in change management relating to healthcare interactions and practices.

To obtain greater insights into the mechanisms driving the behaviour of patients and professionals using MyQuality, it was appropriate to move beyond the insights from review papers and seek more detailed information. Multiple papers exist on ehealth strategies in a variety of settings, incorporating aspects of technological design or implementation strategy, but fewer describe users' experiences of ehealth in practice. Although none of the papers below describe technology that exactly mirrors MyQuality, the elements of telehealth and mHealth described next do shed some light on potential programme theories.

5.2.2 Key features of eHealth, and the impact on healthcare relationships

5.2.2.1 Remote contact

In Australia, Tieman et al. (2016) looked at a group of adults requiring palliative care and considered the feasibility of using telehealth in the community – aiming to provide “usual service” remotely rather than face-to-face. Many of the characteristics of their palliative care ehealth support package were similar to those of MyQuality, namely the ability to identify their own priorities in addition to using established symptom control checklists, the ability to register an alert if a symptom exceeded a pre-set level, and the ability to self-monitor and send information to their healthcare professionals.

Overall, Tieman reported benefits to patients from remote symptom monitoring which led to more timely, proactive, equitable care. However, there were issues around symptom alerts, which did not necessarily result in a clinical contact or response. In many cases these provided clinical information where no action was indicated, either due to knowledge of the patient’s current or “normal” disease state, or to “alert fatigue” amongst practitioners, particularly with growing exposure to alerts and heavier use of the systems by patients (Tieman et al., 2016).

Tieman’s team felt that further work was needed to “normalise” telehealth within a clinic setting, with training for staff and patients as required, prior to use in the community. They suggested that as telehealth represented a new form of practice, staff would require support in developing skills and changing work practices, and they needed to see that such change would have benefits for patients and carers, not just the system or service, in order to support successful implementation.

Collier et al. (2016) reported on the qualitative study of clinicians’ perspectives in the study of telehealth in community palliative care in Australia described above by Tieman. They found that the implementation of a telehealth programme meant that models of care needed to be redefined, enabling staff to work more effectively and safely with patients. Ultimately, some participants viewed telehealth monitoring as a way to place responsibility on patients and families not only for identifying, but also for acting on their symptoms. Most nurses emphasised that the telehealth model was not necessarily useful in isolation and was most beneficial in the context of other knowledge of a particular patient and family. Telehealth was seen very much as an augmentation or complement to existing practice, rather than an alternative for home visits and phone calls.

Collier also discussed some of the drawbacks of telehealth. In some cases, these related to difficulties with IT and internet connections, resulting in a loss of confidence in the technology which promoted reversion to previous practice. In addition to the technical hitches encountered, this also affected views of working relationships. Nurses felt that the “breakdown” in technology would threaten “breakdown” of a relationship of trust with patients and families. Some nurses felt that the technology would deprive them of the additional information provided by a face-to-face encounter, emphasizing the importance of material and affective components of the physical proximity of performing a home visit.

Staff were concerned about the impact on patients of a telehealth approach. The onus on them to provide an electronic daily report meant that they never had “a disease-free day off”, and some were concerned about mapping their decline, an unintended consequence of monitoring which conflicted strongly with the principles of not harming patients (Collier et al., 2016). Other concerns related to professional issues around accountability and role management. Some staff had medico-legal concerns relating to the difficulties of clinical assessment at a distance. Others reported that some carers actively manipulated their entries into the carer screening tool to initiate triggers (or avoid triggers) that would prompt contact from a clinician. Workload management was highlighted, with the burden of having to respond to automatically-generated alerts producing the risk of overload and burnout.

MacNeill et al. (2014) also explored the role of telehealth on front-line UK health professionals supporting adults with chronic conditions. Their study looked at a cohort of patients who collected data (recording key biometric such as weight, blood pressure, oxygen saturations, and blood glucose) and shared these with a team of nurses, community matrons and GPs. The healthcare professionals were interviewed about their experiences with telehealth, and its impact on practice, on professional-patient relationships and on interprofessional communication and relationships. They found mixed views from health professionals, which seemed to reflect their levels of patient engagement. Telehealth was broadly welcomed by nursing staff, who viewed it as a potentially beneficial change in the delivery of healthcare as long as it was presented to patients as optional rather than essential, supplementing rather than replacing traditional health care. Nurses recognised that telehealth patients were becoming adept in recognising a correlation between their health behaviours and their biometric signs and this often led to improvements in, or stabilising of, their condition and quality of life. Nurses also reported that the use of telehealth was empowering for patients. Nurses identified engagement with telehealth as an important new skill for them, in order to refine their ability to understand trends in the management of long-term conditions.

A minority of nurses and most GPs were more concerned about the potential burden on patients who may become prematurely “medicalised” by unnecessary close clinical surveillance, or the appropriateness of telehealth for the severely ill. Most GPs were opposed to it as it potentially provided too much information, creating a “tsunami” of patient-monitoring data. There were clear tensions for GPs between wanting to maintain their central role in caring for the patients, and not having the time and resources to do so. MacNeill concluded that healthcare professionals’ views of technology were linked to their concerns about the impact on the stability of existing patient-professional relationships. Most GP’s saw telehealth as increasing their work burden and potentially undermining their professional autonomy (MacNeill et al., 2014).

These telehealth projects demonstrated the benefits of timeliness, convenience, control and the potential to develop new forms of relationships, and the potential drawbacks of dependence on IT systems, concerns about patient workload, professional accountability, manipulation of data, the lack of physical proximity and risk of burnout due to professional overload. Although these projects focussed on telehealth technology, many of the issues identified for patients and staff could apply with other interactive forms of ehealth.

Issues surrounding telehealth and communication have been examined in some detail by van Gurp et al. (2015) who explored the use of teleconferencing technology (TCT) in palliative care to provide outpatient support in Holland. They found that teleconsultation with video calls enabled long-term engagement that resulted in trustful relationships between patients and healthcare professionals. They found that continuity of care with the same professional facilitated engagement with the palliative care team and enhanced tailor-made care for patients. Patients reported that they were able to define their own roles and co-design their own care in a more equal patient-professional partnership than standard care models. Patients' feelings of safety were enhanced by knowing that access to a specialist team was available via TCT, and this helped to address the needs of families and carers as well as the patient themselves (van Gurp et al., 2015).

Bradford et al. (2014) explored clinicians' perspectives on the barriers to telehealth implementation from a staff perspective, reporting on attempts to establish telehealth support for the provision of children's palliative care in rural Australia. Despite theoretical support from clinical champions and receptive families, adequate funding and supportive management structures, uptake of the programme was disappointing. A purposive sample of ten clinicians (medical, nursing, and other professionals allied to medicine) underwent semi-structured interviews. Four themes emerged: managing relationships, expectations of clinicians, co-ordination of care, and the compromises required in the use of telehealth. As with the studies mentioned above, participants felt that they were missing some of the insights gained from face-to-face contact, despite continuing communication via telehealth. They also described hesitancy regarding situations that provoked emotional distress. There was a range of issues identified relating to the ease of use of technology, personal preferences and cultural contextual factors, and the challenges in establishing new routines and protecting time for new ways of working.

The core concepts that emerged from Bradford's data included changes to control and trust. They suggested that in a traditional consultation, the clinician is "in charge" but when using telehealth with a patient at home, this is reversed - the family's environment becomes dominant and the clinician is invited into that space by the technology. They felt that both parties (clinician and patient/carer) could feel uncomfortable with this arrangement and left with the feeling that the consultation wasn't as "good" as it could be.

In their discussion, Bradford et al. (2014) comment that utilisation of the programme might only be appropriate for a small number of patients, and the original expectations of uptake in their programme were too high. Governments may have a growing expectation that technology should be used to improve access to care and facilitate data collection, but clinicians see the detailed circumstances of families in distress, and take part in therapeutic relationships, and this may conflict with the desires of programme organisers and funders.

In contrast to the previous papers, Heckemann et al. (2016) et al explored the use of telehealth that did not involve a video or visual perspective but simply used telephone calls to support adults in Germany with chronic life-limiting illness. Long-term relationships between the telehealth professionals and the patients grew as patients became accustomed to telephone communication, maintained trust, and acquired competencies in self-management. These findings were mirrored in Mann, Turner & Salisbury (2021) who reported that remote consultations via telephone or video made it harder to establish rapport and trust than a traditional face-to-face encounter, but were more satisfactory when the clinician and patient were already known to each other, a good relationship had been established, and there was a link with a consistent health care provider.

The section above has focussed on the nature of ehealth as an alternative method of communication to face-to-face encounters. Qualitative papers highlight some of the particular benefits and challenges of healthcare provided "at a distance", a complex process with mixed outcomes for patients and HCPs. The next section addresses some of the processes of that communication, the acts of entering, reviewing, and sharing information using ehealth.

5.2.2.2 Data collection by numbers – sharing data about “the quantified self”

Chia-Fang Chung and colleagues examined the issues surrounding the use of technology to acquire data to support quantification of aspects of daily life, both from the perspectives of patients (Chung et al., 2016) and healthcare providers (Chung et al., 2015). Their work explored the use of patient-generated data for the management of obesity or irritable bowel syndrome, using self-trackers (e.g., weightwatchers app) and wearable sensing devices (e.g., Fitbit or Apple Watch), and they investigated the extent to which the data generated supported patient-provider interaction, and co-ordination of care. This qualitative work involved questionnaire surveys and interviews with both patients and healthcare providers, and related this to stage-based models of personal informatics (Li, Dey & Forlizzi, 2010).

In comments very similar to those we noted in the first MyQuality study (Harris, Beringer & Fletcher, 2015), Chung and colleagues described the potential for telemonitoring systems to allow patients to collect data and allow providers to remotely monitor this and communicate with them. Many of these systems could provide necessary contextual information for diagnosis, to facilitate communication, engage patients in the shared decision-making process, and support long-term management. They also noted the personal impact on individuals using these systems, which allowed them to reflect on personal information. However, they observed that many of the attempts at collaboration during healthcare encounters involving self-reported data failed to engage providers, leading to frustration for patients and missed opportunities to maximise the benefits that data could provide to support evidence-based practice.

In order to understand how collaboration between providers and patients occurs, and why it breaks down, Chung drew heavily on the stage-based model of personal informatics developed by Li, Dey & Forlizzi (2010) about the “quantified self”. This model consists of 5 stages that individuals experience in the process of collecting personal data for electronic manipulation – preparation, collection, integration, reflection and action. Preparation includes consideration of what data is to be captured, and the motivations for this. Collecting or recording the data involves people observing or monitoring their activity, events, or emotions. Integration is the stage where information is combined or transformed in order for Reflection to occur, which can facilitate an understanding of trends, patterns, and causation. And finally, the Action stage is when people chose what they are going to do with their newfound understanding, based either on personal reflection or in conjunction with others (such as healthcare professionals, or social media forums for example). Li and colleagues pointed out that barriers to the use of these informatics systems would cascade (so that poor data collection, or sparse data, would impact on visualisation and therefore reflection and action plans). Stages were iterative, so systems needed to be flexible as people adapted to the process of data collection, responded to reflections and modified their actions. When designing data collection systems, there was a delicate balance between the simplicity afforded by systems structured to make each of the stages easier to use, and the flexibility and personal control that individuals desired in order to ensure that relevant data was identified, collected, and visualised to facilitate useful reflection and action.

Chung et al. (2016) explored patient expectations about the use of personal data in their work with individuals seeking healthcare support for the management of obesity and IBS. In their study, patients wanted to get a complete picture of daily life, bridging clinical and home care contexts. They wanted healthcare support to make help to make sense of data, to see patterns and correlations, and develop personalised actionable treatment plans. They also detailed affective goals in sharing their data with providers, such as developing self-awareness, accountability for actions towards their goals, motivational support and recognition of their efforts. Chung's team found that patients reported greater motivation to collect comprehensive and accurate data if this request was initiated by the healthcare provider, but the relationship with the provider determined the nature of what was collected and how it was to be distributed as patients would not always feel comfortable sharing the same information with every provider.

Patient expectations did not necessarily match those of providers, with resultant dissatisfaction for both parties. Mismatch occurred about the type and nature of data collected by patients, particularly when this was not requested by providers but initiated by the patients themselves. In addition, the volume of data, how it was presented for analysis during discussions, and issues around privacy and control of access to data were highlighted. Chung et al. (2016) made many suggestions to mitigate these challenges, some of which already exist in the design of MyQuality such as flexibility in the way the data is presented and patient control over about shared access to data. However, they reflect that increased collaboration at all stages would help both parties to gain maximal benefit from the use of patient-tracked data. This would require joint commitment from the start of the process, including decisions about which tracking tool to use, which data to collect, agreement on tailored visualisations and interfaces for collaborative review, and discussing expectations of review and actionable goals.

In their accompanying paper about the views of healthcare providers on the use of data provided by patients, Chung et al. (2015) explored these issues in obesity and irritable bowel management with 21 healthcare providers from a variety of disciplines though qualitative interviews. The providers could see many benefits from self-tracking and reviewing patient-generated data, including greater understanding, self-awareness, independence, motivation for change, educational opportunities, and support for the patient-provider relationship. Chung comments that “by helping providers learn about patient values, goals and constraints, and by offering them real examples from patient data to use in conversations, data supports patient-provider communication which supports better patient outcomes”.

Healthcare providers identified a number of barriers to the use of patient-collected data, such as the need for time and commitment by patients to the process, and unrealistic patient expectations of benefit (Chung et al., 2015). If providers were expected to review the data, this was a further challenge to time management within a clinical setting, but a lack of review could send a message to patients that their efforts were not valued by the healthcare team. Some providers doubted their ability to advise on symptom tracking or to review the data or were unfamiliar with the tools being used. Some questioned the additional health benefits from provider review of patient-tracked data. Whilst reviewing data together could improve motivation and accountability for managing change (e.g., in diet management) and provide opportunities for personalised treatment plans, the lack of time and expertise emerged as significant constraints on medical enthusiasm for the use of patient-generated data. Sometimes the physicians delegated this to allied health professionals such as the nurses, dieticians or psychologist in this study to overcome the issues around time management; others found that having patients verbally summarise the logs was a more efficient way to gain insights from the data.

Chung et al. (2015) reflected that the use of patient-collected data in clinical settings should consider the range of provider goals and tracking needs, such as using data to support diagnosis and monitor treatment, or for motivating and engaging patients and developing working relationships. These varying goals required different balances of personalisation and standardisation of practice. Failure to agree an appropriate balance could lead to patients and/or providers being overwhelmed by irrelevant data. Healthcare organisations could support the process by recognising the time, training and compensation required by providers to review data and generate personalised treatment plans.

Katz et al. (2018) examined how the impact of the design of the apps themselves could influence the processes of using and deriving benefit from patient-generated data. They pointed out that the work from the “quantified self” range of activity monitors and personalised trackers, such as those used in Chung’s work, had many theoretical overlaps with chronic disease management, but that the use of patient-generated data in the context of illness required specific consideration in light of “the non-elective nature of disease, the frequency of treatment decisions, the need for continuous monitoring, the greater unpredictability of measurements, the emotional impact of unwanted results, and the critical nature of decision-making based on personal data”. Their work explored a variety of apps for monitoring blood glucose levels in patients with diabetes, noting both the cognitive and affective requirements for patients to derive benefit from self-monitoring their progress. Cognitive requirements related to the ease of use of the app, the simplicity of data entry in a structure that provided relevant information, and the ability to interpret the visual display in order to accurately reflect and act on output. The affective components considered the feelings of disease burden, and the resilience to manage both the volume of information and the potential vulnerability generated by negative results.

Miyamoto et al. (2016) explored similar territory with their study to explore users' views of mhealth technology, and the value of integrating mhealth technology with traditional health care. They conducted focus groups of 30 adults employed at an academic institution, who used health apps to track their activity levels. They proposed that behaviour changes to support improved health were more likely to be sustained if patients were involved in identifying and establishing their own goals, and included partnerships with healthcare providers. When considering motivations for using mhealth, initial reactions often focused on practical aspects of the technology, so that it should be reliable, functional and intuitive. Two further themes emerged: firstly, technology should integrate with their existing tools (e.g., smartphones that they already used) and that data storage and visual display should be integrated to give an overall picture; and secondly, there was a desire to control the type and level of data that would be collected and shared with others. (Both of these themes have been addressed during the development of MyQuality.) For most participants, tracking and collecting data was not enough to promote sustained engagement. Participants described needing additional support or structure to help them understand the broader meaning and implications of the data, and this sense-making was encouraged and reinforced by interaction with healthcare professionals rather than with the device. Health care partners not only helped to motivate, but also provided expertise to make sense of the data being generated by the individual. This in turn required opportunities for reflection and action on the information obtained, and study participants noted that providers may or may not have the time, or the interest, to review a patient's personal health goals and corresponding data. These findings mirrored the qualitative feedback obtained in the first MyQuality study (Harris, Beringer & Fletcher, 2015).

Graffigna et al. (2016) examined the role of the healthcare professional in ehealth and mhealth and the mediating role of patient engagement, looking at interventions in diabetes management in Italy. They recognised that ehealth and mhealth interventions are increasingly used to provide continuous monitoring, empowering patients in self-management of their condition, resulting in improved gylcaemic control, greater adherence to prescriptions, and increased effectiveness of behaviour modification. However, they hypothesised that this was dependent on active endorsement from the healthcare professionals in order to legitimise the intervention process and support patient motivation. Their study recruited 93 diabetic patients and measured their engagement with healthcare, levels of activation, medication adherence, and perceptions of healthcare professionals to support their autonomy, and use of ehealth. The frequency of ehealth use was strongly dependent on the level of patient activation, and perception of support by the healthcare professional for patient autonomy. Patient engagement, defined as a multi-dimensional psychosocial process resulting from the joint cognitive, emotional and behavioural response of individuals to their health conditions and their management, was an important antecedent of patient activation. The level of patient adherence to medical advice was not shown to be linked to ehealth use but was linked to support for patient autonomy and motivation by healthcare professionals, confirming that the quality of that relationship was a crucial factor for improving patient care overall. They concluded that healthcare professionals were the enablers, from the patients' perspective, of the clinical potential of ehealth and mhealth. In order to maximise the benefits of these developments, interventions need to be designed and delivered with a goal of sustaining the engagement of all stakeholders (patients, carers, and healthcare professionals), a process which would require consideration of the psychosocial and relational dimensions of the healthcare activity as a whole.

5.2.2.3 Tracking over time

MyQuality depends on action by the individual user to input data. As an individual's memory can be unreliable, personal users are encouraged to enter data regularly and the website is designed to facilitate daily scoring of the individual user's chosen parameters. The data entered is displayed in a graph which can be adjusted to show daily, weekly or monthly averages of each parameter, or combinations of identified parameters. This element of the design of MyQuality aimed to support the identification of patterns or trends in the data, to support a process of sense-making by reflecting on temporal patterns (Barbarin, Klasnja & Veinot, 2016).

The outputs from the MyQuality website develop with time as individual data points create a longitudinal illustration of change. However, the need to input data regularly could be seen as adding to the burden of patient work (Riggare et al., 2019; Piras, 2019; Ancker et al., 2015). Ancker et al. (2015) noted that for many individuals with chronic conditions, tracking data over time did not simply involve recording objective facts but instead could provoke strong positive and negative emotions, value judgements and diverse interpretations of the data. Examples included individuals who perceived themselves as "bad patients" if they did not track their data regularly, or avoided monitoring health indicators that might document failure of self-management (such as weight or blood sugar management in a diabetic clinic). Conversely, others who tracked data diligently were sometimes considered "obsessive" (Ancker et al., 2015). Riggare et al. (2019)'s study of patients with Parkinson's disease reported developing a fixation with tracking was a potential risk, and patients were keen not to let it take over their lives. The emotionally charged process of data tracking over time reminded people that they were sick and could potentially increase comorbidities such as depression or anxiety (Ancker et al., 2015). Even for those who enthusiastically committed to tracking health data, finding insights and self-knowledge could be difficult and any pretence at control over one's health could remain elusive (Bergroth, 2019), thus enhancing uncertainty and the vulnerability of the individual.

In addition, Riggare et al. (2019) reported findings similar to Ancker's about the responses of healthcare professionals to tracked data over time, with only 21% of physicians interested in the outputs of tracking in a study of patients with Parkinson's disease. This perceived lack of value of patient-tracked data further discouraged patients from continuing to track data over time. This finding was echoed in Coolbrandt et al. (2017)'s work on the use of symptom diaries during chemotherapy, reporting that patients perceived a key advantage of the diary being its usefulness to professionals, and keeping it was perceived as the patient's contribution to getting good care, while providing a sense of hope and reassurance. They felt sad or angry when the information was not used, noting that 32% and 37% of nurses and doctors respectively never looked at it. The motivation to continue using it was largely influenced by how they perceived its reception by healthcare professionals.

5.2.2.4 The diary function: the importance of narrative

Stories are a human way of giving meaning to experience. They are a primary way in which we understand ourselves and the world we inhabit, and a primary means of influencing others (Engel, 2008; Zaharias, 2018). Although numerical data can provide one dimension to a story, the use of language allows the speaker and the listener to reflect and create meaning, reframing events, thoughts, decisions and our identities as agents in the stories of our lives (Williams, 1984; Frank, 1998; Charon, 2008).

In healthcare discussions, encounters between patients and professionals take place in a highly structured transactional space, in which the behaviour of both parties is determined by socialised expectations (Greenhalgh, 1999). As Jurate Sakalys points out, if illness is defined by a medical metanarrative, the patient's story is listened to by the clinician, looking for "clinically significant" items. The clinician initiates new topics, actively guiding the patient's account into a specific, predetermined frame of reference, focussing attention on diagnostic patterning of signs and symptoms. The aim is to listen for facts rather than meaning. This story is then translated into a diagnosis and treatment plan that subsequently informs and guides future interactions (Sakalys, 2003). In contrast, the patient narrative brings together the experiences, emotions, hopes and fears of the individual, in a process of "continuous accounting to make sense of the traumatic effects of illness, to reaffirm the impression that life has a course, and the self has a purpose" (Hawkins 1993, in Sakalys 2003). The process of narrative reconstruction is an attempt to reconstitute and repair ruptures between body, self and world by linking-up and interpreting different aspects of biography in order to realign present and past and self with society (Williams, 1984).

Creating a narrative provides meaning, context and perspective for the patient's predicament (Kalitzkus & Matthiessen, 2009) and allows patients to make sense of their circumstances, offering a biographic and social context of the illness experience and suggesting potential coping strategies and opportunities for personal development.

Illness narratives can be formed and changed by the medical encounter, co-creating new meaning by bringing together the patient's perspective and the expertise of the healthcare professional (Greenhalgh, 1999). The process of active listening, exploring differences and connections, reflection, hypothesising and sharing power can support patients in their coping processes, contributing to their personal growth and providing therapeutic potential (Kalitzkus & Matthiessen, 2009; Launer & Greenhalgh, 2017). However, this is not a process that comes naturally to all healthcare professionals, who may require training, time and the appropriate personal skills to adopt the principles of narrative-based medicine (Engel, 2008). The patients risk being devalued by medical judgement of their existence if their story is truncated merely to the illness narrative, and professionals fear being overwhelmed by their patients' narratives (Kalitzkus & Matthiessen, 2009).

Diaries contain the documentation of events in a temporal manner, and may include a private, personal narrative of thoughts, feelings and emotions. In the health context they have been used to log symptoms, daily activities and health indicators as a record for the patient care team or self-management of health, particularly for those with chronic illness or with variable levels of medication or intervention (diabetes, asthma, anticoagulation, food diaries, mood diaries, and many other examples exist). The advent of electronic communication allows this information to be shared between patients and healthcare professionals more effectively. The numerical documentation of symptoms or events on MyQuality fulfils this function, but part of MyQuality's structure incorporates a free text box for additional annotations, in the form of a daily diary note. This facility was used extensively by children and families using MyQuality in the initial hospice study

(Harris, Beringer & Fletcher, 2015) despite the fact that it was more time-consuming to enter text than numerical data. Qualitative review of feedback from participants revealed the need to add further personal reflection to the numerical data in order to assist the user in subsequent interpretation of any subsequent trends or patterns of change.

Similar examples in palliative care noted two types of diarist, those who log events in their health or their lives, and those who use a diary as a reflective process to record ongoing thoughts and feelings (Wilson et al., 2016). These reflections provided valuable insights into the emotions and mental wellbeing of the users. Whilst many diaries about emotions are kept private, these were written knowing that the information would be accessible by the healthcare team. Wilson et al. (2016) reflected that the emotions articulated by patients were not always easy to verbalise in a face-to-face setting and represented patients writing the diary to help themselves come to terms with their situation. This finding was mirrored in a study about ehealth in bariatric surgery, as Das, Faxvaag & Svanæs (2015) reported that online writing described greater detail than face-to-face discussions, either due to difficulties articulating these, or constraints caused by time, shame or stigma restricting opportunities for sharing information in a clinic setting.

Time is important for sense-making in illness, as an individual shifts from a healthy state prior to diagnosis to adjusting to the disruption caused by illness, a process known as “biographical disruption” (Bury, 1982). In a study of information needs of those with chronic illness, Barbarin, Klasnja & Veinot (2016) explored the reasoning processes of patients and families, and how the temporal nature of information was critical for decision-making, health behaviour change, and sense-making. Subsequent adaptation to living with ongoing health issues involved seeking information relating to a patient’s understanding their health status at the current time, how it changed over time, the cause and effect of health status and whether this was linked to events or the behaviours of an individual, and the desire to predict what to expect over the course of an illness (Barbarin, Klasnja & Veinot, 2016). This desire for information reflects a need for control, understanding and sense-making as the individual reviews their sense of self (Lawton, 2003).

5.2.3 Barriers to the use of ehealth and mhealth

Thus far this review has explored the component structural features of MyQuality, but issues around implementation and use of ehealth by the individuals and organisations are also key to its impact on communication. Schreiweis et al. (2019) performed a systematic review of the literature and combined this with expert opinion in a framework that identified the facilitators and barriers to ehealth services, based on individual, technical, and environmental or organisational factors. Amongst these, the top six facilitators included ease of use, improved communication, motivation of individuals, user-friendliness, and access/availability of resources, and the ability to readily integrate data into care. The barriers identified by Schreiweis's team included concerns about the value and benefits of the intervention which would affect an individual's motivation, accessibility, issues around training and technical cognition, and a lack of trust. Environmental and organisational barriers included problems with funding, and the fit of ehealth into organisational structures and policies – issues beyond the remit of this study but important contextual influences on the uptake of ehealth and the behaviour of HCPs regarding its use. Schreiweis's review included a wide range of ehealth approaches, many very dissimilar to MyQuality in design, but still highlighted important concepts about the implementation of ehealth amongst consumers in general.

Many of the barriers to the adoption of ehealth in clinical settings derive from clinicians rather than patients. A review of 171 studies in a qualitative synthesis considered the factors impacting clinicians' adoption of mobile health tools, some of which were related to the technology including its usefulness, ease of use, design, compatibility, and convenience (Jacob, Sanchez-Vazquez & Ivory, 2020a). However, social and organisational factors relating to clinicians were much more prevalent that those related to technology, and were categorised into eight key themes: workflow, patient-related issues, policy and regulations, culture or attitude, monetary factors, the evidence base, awareness, and user engagement. The largest group related to workflow challenges such as the need for staff training, new resources to manage the workload, time or cost-efficiency, technical skills, and changes to roles and responsibilities amongst others. Examples included the need for staff to have the capacity to review large amounts of data and complex charts produced by some ehealth tools. Factors such as information overload and the integration of the generated data into the existing workflow could readily dissuade clinicians from implementing ehealth measures, particularly if there was a fear of exposing knowledge gaps, or if clinicians or care teams perceived new technology as a threat to their own careers and livelihoods. Some studies reported that clinicians felt the need to renegotiate their professional identities in the face of the empowered and informed patient who is sometimes seen as undermining the authority and credibility of healthcare teams. Conversely, educational benefits of ehealth could be enablers for ehealth adoption if the educational resources prompted best practice care, provided novel decision aids, and expanded clinical knowledge (Jacob, Sanchez-Vazquez & Ivory, 2020a).

Patient-related factors included concerns from clinicians about the loss of human contact, potential breaches of patient privacy particularly regarding sensitive medical information, medico-legal issues, an unprofessional image, and the patient's overreliance on ehealth. It was emphasised that ehealth tools should complement rather than replace face-to-face treatment and therapy (Jacob, Sanchez-Vazquez & Ivory, 2020a).

Clinicians were more likely to adopt ehealth when it empowered and engaged patients, giving them more autonomy and assurance about their diseases or condition management, but patient engagement could also be a barrier if ehealth was perceived as a burden by clinicians (Jacob, Sanchez-Vazquez & Ivory, 2020a). Many were concerned about the possibility for a digital divide to marginalise those who could not access technology, or those who were illiterate or unable to use technology effectively. Concerns were raised about the potential for overreliance on practitioner support if patients over-utilised the tool, or tried to access HCP support after hours, or became too dependent on technology and failed to seek medical help in emergencies. Other deterrents included exacerbating patients' worries and anxiety related to the understanding and interpretation of data, or the feeling of being observed, a finding that echoed Chung's (2015) work.

In Jacob, Sanchez-Vazquez & Ivory (2020a)'s review some moderating factors were identified, include age, gender, speciality and years of professional experience, but evidence was mixed regarding the impact of these factors on ehealth adoption and use.

5.2.4 MRTs about ehealth

Jacob, Sanchez-Vazquez & Ivory (2020b) identified middle range theories and conceptual models to explain their findings described in the section above. Key concepts had a bearing on the social and personal factors affecting the decision to use ehealth such as self-efficacy, but also individual characteristics such as being in the habit of using IT, finding it acceptable and comfortable and trusting it, and working within a culture that accepted this development. The authors drew on established frameworks such as the Technology Acceptance Model (TAM) and its derivatives, Diffusion of Innovations theory (DoI) , and the Consolidated Framework for Implementation Research (CFIR) to consider issues related to implementation, and Theories of Planned Behaviour (TPB), Reasoned Action (TRA), interpersonal behaviour (TIB), and Normalisation Process Theory (NPT) to explain the social and personal factors, expanding these or integrating them with other theories or concepts in certain circumstances. However, as Walter & Lopez (2008) point out, the TRA and TPB are well known models derived from social psychology that have proven successful in predicting and explaining behavioural intentions across a wide variety of domains when users have complete volitional control (TRA) or to account for behaviour beyond an individual's complete volitional control (TPB), and do not specifically identify beliefs that are salient for IT users about IT usage.

More recently, Heinsch also considered the theoretical frameworks underpinning development in this field, with a focus on the implementation of ehealth, finding a predominance of theories about predicting or explaining end-user acceptance of this technology, and less representation of theories that captured the intricate relationships and structures required to enact sustainable change (Heinsch et al., 2021). Given the growing acknowledgement of the inherent complexity of ehealth implementation, they suggest that future research should develop and test models that recognise and reflect the multidimensional, dynamic, and relational nature of this process.

5.2.5 Provisional Programme Theories about ehealth and communication

Based on the literature above, a number of areas for theory development were identified, as listed in Table 5-3, p.136.

5.3 Individual roles, responsibilities and relationships in healthcare

In the reviews above which considered IOMs or the impact of ehealth, many of the concepts identified in the literature that pertain to communications overlap. In order to pull together the wide range of potential factors influencing the role of ehealth and IOMs in the delivery of person-centred care, it is useful to reflect on the professional and social structures that interact to shape these processes. As illustrated in the overview of children's palliative care (section 2.1) these structural relationships, and the wide range of individuals involved, contribute to the complexity surrounding MyQuality use in healthcare.

At the core of the communications process is the relationship between the HCP and the patient/family/carer. This is what I shall refer to as the Micro level of MyQuality intervention (Fig 5-2, p.138). In addition to understanding how MyQuality is useful within a healthcare interaction, the use of MyQuality may have an impact on the patients and carers themselves, whether or not they use the website overtly as part of a healthcare consultation process. Likewise, the availability and potential use of MyQuality may influence HCPs separately from their experience of it during the process of a clinical encounter.

HCPs do not work in isolation. Most work collaboratively as part of teams, who need to interact with other HCPs and teams to provide a streamlined service for patients. The impact of a new form of service delivery (ehealth) may affect how individual team members interact with each other, and across teams. This could create variability in the service provided within a team if the new approach is not used equally by all the patients on the caseload. This level of complexity will be referred to as Meso level, illustrated in Fig 5-3, and it influences Micro level interactions.

Table 5-3 Initial rough theory concepts based on ehealth papers

Over-Arching Provisional PT based on papers about ehealth and similar interventions
Ehealth facilitates the collection of timely, accurate observational data which can be explored and shared to facilitate improved understanding of a patient's health status, leading to proactive provision of support from HCPs
Potential contexts and mechanisms: Communications Processes
Access: Ehealth which supports access to healthcare advice outside designated face-to-face encounters will reduce the burden on patients and families
Real Life: Tracking data regularly reflects "normal life" and supports accurate recall of events
Data retrieval: Technology can simplify the process of recording and retrieving data efficiently
Visual Display: Technology which can simplify large amounts of data into visual format will make it easier to understand, and to identify key trends Rival: Technology which transforms data into visual displays requires additional training and time to interpret the outputs.
Daily Diary: A diary function facilitates deeper description of events and documents personal reflections, which will enhance interpretation of numerical information
Emails as timely early warnings: Automated generation of email alerts can generate timely contact for advice and support

Rival: Automated generation of email alerts can create additional workload for HCPs.
Potential contexts and mechanisms: Patients, Professionals and Relationships
Workload: The need to record data regularly and the duty to retrieve it can add additional burdens to patients and HCPs alike
Collaboration: Sharing data online demonstrates a commitment to collaboration
Face-to-face: The loss of face-to-face encounters makes it more difficult to build and sustain supportive relationships between HCPs and the children and families
Potential contexts and mechanisms: Values, Beliefs and Emotions
Medicalisation: Collecting large amounts of data may “medicalise” normal life unnecessarily
Privacy: The diary function contains insights into personal perspectives which may not normally be openly shared, leading to a sense of an invasion of the diary writer’s privacy, or unintended intrusion by the reader.
Potential contexts and mechanisms: Practical Issues, adapting to change
Data Management: Technology may encourage the collection of large volumes of data. Data Management Rival: Collection of irrelevant data may act as a hindrance to HCPs ability to focus on the data that is relevant

Figure 5-2 MyQuality micro level interactions

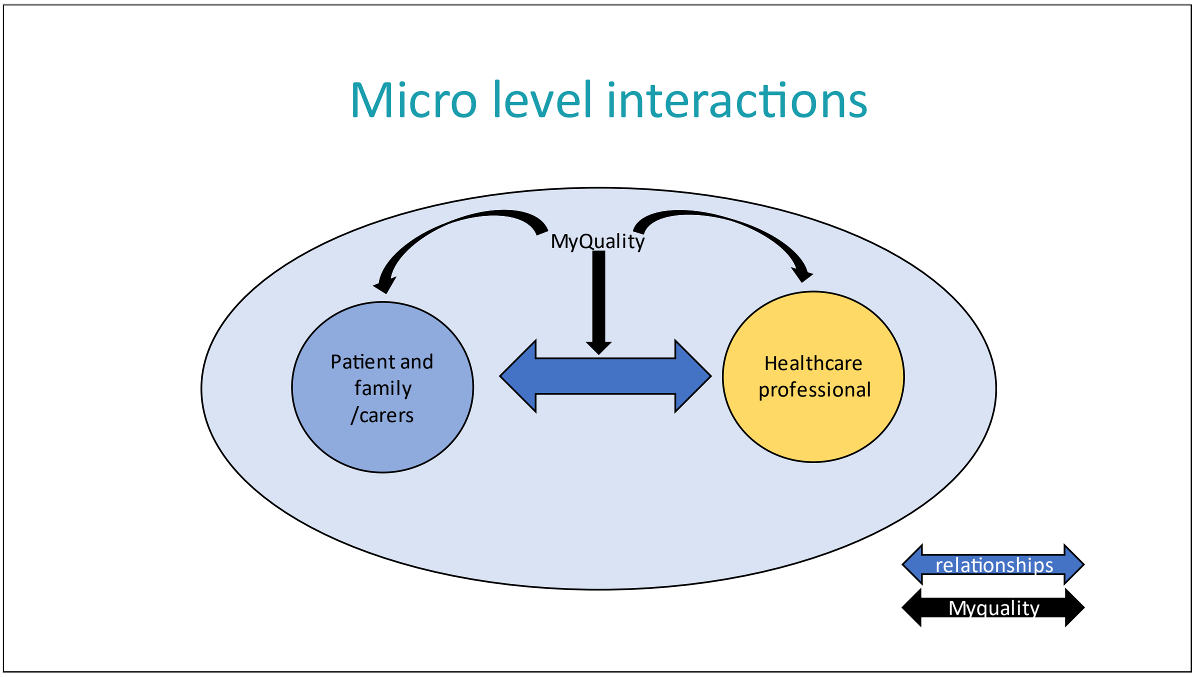
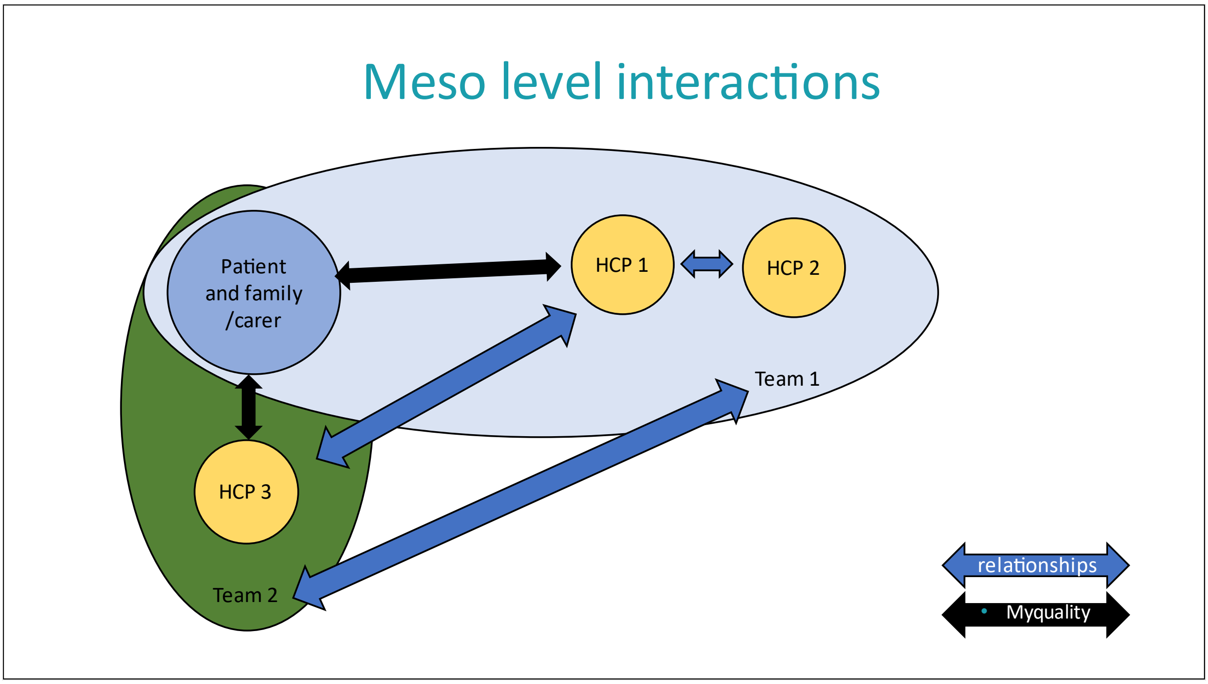

Micro level interactions

Figure 5-3 MyQuality meso level interactions


Meso level interactions

The Macro level refers to organisational or institutional policies that may affect how services are provided. Whilst these can influence both the Micro and Meso level interactions, I do not intend to consider these in detail within the remit of this thesis, save to note contextual influences they bring to activities and behaviour observed at the micro and meso levels.

5.3.1 Evolving Roles and Responsibilities

In order to understand the factors that may support or hinder the uptake of ehealth amongst HCPs providing services for children with palliative care needs, it is necessary to consider aspects of their working relationships, roles and responsibilities in more detail.

From the ancient Greeks to modern times, a myriad of factors has contributed to shape the features of medical practice, and in particular, the forms and rituals of professional-patient interactions. Contemporary healthcare, with its complex, goal-oriented and bureaucratic organisation has led the shift of this interaction from an intimate personal relationship to more brief and impersonal forms of interaction (Botrugno, 2019) and information technology and ehealth has contributed to this process. Relationships are built through communication, and ehealth technologies are disrupting previous patterns of care (Macdonald et al., 2018). At the same time, many Western health cultures are experiencing an increasing challenge in managing long-term conditions, and there is a trend towards encouraging those who are affected to take greater control and ownership of their condition and its management, with partnership and sharing of expertise between HCPs and patients (Hewitt-Taylor & Bond, 2012).

Fernandes, Huising & Peduzzi (2021)'s review of the introduction of new technologies in healthcare reminds the reader that these serve as an occasion for role reconfiguration. Their implementation depends on changes in the tasks, interactions and knowledge of different actors. Previously accepted roles may be enlarged or restricted, clarified or negotiated. Fernandes, Huising & Peduzzi (2021) reported that roles tended to be altered according to the degree of professional authority of the participants, and that if, in a hospital setting, the medical team did not integrate new technologies into their work routines, those working around them would be less likely or able to do so.

Although Fernandes, Huising & Peduzzi (2021)'s review is largely focussed on the wide variety of paid employees within a healthcare team, in children's palliative care the parents or carers take on crucial front-line roles and responsibilities in supporting their child, but they may not always be perceived as key members of the team. Voruganti et al. (2018)‘s qualitative study about the potential disruption caused by the introduction of electronic communication in a cancer setting found that both patients and HCPs had difficulty defining the extent of the team providing care, with patients not identifying themselves as team members. HCPs reflected that the definition of roles and responsibilities needed to be highly flexible as key individuals played more or less prominent roles depending on the patient’s circumstances. HCPs recognised this was leading to a loss of continuity and a holistic sense of the patient as a person (Voruganti et al., 2018). Patients felt that they were the common thread of information between the various HCPs involved in their care, but gaps in communication between HCPs, or the unnecessary repetition of information, or difficulties adapting to a variety of preferred modes of communication of various team members was inefficient and confusing for all. Both patients and physicians in Voruganti's study were clear that electronic communication could not replace the therapeutic value of in-person relationships, and the human dimensions of interaction. Communication between patients and HCPs could not be broadened without negotiating the undercurrents of the relationship, existing care practices, and patient preferences. However, if discussion about expectations of use was facilitated when an innovation was introduced, ehealth communication could present an opportunity to realign the goals and expectations of the patient-professional relationship (Botrugno, 2019).

In parallel with changes in communication, the use of information technology may entail a shift in tasks and responsibilities from health professionals to patients (Botrugno, 2019). Whilst this may be welcomed by some patients who wish greater engagement and autonomy, not all may be willing or able to take on additional responsibilities.

5.3.2 PROMs and communication - theoretical frameworks

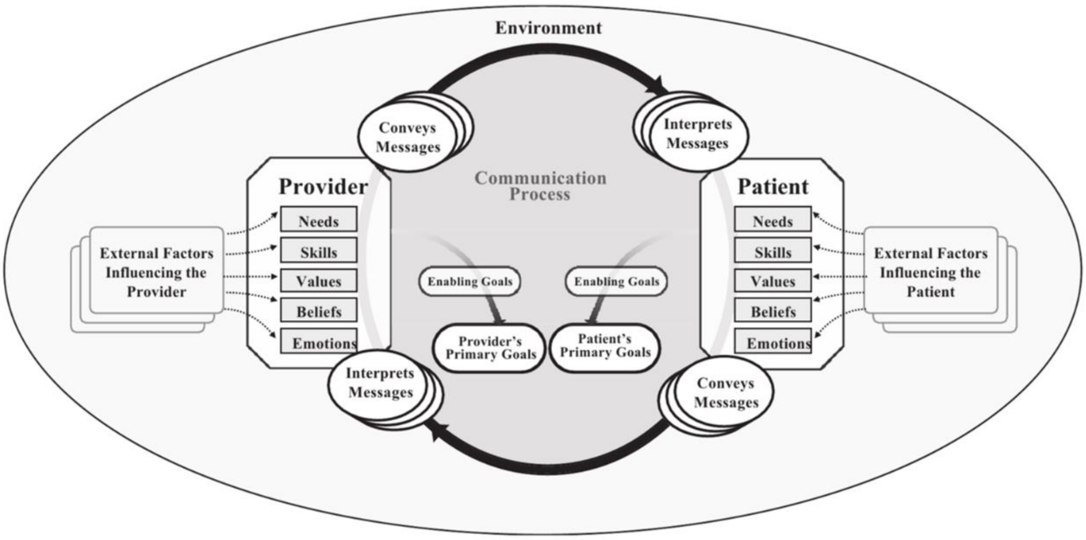
There is an extensive body of literature about communication between healthcare professionals and their patients, some of which has looked specifically at the use of PROMs, which provides theoretical frameworks for the exploration of mechanisms that may be activated by using outcome measures such as MyQuality in the quest to develop a more patient-centred focus in clinical care.

Communication forms a main ingredient in healthcare (Ong et al., 1995). It is critical to the development of effective relationships between healthcare professionals and their patients, and is complex because it involves interaction between individuals in non-equal positions, concerns issues of vital importance, is frequently emotionally laden, often non-voluntary, and requires close co-operation (Ong et al., 1995).

Brundage, Feldman-Stewart & Tishelman (2010) examined PROMs and communication using a model which looks at the specifics of interactions between patients and healthcare providers, starting with the patient-professional dyad (see Fig 5-4). This model could apply to the Micro level of interactions, as described above.

Their first paper (Feldman-Stewart & Brundage, 2009) outlined the framework, which consists of four components. First, the participants communication goals represent what he/she wants to accomplish in the encounter. Secondly, each participant has five key attributes – their needs, skills, values, beliefs and emotions. The third component is the communication process involved in conveying and receiving messages, and the fourth is the environment in which the communication occurs.

Figure 5-4 Brundage et al. (2010) Communications Model: How do interventions designed to improve provider-patient communication work?

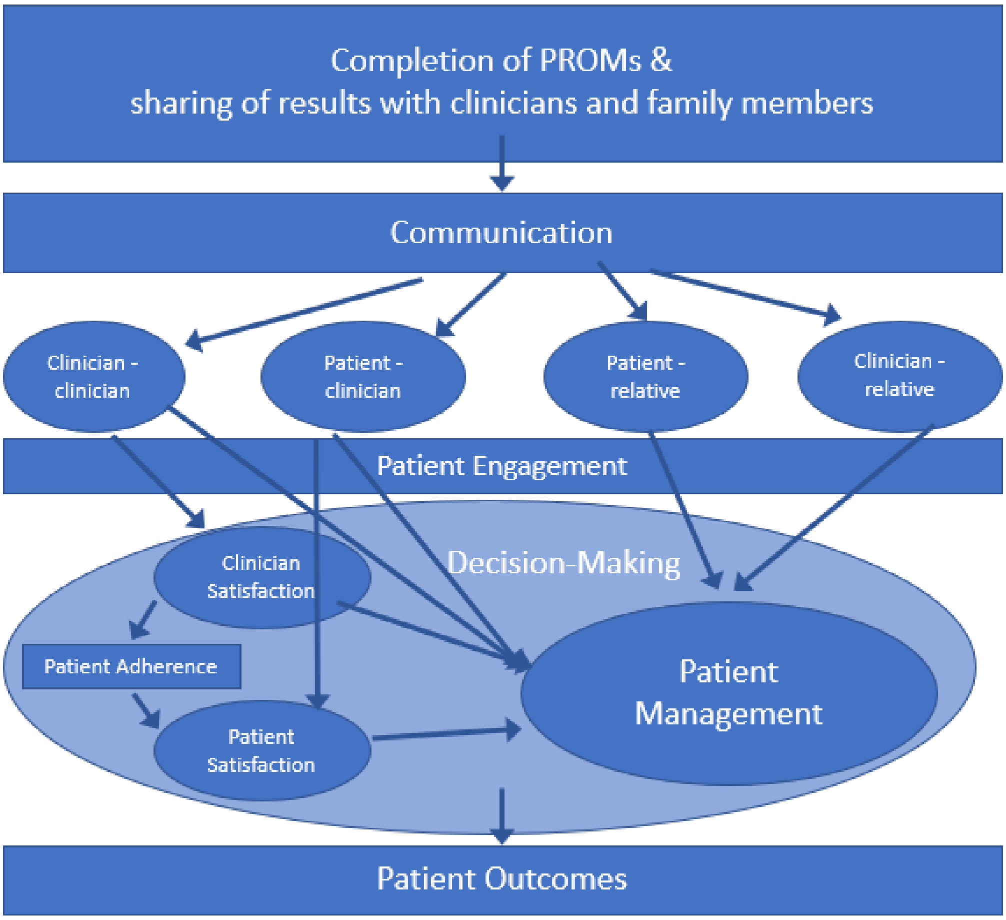


When considering how PROMs influence the communications process, Brundage, Feldman-Stewart & Tishelman (2010) suggested that filling out the PROM improves patients' skills at describing their symptoms, which in turns resulted in the patient being more effective at conveying messages about health issues, facilitating interpretation by the doctor, thus informing the doctor's beliefs about the patient's health state. The shift in discussion to issues identified in the PROM improved patients' emotional functioning because it addressed some of their fundamental needs such as the need to feel cared for, or their need to have a sense of control over their situations. They suggested that PROM feedback may overcome a physician's belief that if the patient doesn't say anything about a symptom, then the patient does not think it to be a problem. The use of PROMs could augment a patient's memory, particularly those who had relatively complicated health conditions which could require discussion of many symptoms. PROMs could help to overcome barriers related to values or emotions (such as shame about certain symptoms) and therefore validated the appropriateness of reporting specific problems to the clinician.

Brundage, Feldman-Stewart & Tishelman (2010) recognised that this framework lacked detail regarding some of the complexities of interaction and suggests knitting this with other complementary communication theories.

In their model Santana & Feeny (2014) built on the earlier work by Brundage et al. (2010). They considered PROMs in chronic care management with a framework that described potential effects, from proximal to distal, including communication, patient engagement, shared decision-making, improved patient management and patient outcomes. This model went beyond the immediacy of the patient/HCP dyad and considered communication on a wider scale, including between clinicians, thus approximating more closely to the Meso level described above.

Figure 5-5 Santana & Feeny (2014), Framework to assess the effects of using PROMs in chronic care management

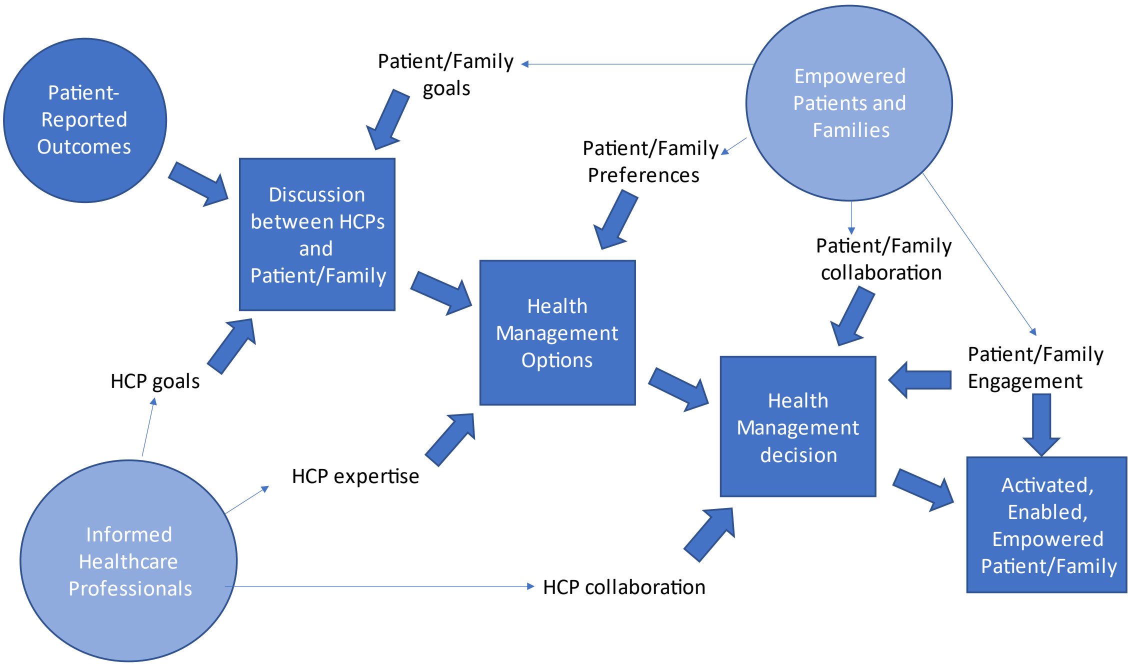


Santana and Feeny theorised that patient completion of PROMs and the incorporation of PROMs into clinical encounters could result in a cascade of effects generating improvements in communication (patient-clinician, patient-relative, clinician-clinician, and clinician-relative), promoting the discussion of issues reflected in the PROMs, and the sharing of the goals, treatments and patient preferences about treatments (Santana & Feeny, 2014), findings echoed in Greenhalgh's (2018) review. These iterative and dynamic processes could result in an improvement in patient-clinician communication, potentially helping to develop a patient-centred care plan.

In addition, Santana & Feeny (2014) proposed that PROMs data could be used to educate patients and had the potential to enhance patient engagement and activation. Patients were activated when they understood their role in the care process and had the knowledge, skill and confidence to carry it out. Activation was enhanced by patients taking ownership, by listening, being involved in problem-solving and collaborating in the decision-making process. Activation was a component of patient empowerment (Fumagalli et al., 2015). Santana and Feeny (2014) suggested that a key challenge presented to patients was to reconsider their roles as recipients of healthcare, and instead see themselves as partners with healthcare providers who could provide advice and tools for individuals to take charge of their own health and self-manage outside clinical settings. Empowered patients, together with the sharing of information from PROMs, should promote patient-clinician partnership and shared decision-making based on mutual agreement, all of which are important components of person-centred care.

These concepts are almost identical to the initial theorising about the potential for MyQuality to support improvements in person-centred care, based on the findings of the original MyQuality study (Harris, Beringer & Fletcher, 2015). The original rough programme theory, illustrated in Fig 4-2 (p. 65) can be developed further on the basis of these models, with Santana and Feeny's model adapted as follows:

Figure 5-6 Initial rough programme theory expanded, based on Santana and Feeny (2014)



5.4 Theory Development following literature survey

Figure 5-6 adds elements of the processes of patient-centred communication but does not give sufficient detail about the underlying drivers for the behaviour of patients or HCPs. This more granular explanation can be hypothesised in rough initial programme theories, for testing and refinement by study participants. When considering micro-level interactions, I have chosen to organise these rough programme theories into four sections following Brundage's model of communication, considering the patient and provider as separate individuals with respective Needs/Skills/Beliefs/Values/Emotions, the process of communication as a whole, and the communication environment, as shown in figure 5-7. For each section, the details of the theories are given in figures 5-8, 5-9, and 5-10.

5.5 Chapter summary

This chapter has outlined the findings in the literature that contributed towards theory development. Key features of MyQuality, including individualised outcome measurement, aspects of ehealth such as the facility for remote data entry in real time with graphic display, augmented by diary notes, and the facility for sharing information with HCPs, have been explored with a view to identifying potential underpinning mechanisms and important contexts that offer explanatory insights into how MyQuality may affect communication and the delivery of person-centred care. The tables in this chapter have listed a range of rough theory concepts extracted from the literature which have been taken forward for further development and refinement. The final section introduced relevant theoretical models that can provide a lens for further clarity about what it is about MyQuality that works, for whom, how and why. The model of patient-provider communication by Brundage et al. (2010) has been used to structure these rough theories, as illustrated in Figs 5-7 to 5-10.

Chapter 6 will report the participants, activities and outputs of the study, and the findings from observations of website use and empowerment scales. The initial programme theories will be discussed in more detail in chapters 7, 8 and 9 where they will be tested against the evidence from this evaluation, and either realised, refuted or refined based on the findings. As an iterative process, the programme theories illustrated below evolved over the course of the PhD. Some were merged with others, whilst others were difficult to test or refine within the limits of this study.

Figure 5-7 Initial programme theories overall schema

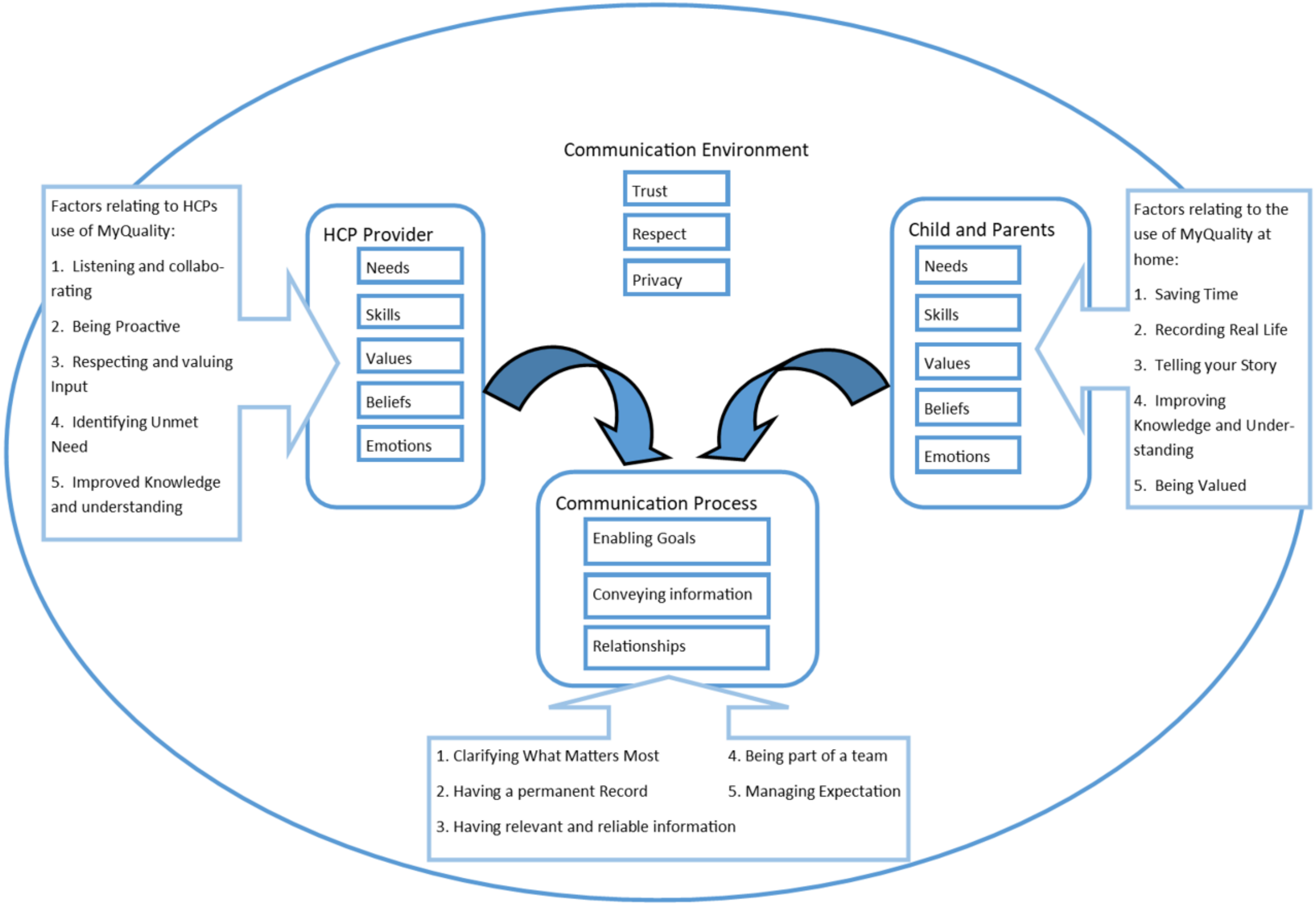
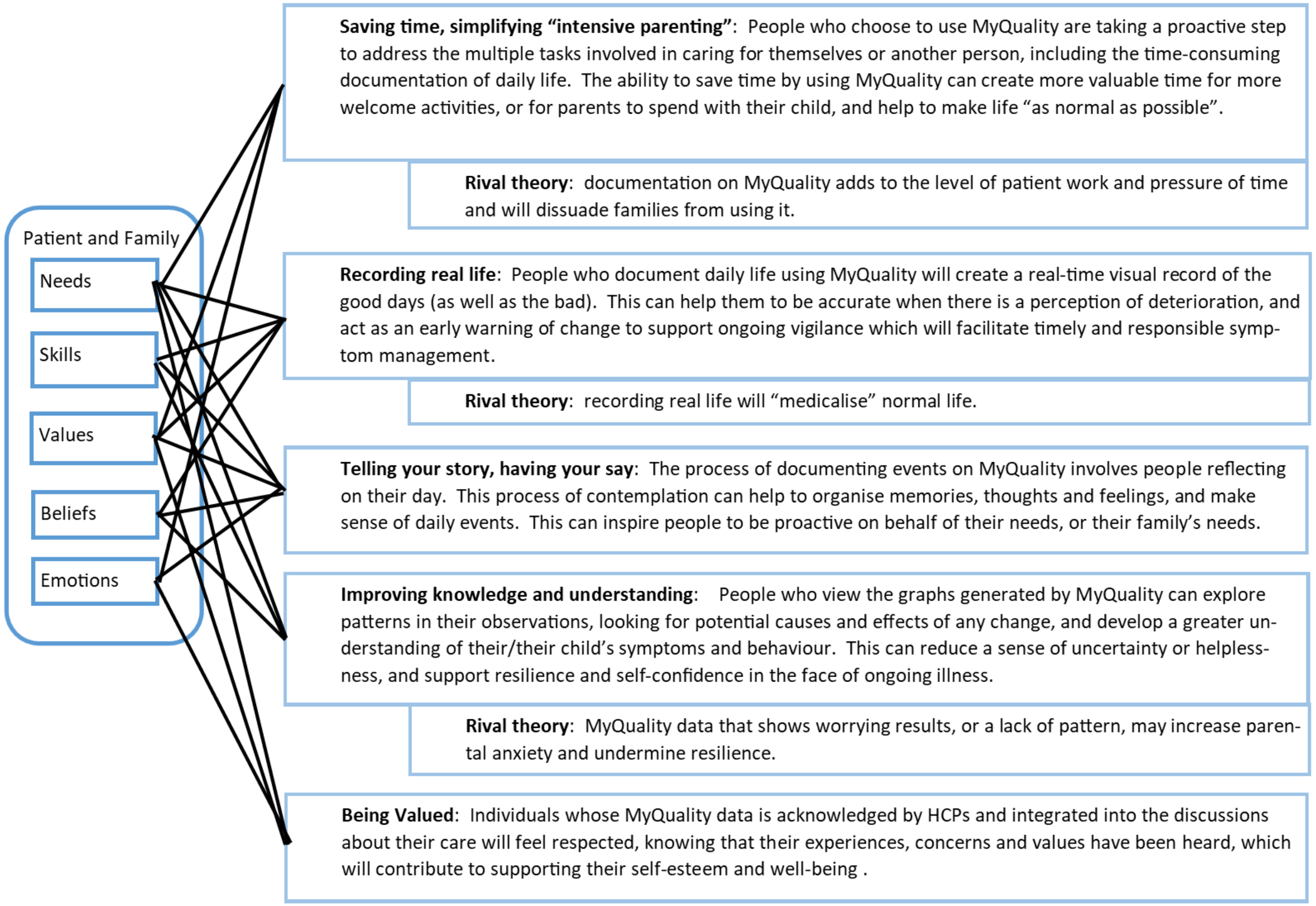


Figure 5-8 Initial programme theories for patients and families



Saving time, simplifying "intensive parenting": People who choose to use MyQuality are taking a proactive step to address the multiple tasks involved in caring for themselves or another person, including the time-consuming documentation of daily life. The ability to save time by using MyQuality can create more valuable time for more welcome activities, or for parents to spend with their child, and help to make life "as normal as possible".

Rival theory: documentation on MyQuality adds to the level of patient work and pressure of time and will dissuade families from using it.

Recording real life: People who document daily life using MyQuality will create a real-time visual record of the good days (as well as the bad). This can help them to be accurate when there is a perception of deterioration, and act as an early warning of change to support ongoing vigilance which will facilitate timely and responsible symptom management.

Rival theory: recording real life will "medicalise" normal life.

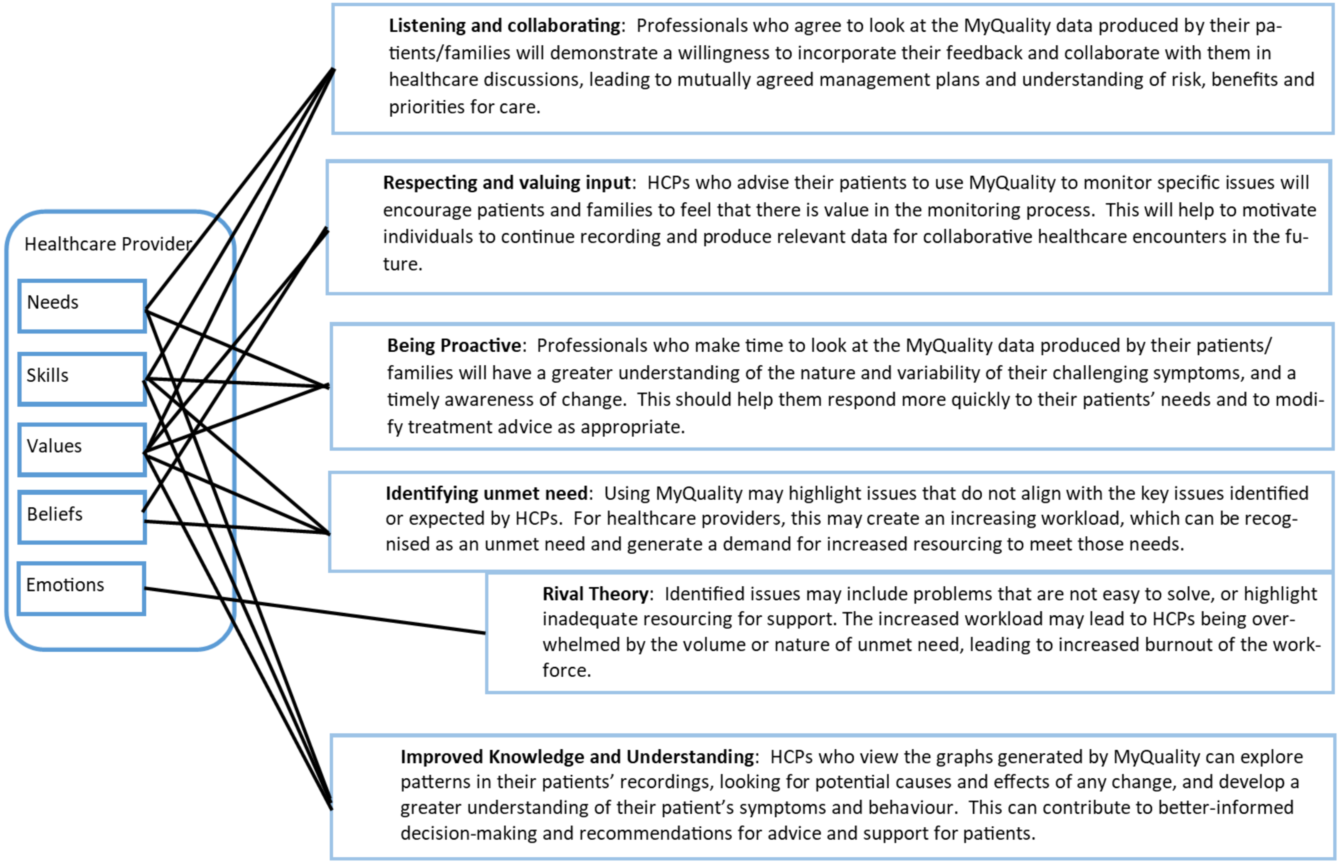
Telling your story, having your say: The process of documenting events on MyQuality involves people reflecting on their day. This process of contemplation can help to organise memories, thoughts and feelings, and make sense of daily events. This can inspire people to be proactive on behalf of their needs, or their family's needs.

Improving knowledge and understanding: People who view the graphs generated by MyQuality can explore patterns in their observations, looking for potential causes and effects of any change, and develop a greater understanding of their/their child's symptoms and behaviour. This can reduce a sense of uncertainty or helplessness, and support resilience and self-confidence in the face of ongoing illness.

Rival theory: MyQuality data that shows worrying results, or a lack of pattern, may increase parental anxiety and undermine resilience.

Being Valued: Individuals whose MyQuality data is acknowledged by HCPs and integrated into the discussions about their care will feel respected, knowing that their experiences, concerns and values have been heard, which will contribute to supporting their self-esteem and well-being .

Figure 5-9 Initial programme theories for healthcare providers



Listening and collaborating: Professionals who agree to look at the MyQuality data produced by their patients/families will demonstrate a willingness to incorporate their feedback and collaborate with them in healthcare discussions, leading to mutually agreed management plans and understanding of risk, benefits and priorities for care.

Respecting and valuing input: HCPs who advise their patients to use MyQuality to monitor specific issues will encourage patients and families to feel that there is value in the monitoring process. This will help to motivate individuals to continue recording and produce relevant data for collaborative healthcare encounters in the future.

Being Proactive: Professionals who make time to look at the MyQuality data produced by their patients/ families will have a greater understanding of the nature and variability of their challenging symptoms, and a timely awareness of change. This should help them respond more quickly to their patients' needs and to modify treatment advice as appropriate.

Identifying unmet need: Using MyQuality may highlight issues that do not align with the key issues identified or expected by HCPs. For healthcare providers, this may create an increasing workload, which can be recognised as an unmet need and generate a demand for increased resourcing to meet those needs.

Rival Theory: Identified issues may include problems that are not easy to solve, or highlight inadequate resourcing for support. The increased workload may lead to HCPs being overwhelmed by the volume or nature of unmet need, leading to increased burnout of the workforce.

Improved Knowledge and Understanding: HCPs who view the graphs generated by MyQuality can explore patterns in their patients' recordings, looking for potential causes and effects of any change, and develop a greater understanding of their patient's symptoms and behaviour. This can contribute to better-informed decision-making and recommendations for advice and support for patients.

Figure 5-10 Initial programme theories about communications processes and environment

Clarifying what matters most: When people contemplate and identify the key issues that they would like their healthcare practitioners to address, they will clarify their priorities for support and be able to emphasise these issues to their HCPs, which will increase the focus on the individual's priorities for care, and emphasise a more holistic, person-centred approach for the delivery of care by HCPs.

Having a **permanent record:** If individuals monitor, quantify and document their/their child's symptoms on a daily basis, they will develop a record which will support accurate recollections. This will improve the reliability of information exchange, and their confidence during discussions with HCPs.

Having **relevant and reliable information**: People using MyQuality will be documenting their/their child's health in a "normal life setting" (eg at home), resulting in a more realistic, continuous record of health concerns. This can increase the relevance of their observation and interpretation of change over time and support more accurately informed collaborative decisions with HCPs.

Being part of a team: Individuals who choose to share their recorded MyQuality information with their healthcare professionals will demonstrate a willingness to share the challenge of improving their quality of life by engaging in dialogue. This may reduce the sense of isolation and support resilience for individuals and families and will support collaborative working practices with HCPs.

Managing expectation: HCPs may find it difficult to ignore the expectations of patients/families and feel that they are letting their patients down if they are not constantly aware of MyQuality feedback. This could lead to work overload, poor decisions, and burnout.

The ehealth interface: Giving and receiving healthcare has rewards and benefits for both participants. The benefits of social interaction may change for both parties if face-to-face healthcare encounters are replaced with e-health interaction.

Trust: Both parties need to trust each other. Healthcare professionals need to trust patients to record data honestly if they are going to make decisions based on personalised data collection. Patients need to trust that information which they share electronically will be subject to the usual confidentiality of a personal medical encounter and not be used otherwise without their permission.

6 Findings

The next four chapters contain the findings of the study. This chapter provides details of the participants and data collected and reports the analysis of the website data and empowerment questionnaires. The following chapters include interview data and details of how these contribute to the development and refinement of programme theories.

6.1 Study participants - HCPs

The study timeline is outlined in Fig 6-1. Once NHS ethical approval was in place, organisations providing palliative care services were approached to confirm their willingness to take part in the MyQuality study. Four separate NHS trusts and the local children's hospice organisation provided research governance approval between November 2018 and September 2019. Recruitment of healthcare professionals and patients began in December 2018, with active recruitment of participants until December 2020. The majority of this took place in 2019 as attempts to recruit patient participants after March 2020 were severely hampered by the Coronavirus pandemic which meant face-to-face meetings were no longer possible.

Forty-seven healthcare professionals from ten teams received a demonstration of MyQuality and participated in interviews, as shown in Table 6-1 (p. 155).

The four paediatric teams based in the regional hospital did not directly recruit any patient participants but did provide care for some of the patients that were identified by other teams. Barriers to recruitment from the regional site included having no children on their caseload who would fit the study criteria (n=1), a heavy pre-existing commitment to other research projects and limited resources to participate in additional clinical trials (n=2), and concerns about additional unresourced workload that might be generated as a result of participating in the study (n=1). These issues are explored in more detail in chapter 11.

6.2 Patient and Parent Participants

The healthcare teams identified 22 potential participants who met the study criteria, and all were sent written details of the study for their consideration. Fifteen of these enrolled in the study, listed in Table 6-2, (p.156). The reasons given for unsuccessful recruitment included parents being too busy with the care of their child to take on any additional demands (n=4), previous involvement in research and no wish to do this again (n=1), limited confidence with IT (n=1), and in one case parents did not respond to requests for further feedback and declined to engage further.

Fourteen of the fifteen participating families were recruited to the study prior to the first coronavirus lockdown in 2020 and the majority of interviews were conducted face-to-face in 2019/early 2020. After the coronavirus pandemic hit the UK, some families continued to use MyQuality and took part in telephone follow-up but all were reluctant to meet again due to the social restrictions at the time. All the children who participated during the pandemic were shielded (as was the researcher) so further face-to-face meetings were not advisable. Alternatives such as video calls were offered but declined.

Seven families used MyQuality on a regular basis for longer than 6 weeks. All were interviewed at the start, completed empowerment questionnaires, and used the website on a regular basis. Six of the seven completed a second interview and empowerment form, but one child died unexpectedly and administration of the final interview and questionnaire was not appropriate under the circumstances.

The remainder of the family participants in the study engaged with MyQuality at the stage of the initial interview and demonstration but did not develop a habit of using MyQuality as part of their daily routine. Their insights are important in the context of realist evaluation as it is necessary to understand the challenges of adopting this approach.

Key extracts from the interviews with patients and parents have been included in the next chapters, as this information was fundamental to understanding what it was about MyQuality that worked for them, and why, and this has contributed to the development or refinement of programme theories.

I am deeply indebted to all the participants for sharing their stories with me, and their time, sincerity and candour.

Figure 6-1 Gantt chart - MyQuality project recruitment

	Q4 2018	Q1 2019	Q2 2019	Q3 2019	Q4 2019	Q1 2020	Q2 2020	Q3 2020	Q4 2020
Permissions and Approvals	1	2	1	1					
Clinical Team Recruitment	1	6	1	2					
Patient/Parent Recruitment			6	4	4	1			
Follow-up interviews				4	1	1		1	
HCP interviews						1	2	1	1

Table 6-1 Recruitment sites

Site/team	**Date of first contact**	**Number of HCP interviews**		**HCPs involved in team interviews**	**# potential patient participants identified**	**# of patient participants subsequently recruited to study**
		Initial	Follow-up			
Regional hospital Specialist children's palliative care team	5/12/18	2 - team	1 – doctor	1 psychologist, 1 doctor, 2 nurses, 1 family support worker, 1 administrator	0	0
Children's Hospice site 1	25/2/19	3	Email	2 nurses, 3 doctors	3	2
Children's Hospice site 2	26/2/19	2 – team	1 - doctor	3 nurses, 5 doctors	4	3
Regional hospital Paediatric oncology service	27/2/19	1	0	1 doctor, 2 nurses	0	0
Regional hospital Teenage/young adult oncology service	27/2/19	1	Email	1 doctor, 2 nurses, 1 psychologist	0	0
Community children's palliative care service, County 1	28/2/19	2 - team	1 - doctor	1 doctor, 4 nurses, 1 psychologist, 1 manager	4	3
Children's hospice site 3	11/3/19	1	0	2 nurses	5	2
Community children's palliative care service, County 2	9/5/19	1 - team	1 - team	9 nurses	3	2
Regional hospital Paediatric neurology service	22/10/19	1	0	1 doctor	0	0
Community children's palliative care service, County 3	23/10/19	1 - team	1 - doctor	1 doctor, 1 nurse	3	3

Table 6-2 Patient participants

Patient identifier[1]	**Age when recruited (yrs)**	**Diagnostic Group[2]**	**Duration of poor health**	**Use of MyQuality**	**Person inputting data**	**Comments**
George	11	4	From birth	Registered priorities only, did not enter data	Mother	Existing paper system already in use Died later during study
Harry	2	3	From birth	Registered but did not enter data	Mother	Did not engage with MyQuality
Tom	11	4	From birth	Registered priorities only, did not enter data	Mother	Went on holiday, and then unanticipated hospital admission, didn't get into the habit of using it
Adam**	5	4	From birth	Extensive	Mother	Retrospective data entry. Continued use beyond duration of study
Daisy**	3	4	From birth	Extensive	Father	Used for duration of study
Arthur	4	3	3 years	Very little. Registered priorities but did not continue to monitor change.	Mother	Shortly after first interview he deteriorated and was admitted to hospice where he died.
Daniel**	4	3	From birth	Extensive	Both parents	Continued beyond duration of study
Emily	14	2	10+ years	Registered priorities and personalised these, did not enter data	Self	Anticipated monitoring change after surgery, which was cancelled

Patient identifier[1]	**Age when recruited**	**Diagnostic Group[2]**	**Duration of poor health**	**Use of MyQuality**	**Person inputting data**	**Comments**
Katie**	7	1	5 years	Extensive	Mother	Continued beyond duration of study
Matthew**	4	3	From birth	Extensive use	Mother	Used for duration of study
Toby	14	3	10+ years	Some regular use, then stopped	Mother	Admitted to hospital and didn't restart after discharge home
Willow	2	3	From birth	Registered but did not enter data	Both parents	Not usual diary keepers, didn't get into a habit of monitoring regularly
Charlotte**	2	4	From birth	Extensive use	Mother	Regular daily use until she suddenly deteriorated and died
Sophie**	5	3	4 years	Extensive use	Mother	Continued beyond duration of study
Leo	9	3	From infancy	Some regular use, then stopped	Mother	Started, stopped, restarted, stopped over a 2 month period.

** Extensive use – regular data entry (numerical and text) throughout study period, and many continued to use MyQuality afterwards. These participants have provided the majority of interview data for this study.

1. All names are pseudonyms. Further anonymised details in appendix P.

2. ACT Groups: 1= conditions where treatment is possible but may fail (e.g. cancer, organ failure); 2= conditions where treatment may support life but the condition will ultimately cause premature death (e.g. cystic fibrosis, muscular dystrophy); 3= conditions where no curative treatment is available and management is palliative from the time of diagnosis (e.g. metabolic or neurodegenerative conditions) ; 4= static conditions where accumulating complications result in increasing likelihood of premature death (e.g. severe cerebral palsy or epilepsy).

6.3 Patterns of website use amongst patient/parent participants

Overall, seven families used MyQuality extensively and an additional three used it on an intermittent or short-term basis. Five families did not engage with the website. The ten who entered data did so for a total of 1882 days up to April 2021, and two families have continued to use the website on a regular basis beyond the duration of the data collection phase of the study. In one case this represents more than two years of data, and another nearly 20 months of regular daily data entry.

Given the small number of regular users and their individual background circumstances, I have not used inferential statistics to analyse website use. However, the website data provides useful insights into the range of approaches taken by families about recording their information. The statistical significance of the incidence of a finding is of much less relevance in a realist evaluation where even the rare occurrence of an event may shed light on an important aspect of causation. Thus, I have focussed on a descriptive analysis of website use and will be relating this to the programme theories that develop. Further information about website use can be found in appendix Q.

6.3.1 Diary keepers

Five of the seven regular users had previously kept a paper diary as a daily record, so transferring the concept of regular recording to an electronic system was less of a change than for those who did not have a diary habit. The other two (Matthew and Charlotte's parents) had previously kept diaries but did not do so on a regular or long-term basis, having concluded that the benefits of keeping a diary were not outweighed by the challenges. For both families, the additional benefits potentially provided by MyQuality in terms of being able to see patterns in their child's health or behaviour which might influence future management meant that they were prepared to use this approach, at least for the duration of the study. Matthew's mother announced that she would use MyQuality again should her son become unwell.

Four of the five families who did not engage at all with MyQuality were either not accustomed to maintaining a paper diary or admitted to having struggled with this in the past. In contrast, George’s parents already had a highly detailed colour-coded hour-by-hour paper-based system, and MyQuality was not designed to accommodate that degree of data density and thus did not meet their needs.

6.3.2 Opportunities for personalisation

Regular users all took the opportunity to personalise the data they collected, often by using the free text facility in “Make Your Own” to define the chosen priority issue in their own words. In total the seven regular users documented 51 issues to monitor, a mean of 7.4 identified priorities each (range 2-11). This included 37 items on the drop-down list in MyQuality, and 14 free-text entries. The most common concerns were seizures (5/7 cases), and breathing problems, mobility issues, sleep difficulties and tiredness, each occurring in 3/7 cases, as outlined in Table 6-3. In addition, 4 families cited difficulties managing secretions, an issue not identified in the initial pilot work and not listed on the drop-down lists on MyQuality.

All the regular users had edited at least one aspect of the listed priorities, either adding a description to supplement the definition of “slightly” or “moderately” for example, or by amending the numerical scoring scale from the default Likert model (a range of none, slightly, moderately, severely, overwhelmingly covering numerical values 0-10). In some cases, this was done on multiple occasions as the child’s circumstances or the parent’s focus changed over time.

The eight families who used MyQuality briefly, intermittently, or who struggled to engage with it identified fewer priorities for ongoing monitoring: a mean of 6.3 issues each for the three families who demonstrated limited use of the website, and only 2.8 issues each by the five families who did not engage. The types of issues being recorded were broadly similar to those identified by the seven families who used MyQuality extensively.

Table 6-3 Identified priorities for symptom tracking by families

Priority Name - Physical	**# entries**	**Free text additions**
Breathing problems	5	Secretions – described by 4 separate users • 3 added “secretions” to their list • 2 – Suctioning Dystonia – 4 separate users • 1 identified 3 time slots for dystonia and later added “dystonia breakthrough” • 2 simply identified dystonia • 1 described “twitching” which may or may not be the same thing 2 entered numerical records: • Oxygen levels • Oxycodone top-up Discomfort – 2 separate users • 1 simply identified discomfort • 1 “gut discomfort” • (neither user had listed “pain”) Others identified specific issues for their child or family: • Cognitive shutdown • Hyperphagia • Obsessional behaviour • stress/anger • sibling upset • cold feet
Bruising or Bleeding	1	
Change in Appetite	1	
Constipation	3	
Diarrhoea	3	
Feeding problems	2	
Mouth Problems	3	
Mobility Issues	3	
Muscle weakness	2	
Nausea or vomiting	3	
Pain	5	
Seizures	8	
Skin problems	3	
Sleep problems	5	
Tiredness	5	
Urinary problems	1	
Priority Name – Emotional/Psychological		
Anxiety	2	
Changes in mood or behaviour	3	
Depression	1	
Friends and Relationships	1	
Self-esteem	1	

6.3.3 Automatic email alerts

One of the features of MyQuality was the ability to detect worsening levels of any priority and automatically generate an email to the clinician dealing with the symptom or priority in question in order to alert the healthcare professionals to a problem occurring at home. Of the 79 priorities identified by families, only three were set up with an email alert, and none of these were triggered during the course of the study. It was thus impossible to see if there was any impact from this aspect of MyQuality design in practice.

6.3.4 Numerical or verbal records

All the parents who used MyQuality regularly supplemented the numerical recording of change over time with the use of free text diary notes. Many used these daily, documenting the impact on everyday life ("collected her from school early today due to pain", or "witnessed prolonged seizure, much worse than normal") which provided additional qualitative insights to the reader. Good days were described as such, and the use of emojis by some participants provided further understanding of the emotional significance of some entries. The use of free text in the diary section is significant in that it takes rather longer than simply scoring on the numerical interface, and so represents an investment of more time into the process of recording.

Two mothers (those of Adam and Leo) tended to use MyQuality to record information in large batches, translating this from their paper records into an electronic format when the time was convenient. They recorded many fewer diary notes, but those that were present gave more insights into particularly important or memorable events. They appeared to have been highlighted by the reflection required to retrospectively review the events in question, and often included thoughts about the significance, implications or outcome of the incident mentioned.

6.3.5 Use of the graphic interface

All the regular users of MyQuality plus Leo and Toby (whose parents used it for a temporary period) looked at the graphs generated by data entry. In total there were 4714 occasions where a chart was interrogated by the family using MyQuality, and in most cases the graphs were accessed multiple times covering different display formats such as showing daily change, a weekly or monthly average over a longer timeframe, or differing combinations of priorities in the search for associations or patterns. Examples of graphic outputs are attached in Appendix R.

All the participants had described the desire to use information from the graphs to predict or explain change as one of the motivating factors for embarking on this study. The inclination to explore the graphs continued even though most of them did not find patterns in the data, though they then reported that the lack of pattern was information in itself.

6.3.6 Access to MyQuality data

Six of the seven regular users chose to share their MyQuality data electronically with a member of their healthcare team. In most cases this included a consultant paediatrician, a community specialist nurse, or a hospice duty team, and in some cases all three. The advantages of sharing the data electronically meant that it would be accessible to HCPs at any time, allowing discrete remote supervision and more timely intervention if necessary. MyQuality is not linked with NHS electronic patient records, so this process depended on the HCP first registering on the MyQuality system, and then logging in to check it regularly. Many of the children were under the care of multiple specialist teams whose members were not registered on MyQuality, so the possible opportunities for sharing electronic access to data were limited. Matthew’s mother reported that the clinician whom she felt was most involved with her son was not registered on it and she did not want others to access the information she chose to record about life at home, so chose not to share MyQuality information with anyone.

Although real-time electronic access to MyQuality data was possible through the website portal, this represented only one method of sharing data. All the regular users reported that they would or had shared the information from MyQuality during face-to-face meetings with relevant health or social care professionals by taking printouts, emailing screenshots, or showing them the data on their phones.

6.4 Empowerment

Empowerment was hypothesised as a potential mechanism that could explain changes in the dynamics of communication or interaction between patients and families and their HCPs that might derive from the use of MyQuality. Empowerment was measured using the Family Empowerment Scale (FES) and Youth Empowerment Scale (YES) as described in section 3.4.2, and the details of the scales are included in Appendix C. The specific questions around empowerment included whether there was any correlation between the extent of engagement with MyQuality and the extent of empowerment observed, and to explore whether MyQuality supported empowerment at a personal level or within the immediate family setting, as contrasted with more outward effects around interactions with services or the community.

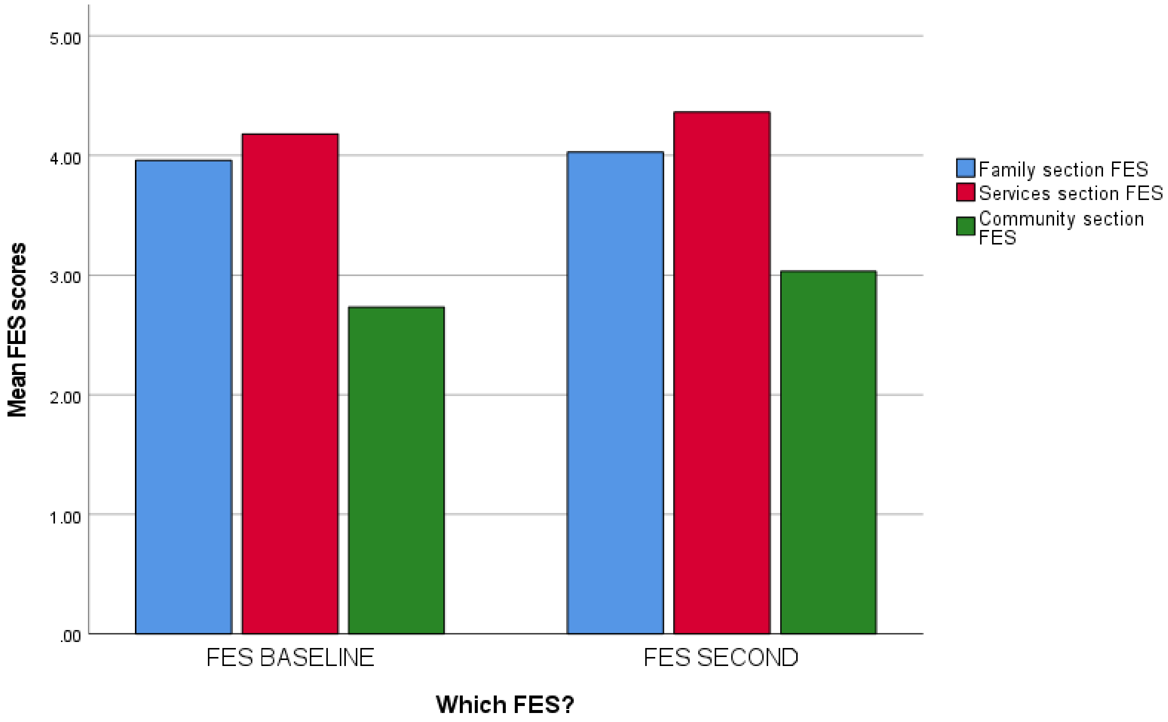
Emily was the only participant in the study who completed the YES. She completed a baseline questionnaire but then withdrew from the study, so it was not possible to analyse her baseline scores with any comparator.

All 15 parents or carers completed the FES at baseline, and the six participants who used MyQuality extensively completed the follow-up FES. Those who only used MyQuality temporarily, did not engage with it, or the bereaved did not complete further questionnaires.

When considering statistical evaluation of these scores, the null hypothesis was that MyQuality would not affect levels of empowerment. Finding a statistically significant difference between scores at baseline and those after MyQuality use would suggest that MyQuality use was empowering for patients and parents. The full FES results are included in Appendix S.

The FES has three sections and 34 questions. The Family section contains twelve questions which explore issues relating to parenting, such as “I know what to do when problems arise with my child” or “I feel I am a good parent”. The Services section focusses on working with relevant health and social care professionals, with twelve questions such as “I am able to work with agencies and professionals to decide what services my child needs”, or “I tell professionals what I think about services being provided to my child". The final ten questions in the Community section cover engagement with service development in general, such as "I feel that my knowledge and experience as a parent can be used to improve services for children and families". In common with the results from the 2014 MyQuality study the community empowerment section was consistently scored less highly than the sections relating to empowerment within the family setting and concerning interactions with services supporting their child. Figure 6-2 illustrates how the empowerment scores vary across the Family, Services and Community sections, before and after using MyQuality.

Figure 6-2 FES scores at baseline (N=15) and after MyQuality use (N=6), by empowerment scale domain



When comparing before-and-after scores using the paired Student's T-Test as shown in Table 6.4, Pearson's correlation between the FES scores pre- and post-MyQuality use was 0.774 with a p value of 0.07, which suggests that empirically measurable evidence of empowerment resulting from MyQuality use was not strong.

Table 6-4 FES score T-Test

Comparison of Baseline and Follow-up FES scores

		baseline FES scores	Follow-up FES scores
Baseline FES scores	Pearson Correlation	1	.774
	Sig. (2-tailed)		.071
	N	6	6
Follow-up FES scores	Pearson Correlation	.774	1
	Sig. (2-tailed)	.071	
	N	6	6

This finding contrasts with the finding from the first MyQuality study (SHINE 2014) which showed that empowerment as measured by FES scores increased after using the website (p=0.009). To explore this further, the baseline FES scores in both studies were compared to see if the current study participants had different levels of empowerment as a baseline. There is no statistically significant difference between the two groups (p=0.22), as illustrated in Fig 6.3. Figure 6.4 illustrates the range of baseline FES scores between the two groups.

Figure 6-3 Comparison of mean total baseline FES scores of current study participants (N=15) with those in 2014 MyQuality study (N=30)

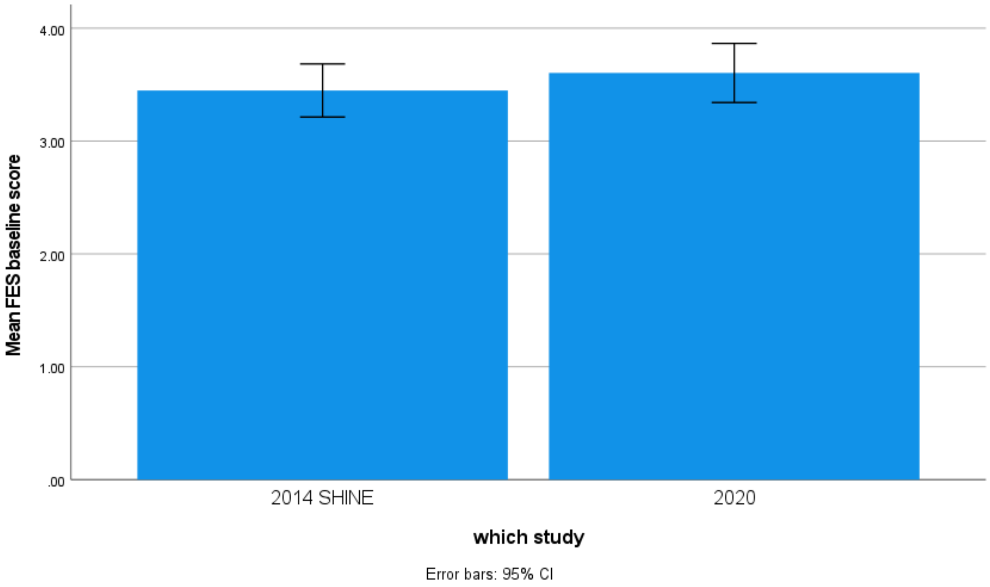
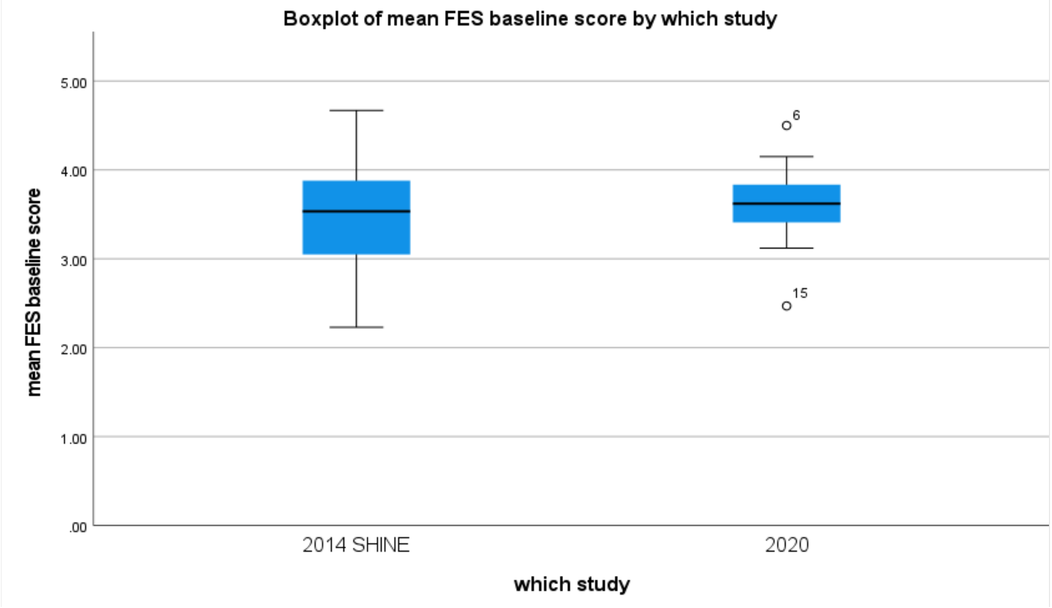
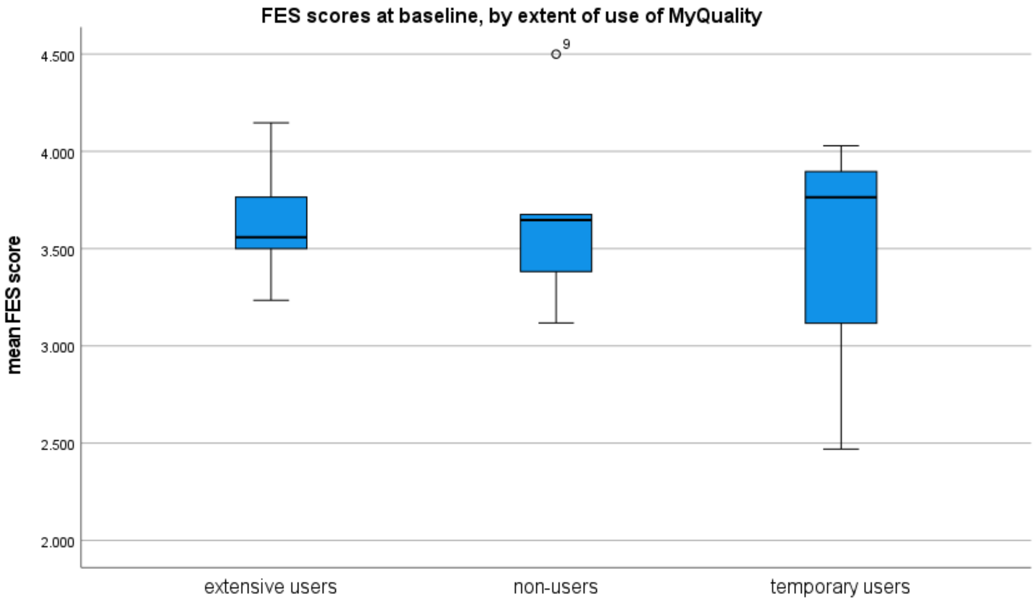


Figure 6-4 Boxplot of Mean FES scores in 2014 and 2020 studies



Although the results overall do not show a statistically significant relationship between FES scores and with MyQuality use, some of the FES baseline results included individuals who did not engage with MyQuality subsequently, raising the question of whether there were underlying differences between the group who did engage with the website and those who didn't. This could imply that feeling more empowered might represent an important contextual feature, encouraging website use. The 15 participants were categorised into those who used MyQuality extensively (7), in a limited fashion (3), or not at all (5). Their baseline FES scores, as illustrated in Fig 6-5, did not differ significantly (Pearson correlation -0.21, p=0.9).

Figure 6-5 Boxplot of FES scores at baseline, grouped by extent of use of MyQuality

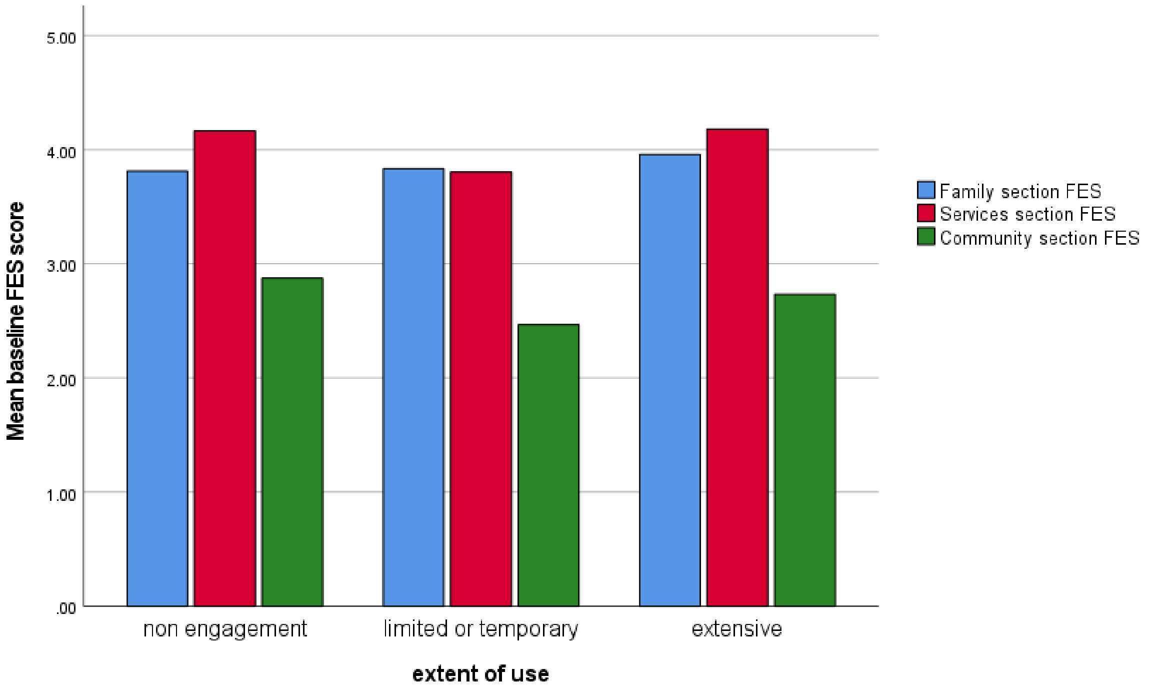


Scores for each FES domain are illustrated in Fig 6-6. There is no statistically significant difference when comparing the mean scores in any individual section of the FES, as shown in Table 6-5.

Table 6-5 FES domain baseline scores, by extent of use

		extent of use	mean score Family section FES	mean score Services section FES	mean score Community section FES
extent of use	Pearson Correlation	1	.100	.046	-.092
	Sig. (2-tailed)		.723	.875	.755
	N	15	15	14	14

Figure 6-6 Mean FES baseline scores for each domain, grouped by extent of MyQuality use



The structure of the FES allows investigation of the various components of empowerment that may become apparent within individual or family situations, during dealings with support services, and in wider interactions within the community in which a family lives. There were only six paired pre-and-post samples, which did not demonstrate any statistically significant differences in FES mean scores overall. However, when the group was divided into those families whose MyQuality data was viewed remotely by their HCPs (Katie, Sophie and Daniel) compared to those whose data was not shared or not regularly viewed (Adam, Daisy and Matthew), all three families with active engagement by HCPs increased their overall FES score after using MyQuality whereas those whose HCPs were less engaged showed minimal change or sometimes a small reduction in overall FES score. This data is illustrated in Fig 6-7 and Table 6-6. Despite the small numbers in this study, this subgroup analysis does demonstrate statistical significance in the “Family” and “Services” subsections of the FES with p values of 0.01 and 0.04 respectively, though not in the “Community” section, as shown in Table 6-7.

Figure 6-7 Baseline and Follow-up FES scores, by individual

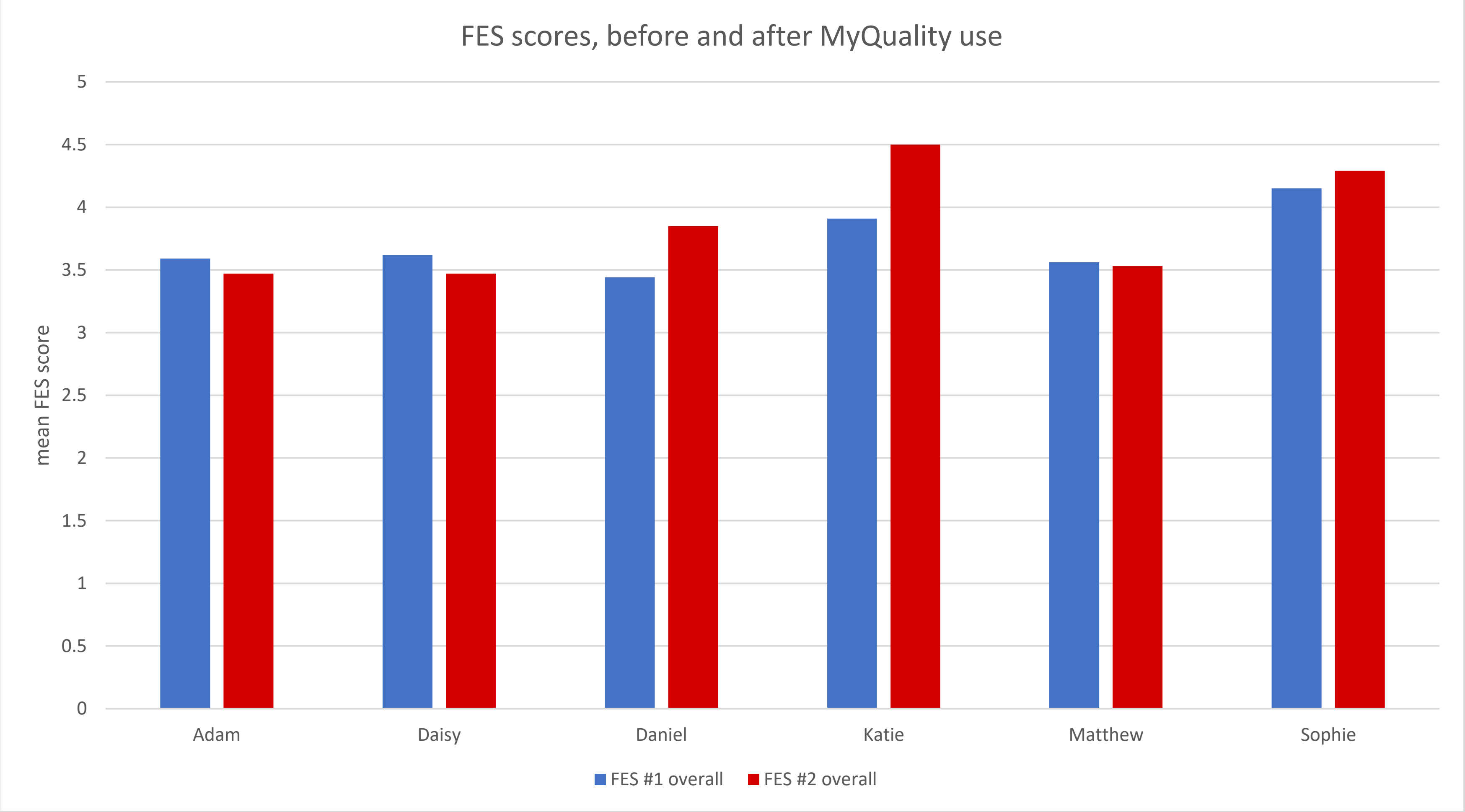
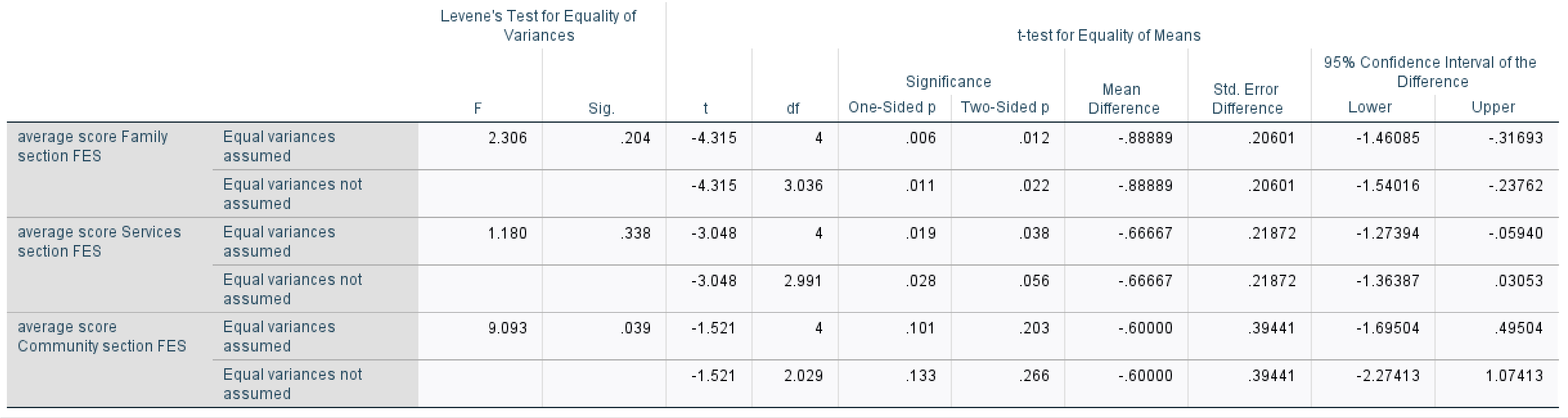


Table 6-6 FES domain scores for extensive users, before and after MyQuality use

	Section 1 Family baseline	Section 2 Services baseline	Section 3 Community baseline	Section 1 Family post MyQuality	Section 2 Services post MyQuality	Section 3 Community post MyQuality	Section 1 Family change post MyQuality	Section 2 Services change post MyQuality	Section 3 Community change post MyQuality
1	3.92	3.920	2.70	3.75	3.83	2.70	-.17	-.09	.00
2	3.83	4.000	2.90	3.42	4.10	2.80	-.41	.10	-.10
3	4.00	3.750	2.40	4.25	4.30	2.80	.25	.55	.40
4	3.92	4.100	3.70	4.33	5.00	4.10	.41	.90	.40
5	3.67	4.580	2.20	3.58	4.17	2.70	-.09	-.41	.50
6	4.75	4.670	2.80	4.83	4.75	3.10	.08	.08	.30
Total	6	6	6	6	6	6	6	6	6

Table 6-7 Changes in FES domain scores, by engagement or non-engagement of HCPs



		Levene's Test for Equality of Variances		t-test for Equality of Means							
						Significance				95% Confidence Interval of the Difference	
		F	Sig.	t	df	One-Sided p	Two-Sided p	Mean Difference	Std. Error Difference	Lower	Upper
average score Family section FES	Equal variances assumed	2.306	.204	-4.315	4	.006	.012	-.88889	.20601	-1.46085	-.31693
	Equal variances not assumed			-4.315	3.036	.011	.022	-.88889	.20601	-1.54016	-.23762
average score Services section FES	Equal variances assumed	1.180	.338	-3.048	4	.019	.038	-.66667	.21872	-1.27394	-.05940
	Equal variances not assumed			-3.048	2.991	.028	.056	-.66667	.21872	-1.36387	.03053
average score Community section FES	Equal variances assumed	9.093	.039	-1.521	4	.101	.203	-.60000	.39441	-1.69504	.49504
	Equal variances not assumed			-1.521	2.029	.133	.266	-.60000	.39441	-2.27413	1.07413

In summary, the empowerment score data suggest that it was not possible within this study to demonstrate that the use of the website is empowering for all families, nor that being empowered encourages website use by families. However, the extent of interest shown by HCPs in the outputs of MyQuality does appear to help families to feel empowered within the context of their daily family activities and when interacting with the services providers who support their children.

6.5 Healthcare provider participants

Of the ten teams approached to participate in this study (Table 6-8), six recruited patients and/or their parents as participants. These included three separate hospice teams covering most of the southwest of England, a specialist community nursing team providing children's palliative care for one county, a specialist multidisciplinary team for children's community palliative care for another county, and a community paediatric service (which included palliative care) covering a third county. Whilst the community services supported residents in discrete geographical patches, the hospice referrals and regional services covered all areas, so in some cases a child referred by a community team was already receiving shared care from hospice and/or regional hospital providers of specialist care. There was no attempt made to enrol general practitioners to this study as in many cases the children have open access to hospital services and relatively little contact with their GPs (Jarvis et al., 2020).

Representatives from all ten teams took part in introductory interviews to ascertain their motivation, concerns and practical issues concerning the use of MyQuality. These introductory interviews were not specifically designed to test or refine theories. Although many teams willingly engaged with the study, a number didn't try to recruit any patient participants for a variety of reasons, and thus failed to gain practical experience with MyQuality.

Table 6-8 HCP teams characteristics

Team	MyQuality use	comments
Hospice 1	3 participants identified, 2 recruited	Medical and nursing support for MyQuality use, infrastructure for regular checking and sharing responsibility in place, regular proactive contact role for patients in community.
Hospice 2	4 participants identified, 3 recruited	Medical and nursing support for MyQuality use, infrastructure for regular checking and sharing responsibility in place, regular proactive contact role for patients in community.
Hospice 3	5 participants identified, 2 recruited	Nursing support for MyQuality use, infrastructure for regular checking and sharing responsibility in place, regular proactive contact role for patients in community. Limited medical or senior management engagement.
Community team 1	3 participants identified, 2 recruited	Strong leadership support, culture of shared responsibility with others, primary carer role. Nurse-led service, integrating across primary/secondary/tertiary care.
Community team 2	3 participants identified, 3 recruited	Strong leadership support across disciplines, culture of shared responsibility with others in primary/secondary/tertiary care. Hospital outreach with front-line response role.
Community team 3	3 participants identified, 3 recruited	Strong leadership support across disciplines, culture of shared responsibility with others in primary/secondary/tertiary care. Hospital outreach with front-line response role.
Hospital team 1	0 participants recruited, but shared care with 3 pts recruited by others	Strongly support PCC in principle but concerned re resource implications and shared care communications. Tertiary advice role for in/outpatients, limited community input.
Hospital team 2	0 participants recruited, 0 shared care	Strongly support PCC in principle, but concurrent studies taking place, limited research resource.
Hospital team 3	0 participants recruited, 7 shared care	Strongly support PCC in principle, but concurrent research study taking place so it was not appropriate to recruit at this time.
Hospital team 4	0 participants recruited, 1 shared care	Concerns re raising expectations of families by using MyQuality. Medical and nursing lead felt that they had no patients that would fit the study criteria.

Five of the six teams who recruited participants contributed to follow-up interviews, the sixth responding by email and telephone instead as the families they recruited did not regularly use MyQuality subsequently. The follow-up interviews involved team members who had experience of using MyQuality individually or as part of their team's approach, and were specifically aimed at exploring, testing, refining or refuting theories about the impact of MyQuality on communication. The interview participants were often but not always the same individuals who participated in the introductory sessions, as with changes in staffing over time and the limitations of access due to coronavirus when the follow-up interviews were being conducted it was difficult to contact everyone. Quotes from the interviews with HCPs are presented in chapters 8 and 9.

During the interviews with staff members several potential barriers to MyQuality uptake were identified. Some were easily rectified, such as ensuring the provider organisations arranged for MyQuality to be a "permitted" rather than a blocked site on their internal networks. Others, such as linking MyQuality data to NHS electronic patient records, were not possible. Several HCPs requested further training materials to illustrate how to approach the analysis of patient-generated feedback, which were supplied and discussed with practitioners as needed. However, as each personal user could identify, define and describe the measures to reflect their own circumstances, it was impossible to provide standardised approaches to data analysis on graphs. For some HCPs this appeared to be quite disconcerting.

The concept that generated the most concern was the email alert system. Many of the front-line staff across all settings were wary of the potential for email alerts to overload their inboxes, demand their attention, and imply the continuous responsibility for responding to a child or family's concern when this might be inappropriate (such as circumstances where the recipient of the email alert was not the local first responder, or not the person on-call for emergencies within a team).

Attempts were made to contact members of the four teams who did not enrol any participants via telephone and email, and limited feedback was obtained. In two cases, managers or consultants leading the teams were actively involved in other research projects and although they supported the concept of MyQuality in principle they reported that they did not have adequate resourcing to contribute to further clinical trials. Both volunteered views that recognised the value of identifying patient priorities, understanding the patient's perspective, and the importance of effective collaborative discussions between patients and HCPs. Discussion with their team members at the introductory meetings had revealed different concerns, largely relating to the time needed to view patient data, the potential for MyQuality to identify unmet need and uncertainty regarding how to accommodate this into their existing workload, and how to manage patient expectation if they could not commit to viewing patient-generated data.

Another hospital team strongly endorsed the principles behind patient-centred care but had multiple practical concerns about the use of MyQuality with families on their caseload. Their issues frequently related to care co-ordination between the various local and community teams providing support to participating children. However, their single biggest concern was the potential for uncontrolled workload expansion, particularly if email alerts were set up with patients, or if other teams or agencies used MyQuality to divert work in their direction. Despite extensive email communication, it proved impossible to persuade the team to try to adopt MyQuality for even a limited number of their patients. Email and telephone conversations did shed some light on their reservations, and these insights have been included in the theory refinement process.

A further team showed reluctance at the introductory meeting, citing concerns about raising family expectations of response when there were no additional resources available to manage workload, and then stating their view that none of the children for whom they provided care would fit the study criteria. Their concerns were noted, but it was not possible to gain feedback about potential programme theories from that group.

6.5.1 HCPs and use of MyQuality website

Many of the HCPs with individual experience of seeing MyQuality outputs reported that this took place during home or clinic visits, where a parent produced a graph on paper or on their own electronic device, or when multiple practitioners shared a look at a computer screen, so it was not possible to glean information about HCP access to MyQuality data from looking at website activity statistics. Information about HCP interaction with the MyQuality website came instead from verbal reports from the HCP, or interviews with parents where they described HCP activity and evidence that they had responded to the information presented in the child's MyQuality data.

6.6 Chapter summary

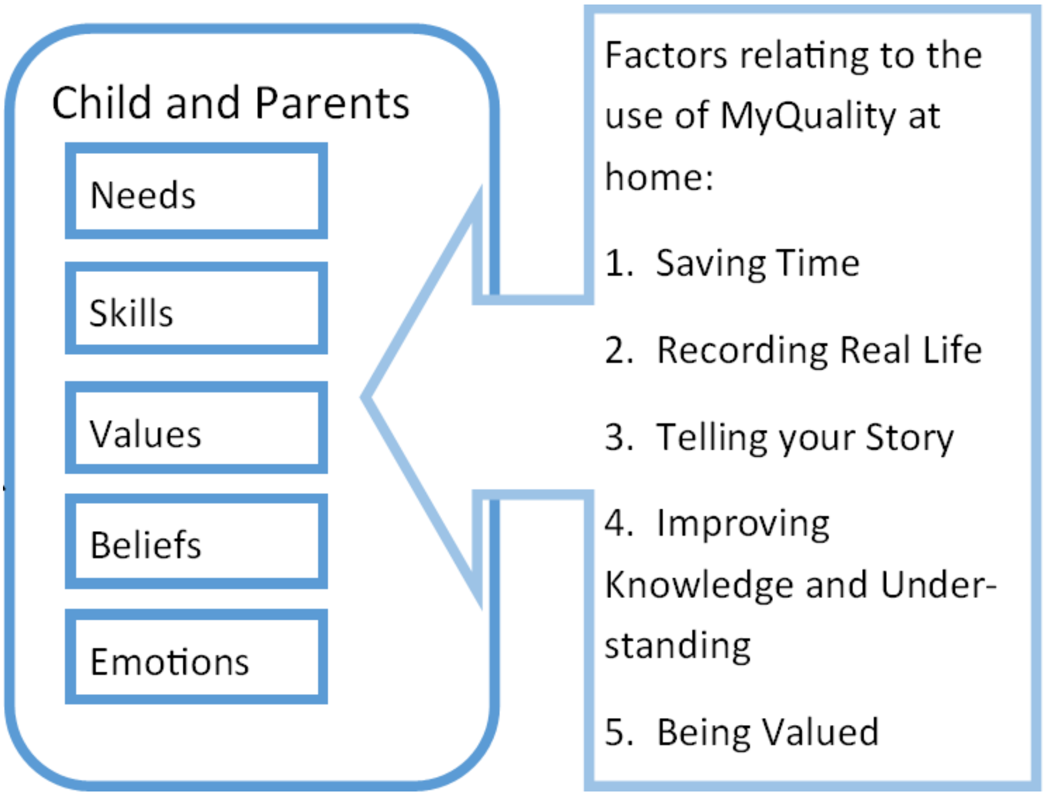
This chapter has described the study participants and study activity, the quantitative data gathered from the website, and analysis of the empowerment questionnaire. This data will contribute to the process of defining, testing and refining provisional programme theories about how MyQuality may support communication and a person-centred approach to care. The next three chapters will outline those programme theories in more detail, drawing on the evidence from the literature as outlined in Chapter 5, the findings reported here, and illustrated using insights from interviews from the participants described above.

7 Developing programme theories – supporting children and their parents at home

This section of the thesis reports the feedback from those who have used MyQuality. The quotes derive from the interviews about their experiences with MyQuality, and their responses to questioning about potential theories to explain their observations. The comments have been configured to illustrate detailed aspects of context, mechanisms or outcomes, building on the initial theory structure described in chapter 5.

Using the communications model of Feldman-Stewart & Brundage (2009), the theories have been considered in categories reflecting the patient and parents (this chapter), healthcare practitioners (chapter 8), and the communications process (chapter 9). Although presented in three sections, these theories connect with each other as part of the communications process as a whole (see fig 5.7), with details in this chapter outlined in Fig 7-1. The final section will bring these findings together to develop an overarching theory.

Figure 7-1 Overview of programme theories about supporting children and parents at home



This section considers the use of MyQuality by patients and their parents, reporting views in their own words wherever possible. The following programme theories were discussed with them to confirm, refute, or refine the details:

Table 7-1 Initial theories - supporting patients & parents at home

Initial Programme Theory	**Rival Theory**
1. Saving time, simplifying “intensive parenting”	Increasing “patient work”
2. Recording “real life”	Medicalisation of normal life
3. Telling your story, having your say	(-)
4. Improving knowledge and understanding	Unwelcomed evidence of deterioration

The final theory in the diagram, Being Valued, was merged with similar concepts in the section about “relationships” in chapter 9.

7.1 Programme theory 1: simplifying intensive parenting

Exploration of the literature and prior experience and discussions with parents led to the following initial programme theory:

> People who choose to use MyQuality are taking a proactive step to address the multiple tasks involved in caring for themselves or another person, including the time-consuming documentation of daily life. The ability to save time by using MyQuality can create more valuable time for more welcome activities, or for parents to spend with their child, and help to make life “as normal as possible”.
>
> An alternative theory was that the work involved in using MyQuality would dissuade parents from using it by consuming even more time.

7.1.1 Context: time pressures

All the patient/carer participants who took part in this study shared several common experiences relating to the nature of long-term conditions and living with uncertainty. The multitude of roles carried out by parents closely mirrored those identified by Woodgate et al. (2015) (see section 2.1.2) and all described elements of their daily routine that were defined by time constraints, such as the timings of feeds, medications or physiotherapy on a daily basis. The following discussion took place with Toby’s mother but was similar to several others.

> Interviewer: “when you say things have been good, you are still juggling a lot of – bi-pap* *(ventilator*) at night, and how many medications?”
> Toby’s mother: “13, 14 maybe.”
> Interviewer: “feeding regime?”
> Toby’s mother: “Yeah, every 2 hours”
> Interviewer: “And is he fully PEG* fed?”
> Toby’s mother: “yeah, completely, with overnight water. Feeds throughout the day. Overnight water. He's got a suprapubic catheter*.”
> Interviewer: “And you deal with all of that as well?”
> Toby’s mother: “Yeah, I used to intermittent catheterise him, but 2 or 3 years ago it was taking me up to 3 hours to catheterise him. Thankfully it was in the summer and I wasn't at work, but it was awful, and I was getting so stressed … We have to suction* him, I would say at least 25+ a day, at least that. You know once or twice you can get away with it, some nights I only need to do it 3 times, sometimes I could do it 9 times, it really varies.”
>
> *(medical terms with * are defined in the glossary)*

The rhythms of their lives were set by their roles as carers for their ill children, to a much greater extent than other constraints such as the demands of work or the length of school terms or holidays. This was met in a spirit of acceptance rather than resentment, as summed up by Arthur’s mother:

> “Yeah, full time job [laughs] not that I like to call my son a job, but it keeps me busy.”

7.1.2 Context: additional responsibilities

Woodgate et al. (2015) identified a multitude of other roles taken on by parents who become healthcare providers, case managers, detectives and advocates for their children. Every parent in this study mentioned an example of the difficulties they encountered to ensure that their child received the intended medications, interventions or support that had been recommended, and felt that as a parent this was a responsibility that fell ultimately on their shoulders. In this excerpt, Tom’s mother describes several:

> “We have loads of problems, like getting the correct dosages of medication (*case manager, pharmacist*). The paediatrician will increase them, but the letter won't get to the GP in time, and then they won't prescribe it because they've not got it in writing, but you've already increased the doses at home, so now you are running out.... all things like that really. And also, I think for [son], we're always playing a guessing game with him (*detective*). Like at Christmas he was unwell, it was really hard to track what was going on, but he has intermittent catheters because of his bladder function - we realised he had a urine infection. It’s keeping on track of all those subtle - because I do things at home, without even thinking, so I'll test his urine, do a set of obs (*healthcare provider*) ...”

The demands of parenting a child with multiple and/or complex needs were a constant pressure on the time and energy levels of parents. In addition to the tasks involved in parenting a child with complex needs, the documentation of those activities imposed further time constraints and organisational challenges. The process was described by Adam’s mother as:

> “it’s chaotic. Organised chaotic though. If somebody else were to come into our house and you gave them this they wouldn't know where to start. Me and my husband have got this now, like, military precision… for [son], his epilepsy is polymorphic, he's on a ketogenic diet, and it’s just trying to record everything in different places … We've got input from a learning disability nurse now … she said can you record this, and you've got sheets and sheets of paper, and if I do that for her, and stuff for his ketogenic diet for the dieticians, and then everybody else wants all these sheets of paper…”

Although each child and family’s situation differed in terms of clinical circumstances, all the parents participating in this study described their lives at home during their initial interviews, and the constraints of pressure of time and the additional responsibilities required to care for a child with complex needs were an important context when considering the use of MyQuality.

7.1.3 Mechanisms – convenience and organisation

MyQuality provides a simple interface for users to record their observations quickly and easily and store them safely. Most participants said they used MyQuality on their mobile phones or other portable devices. This resource, in the context of the busy lives described above, generated a range of responses from parents. They reported practical benefits such as getting organised, more efficient documentation of daily life, co-ordinating the information to reduce the duplication of effort required to share information with multiple healthcare professionals, or the convenience of a digital format, all of which saved time.

> Daisy’s father: “I've always tried to keep a diary of what's happened with [her] health, her weight, stuff like that, but I'm not disciplined enough to do it properly. So actually, MyQuality is one of those things that helps me be more organised.”
>
> Matthew’s mother: “It - it - kind of - motivates isn't the right word. [MyQuality]’s a way of reminding you to keep a record. It’s all very well having a diary and making a note in there of seizure activity or whatever, but if it’s like a daily thing that you know you've got to do, it’s a more efficient way of doing it I suppose.”
>
> Adam’s mother: “this is like heaven, it’s all in one place, I haven't got to keep an extra filing cabinet for my paperwork, it’s just there, all there… [record-keeping] gets very tedious, it kinda takes over my life, but then, this is just - every day, 2 minutes, done… I'll put it all on MyQuality, it records it all and I'll put notes in for everybody, and they can see it. I'm not going to record all this stuff in all sorts of different places.”
>
> Katie’s mother: “I can use it on the go, which I love. I mean I love my planner (*paper notebook*), but it’s not always with me, whereas this [OPENS MYQUALITY ON PHONE] - it’s just right there, it’s that technology thing isn’t it … so then I haven't forgotten [anything], I'm not going to sit down at the end of the night and go "right what happened today" cause it’s been a long day. It’s instant, and it’s there, and I just really like it.”

7.1.4 Outcomes – spending time wisely

Whilst many of the outcomes related to documentation of daily life became apparent during interactions with healthcare professionals (see chapter 9), other outcomes were identified that pertained more specifically to life at home. The immediate outcome for parents was the practical benefit of saving time, which could be put to other use. In several cases the documentation process served as a way to offload events and support personal coping mechanisms, as described here:

> Katie’s mother: “I think we ARE at the point where we need to medicalise everything with [child]... [MyQuality] helps. It does help…. it’s that way of getting it out, it’s not left inside. Putting it on the app, it’s out, it’s done, and it’s almost like you draw a line under it and start again tomorrow.”
>
> Adam’s mother: “I feel like when I've just done it (*entered data on MyQuality*) … I can offload information and my head's a bit freer then, I can cope with things. I can shut that box and move onto the next thing.”

The combination of saving time and improving parental capacity to cope could have downstream positive benefits for the child and parents alike, but this study was not designed to explore longer-term outcomes so these potential benefits cannot be demonstrated.

7.1.5 Refined Programme Theory

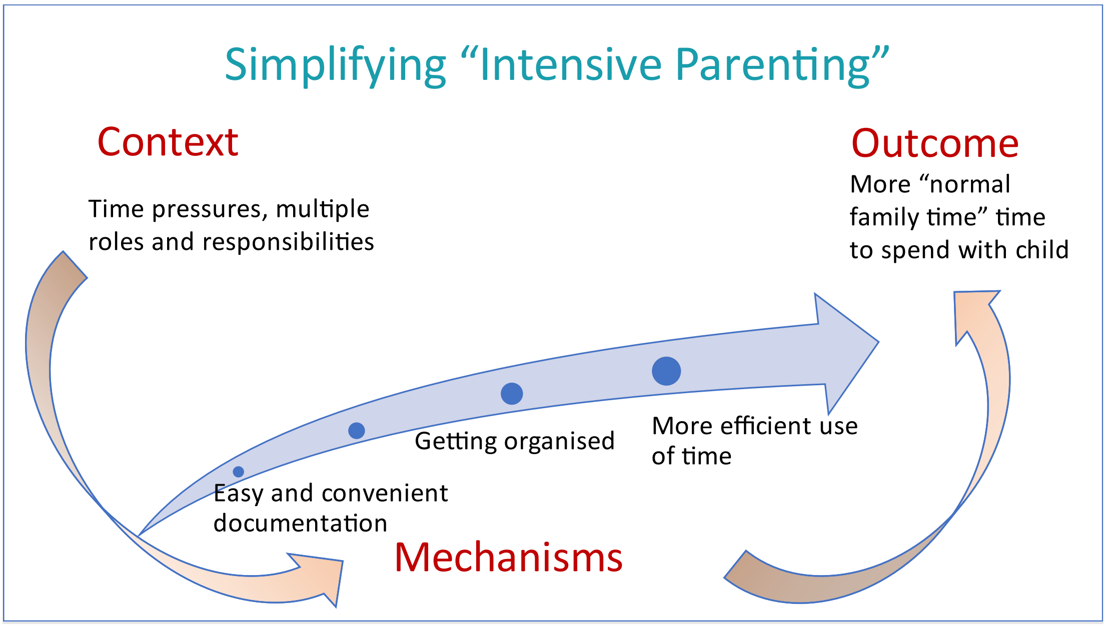
The attributes of MyQuality such as the simplicity and convenience of its use are similar to many other digital applications, but took on particular significance in the context of the dynamics of time for parents with a child with a life-limiting condition. During many of the home visits undertaken for interviews for this study, finding a convenient time was quite a challenge as parents juggled appointments, therapy sessions and a detailed daily regime of feeds and medications, such that many days were dominated by keeping one eye on the clock. The emphasis on time management accentuated the benefits of the resources provided by MyQuality to use time most efficiently. The longer-term context for parents included the prospect of a shortened lifespan for their child, not directly mentioned by most of the participants but an unspoken reality for families. This focus on time management, and the recognition of limited opportunities to enjoy time with their children as part of “normal family life”, was strongly endorsed by the parents in the PPI discussion.

During the process of theory testing and refinement a rival outcome was explored: the task of entering data on MyQuality might increase the level of patient work and add time pressure on parents of children with LLC, thus distracting them further from “normal family life”. This outcome was strongly refuted by the parents who engaged with it, who emphasised the efficient use of time. All of those who participated reported they felt very or fairly confident about the use of IT, which may be an important contextual factor in some cases where parents did not choose to participate, but it was impossible to explore that further in this study. Additional "patient work" or difficulties with computer literacy were not mentioned by study participants who did not engage with MyQuality, the explanations given relating to the challenge of developing a diary habit, and the unpredictable routine of life (through illness and hospital admissions, or holidays).

This PT was refined as follows:

> **Simplifying "intensive parenting"**: For parents supporting a child with a life-limiting condition, those who use MyQuality are taking a proactive step to address the multiple tasks involved in caring, including the time-consuming documentation of daily life (Context). The ability to save time (Mechanism) by using MyQuality can create valuable time for more welcome activities, for parents to spend with their child, and help to make family life "as normal as possible" (Outcome).

Figure 7-2 CMO 1 - Simplifying intensive parenting



7.2 Programme theory 2 – recording "real life"

The initial programme theory that emerged from literature reviews and feedback from the first MyQuality study was as follows:

> People who document daily life using MyQuality will create a real-time visual record of the good days (as well as the bad). This can help them to be accurate when there is a perception of deterioration, and act as an early warning of change to support ongoing vigilance which will facilitate timely and responsible symptom management.
>
> A related theory considered that recording real life would "medicalise" normal life, an unwanted outcome.

7.2.1 Context: uncertainty and unpredictability

Although all the children and young people in this study had a life-limiting condition where premature death was expected at some point, the illness trajectory often remained unclear. This unpredictability was a feature of the challenges of long-term prognosis, due at times to diagnostic uncertainty. Leo's mother's experience is typical of many:

> "They didn't expect it *(the metabolic condition*) to last this long. When he had that epilepsy when he was 3 1/2 months old, that was 24 hours fitting. (*They told me*) he will have midazolam, one midazolam, and he will have pills. That is daily. And then, that was only 7 months and he was *(diagnosed)* like that. And of course we were just told that he will die by *(the age of*) 2, but he didn't, he went 4, now he is 9, so..."

Even if a diagnosis had been established, for many rare conditions there was insufficient knowledge or experience to be able to predict likely events or timescales. In addition, these children and young people faced confounding factors such as the development of intercurrent complications, or new treatments.

> Sophie's mother: "Because, like with her condition, I mean you have that initial diagnosis, and if you read about what it is, you've got that. But the actual living with it is so different. Because you might have this - you know, a paragraph of "what it is". But that's NOT actually what it is. It's everything else that goes on, and most people when you speak to them, doctors, whoever, haven't even heard of it."

In the short-term, day-to-day life was also unpredictable as deterioration in the underlying progressive conditions was rarely linear, and often affected by intercurrent illness which resulted in temporary improvements or exacerbations of poor health. Parents in this study recognised that it could be difficult to recall all aspects of this variability over time:

> Charlotte’s mother: “And it is difficult to remember. Like I know last week was horrendous because she was poorly, and then I think - but is this normal? I feel like we've always got problems. So it would be good to have something to look back on and think, no, that day, it was a good day. I feel like I can't remember the good days, so when you have a period of a lot of bad days you think, did she ever have a good day, am I dreaming? Is this real?”

The importance of remembering the good days was mentioned by others, hoping for a more positive and holistic view of their child’s life:

> Sophie’s grandmother: “It’s so important to record the good stuff, not just the problems. To see the full Sophie, not just the difficult bits.”
>
> Toby’s mother: “The consultants see the condition, not the child. They don’t know him. They don’t see his quality of life.”

The challenges of living with uncertainty, both for the parents and HCPs, and the strong desire for parents to provide a true report of their child’s circumstances, combined to shape the way in which MyQuality was used in practice.

7.2.2 Mechanisms - personalisation

The unpredictability of life on a day-to-day basis, combined with the unique circumstances of each child in the study, underlined the importance of personalisation of MyQuality priorities to suit individual circumstances. MyQuality provides a resource to facilitate this using free text at multiple stages. The website has drop-down lists of commonly identified priorities for convenience, but also allowed individuals to “Make Your Own” using free text, or to edit individual issues to describe the nature of the parameter that can distinguish between routine or concerning exacerbation in health. These were used frequently, as outlined in section 6.3.2 (p 159). Examples included individuals who described chest infections using categories of oxygen saturation levels, seizures by duration and associated cyanosis or breath-holding, or descriptions of levels of distress by the types, volume and duration of crying or vocalisation. Many identified “normal for (child’s name)” as measures that would be considered worryingly abnormal in children without life-limiting conditions.

All the participants in this study who used MyQuality regularly personalised some aspects of the data they chose to record, either through defining their priorities in their own words, using written descriptors in addition to numerical values to describe the severity of the item in question, or by using the daily diary to document life at home as described in section 6.3.4 (p 161). Katie's mother described this process in relation to feeding her daughter, but in many cases this personalisation applied to multiple aspects of the child's health:

> Katie's mother: "it's around food. Because the child has done a complete u-turn, and now getting her to eat can be tricky…… she's either not hungry or she's ravenous, can't think of anything else (*hyperphagia**) … So I wanted to change the whole hyperphagia thing so that hyperphagia *(is*) at one end, but actually "getting her to eat is a bit of a bugger" (*is*) at the other end (*of the numerical scale*)."
>
> Arthur's mother: "I liked that it (*MyQuality*) could be really specific to [son] as well, so I can make it fit [son], 'cause nothing fits [son], so it has to be something that can be made to fit him."

The resource provided by MyQuality (the ability to personalise data collection) generated positive responses from parents who were encouraged to engage with data recording because MyQuality supported the collection of sensitive, meaningful, relevant observations about their children's health issues.

7.2.3 Outcome – a balanced overview

The ability to record "real life" provided aspects of psychological support for parents. Several described the need to recall good times as well as bad, noting that memories of difficult days could become dominant over good days, and needing to keep a balanced perspective:

> Willow's mother: "Even if (MyQuality) is just for us, just to say, "my God, she was sick 16 times in 3 days there", and then we haven't had a single sick, (*turns to partner*) because we tend to catastrophise don't we… And then when she hasn't been sick for ages, we forget that she's ever been sick and it feels amazing, and then she's suddenly sick again… So yeah, it'll be interesting to see if maybe it's not as bad as I think it is."

Katie's mother consciously managed the psychological demands through the process of recording daily events on MyQuality:

> "it's almost - not a release, but you know putting it down, writing it down (*on MyQuality*), especially when I do it at the end of the day it's like, that day is done. That was a bad day, everyone is still here, we're all still fine, we'll start again tomorrow……. several times I've gone through (*the diary notes*) reading, and it's like oh I remember that, but actually it wasn't that bad compared to what we have had."

Adam's mother reflected on her role as vigilant observer of her son's health, reflecting on when she stopped recording daily life for a period:

> "I dropped it (*stopped using MyQuality*) for a while, but I don't know why …. I wish now I'd gone back and kept at it, as at least then you know how long it was stable for. Otherwise, it's stable and then gone off the scale, and there's no lead up to it, and it could have slowly been building without you noticing it, and I wish now I'd stuck with it. My lesson learned!"

7.2.4 Refined programme theory

The unpredictable nature of life for those with life-limiting conditions meant that the resources provided by MyQuality in terms of meaningful, personal recordings and a quick visual way to review recorded entries were welcomed by parents who sought a more balanced view of change over time. This process supported them in their role as guardians of their child's health and could support their psychological resilience over time. Longer- term outcomes, such as timely and responsible symptom management that might result from this more accurate documentation, could not be tested as part of this study and warrant further exploration. The importance of having "balanced" memories, including good times as well as bad, was strongly supported by the parents in the PPI session when discussing this programme theory.

A possible adverse outcome was raised by the literature on the "quantified self" movement (section 5.2.2.2) and by healthcare professionals during their interviews for this study, where the emphasis on recording real life could medicalise aspects of life unnecessarily. This could lead to a distorted focus on issues which were normally variable or unpredictable and increase anxiety as a result. This concept was explored and strongly refuted by parents in this study, whose children had such complex needs that life was dominated by the need to manage those needs effectively, whether or not MyQuality was used for documentation:

> George’s mother: “I think when you've got a really complex child, you DO monitor them hour by hour.”
>
> Sophie’s mother: “I literally do watch her like a hawk, all the time.

However, in this study, many parents were highly selective in what they chose to record on MyQuality and why, reflecting that recording everything was not “a healthy thing to be doing”.

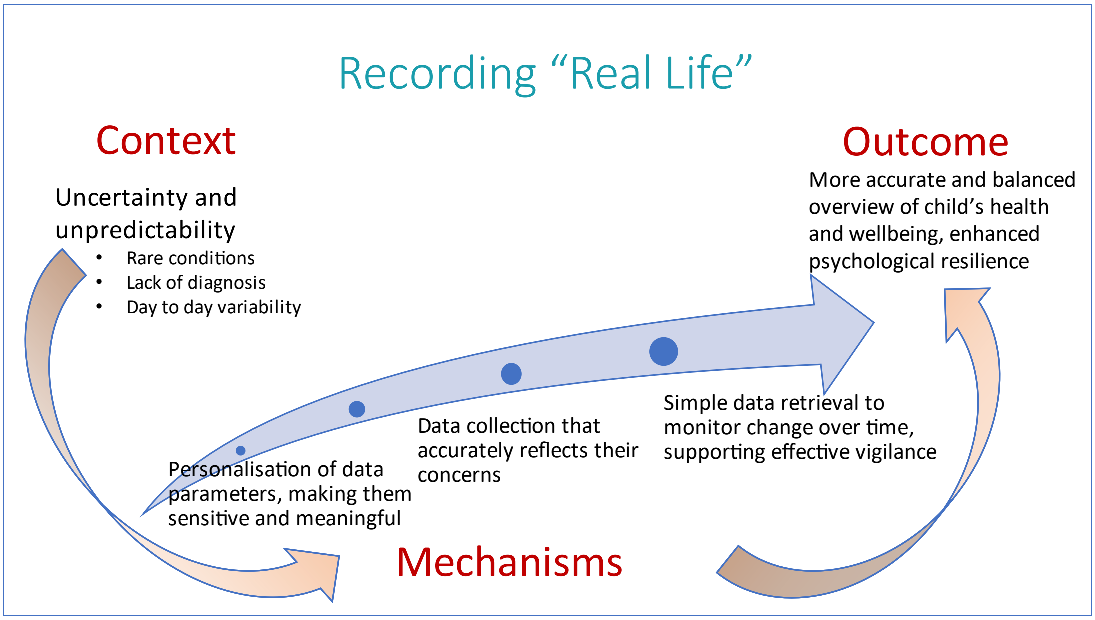
> Daniel’s mother: “you've got to get on with the process of living, you can't be analysing the whole time.”
>
> Matthew’s mother: “I'd already been through the experience of NICU and all of the ups and downs and how a lot happens in a very short space of time…. Yes, it’s important to record certain things, but also - I know the doctors for example say "I noticed this, let’s test for this, or I noticed that, let’s test for that" and then it comes to nothing. And so I try not to latch on too much to what one person might say and record it and think "Oh this could be it". That emotional roller-coaster was not helpful.”

The concerns about the medicalisation of normal life were mitigated by the ability of parents to choose what aspects of life to record on MyQuality, and when to record them. Matthew’s mother used MyQuality regularly as part of this study but said that she would stop at the end of the project as he was currently well and stable, but would restart should he become unwell when she found monitoring of more value. This approach sums up the judicious use of MyQuality as parents exercised their agency, rather than a desire to medicalise life.

The Programme theory was refined as follows:

> **Recording “Real Life”**: Parents of children with LLC who choose to document aspects of the variability of daily life (Context) using personalised, detailed descriptions on MyQuality generate a real-time visual record of the good days (as well as the bad) (Mechanism). This record can help them to be accurate when there is a perception of deterioration, and act as an early warning of change to support ongoing vigilance (Outcome), whilst the process of daily recording can support psychological resilience.

Figure 7-3 CMO 2 – Recording "Real Life"



7.3 Programme theory 3 – telling your story, having your say

The initial PT, derived from the first MyQuality study and literature about the role of narrative in healthcare, was as follows:

> The process of documenting events on MyQuality involves people reflecting on their day. This process of contemplation can help to organise memories, thoughts and feelings, and make sense of daily events. This can inspire people to be proactive on behalf of their needs, or their family's needs.

7.3.1 Context: role as isolated primary carers

Parent participants in this study saw themselves as the primary caregivers for their children, being in the front line to protect their child's wellbeing regardless of their legal role as biological parents, foster parents, stepparents or grandparents. Their unique perspective illustrates the child's day-to-day life and contains insights not apparent in other settings. Sharing this was important to them in their role as responsible parents, seeking support for their child and for themselves:

> Leo's mother: "Many times (*the things*) that I see, they don't see."
>
> Katie's mother: "I think it's important that other people know (what) does go on, and it's not just the mum sat in clinic saying, "Oh it's been really bad at home today", but actually, you know …. it's not good. [LAUGHS]. And I

> want people to know that! ….. I needed those [details] down (*on MyQuality diary page*) and for other people, professionals, to know that this is actually what we are living with daily with this child. …. I need people to understand how difficult it can be."

Part of this parental role was to be the voice for their child, which could be difficult in high-stress situations when dealing with healthcare personnel. Parents voiced a strong desire to have their expertise in the care of their child recognised by HCPs:

> Matthew's grandmother: (*directed at her daughter*) "You obviously know your child much better than they do, you know what's normal for them and what's not, and they (*HCPs*) have to accept that."
>
> Toby's mother: "I don't always feel confident with healthcare professionals. I want to say "I'm [son's] mum, I'm there, at home, at night." I don't want to be confrontational but "this is our angle on things" needs to be said. I know my child."

7.3.2 Context: power imbalances in healthcare

In an ideal world HCPs would respect parental expertise, but in practice it can be difficult for a parent to navigate the language, pace, systems and organisations in healthcare. Every parent interviewed as part of this study mentioned the limitations of their knowledge compared to HCPs. Daisy's father sums up the experience of many:

> "I imagine there's a lot of parents or patients who feel nervous and inferior in a face-to-face situation... And it can be daunting. Because you don't know, you aren't the expert. They are the experts. They know what they're talking about."

Some parents refuted this concept of expertise:

> Adam's mother, discussing a community nurse: "She knows EVERYTHING, um and yeah, I just think, you haven't got a clue…. she's very much "I've been to college, I've done this, I've done that, I know what I'm doing" and then you present something to her and she's like "Oh, well, that isn't what I've learned" and like no, you are not going to learn everything from a textbook. And this is my real life, my 24/7."

The feeling of being on the back foot, lacking expertise in healthcare matters, could lead to resentment and a lack of trust.

> Daisy’s father: “There are just so many of them (*professionals*) involved in [child]'s life, and they change. … They do not consider me – it’s not just healthcare, it’s education as well, social services …. parents are not part of that circle. And they never will be will they. They are outside, they are humoured, by and large… If I were a professional some people would listen to me, straight away. But because I'm not a professional, that's the difference. So at a meeting, where there's a dozen professionals and me, you know, my voice - they go away and have another meeting or discussion on the phone or via email or something that I'm not part of, very often, put it that way. That happens.”

7.3.3. Context - history of conflict

Misunderstandings, frustrations and disagreements with service providers are frequently reported by parents of children with LLC (Whiting, 2013; Parsons & Darlington, 2021). Many of the participants in this study reported disappointments, frustrations or conflict during the interviews, the information being freely volunteered as it was not specifically sought during our discussions. Examples included delays in diagnosis, repeated failed applications for support such as DLA funding or additional educational provision, and poor communication where parents were the last to be informed about critical information. A history of feeling overlooked, unheard, ignored, or challenged highlighted the need for parents to amplify the voice of their child and defend their perspectives.

> Matthew’s mother: “I have come across a number of doctors who I felt totally dismissed by. And that's just not helpful and leaves you as a parent feeling really cross and upset, and also at a loss about what to think and feel and - it adds to the worry… that’s not helpful.”
>
> Daisy’s father: “A number of times I've been in hospital or somewhere or meetings wherever, and the professionals, often nurses but not only nurses, will ask you what you think so you start talking. And you can see their eyes start to glaze over. And they listen and then when they finish, they say "yup we'll take that into consideration after all you know best and we must listen to what you think", and then they do something completely different. They've obviously been told that the parent knows the child best, we must listen to the parent... and some of them are obviously only going through the motions.”

The quotes above illustrated an aspect of the context in which MyQuality aims to support children and their parents. Taking on the day-to-day responsibility for a child with complex needs when professionals could be variably supportive, trusted or even confrontational, meant that the parental role of spokesperson and advocate for their child could at times be more difficult than anticipated.

7.3.4 Mechanism – amplifying the parental voice, controlling the narrative

The role of parents as primary carers, often in the home with limited professional support for much of the time, meant that they had to quickly learn to recognise what was normal for their child and act as the lookout for signs of illness. There is no training to be a parent of a child with LLC, and a lack of confidence in their own abilities could be exacerbated by perceptions of professional expertise. MyQuality produces a resource to support parents to advocate for their children by providing written records of events in the home to demonstrate more clearly what was normal or abnormal for their child's specific circumstances.

> Adam's mother: "when we've had issues (*with seizure management*) in the past, like with our community nurse when we started out, there was no correlation. Like she'd say, "well surely seizures and sleep are correlated", and I could actually say "well actually no they're not, because he's been sleeping really well and he's still having seizures" … So I'd have to get MyQuality out and go "Look, this is what's going on"… I think MyQuality is a good setup to back you up and say - here you go" [PICKS UP GRAPH AND PUTS IT FIRMLY ON THE TABLE].

The ability to personalise the key parameters to be monitored, and the daily diary function, allowed parents to be highly specific about the detail they felt was required to ensure that HCPs really understood the message they were trying to send. Controlling the narrative was clearly important to many of them.

> Daniel's mother: "I think the fact - the way it's set up is we have got oversight of where the information is going, so that control is with us, so we've got to allow others to look at it. Whether they choose to pick it up is

> still their choice, but the control remains here rather than somewhere else. So whether the alerts go, and whether they've got access in the first place…"
> INTERVIEWER: So that control bit is quite key, is it?
> Daniel's mother: "Yes, I think so, I think that's why we enrolled actually."

> Katie's mother: "I think that they should know me well enough to know where I'm coming from with the things I write (*on MyQuality*), and that they would feel comfortable saying "we don't understand, what do you mean"…. I've even started putting emojis in it, to express like "No vomit, YES!". I think that shows how comfortable I am with it. I think it's that - you know, I'm comfortable with them, and after 6 years I should think they are comfortable enough with me, and reading this should be like they are literally hearing my voice in their heads when they read it."

Parents described the reassurance they felt that the important messages were available to be read, regardless of distractions, thereby ensuring that their story could be heard by HCPs:

> Katie's mother: "she hasn't just got leukaemia or hasn't just got something where you can set - a set plan. So this (*MyQuality*) for her is perfect. And I think it's vital to get the information across. Because quite often they go "any other questions?" and even with my list I'm saying "no" [LAUGHS]. No, not at the minute. You are just in the moment, trying to sort out your child who is chatting, and there's a lot going on, whereas this - I know it's down, if they can give 5 minutes to read it, it has everything they need to know."

> Daisy's father, explaining why he added diary notes: "(*the MyQuality graphs*) are a record. Behind the graphs there is an explanation. Sometimes there's something simple or obvious, very often it's not, or it doesn't seem to be obvious. So I just tried to put a bit of explanation in."

The resource provided by MyQuality in the form of a written record acted to amplify the voice of parents, re-iterating their observations by using documentation. This process encouraged reflection to support the parental narrative of events and helped parents to communicate more effectively with HCPs.

7.3.5 Outcome – confidence

The use of the MyQuality data gave parents a sense of confidence in discussions where previously they might not have been spoken out.

> Adam’s mother: “it’s given me more empowerment and more confidence to go to clinic and confront people, whereas before I was "I think this, I think it’s getting worse (*said in a small voice*) …. Now because you can physically see it on the lines (*on the graph*), and it gives me that confidence to say actually for the last 3 months, this is getting worse or this has improved. So yeah, I think it (*MyQuality*) has empowered me and given me confidence, rather than going in and saying, "oh they're professionals, they KNOW and I don't know anything". Now I can say "I can see this is changing and I need help with this or that now".

The sense that parents, rather than HCPs, could control the dialogue in clinical encounters was articulated by Sophie’s mother:

> “I actually changed the markers (*descriptive free text on MyQuality*) for the - each individual priority thing. ... I suppose to make a bit more sense, so it works for her a bit better. I think it’s - so other people can see more exactly what I'm trying to get at. And then I suppose also the satisfaction that I feel when I've written it down exactly how I want it to come across.”

This sense of satisfaction translated into confidence and assertion when speaking to HCPs:

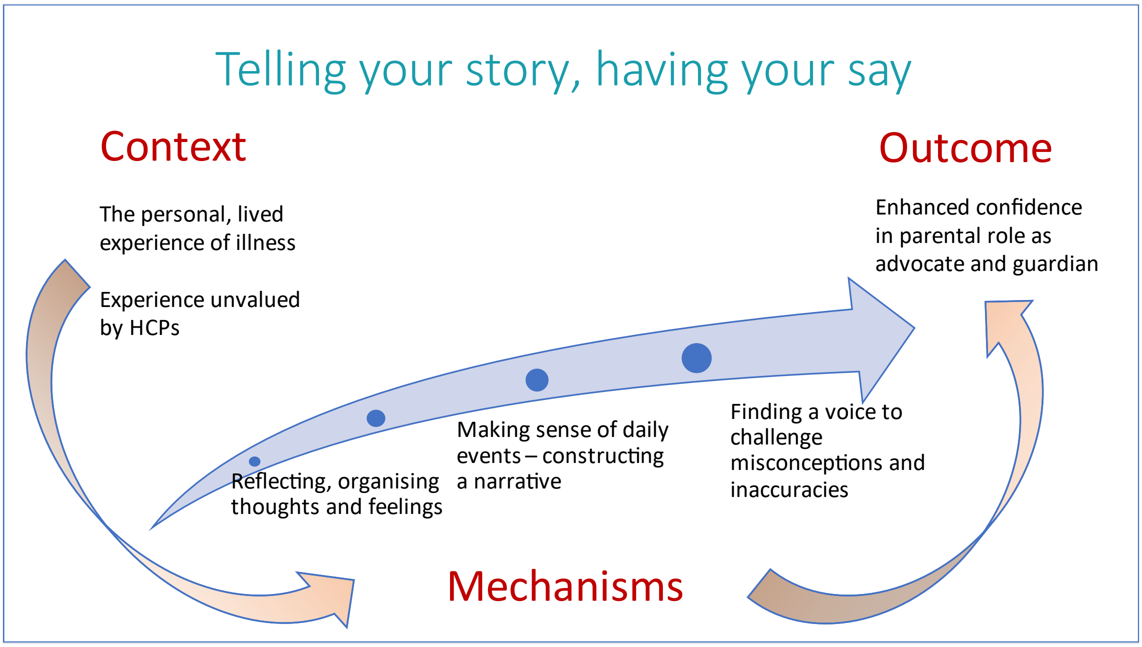
> Sophie’s mother: “they know that'd I'd do everything in my power for (daughter)… I'm not scared to say if I don't like something, or if something is not right. Basically, that is my job [to fight her corner]. I think they know that I know what I'm talking about a lot of the time.”

7.3.6 Refined Programme Theory

Parents caring for a child with LLC developed expertise about their normal daily lives that they did not feel was always recognised or respected within healthcare encounters. The power imbalances and frequent frustrations or conflicts with statutory agencies meant that parents felt strongly that they needed to be a voice for their child. Many recognised that in order to support their ill child, they must also support themselves by reflecting on events and coming to terms with their role, their decisions and their contribution to their child’s wellbeing, an empowering process. The therapeutic process of “telling their story” not only educated others about their situation, it allowed individuals to affirm to themselves that they were doing their best, thus enhancing their confidence as advocates and guardians. The programme theory was refined as follows:

> **Telling your story, having your say**: Parents of children living with LLC have valuable, personal knowledge of the lived experience which can contribute to their child's wellbeing (context). When they document daily life using MyQuality are reflecting on their lives and creating a narrative of change over time (Mechanism). This process assists them in making sense of current events and empowers them to be proactive on behalf of their child and family needs (Outcome).

Figure 7-4 CMO 3 - telling your story



7.4 Programme theory 4 – improving knowledge and understanding

The initial PT, derived from the first MyQuality study and literature about the outcome measurement in healthcare, was as follows:

> People who view the graphs generated by MyQuality can explore patterns in their observations, looking for potential causes and effects of any change, and develop a greater understanding of their/their child's symptoms and behaviour. This can reduce a sense of uncertainty or helplessness, and support resilience and self-confidence in the face of ongoing illness.

A related rough programme theory, also voiced in the initial MyQuality study, was that parents would not wish to visualise the deteriorating health of their child, as follows:

> MyQuality data that shows worrying results, or the lack of an expected pattern, may increase parental anxiety and undermine their resilience.

7.4.1 Context: complex needs, rare conditions

All the patient participants in this study had conditions where medical problems affected multiple organ systems which led to an array of life-threatening or life-limiting complications. Many of these were rare conditions, making it difficult for patients, parents or healthcare professionals to rely on the previous experience or access adequate expertise on disease trajectory or evidence-based best management principles. The recognition of clinical complexity and a desire for knowledge to understand what was happening and predict what might come next was articulated by all the parents taking part in this study and was the most common motivating factor prompting them to consider using MyQuality.

> Sophie's mother: "yes there are a lot of complex cases out there with different types (of her metabolic condition), but she REALLY is complex, in a lot of different ways."
>
> Leo's mother, asked about motivation for using MyQuality: "For me, it's really to know what's going on with him."
>
> Daisy's father: "Once I looked at it (*MyQuality*) I thought yeah that sounds like a really good idea. Measuring all the different aspects of what's going on with her health and her condition at any one point in time … I soon realised that one condition affected the other conditions, and vice versa, so it wasn't the case of just going to see this specialist about this problem over here, and a different specialist about this problem there and so on and everything would get better. It doesn't work like that. When one of her conditions was bad it made the other things worse as well and vice versa. And none of those specialists in those areas were interested in the other areas."

In many cases patients and their parents were learning about the condition alongside members of the healthcare team. The desire for improved understanding of complex symptom management was to support healthcare management in conjunction with professionals, rather than purely for their own reassurance.

> Daniel's mother: "It was just to try and monitor seizures and dystonia. So it's just really to see how - if there was a pattern, and to monitor it completely. I think we thought that if the seizures were bad then the dystonia wasn't usually so bad, and vice versa. But that was just theoretical, we thought if we could monitor it (*on MyQuality*) we might be able to see."
>
> Matthew's mother: "One of the things that's difficult to keep track of is seizure activity, and that would be really helpful when I see his consultant. Particularly when he's starting a new med, or when the dose of a med has changed, when they kind of like tweak things, to see if something is really helping or not."

7.4.2 Context: Parental responsibility and uncertainty

Raising a child with complex medical needs represents a significant disruption in the initial narratives of most families' lives. Parents are legally responsible for the safe upbringing of their children. When dealing with complex and uncontrollable medical issues, this responsibility could sit heavily on parental shoulders. This became apparent particularly when they did not feel confident in their own abilities:

> Adam's mother: "It's a bit worrying, like you've got this special needs child and everyone's just going "it's fine, you're doing a great job" and I'm just like "I don't know what I'm doing!" [LAUGHS] so from that point of view it's a bit worrying, but I don't know...."
>
> Daisy's father: "There are so many variables with [child]'s health issues, that it's very, very difficult to see what is affecting what and why some things are happening. I don't know, I'm not an expert in any one of them, let alone all of those areas, obviously I'm just a non-medical person, I don't know anything ... [PAUSE] The hardest thing is not knowing – she is so trusting of me, and I could be getting it wrong."

When a child was not able to communicate their needs or the significance of observed changes were unknown, parents felt a need for greater knowledge and understanding in order to make sense of daily life.

> Daniel’s father: “I don't know if it’s a control thing, or just our own duty of care actually because (son)'s medication base is - 15, 16 different drugs or combinations thereof, probably more like 20 combinations thereof with some of them used for more than one thing, so we have got a spreadsheet.”
>
> Katie’s mother: “I’m a little bit of a control freak so this is perfect. I like to control everything.”

References to the need for a sense of order and establishing some control over the unpredictable nature of daily life peppered many of the interviews with parents.

7.4.3 Context: – advanced notice of ongoing change

Parents often took on roles of heightened vigilance with a responsibility to monitor change as an early warning of problems, or to indicate response to interventions.

> Sophie’s mother: “The whole chest and respiratory thing is so new to us… I know she's been poorly, and I know she's got (*underlying*) breathing difficulties, it’s trying to differentiate what is (*significant*) breathing difficulties and what's not. You're constantly learning, there's new things that crop up all the time…. When you've got that and you've got all the other things to look out for, and it feels like I'm an intensive care doctor all the time, trying to pinpoint why is she grumbling.”

MyQuality was designed for use by families whose children had complex needs arising from rare conditions, where the parents took on the primary responsibility for them despite the unpredictability of day-to-day events. In this context, astute observation could provide vital information to prompt intervention, and understanding the implications of subtle signs of change was crucial.

7.4.4 Mechanism: – a picture tells a story

The challenge of navigating a world of uncertainty by parents unprepared for medical complexity meant that parents were keen to use all available resources to educate themselves about their child’s current health status and anticipate problems as early as possible. MyQuality provided a resource to do this as a display of graphed data which allowed users to explore trends over time and postulate correlations between observations. This helped the process of understanding.

> Adam’s mother: “it’s just - the charts more than anything, just to see if there is any correlation ‘cause you can't really see, when you're writing in a diary, any correlation without reading through all of it, whereas on MyQuality there's the charts and it’s great. It's just - you can take away certain lines and see what's tallying and what isn't, so yeah, it’s really handy to have it.”
>
> Katie’s mother: “just look at it (*points to MyQuality graphic display*) – I’m such a visual learner.”

This ability to use the graphic display provided valuable reassurance to parents.

> Katie’s mother, discussing her daughter’s graph, and side effects from recent medication change: “she's complicated, and I kind of need to just get it all out. Trying to find the patterns…. sometimes everyone needs to know that they are not going mad… And sometimes I notice things and everyone is saying "what are you on about". But it ties in, and trust me it makes sense.”
>
> Adam’s mother: “a bit of relief that I'm not going crazy. I'm seeing, right in front of me (*looking at MyQuality graph*), what is fluctuating and what is steady.”

7.4.5 Outcome: learning through experience

The improved understanding of their child’s health status had both practical and psychological benefits for parents as they supported their children at home.

> Adam’s mother: “even when he's unpredictable, it might be when I put it all on MyQuality and get the graphs up, there might be something, and you go, ah, actually that's why it’s like it is. So you think how am I going to change this, how am I going to change this pattern.”

This was reported as helpful even if anticipated correlations were not illustrated on the MyQuality graphs. Confirmation of the lack of correlation could be helpful as parents stopped worrying about unnecessary concerns, and accepted elements of uncertainty more readily.

> Katie’s mother: “I think I was a bit surprised looking back that there were not more patterns (*on MyQuality graphs*), I thought we might have some patterns, and actually we don't, [child] is just very complicated.”
>
> Adam’s mother, discussing MyQuality graphs: “It’s really odd how things that I thought would tally didn't, and yet other things that I wouldn't have

> associated with each other have correlated… but it's reassuring, once you get your head round it… you relax more about it and think, it really isn't the end of the world. It's quite reassuring to look at it and think, yeah, actually, its ok."

7.4.6 Rival Theory: unwelcome evidence of deterioration

For children with progressive conditions there was the potential that the graph could show a deterioration in a child's health status, paraphrased by one hospice user as "you wouldn't want to plot your daughter's demise". In this context, seeing visual confirmation on a graph that issues were getting worse could lead to parental anxiety, a sense of medical futility, and disengagement with MyQuality use. However, discussion with parents did not confirm this theory. Seeing worsening features on a graph did not appear to be an unwelcome event but rather a useful warning system to support parents as vigilant observers for their children.

> Daisy's father: "The main benefit (*of recording on MyQuality*) is as an alarm system if something is going horribly wrong. So you'd want to monitor it even more closely if things were deteriorating."
>
> Katie's mother, responding to a question about how she reacted to seeing high scores on the graph: "It's going to sound a bit weird, but it's almost - not a release … but I do think it's a little bit of acceptance – it's accepting that she is going to have pain daily, it does suck, we can't change it, but the way we manage it and deal with her when she is in pain, is better."
>
> Sophie's mother: "there's things that are calm now but in the past they would have been like this [POINTS HIGH], and it doesn't really concern me as such seeing it like that (*on the graph*). I think I already know. I think if there's something I'm already worried about it's in my head to talk to (HCPs) about it anyway."

7.4.6 Refined Programme Theory

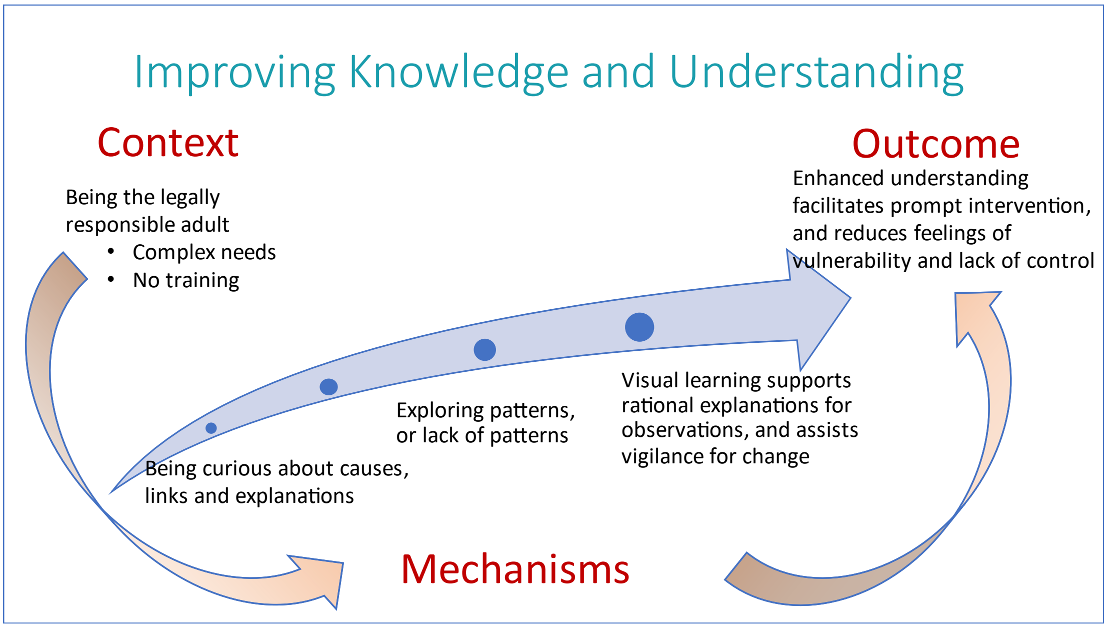
The MyQuality program's ability to convert numerical data entered by personal users into a graphic display that allowed simple interrogation of trends and potential correlations provided a resource to parents to improve their understanding of their child's health status, and to predict patterns which might help to anticipate future complications. This supported them in their roles as guardians of their children's wellbeing.

A rival theory asserted that seeing worrying information on a graph might cause distress to parents. This was strongly refuted by participants in this study who felt that they had a responsibility to be alert to change in order to anticipate problems and proactively seek help.

The final programme theory was refined as follows:

> **Improving knowledge and understanding**: Patients with LLC or their parents live with complex, unpredictable medical needs for which they are often unprepared and lacking in confidence. They carry a burden of responsibility to manage these needs and to be alert for signs of deterioration in order to seek appropriate help in good time (Context). Parents who interrogate the graphic display generated by regular inputting of data into MyQuality can explore patterns in their observations, looking for potential causes and effects of any change, and develop a greater understanding of their/their child's symptoms and behaviour (Mechanism). This can reduce a sense of helplessness and support prompt intervention, or acceptance of reality (Outcome), contributing to resilience for them as carers.

Figure 7-5 CMO 4 - Improving knowledge and understanding



7.5 Supporting Children and Parents at home – overview and consolidation

The CMOc's listed above illustrate a range of the needs, skills, values, beliefs and emotions alluded to by Feldman-Stewart & Brundage (2009) in their work about communication. The parents interviewed for this study described in great detail the roles, responsibilities and pressures of their daily lives, and how they found MyQuality to make a useful contribution to managing these.

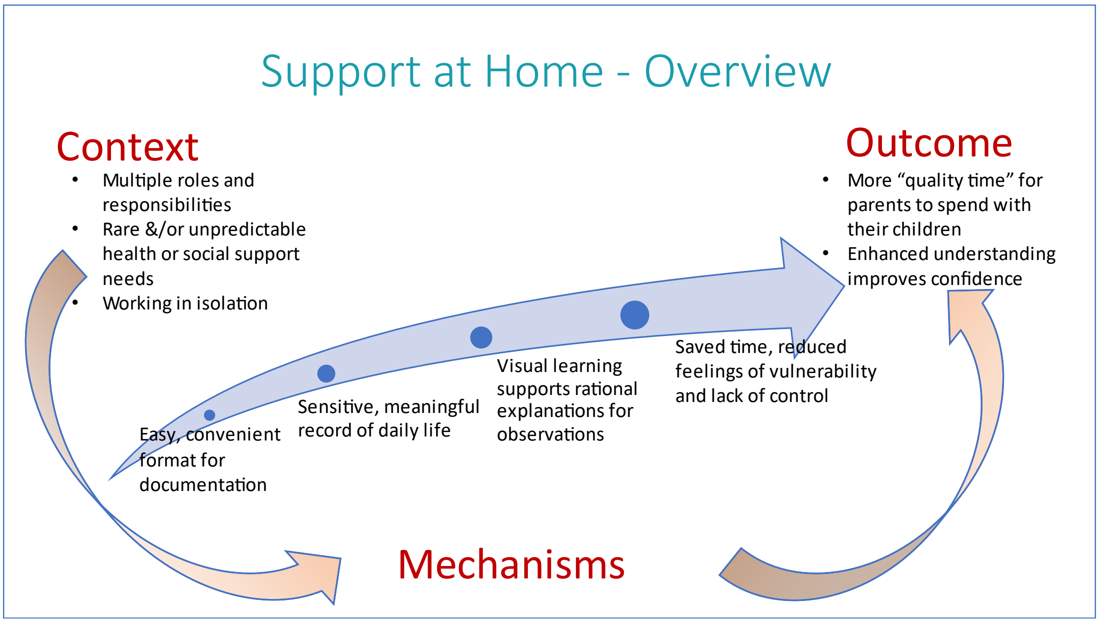
Parents of children with LLC face a unique set of circumstances that affect their needs for, and ability to, communicate with HCPs. As outlined in the contextual descriptions above, the demand for "intensive parenting" with all its respective components can lead to isolation, exhaustion, and self-doubt. The parents in this study described the benefits of practical supports such as the simplicity and convenience of recording their observations on MyQuality, and a range of psychological benefits, valuing the insights gained from improved knowledge and understanding, and the respect that follows being heard, trusted and believed. Several parents mentioned that their main "job" was to be a parent to their child and the critical need to do this as well as possible, given the range of adverse health consequences that could ensue if they didn't. The unpredictable nature of life and the urgent nature of the demands of care for a child with complex needs meant that time for "normal life" was a highly valued priority. Many alluded to their need for control in their unpredictable domestic world. These are outlined in Figure 7-6.

The CMOc's can be amalgamated to give a less granular overview about the contribution of MyQuality, as pictured in Fig 7-7.

Figure 7-6 PT: Supporting children and parents at home

Context	**Mechanism Resource**	**Mechanism Response**	**Outcome**
Multiple roles and responsibilities associated with caring for ill child, taking much time	Easy and convenient format for documentation	Saving time	Less time spent on documentation allows more “quality time” for parents with their children
Rare and/or unpredictable nature of health and social support needs	Personalised data entry provides a sensitive meaningful record of daily life	Reflection on events supports sense-making	
Care at home means caregivers are isolated from HCPs or peer support	Data transformed into a visual illustration of change over time	Opportunity to learn and improve understanding of illness though exploration of patterns in data	Improving knowledge and understanding of complex or unpredictable events gives a greater sense of control and confidence for parents

Figure 7-7 Overview - Supporting children and parents at home



Thus far I have reported on the interview findings with study participants, but a few potential participant families were identified by HCPs who did not subsequently elect to use MyQuality or join the study. Feedback from HCPs revealed several potential contextual factors that appeared to hinder the ability of parents to benefit from the MyQuality process. These included the lack of a “diary habit”, unexpected disruptions to usual family life such as a hospital admission or going on holiday, or situations where the child’s condition was either too erratic, or too stable, for consistent identification of priorities or meaningful measurement. It was not possible to explore these responses directly with those who chose not to participate in the study.

8 Healthcare Professionals and MyQuality

In this chapter I will examine the comments from HCPs about their hopes, concerns and expectations from MyQuality, and the feedback from individuals and teams who used it in practice with patients on their caseloads.

Figure 8-1 Overview of Programme Theories about HCPs

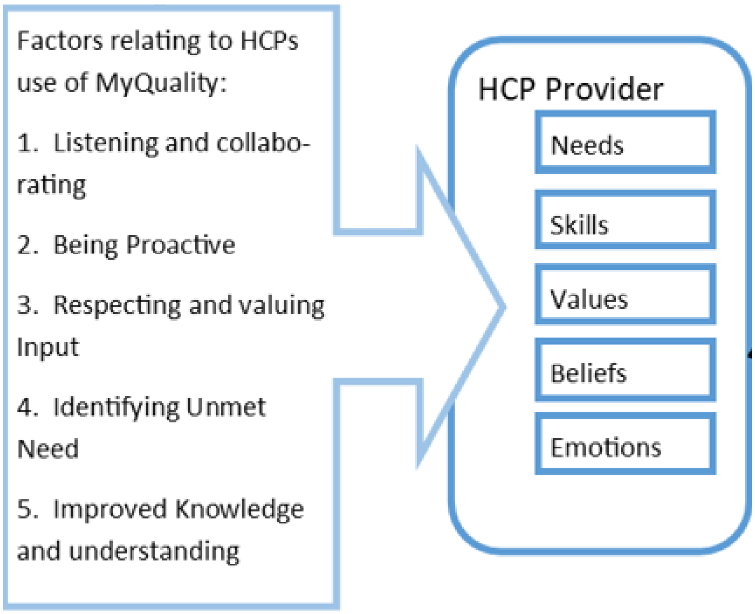
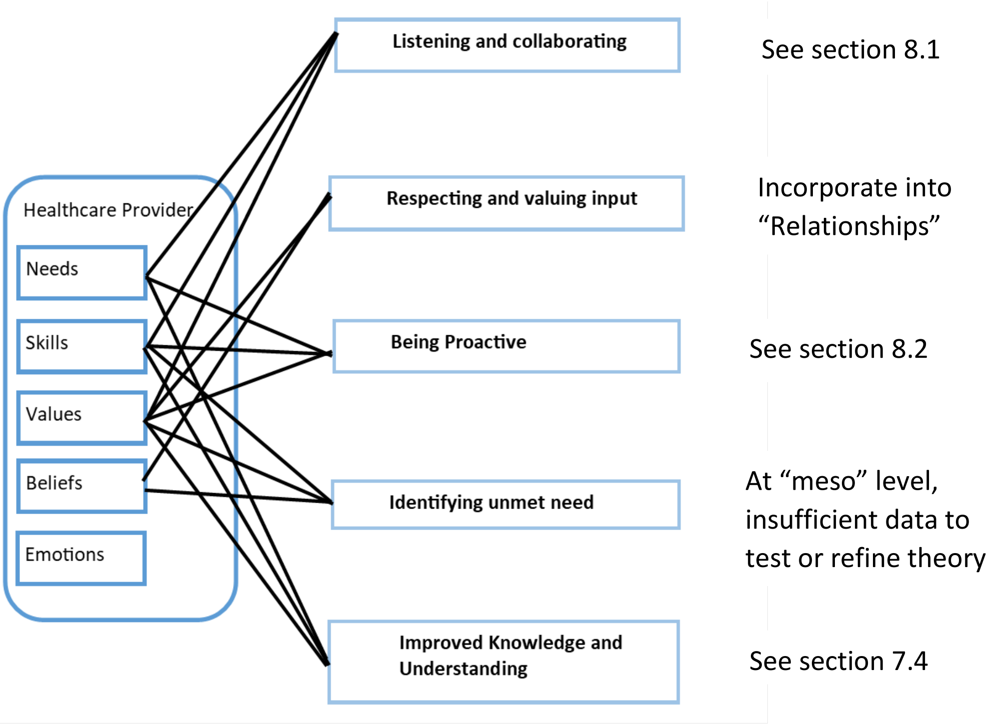


Figure 8-2 Details of HCP theories



HCPs worked in a variety of locations, providing support in homes, hospices, or hospital settings, as front-line responders or as advisors at secondary or tertiary levels. The variety of settings, professional backgrounds, and extent of palliative care experience provided a mixture of viewpoints, with some strongly divergent opinions expressed. Consequently, I have presented programme theories and rival theories, highlighting the tensions apparent in clinical practice. As with the patients and their parents, the Feldman-Stewart & Brundage (2009) model points out that individual professionals have a range of needs, skills, beliefs, values and emotions. These affect their professional decisions and behaviour during direct encounters with patients and families, as do external factors involving their colleagues, team, and wider organisational policies.

Table 8-1 Initial Programme Theories - Supporting HCPs

Provisional Programme Theory	**Rival Theory**
5. Listening and Collaborating	“Outside my Remit”
6. Proactive management	Energy Conservation

The programme theories identified in the literature that were explored in this study included those relating to direct relations between HCPs and patients, typified by micro-level interactions, and theories that relate to meso-level issues. This latter group refers to communication within teams or between teams that concerns support for the child and family (see Figs. 5-2 & 5-3, p 138). Some of the theories identified in the literature review, such as “Improved Knowledge and Understanding” (section 7.4), apply to HCPs as much as to patients and parents and will not be repeated here. Others were merged into the “relationships” theory in chapter 9. The theory about “identifying unmet need” could not be further explored from the findings from this study, whilst other rough theories, not identified in the literature, were derived from the feedback from study participants as outlined later in this chapter.

8.1 Programme Theory 5 – Listening and Collaborating

Fundamental to person-centred care is the development of supportive clinician-patient relationships (Castro et al., 2016; Street et al., 2009), but these are not relationships founded on a meeting of matching equals. Parents bring their intricate experience of their own circumstances but generally do not have the depth or breadth of training and clinical experiences of HCPs. HCPs bring relevant professional expertise but may lack the detailed insights into the lived experience of the children and families that they meet. A variety of patterns of interaction may occur, related to the characteristics of the individuals involved, the urgency of the clinical situation, and habitual tendencies towards paternalistic or collaborative relationships. Patients and their parents generally want to be seen as constructive partners in a dialogue that is ultimately in their best interests, rather than considered assertive or “difficult”, but it can be hard for them to judge the extent to which HCPs welcome collaboration in any given clinical circumstance. By suggesting the use of MyQuality, clinicians can signal their willingness to adopt a collaborative approach and give permission to patients to raise their issues and concerns. The initial programme theory was as follows:

> **Listening and Collaborating**: Professionals who agree to look at the MyQuality data produced by the patients/parents will demonstrate a willingness to incorporate their feedback and collaborate with them in healthcare discussions, leading to mutually agreed management plans and understanding of risks, benefits and priorities for care.

8.1.1 Context: wide range of concerns

The wide range of medical, social and cultural circumstances encountered by children with LLC means that every child or family will present a unique scenario for HCPs involved in supportive care. It can be difficult for any individual HCP to be familiar with the full range of relevant issues for families, so teamwork that allows the collaborative expertise of a range of professionals facilitates maximal benefit of professional advice for children and their families.

Holistic care requires an awareness of the range of issues faced by patients and families, even if many of them are outside the area of expertise of the individual HCP. Many HCPs working with children with complex needs are accustomed to the wide range of issues that could be encountered during discussions with patients and their parents, and have accepted this as part of normal working life:

> Consultant, team C: "most of what you are asked about in clinic is stuff you can do nothing about. So that's my day-to-day life as a community paediatrician… Up to 80% of a consultation can be people telling me about things that I can do nothing about."

Some HCPs recognised the advantages of this holistic approach as it could highlight unrecognised or unmet needs of children and families:

> Community nurse: "I think if you are using it (*MyQuality*) as a holistic tool, it doesn't matter if it isn't a high medical need, it's still a priority to those parents so it's worth addressing … and twisting that round, if it's not something that is a high health or medical priority, we might not have picked up on it."

Feedback from parents confirmed that the paediatricians were perceived as key co-ordinators of care, as many specialists chose to avoid dealing with issues that they felt were outside their remit.

> Daisy's father: "none of those specialists were interested in the other areas … they are just concentrating on their one area ... the paediatrician should pull it all together."

Whilst some HCPs found the extent of MyQuality data informative, others seemed to struggle with the concept of a wide range of parental priorities and the extent of their professional role in addressing these. Comments to this effect came from seven of the ten teams interviewed and were raised and endorsed by HCPs from a variety of professional backgrounds, rather than being primarily from one professional group. This could lead to tensions between teams, or professionals within teams, about the value of a wider view of information.

> Community nurse: "We should be working in partnership with our families … we recognise them as experts in care, so therefore we need to give them the tools (*like MyQuality*) to be able to report effectively, and for us to be able to partner effectively with them and alongside them. It shouldn't be this us-and-them about 'I'm suddenly going to have a load of work to do because you've told me all of these things', it should be actually, 'how are things for you, how can we support you'?"

When the theory that excessive information gleaned from MyQuality might act as a barrier to its use by HCPs was explored with parents in this study, there was little sympathy for the challenges faced by HCPs:

> Daisy’s father: “You mean it's all unnecessary information and noise that's not relevant to them and they'll have to spend time wading through it? Yeah, well I imagine a good doctor or nurse has a lot of information that they need to sort out and consider, but surely the more information they have, the better the decisions they are going to be able to make. And they should be skilled enough to discard unnecessary information quickly and just focus on what's relevant to them.”
>
> Matthew’s mother: “that's part of their job, isn't it? You know, to be able to have - for want of a better term - a good bedside manner, and to alleviate patients’ parents’ concerns and be able to say that the information you've gathered is interesting, but I don't think it is necessarily pertinent. … I think that, yeah, the ones who are threatened by it should actually step up a bit, and think well I do have to speak to patients and parents and at times what they raise may not be relevant, but they've got to find a way of managing that. Basically.”

8.1.2 Mechanism: active listening, improved understanding

The use of MyQuality presents patients and their parents with the opportunity to identify and monitor a full range of priorities, and the website acts as a resource to facilitate sharing of this information. As identified in the literature on PROMs (Greenhalgh et al., 2017), this acts to give them permission raise issues with HCPs. In the case of MyQuality, if HCPs recommended its use, this helped parents to feel that their opinions were valued and encouraged them to highlight issues that might not have otherwise been raised.

Once HCPs could see the breadth of topics prioritised by parents, they could assist with clarification of key goals. Understanding what was prioritised, and why, helped HCPs to advocate or intervene on their patients’ behalf to address their needs.

> Consultant paediatrician: “they (*the MyQuality data*) did give me a feel for how things are for the family and what matters to them and what's important. The fact that I can't do anything about them I don't think would

> change that. It makes me feel that I know where the family are at, if you know what I mean."
>
> Community nurse 2: "I think it is always important to acknowledge what is the priority to the parents, even if you don't think it is (*a priority*). That's going to aid you with your communication with them. You are going to be really well informed about what IS their priority, and it's about breaking that down, and working through it with them about WHY it's their priority"

These comments illustrate how HCPs can use MyQuality data to better understand the perspective of the individual patient or parent, a key component of PCC (Hudon et al., 2012).

8.1.3 Outcome – improved communication and shared decision-making

Greater awareness of the needs and goals of patients could lead to open discussion and facilitate shared decision-making based on improved understanding by HCPs of the patient and parent's perspectives. In circumstances where professional and patient or parental priorities were not clearly aligned, MyQuality could provide a focus for discussion to ease communication.

> Community nurse: "I think it would be easier to have conversations (*with patients and their parents*) because if you've got this [POINTS TO MYQUALITY PRINTOUT]– "OK, show me how that's been", and then you can discuss that, and say, "and now if we think about this, another symptom, might that be affecting that, and why don't we think about them together"? I think it might be a helpful tool, rather than a barrier."
>
> Hospice doctor: "it may be a useful tool to evidence that "you are saying this but actually what I'm seeing here is …" – or "have you ever thought about it like this" – it may be that just having that (*MyQuality*) data in black and white is just actually quite a helpful tool to say let's try thinking about this another way, could we interpret this differently."

Rather than seeing additional data as a barrier to MyQuality use, many HCPs could see the value in using the MyQuality outputs to explore an individual's understanding, beliefs, fears and misconceptions about management options.

8.1.4 Refined programme theory

The initial programme theory was based on the concept that additional information from patients would add depth to HCPs' understanding of their circumstances, and thus enhance the delivery of care. It became clear during the interviews with HCPs that this was welcomed to variable extents, some HCPs finding that additional insights added too great a burden of workload or responsibility. Teams with this mindset did not participate further in the study by recruiting patient participants, thereby avoiding this potential burden. Thus, depending on the tolerance of HCPs for unsolicited information, they either recognised the MyQuality data as providing valuable contextual information to aid their understanding of a patient or parental perspective, or saw this as a reminder of the limitations of their skills, abilities or resources. Theory was refined as follows:

> **Active listening**: MyQuality data can highlight a wide range of issues that patients or their parents perceive to be challenging and present this information to HCPs. Many of the issues raised may be outside the remit of the professional. Despite this, HCPs with adequate time and personal resilience (context) can improve their understanding of this perspective by actively listening and recognising patient or parental concerns (mechanism), supporting open communication and the opportunity to collaborate in discussions (outcome). (Fig 8-3)
>
> **Outside my remit**: Alternatively, HCPs may feel that the issues raised are outside their area of expertise and feel threatened by the scale or nature of information produced by MyQ (context). This can result in them ignoring or delegating key priority areas identified by their patients (mechanism), which may obstruct constructive dialogue with patients/parents, or threaten the resilience of HCPs (outcome). (Fig 8-4)

Figure 8-3 CMO 5 - Active Listening

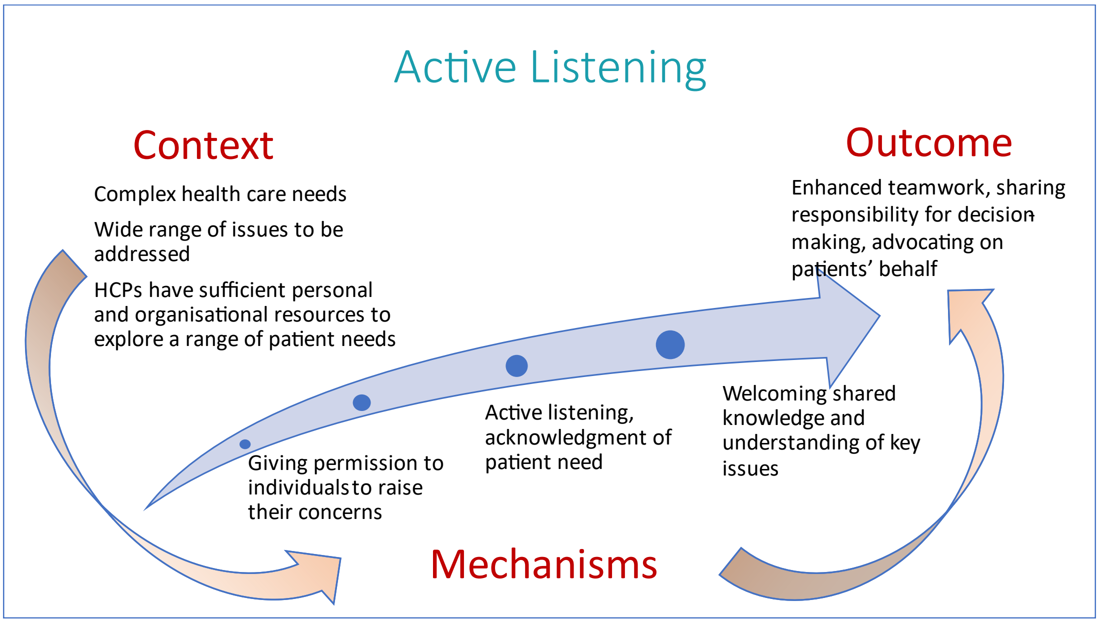
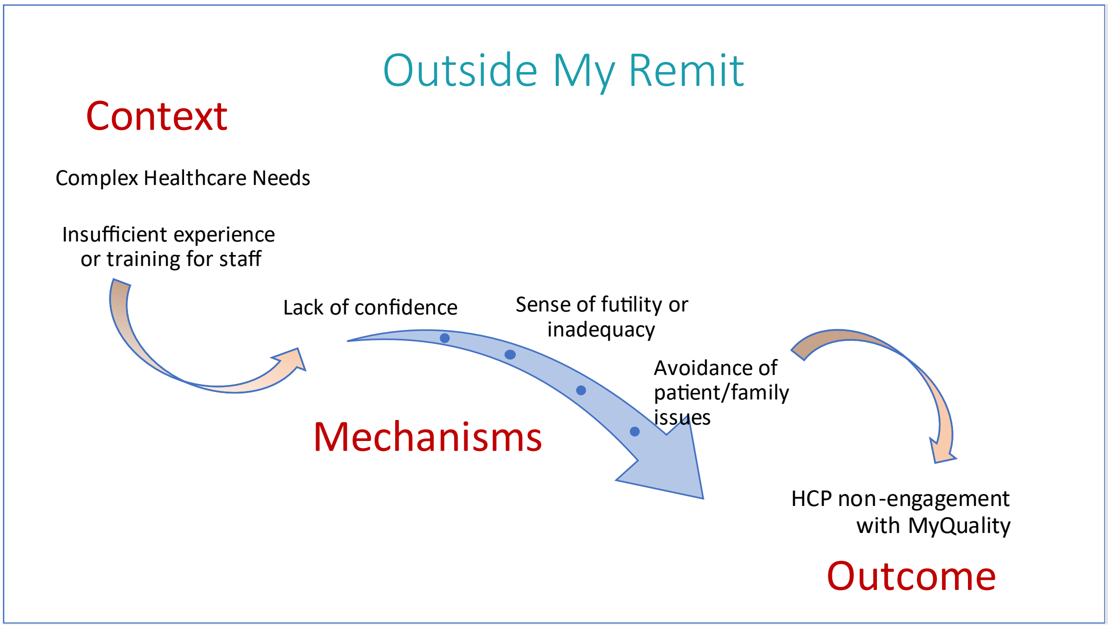


Figure 8-4 CMOc - "Outside My Remit"



Bringing these theories together allowed further consideration of the skills, needs, values and beliefs of HCPs. Engagement with MyQuality would require HCPs with adequate time to consider the details of what their patients/parents were telling them, sufficient personal resilience to accept that many of the issues may be unfamiliar to them and highlight gaps in their knowledge, and the skills to discuss these limitations with their patients or their parents. It would be important that HCPs could value the information that MyQuality was providing, which would encourage them to signpost their patients to other service providers who might be better able to address their needs. HCPs who believed that they were making a difference to their patients and their families in this way, rather than "failing them", would continue to engage with MyQuality.

8.2 Programme Theory 6 – Proactive Management

The uncertainty and unpredictability of caring for a child with a LLC means that healthcare resources must be able to respond flexibly to unplanned events. Early intervention can often save time, inconvenience and effort when compared to a more reactive problem-management approach, but in a healthcare service with finite resources it may be difficult to prioritise preventative or proactive health measures against the need to respond to emergency or crisis management.

One of the clinical challenges for clinicians caring for children with LLC is that the evidence base for interventions is often weak (Fraser, Bluebond-Langer & Ling, 2020; Beecham et al., 2016; Cooley et al., 2000) and management may be based on a "best guess" or "try-it-and-see" method when the best approach to addressing the problem at hand is not clear. This method comes with a caveat in that it requires regular reassessment of response so that if one intervention does not work, or worse causes harm, it can be promptly stopped and replaced with an alternative. However, it can be difficult to accommodate this need for rapid reassessment of response in standardised follow-up regimes or overloaded services.

One of the theories about how MyQuality may support person-centred care focused on improving the ability of HCPs to target their support in a timely, proactive manner:

> **Being Proactive**: Professionals who make time to look at the MyQuality data produced by their patients will have a greater understanding of the nature and variability of their challenging symptoms, and a timely

> awareness of change. This should help them respond more quickly to their patients' needs, and to modify treatment advice as appropriate.

8.2.1 Context – clinical time as a commodity

Healthcare practitioners needed to balance the needs of each patient against those of others on their caseload, and the other requirements of their posts such as time for training, management, emergency care, research and teamwork. This process meant continually juggling how time could be allocated between clinical and non-clinical demands, between individual clinical encounters, or between specific issues within those discussions with individuals. Many practitioners recognised the potential for using their patients' MyQuality data to manage time proactively:

> Community paediatrician: "I can say that for any one of [my] patients, I can have a look at it (*MyQuality*) and have a priority list in my head, prior to seeing them, about what's been going on over the last period of time, so I can prioritise what it is that they want to talk about in the next appointment and get my head around it. Because for each of those patients you end up time-managing the consultations. They always run to at least double. And it's kind of how that time is focused a little bit more. So that's my buy-in to this - can it focus consultations better."

This approach depended on the clinicians not feeling so overwhelmed that any additional responsibilities or activity became a barrier to MyQuality use.

> Consultant, team C: "Capacity and demand are not aligned with each other … I think instantly, a question that will come (*from work colleagues*) is "when are we meant to find the time to look at what the patients who've had needs put on there?"
>
> Hospital Consultant team D: "If you think about that cohort of children within the hospital, all the children, the teenagers, we just don't have the resource to respond to people's ups and downs of symptoms."

In these examples, the other consultants in Team C, and the whole of team D, did not participate further in this study, citing inadequate time as the reason.

8.2.2 Context – up to date information

The advantages of early access to information were identified by the community nursing team as essential to their model of care, as outlined in this exchange:

> Community Nurse 1: “we want to know as soon as possible if things are changing, that's the way we manage [our patients]. All of our children are very individual and actually their management needs to be individual, so we need to know what's going on.”
>
> Community nurse 2: “We also struggle more if we can't get that communication… that constant update makes it much easier to make decisions.”

The desire by some teams to monitor change closely was not shared by all respondents. An alternative view was expressed concerning the dangers of falsely raising expectations of patients or their parents that MyQuality would provide an overview of care at home which was not realistically achievable.

> Doctor, Hospice A: “If a family are sharing info with someone, I guess they are expecting some form of action from them at some point?”

The question of email alerts from MyQuality was particularly vexing for many teams, with the implication that an urgent response was required.

> Doctor, Hospice B: “I’m not sure I'd want an email alert, I’d much rather get a phone call, so then I know that they're going to speak to someone: ‘can you look at this, can you give me some advice?’ I wouldn't want the patients thinking ‘oh I’ve dealt with that; the email has gone’."
>
> Hospital Consultant, team C: “as a tool in the NHS, actually its role at the moment should be without the email link, that it’s an overview when you come to clinic… and you that you disable the email alert system within the hospital. What we want is a sort of bigger overview of symptoms, to say ‘OK, well what happened last week when all these symptoms were like this?’... I think it would be really difficult to think there was capacity in a hospital to address a whole pile of emails on a Monday morning (*multiple voices: “agreed, absolutely”*) … and with everybody sending you stuff, or even on a daily basis, I just, I don't think you could do that, but I think this is a great tool for looking at in clinic.”

In many cases parents of children with LLC already had open access to hospitals for advice and were given email addresses as part of routine care in order to contact their HCPs directly. The challenge for HCPs appeared not to be solely around the potential for greater direct contact from patients, but around the concern that patients or their parents might expect that HCPs were reviewing their data regularly in a proactive manner, rather than reacting to a patient-initiated request for help.

> Consultant, team A: "All of the families that we meet have our email address. We give it out… so I think it's just being quite clear about saying that just because they're using the system (*MyQuality*) doesn't mean that our capacity to answer their questions is changing." [*lots of nodding and general agreement from team about this*]

The expectation of additional resources generated by MyQuality was not shared by parents, as illustrated by this reaction:

> "… because [team A] are only (*working*) Monday to Friday, and they were concerned that if something happened over the weekend and we were expecting - or anyone was expecting - an immediate response they wouldn't get it. But we wouldn't (*expect that*). We know they're only Mon-Friday, it just might be helpful for them to know if we were going through a difficult patch, but we don't expect an immediate response, and if it got really bad, we'd be in hospital anyway."

The sections above, and the variety of contextual limitations identified by participants, highlight some of the difficulties surrounding the introduction of MyQuality. The tensions between pressurised time, the desire to be up to date with the latest patient feedback, and the volume of work created implementation challenges in the context of a workforce with limited scope for flexibility, innovation and exploration of new ways of working.

8.2.3 Mechanism: thinking time

One way to save time would be to narrow the HCPs' clinical focus to their specialist area rather than encouraging a more holistic approach. In practice this would mean delegating issues that are outside their remit to others and concentrating on those areas where they can provide maximum expertise to the patient. However, this is more difficult when there are a variety of interrelated problems being presented by the patient, a situation that is common with the multi-morbidity of children living with chronic healthcare conditions.

The clinical management of children with LLC is complex, often requiring careful balancing of a range of options, benefits and consequences. Even experienced HCPs working in children's palliative care may struggle to advise which options are in the best interests of the child and family, as there may be multiple competing priorities and limited evidence to guide decision-making. Having additional time to consider the wider implications, check latest guidance, consult colleagues and weigh options in the balance can make a difference to the manner and ability of HCPs to discuss potential choices with patients and families. Advanced knowledge of a child and parent's priorities and the impact of these on their daily lives could allow a more informed dialogue to follow.

> Community paediatrician, asked what was most useful about MyQuality: "thinking time… As in, if you look at what the symptoms are before you see them, you can have a bit of a think about how to manage things beforehand. Because we've got the various thinking processes that we have - your reactive thinking process, your fight and flight thinking process, and you've got slightly deeper thinking processes. And this allows slightly deeper thinking."

Despite the advantages of additional "thinking time", some teams could see that proactively looking at patient data in MyQuality by the multiple teams involved in a child's care could represent a duplication of effort, a source of confusion and less efficient use of NHS resources overall. This could present teams with some challenges:

> Lead nurse, team A: "so you might see a list of all the people involved in that family, and there's a community nurse, and we're on that list, and we get that alert, and then the question for me would be has that community nurse seen that alert, and then... and suddenly we're chasing a whole piece of work..."

In addition to issues about workload management, there may also be more challenging practical and ethical decisions about how to manage a child whose MyQuality data suggests increasing problems at home.

> Lead Nurse, team A: “my concern would be that we might be getting email alerts, we’re a hospital-based team and it might be that child is in the community and we are not a community service, but my decree would be that morally and ethically you can see that this child's in pain, what do I do about it (*colleagues: “yeah, yeah”*) That would be my concern.... And how we might manage that as a team, given that we aren't an outreach team.”

More general issues around workload and the potential to be overwhelmed were raised by most teams at the initial interviews. Not all teams were put off by this problem, some seeing it as an opportunity to proactively improve service co-ordination, a key part of person-centred care.

> Community Nurse: “It’s about highlighting team working and how you might want to do that - if you've got a child with that many complex needs, you actually want to co-ordinate WHO is the person who acts initially on that information, and then what everybody's role is. So I think this (*MyQuality*) is a really helpful tool, but there needs to be maybe an understanding of how that is used by various professionals … I don't think its un-doable, I think it’s just making sure that is discussed as part of a child's care. So it may well be that there is one person that takes a lead on responding (*to MyQuality data*), but that information is then shared with others.”

8.2.4 Outcome: improved confidence and time management

Given the duration of the study and the small number of participant patient/HCP pairs, it was difficult to get definitive clinical examples of outcomes that followed a more proactive approach from HCPs. Many children had routine six-monthly or annual reviews for chronic conditions, so the ability to see any benefits of proactive intervention or changes in workload management was limited. However, the advantages and practical benefits of MyQuality use were identified by some HCPs as a technique to manage both individual patients, and their caseload.

> Consultant paediatrician: “I think it IS quicker, to be fair, once you've got into the swing of it (*using MyQuality*) you can see at a glance what would take you quite a long time to actually get by talking to someone, and it allows you to concentrate on the points that look like they're an issue. So I think it is helpful.”

> Community paediatrician: “we can all work as a team to go - "[re patient X], everything's getting worse, we have evidence of this (*on MyQuality graph*), now's the time to bring together a TAC* meeting to discuss going forward."
>
> Hospice nurse, describing prioritising her caseload: “when we do calls to patients, as a contact role, it would be quite good to be able to look at the graphs and say, so actually last week, this was not so good, and I should touch base with that person....”

Parents of patients who used MyQuality could also see potential benefits for them in the ability of HCPs to make informed prioritisation decisions.

> Adam’s mother: “I think it’s going to reduce their (*HCP’s*) workload. Because they can then say "well these ones (*patients*) are ok, so we've got somebody here that really needs our help and we'll put that one back a month and see the urgent things now, so I think it would probably help them. And possibly reduce their workload or manage their workload I think.”

8.2.5 Refined Programme theory

Exploration of the issues surrounding changing work practices with HCPs revealed multiple opportunities and potential barriers to MyQuality use, as key contextual features at micro- and meso- level for HCPs became evident. The theory was refined as follows:

> **Being Proactive**: Professionals who view the MyQuality data produced by their patients will have a greater understanding of the nature and variability of their challenging symptoms, and a timely awareness of change. To do so they require adequate time and control of their workload, and a clear delineation of responsibilities with others involved in the child’s care (contexts). If these conditions are met, accessing MyQuality data may allow time for more effective contemplation of patient issues (mechanism). This should help HCPs respond more quickly to their patients’ needs and to modify treatment advice as appropriate (outcome).
>
> **Rival theory**: **Energy Conservation**: HCPs who already feel under pressure (context) will avoid using MyQuality (outcome) if they perceive that it will add to their workload (mechanism).

Figure 8-5 CMO 6 - Being Proactive

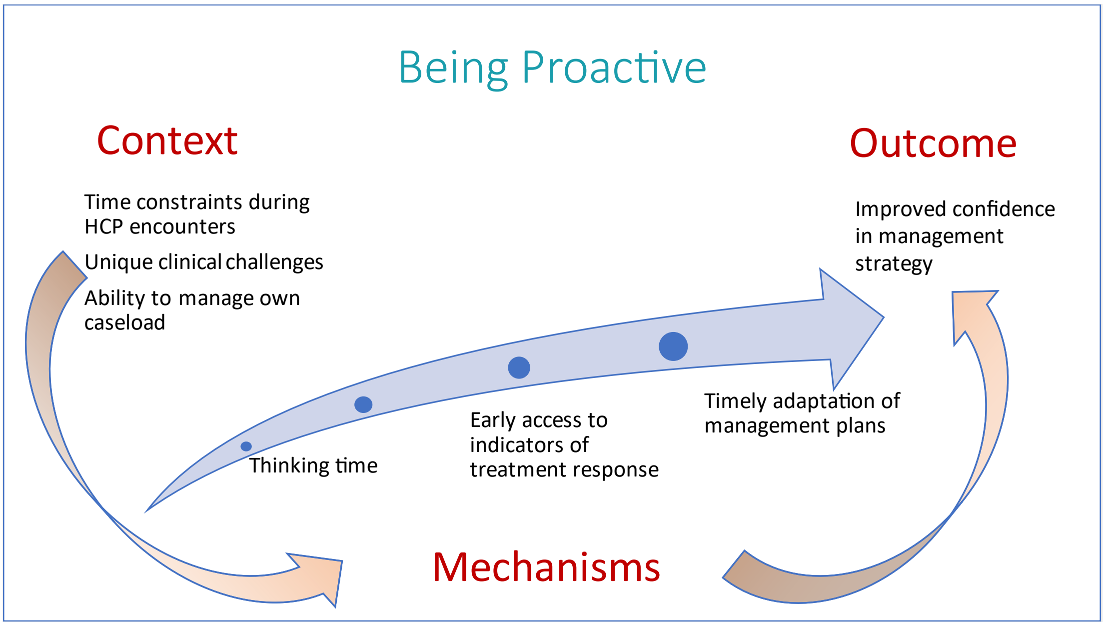
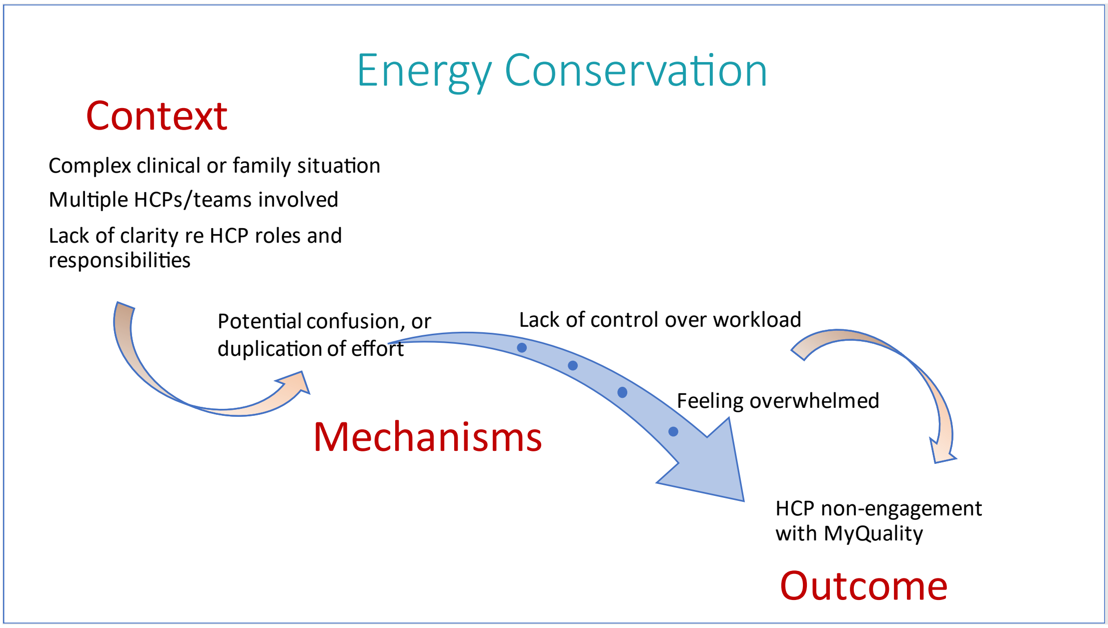


Figure 8-6 CMOc - Energy Conservation



8.3 Unanticipated outcomes

The chance for HCPs to use MyQuality and report their experiences was a valuable opportunity to gain feedback about any unforeseen outcomes of its use. These outcomes may not have been identified in the literature but are important for the design, implementation and support needed to use this intervention. They provide insights into the thoughts of HCPs working in children's palliative care which may help to understand their values, beliefs and emotions.

8.3.1 Micro level issues: HCP resilience

In the field of children's palliative care, empathetic relationships develop between HCPs and the children/parents requiring their support. Many HCPs see repeated examples where misfortune has adversely affected the anticipated course of the lives of children and families. The proximity to suffering can be highly discomfiting and many HCPs develop coping mechanisms to prevent dwelling on the adversity of others, distancing themselves from tragedy in order to maintain a balanced view of life. This approach can protect their own psychological wellbeing and support the wider workforce by reducing burnout and improving staff retention. MyQuality may inadvertently undermine these psychological survival strategies, and a few examples which were encountered during this study are outlined below.

8.3.1.1 Hindsight

The assumption underpinning MyQuality is that accurate, relevant, timely information is helpful to HCPs. However, the nature of CPC is that unexpected events happen, complications may occur suddenly, and the best laid plans may not work as expected. There was one such example in this study, when Charlotte deteriorated and died quickly. Her parents had documented her symptoms on MyQuality on a daily basis for the previous six weeks, sharing this with key members of her team. Her doctor reviewed her MyQuality data again after her death and discussed her reactions:

> "(Charlotte's) symptoms were at a very high level before she died - my first reaction was 'goodness me'… Could I have predicted it happening - who knows? … I had very difficult emotional journey as a result of her death, because I had guilt and blame over her death ... you know occasionally you do take things terribly to heart, and maybe you shouldn't, maybe it's hard being both a human being and a clinician."

Hindsight may provide valuable learning, but this can be a painful experience which can add to the psychological burden of HCPs, diminishing their resilience.

8.3.1.2 *The impact of unsolicited information*

A common distancing technique is for HCPs to remind themselves that the life tragedies that they witness “happen to other people, not to you”. MyQuality can weaken this defence by highlighting details of daily life of the children, young people and their families. Exposure to this on a regular basis may reinforce to HCPs the similarities between “us” and “them”, leading to a sense of vulnerability and reminding HCPs that “There but for the grace of God go I”. As one consultant said, "The scary thing is that we can't bear to see the realities of our children's lives." This was echoed by reflections from a community nurse:

> “particularly from a medical point of view, when people see them (*patients and their parents*) exclusively in clinic … that clinic letter really doesn't [show] the complexity. And actually that can be too much to bear, if HCPs are suddenly exposed (*via MyQuality*) to ‘this is how bad it is’.”

The regular and intensive insights delivered by MyQuality, in contrast to the infrequent short encounters in outpatient reviews, mean that the challenges faced by patients and their families may rarely be “out of sight, out of mind”, and may add to a continual burden of responsibility for HCPs.

8.3.1.3 *Managing expectation*

Healthcare professionals have responsibilities to their patients but also to their employers, work colleagues, professional bodies and others. This can lead to tensions when conflicting emotions are activated, such as wanting to support patients and families whilst also wanting to support team members by not creating unrealistic demands on them. This was a dilemma that was highlighted in particular by the email alert function of MyQuality as teams questioned their capacity to deal with these and to manage expectations of patients and HCPs.

> Hospice doctor: “so it’s family-held information, that they can ask [professionals] to tap into if and when they need it? Cause I don't think we could deliver *(on that)* … families might feel really disappointed in us and we might let them down.”
>
> Hospital consultant: “we don’t like being the ones to say ‘no, we won’t do this’ about email alerts. We don’t want to get a reputation for being difficult (*by opting out of MyQuality*) but we are a secondary advice service, not the primary contacts.”

Ultimately the sustainability of the clinical teams depends on their ability to meet managerial expectations and targets, work with colleagues across organisational boundaries and deliver safe and effective services to patients and families, and a new ehealth technology that could disrupt existing work patterns could be perceived as a threat. Some responders suggested that their team's funding could be vulnerable should their reputation be tarnished by non-engagement with MyQuality.

8.3.1.4 Confidentiality and Medicolegal implications

The question of confidentiality was raised during the introductory discussions by HCPs, who are used to working within the guidelines for confidentiality when recording information about patients. Breaches of confidentiality are serious professional offenses.   Members of the public are not held to the same standards of confidentiality in these shared encounters. In the case of MyQuality, the data on the website is determined and entered by the personal user, who makes decisions about access to it. Personal users can copy or share what they have recorded with others as they control the data, rather than healthcare organisations.

In an ideal world both patients and their parents, and HCPs, would work together with common aims, but it is often the case that differences of opinion arise in children's palliative care (Parsons & Darlington, 2021), sometimes leading to conflict (Forbat, Teuten & Barclay, 2015) and occasionally legal action. Unfortunately, several high-profile cases in recent years (Wilkinson & Savalescu, 2017; Dyer 2018) have shown how public sympathy can be mobilised by desperate parents using social media, leading to circumstances where one version of a complex situation is presented to the public without the opportunity for HCPs to voice their perspective or justify their actions.

During preliminary discussion with teams about this study, some HCPs identified the possibility that data that was not subject to the normal bounds of confidentiality could be shared to the public by patients or family members. This was viewed with some concern on two fronts: firstly, that the data could be altered by the MyQuality user and therefore could not be trusted (and wouldn't stand scrutiny within legal proceedings); and secondly that it could provide additional material to be distributed to the public, in contrast to “official” medical notes where access is strictly limited to protect the confidentiality of those involved.

This scenario did not arise in practice and was not explored in detail during discussions with study participants. However, it remained a hypothetical concern for some potential HCP users who viewed this as a potential threat. For some teams this influenced their decision not to participate in this study.

8.3.1.5 HCP resilience – hypothesis

The factors described above were unanticipated outcomes identified during HCP interviews, but collectively they shine a light on elements of the needs of providers. An initial theory for testing in future research is as follows:

> Healthcare professionals working in CPC develop self-protective techniques to maintain their psychological resilience in this challenging field. HCPs who feel that these are potentially undermined by aspects of MyQuality may need to define clear boundaries of responsibility and agree mutual expectations with patients and their families in order to reap the potential benefits provided using MyQuality. Without clear agreement on the roles and responsibilities of all users of MyQuality (context), HCPs may feel intimidated and fearful of the potential of the data to question their commitment and expertise (mechanism). This challenge to their resilience may lead to disengagement with MyQuality (outcome).

8.3.2 Meso level team issues:

The issues about resilience described above, which can have an impact on individual HCPs, can also affect meso-level issues such team ethos, staff retention, levels of productivity and the quality of team performance. These meso-level influences can all affect the team’s decision to engage with MyQuality, the way in which is it used, and the extent to which it shapes the delivery of service. This study was designed to focus on the dynamic of interactions between individual HCPs and their patients/parents, so these factors involving the sustainability of clinical teams were not assessed in detail. However, the potential for a digitally inequitable service was mentioned by several participants.

8.3.2.1 Digital divide and inequitable service

One of the issues identified in the literature and echoed by teams in this study was the potential for a digital divide, whereby patients on the caseload who could not access MyQuality were disadvantaged compared to those who could. This could happen for multiple reasons: access to IT hardware, software and infrastructure; levels of IT confidence and literacy; the range of distractions due to unstable healthcare needs or extenuating family circumstances; or more general age and culture-related potential barriers to MyQuality use. Several teams suggested that introducing ehealth communication could result in some patients receiving more attention than others based on their digital accessibility rather than the level of clinical need, which was ethically unacceptable.

> Hospital doctor: "we are one of many players looking after that particular patient aren't we, we don't want to become the case-holders, the case managers in isolation, or offering a better service to those families than we are to others (*i.e. families not using MyQuality*) so it's keeping it all in balance. … we would much rather they (*families*) go via their usual routes for advice."

HCPs reported that this concept of equitable access to services applied not only to personal or parental decisions to use MyQuality but also to its use across teams across the NHS, as an imbalance in access to MyQuality data from different teams would upset normal case management arrangements across services.

8.4 Healthcare professionals and MyQuality – overview and consolidation

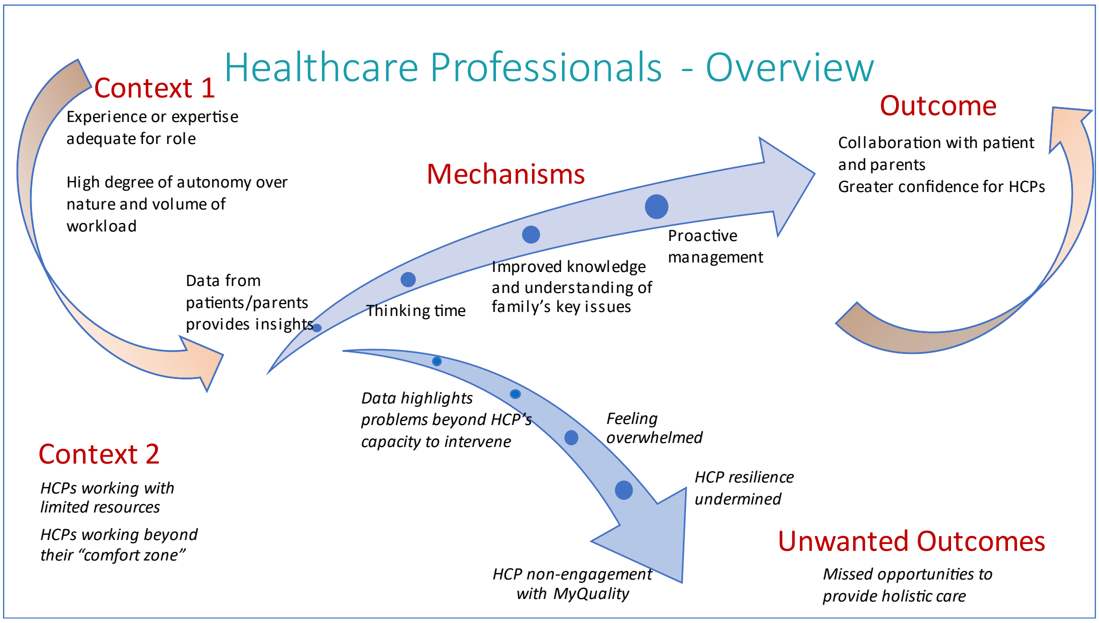
This chapter has explored the views of healthcare professionals about the use, or decision not to use, MyQuality. The PT's listed above illustrate a range of the needs, skills, values, beliefs and emotions outlined by Brundage, Feldman-Stewart & Tishelman (2010) in their work about communication. For some HCPs, the nature of the issues raised by patients' parents using MyQuality provided useful additional insights, enabling them to have a greater understanding of their perspectives and priorities and motivating HCPs to work in a collaborative, proactive manner to address their needs. This outcome was contextually dependent on HCPs having sufficient time, training, experience and resilience. When these were lacking the use of MyQuality data added to the workload pressures perceived by HCPs, so they were reluctant to engage with it, thus missing the opportunities provided to facilitate person-centred care.

These contrasting outcomes mean that consolidating them into one overarching CMO is not possible; furthermore, this would ignore the value of the opposing views described rather than appreciating their presence as demi-regularities in the complex processes surrounding the use of MyQuality. As such, I have divided the overview and identified adverse contextual factors separately in Figs 8-7 and 8-8.

Figure 8-7 Programme theory – healthcare professionals

Context	Mechanism Resource	Mechanism Response	Outcome
Variable levels of HCP experience and expertise HCPs have variable levels of control over nature and volume of workload	Data provided by patients gives detailed insights about nature of health and social challenges + Viewing data in advance of clinical encounter provides thinking time	Confident, with adequate time: Opportunity to learn and improve understanding of illness and patient/family situation	Pro-active problem management, timely intervention Collaboration with patient/parents Improving Knowledge and Understanding by HCP
		Inadequate time or resources or training or experience: Feeling overwhelmed by complexity and/or futility of intervention	Missed opportunities to provide holistic care to child and family

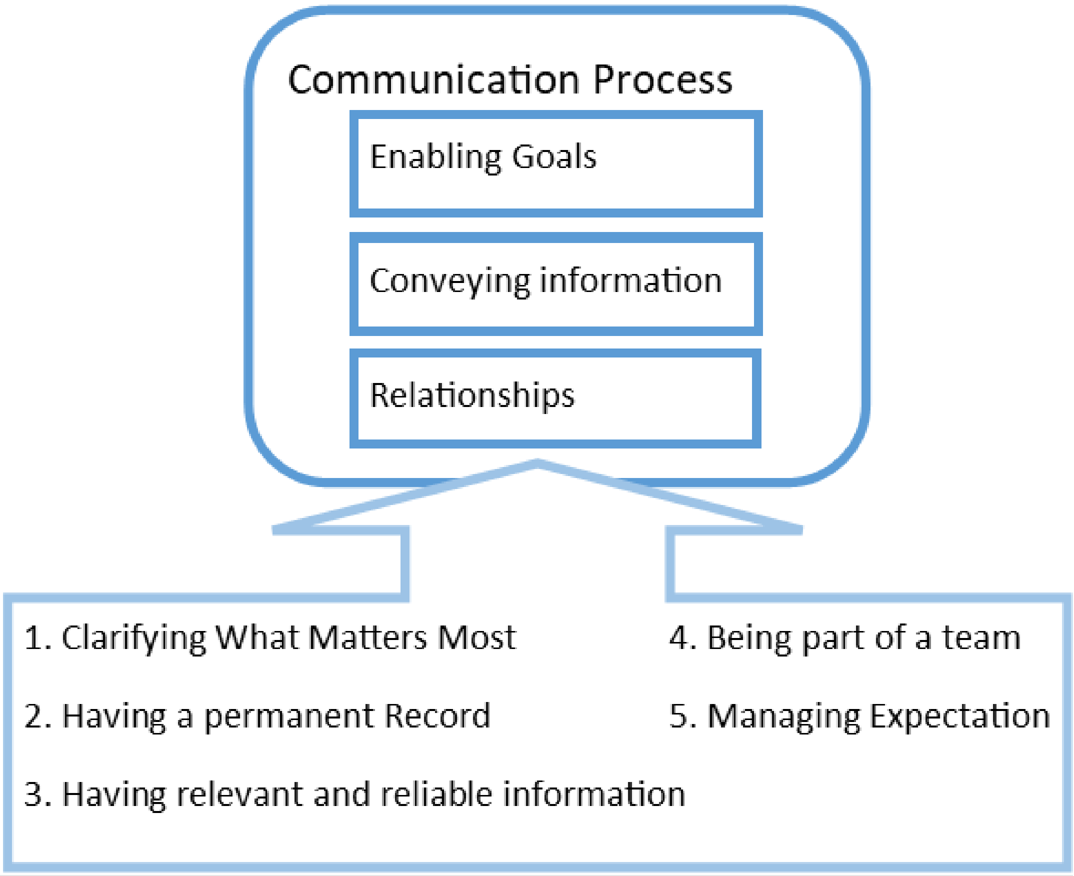
Figure 8-8 Overview - HCPs and MyQuality use



9 Supporting Communication

Part of the challenge of delivering person-centred care, as described by Santana and Feeney (2014), is bringing together the disparate goals and variable sources of information and expertise in order to share decision-making and develop an agreed plan for care. This section will bring together Brundage, Feldman-Stewart & Tishelman (2010)'s detailed look at the micro-level interactions in the communication process, considering the patient and providers' primary goals, enabling processes, with the larger picture of the delivery of PCC as outlined by Santana et al. (2018). It builds on what we have already seen in the last two sections about how MyQuality supports patients and their parents at home, and how it supports HCPs to deliver PCC. Some of the content of the initial theories mentioned already overlaps with theories that are relevant in this section.

Figure 9-1 Overview of Programme Theories about the communications process



Some of these initial theories have been merged together in this chapter, leaving three CMOs for detailed discussion, alongside relevant rival theory concepts.

Table 9.1 Initial Programme Theories – Supporting Communication

Provisional Programme Theory	**Rival Theory**
7. Clarifying What Matters Most	Anxious and overwhelmed
8. Having Reliable Information	Is information trustworthy?
9. Teamworking and Sharing Responsibilities	Absent connections

9.1 Programme theory 7 - clarifying what matters most

Exploration of the literature and findings from the first MyQuality study suggested the following rough programme theory:

> Parents of children living with LLC may contemplate and identify the key issues that they would like their healthcare practitioners to address and record these on the MyQuality website. In doing so, they will clarify their priorities for support and be able to emphasise these issues to their HCPs, which will increase the focus on their concerns for care and give a more patient-centred focus in clinical encounters.

A rival theory identified by HCPs included the concept that such contemplation may increase anxiety, leading to individuals feeling overwhelmed by the number of issues that they face.

9.1.1 Context: Multiple competing issues

Children with complex needs often have multiple health issues that require monitoring, and other health-related obligations that parents and professionals need to attend to (such as reports for schools, funding bodies, social services etc). In addition, there may be pressures on HCPs to deliver requirements for their service in order to demonstrate the safety, effectiveness, timeliness and response to their interventions. These competing agendas, and the tendency for some HCPs to assume a dominant role in healthcare settings means that additional concerns identified by patients or parents may be overlooked or relegated to a less prominent position within a healthcare encounter. It may be difficult to address all their issues during the limited time available, and prioritisation of topics is one approach to ensure that time is used most wisely. Prioritisation does not always come easily when there are multiple competing clinical concerns, as patients and parents are often exhausted, working in “fire-fighting” mode as one crisis follows another, and for many the precise articulation of concerns can be difficult.

> Matthew’s mother: “It (*MyQuality*) makes you focus on particular areas of concern, and I think sometimes when you go to see a healthcare professional you have got a limited time, they very much kind of lead the appointment don't they, if you know what I mean. They take the lead, they'll determine what is discussed, and unless you have clear ideas about what you're concerned about in your own mind, then it’s easy to come out and think “Oh I didn't ask that”, or “I didn't mention that”. So I think from that point of view, yeah it’s really good to go through that thought process.”

Healthcare professionals also found the process of prioritisation of concerns could be a challenge:

> Paediatrician: “I was finding, as I see them every week I was going “how's your week been” and [mother] would go “Oh yeah, you know, you know how it is, good days and bad days”, but I think there's so much going on for them that it’s difficult for her to come to clinic and express what actually was happening.”
>
> Community paediatrician: “It’s when you feel like you're in "cognitive soup" - that's the word that I use. You just come to clinic and you get this BARRAGE of stuff, and you think ‘how do I separate this out?’ And I call that cognitive soup, when I come out and I feel dizzy, and like I don't know where I'm going.”

During healthcare interactions HCPs could have additional professional responsibilities in addition to meeting the needs identified by patients and their parents. These might include essential checks to ensure patient safety, meeting departmental targets, time constraints brought about by booking patterns, and juggling multiple duties simultaneously (such as being on-call whilst conducting an outpatient clinic).

> Consultant psychologist: “I guess one of the challenges might be about when you've got clinicians who have specific tasks that they need to cover in a clinic appointment, and then how that may or may not map into the issues

> for families … if you've got particular things that you've got to tick off in order to fulfil best practice tariff, or something along those lines, then that's where things might become more tricky.

These conflicting responsibilities mean that the ability to clarify the most important topics for discussion is even more important.

9.1.2 Mechanism – reflection, focus and clear articulation

When setting up MyQuality, the personal user (patient or their parent) chooses the parameters that they would like to monitor. Identifying these requires a process of reflection by each personal user to reach a decision about the most useful items on which to focus attention. The process of getting organised and focused was mentioned by parents and HCPs alike:

> Adam's mother: "(*MyQuality*)'s made me more aware of what I'm recording… rather than just recording every single detail. So it's the process of organising things, rather than just writing a journal type thing… Yeah, it has made me realise what my priorities are."
>
> Community paediatrician: "as a clinician I can't tell you how useful it's been for [patient] in particular. Because whenever I've had consultations before I've had real difficulty with priority and goal setting, I found getting stories from her really unclear... either Mum's become way more articulate, or actually the tool (*MyQuality*) is a good way of her working out what she wants to prioritise for consultations."

This paediatrician went on to report the experience of a colleague who looked after the same patient, but did not have shared access to the MyQuality data online:

> "But, um it came as a great surprise, because the respiratory consultant down in [city] also fed back how clear Mum had been about her concerns."

This implied that it was not the act of viewing the website that identified the priorities for that child, but the ability of the mother to articulate her thoughts. The importance of clear and open dialogue as a mechanism was recognised:

> Katie's mother (discussing how and why she chose her priorities): "I think if it (*MyQuality*) makes it easier for them, and easier for me to get the information across I'm all for it. The communication is key, isn't it? About

> being open and honest, and just laying (my concerns) out there, not pussyfooting around with it."

9.1.3 Outcome – focus on patient need

There were multiple examples from parents and from professionals about how this process translated into improved care, as it demonstrated how the information provided by MyQuality ensured that input from professionals was directed appropriately. This helped to ensure that patient and parental concerns were addressed, and reassured HCPs that they were working most effectively.

> Paediatrician: "I think it's useful for me to first look at it (*MyQuality graph*) and I can see in a snapshot whether it's been a good week or a bad week and can concentrate on which symptom is highlighted. To see if there is anything we can do about it. So it is helpful in that respect."
>
> Community paediatrician: "I reviewed her symptom management … it's interesting to see that it looks like we've responded to each of her concerns (*mother's priorities on MyQuality*). So firstly, it's reassuring (for me), and secondly it's prioritising what mum's concerns are, and thirdly in terms of symptoms tracking I think all of that's really useful."

A rival theory raised during initial discussions with healthcare professionals was the possibility that contemplation and prioritisation of healthcare issues could increase parental anxiety, but this was refuted by several members of frontline community teams who were seeing families regularly.

> Interviewer: the rival theory is that if you're thinking about these things all the time, you're over medicalising, or that you're increasing anxiety. Does that make sense, or do you think that's wrong?
>
> Community nurse 1: "I think they're thinking about them anyway… I think the anxiety is all there anyway. I think these parents live and breathe these children's symptoms."
>
> Community nurse 2: "And they might feel reassured then that it's been shared with someone else, and that other professionals are seeing what they're seeing."

This mirrored the feelings from parents about the risks that recording real life could prove distressing in the face of potential deterioration.

9.1.4 Refined Programme Theory:

There is frequently a tension between the large number of healthcare issues that are faced by families with children with LLC and the limited time available to discuss those needs in many NHS clinical interactions. Opportunities to prioritise needs away from the time pressure of a healthcare encounter could ensure that both providers and recipients of healthcare used their time most wisely and gained maximal benefit. MyQuality supported this process by providing a structured approach to reflection for parents, encouraging them to organise their thoughts, bringing clarity to subsequent discussions. This could redress some of the challenges faced due to professional-patient hierarchies in healthcare encounters, ensuring that the voice and concerns of the patient and parents were shared during the dialogue.

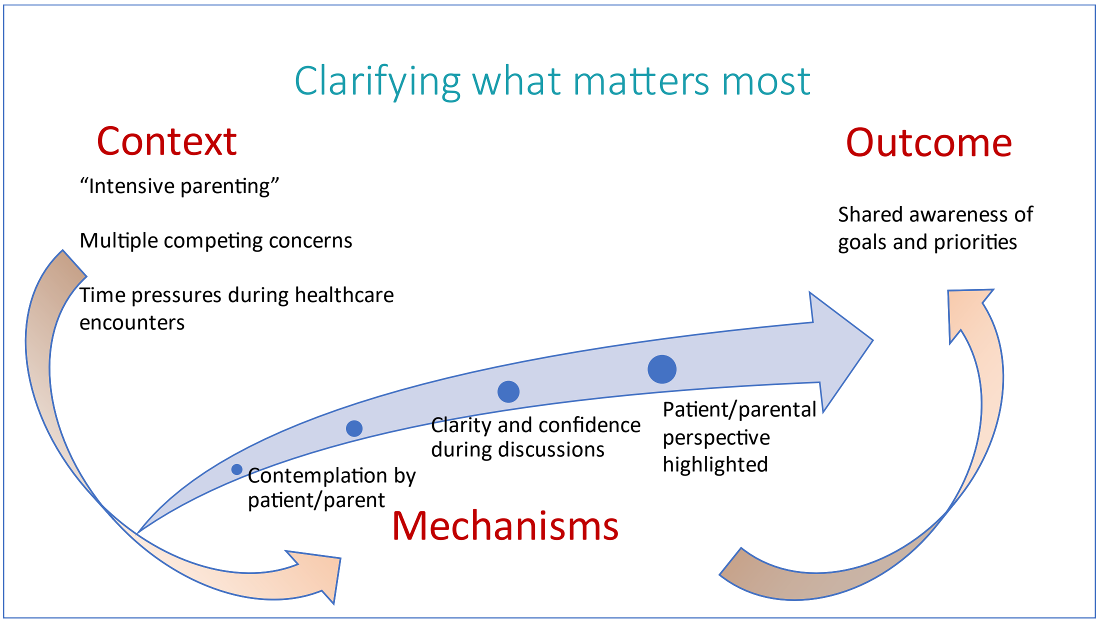
This theory builds on the actions of MyQuality to support children and their parents at home (chapter 7), enhancing parental resilience as parents and HCPs work together.

The refined theory is as follows:

> **Clarifying what matters most**: Parents of children living with LLC must juggle a wide range of healthcare issues as they manage their lives. Available professional support and guidance is often constrained by organisational limits such as time and manpower (Context). When parents contemplate and focus on the key issues that they would like their healthcare practitioners to address, they clarify their priorities for support and emphasise these issues to their HCPs in clinical encounters (Mechanism). This will give a more patient-centred focus for the delivery of care by HCPs (Outcome).

The rival theory, that the process could increase parental anxiety, was not supported by many HCP or any parental participants in this study, who felt that use of MyQuality would make no difference to underlying levels of anxiety but that sharing details might alleviate it.

Figure 9-2 CMO 7 - Clarifying what matters most



9.2 Programme theory 8 - having reliable information

Two rough programme theories developed in the literature were as follows:

> Having a **permanent record**: Individuals who monitor, quantify and document their child's symptoms on a daily basis using MyQuality will develop a record which will support accurate recollections. This will improve the reliability of information exchange, and their confidence during discussions with HCPs.
>
> Having **relevant information**: Families will be prospectively documenting their child's health in a "normal life setting", resulting in a more realistic, continuous record of health concerns. This can increase the relevance and reliability of their observation and interpretation of change over time and support increased confidence during discussion with HCPs and more accurately informed collaborative decisions.

As both of these contribute to the quality of the information that will be vital to informed discussions, they will be considered together in this section.

A rival theory that emerged from the interviews with HCPs challenged the assumption that patient-recorded data can be reliable by questioning the trustworthiness of data recording by patients, who may have ulterior motives and may explore the potential to manipulate data to their own ends.

9.2.1 Context – unreliability of recall

As has already been described, living with a child with complex medical needs means juggling multiple demands and is an all-consuming way of life for parents. Precise memory of events can be distorted over time. Several parents in our study recognised that their memory could fail them at times:

> Tom’s mother: “I think it will be really good for … just tracking. Because days run into days don't they, and then you lose track of how many days things have been going on for.”
>
> Hospice nurse: "because they forget, don't they, parents, because they go through these things every day and asking how is last month different to this month is difficult".

The time pressure associated with attending an assessment with a professional was cited by several parents and staff as an additional challenge to accurate recall.

> Matthew’s mother: “they ask me at times how many seizures has he had in a day, you know, you can't just pluck that out of the top of your head for a given amount of time.”
>
> Sophie’s mother: “And we're literally like, trying to go through it all so quickly (*in clinic*), it always feels quite rushed. You're put on the spot a bit sometimes, because even like I know the answer, I'm trying to think back to this or that. "When was the last time this happened, or that happened?", and like, a million things have happened since then and I really can't tell you the answer! [LAUGHS]”

As well as difficulty recollecting details at a given time, the accuracy of recollection was sometimes questioned by HCPs involved with parents, as recollections varied:

> Community nurse, team A: “A parent whose child has symptoms which are actually really well controlled, but then they have a particularly bad day, can roll into "this is the worst thing that's ever happened" and it’s really difficult.”
>
> Community nurse, team B: “You get ‘Oh he's been unwell for months and months and I don't think we've had one good day’ and I'm thinking, ‘I'm sure

> you have (*said in a whisper*) because I've seen you, I've been to visit' - … but sometimes when things are bad they can only see the bad things."

9.2.2 Context – a normal environment

Parents of children with LLC may record information on MyQuality whilst they are away from healthcare support (i.e., outside hospital, hospice, community nursing or GP settings). The influence of unusual noise, smells, changing diet, sleep patterns and light levels can exert variable effects on adults and children. In some circumstances the focus of the healthcare environment can produce abnormally good results due to controlled adherence to treatment regimens and the removal of distractions, which cannot be maintained outside this artificially supportive environment. In other cases, where symptom control is a delicate balance between treatment and side effects and is easily upset by changes in normal behaviour, diet and sleep patterns, the artificial environment in healthcare may exacerbate the challenges rather than alleviate them. Thus, parental observations taken under "normal living conditions" may have greater relevance to a child and family's quality of life and provide more significant insights when making appropriate recommendations for interventions and support.

Many parents recognised the benefits of opportunities for them to record their observations at home in conjunction with HCP requests for monitoring.

> Matthew's mother: "if you are inviting healthcare professionals to view the data then it makes sense that you both agree priorities that you feel are important... it's working more collaboratively, isn't it? Ultimately it would build a better relationship between parent and doctor."

9.2.3 Mechanism – permanent, contemporaneous, relevant recording

MyQuality provides a resource for patients, parents and staff as it creates a permanent record, updated daily, producing a visual aide-memoire unhindered by loss of recall over time or affected by the influence of hindsight. This record provides a reminder of what has occurred, which can provide both the precise detail required and a useful overview of an extended period of time.

> Willow’s mother, discussing the graphs: “Oh that's useful. It’s amazing how skewed your memory can get.”
>
> Consultant: “so when you say to people "how've you been for the last month" and they look at you, and their mind empties … actually this (*MyQuality record*) is an overview.”

This could be particularly useful if recollections or opinions differed.

> Community Nurse 1, team B: “the other thing is that sometimes we see improvement over time, but then [the family] have a particularly bad day, and they catastrophise a day because something has gone wrong. Actually having a (*MyQuality*) graph that they can look at, where actually you can see it, that things have improved – positive affirmation – really really useful.”
>
> Community Nurse 2, team B: It (*MyQuality*) is providing the evidence, isn't it, to back up what they (*parents*) are probably thinking because they know their children well, but often feel anxious about raising… We had a situation the other day, where the parents were recognising that there is always a link, a causal link, between this and this, however, they have been told that there is no possible way that that is the case, medically or whatever. But actually, they know that happens, so it’s having the evidence to say, ‘this is what's happening to my child’."

The advantage of contemporaneous recording could help HCPs to trust the MyQuality data by removing inaccuracies caused by distorted recall:

> Daniel’s mother, asked about whether she thought the HCP’s trusted her to record honestly: “I'd like to think so! [LAUGHS]. I think they would, because it’s done on a daily basis. I think they probably would believe it because you are not trying to remember back… I suppose as long as you DO do it on a daily basis, and you don't have to remember the details.”

The documentation of events on MyQuality as they happened meant that the record was trusted more than verbal recollection.

9.2.4 Outcome – confidence in discussions

The presence of documented information served to increase the confidence of parents during healthcare encounters and could serve as a focus for discussion with HCPs.

> Sophie’s mother: “I still have a list of things to talk to them about if something's come up, but [MyQuality]’s sort of like a backup, that in case I've missed something, or - because you can obviously record the stuff and it can leave your brain? …. yeah, it gives you piece of mind really.”
>
> Adam’s mother: “I don't have to show them this (*the graphs*), I know I've got the information there to back me up, so if you're not listening to me, this is what's going on.”
>
> Consultant: “I'm a very visual person so I think being able to show it (*their MyQuality graphs*) back to them is really useful.”

9.2.5 Rival Programme Theory – is the data trustworthy?

A reliable record is only as good as the information entered to create it, and suggestions were made that data could be manipulated in order to get specific results. The insinuation that MyQuality data may not be trustworthy came from several different teams during the preliminary interviews.

> Hospice doctor: “you run risk of the people skewing what they are recording because they want to make sure things look as bad as possible to get more respite care, so there’s always a few people who will, you know, not use the tool in the way that you had intended.”
>
> Community Nurse, team A: “it’s not like you could use this for panel* for evidencing or anything, if it’s produced by the parents...”
>
> Community Nurse manager, team A: “how do you counteract fabricated illness? Presumably you can't on this platform? ….. I'm just aware of the child protection aspect, we always have to think about it. If hypothetically [X] had (*used MyQuality*) would it have changed our approach or not? Or would it have made us collude with [an abusive parent] because she was ‘evidencing’ what she was saying at the time (*with a MyQuality graph*)?”

Although the theoretical risk of using MyQuality for secondary gain was recognised by parents and professionals alike, there was also recognition that this issue was not limited to MyQuality.

> Adam’s mother, asked about the possibility of manipulating data: “it’s the same if you go into an appointment or if you go into a clinic, you can say ‘Oh my pain is really bad’ when actually it’s no different, is it. There’s no difference, really, recording it or seeing somebody face to face… If somebody

> is going to manipulate data, they’re going to do it, whether it’s on-line or face-to-face.”
>
> Community nurse, team B: “They can do that (*manipulate information*) when you speak to them. How is that any different, when they can tell you what they want to tell you. We're not with them 24/7 so we always have to rely on parental information, so – we just have to trust them.”

The practical limitations to using MyQuality to manipulate data for personal benefit were identified by patients’ parents, who questioned the motives and time required to use it for this purpose.

> Katie’s mother: “[LAUGHING] I wouldn’t have time to think about it (*manipulating data*)! For me personally, it is literally – I don’t have time. It’s there, I type down what has happened (*onto MyQuality*) and it’s there and I move on. I wouldn’t have time to think about that in all honesty.”
>
> Daniel’s mother: “There's always the potential to manipulate data, and to be honest I quite like to steer clear of hospitals so [LAUGHS] I have no desire to go for extra appointments or admissions.”

Others recognised the value of trusting relationships:

> Daniel’s father: “And trust takes a long time to build up and is very easily shattered. It’s one of those things that is very difficult to repair if it’s broken, unfortunately.”

Many HCPs recognised that the risk of using MyQuality data as “evidence” was not significantly different from face-to-face discussions, where trust was an essential component of the clinician-patient relationship.   Responsible professionals would recognise the need to consider all the “facts” presented before them when advising their patients and families on appropriate action.

> Community paediatrician, team C: “I guess, you know, an example theoretically where there was a child where parents were fabricating symptoms, it (*MyQuality*) could be utilised as a tool for secondary gain under certain circumstances. I think that's a theoretical risk of the system. And I guess if you were seeing a child and physically they looked very different from what was being reported, and you were cross-correlating the evidence with school, parents, and what you were seeing in clinic, and it didn't add up then there's a risk associated with it… It’s a question of trying to triangulate information and then managing it on a case-by-case basis.”

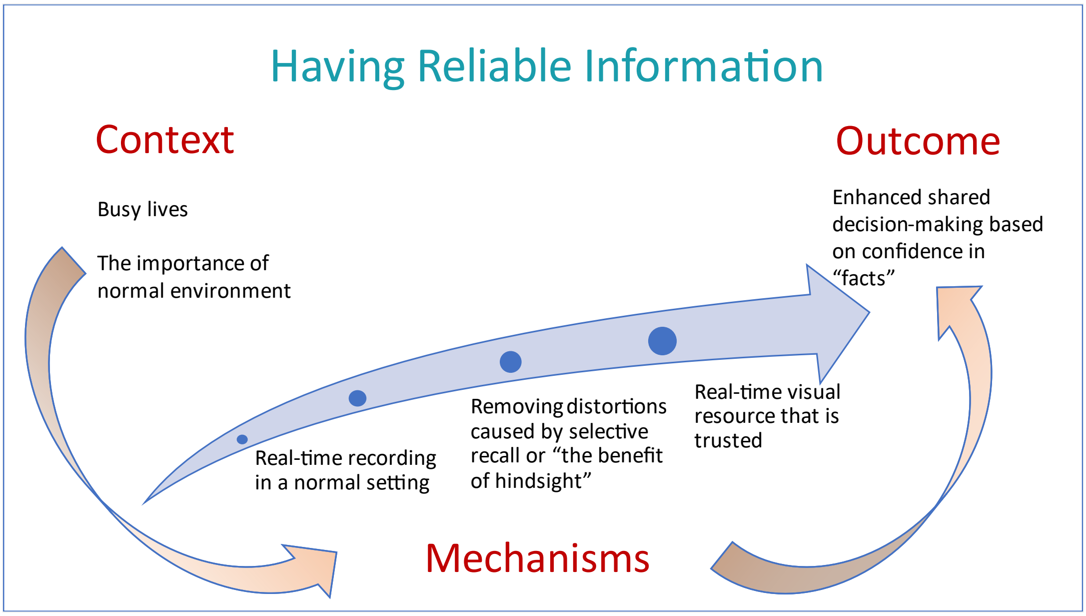
The concept of fabricating data using MyQuality was refuted by parents in this study for a range of reasons, including the presence of simpler options for data manipulation for those inclined to this, and the pointlessness of the endeavour.

9.2.6 Refined programme theory

The concepts about having a permanent record and relevant information have been brought together to form a programme theory to consider the reliability of information available during healthcare encounters and how that could influence the processes of communication, teamwork and shared decision-making. The refined programme theory is as follows:

> Having a **reliable record**: Parents of children living with LLC carry a considerable burden of responsibility to be the eyes, ears and voice for their children. The precise memory of events can be distorted over time (context), or behaviour may be affected by changes in the environment (context), both of which could increase the unreliability of the data. If individuals can monitor, quantify and document their symptoms daily using MyQuality, they will develop a real-time visual record which acts as a trusted resource for them and for their healthcare professionals (Mechanism), unaffected by the hindsight, loss of recall, or unusual surroundings. The accuracy of this information can support greater confidence (outcome) that no details have been inadvertently omitted or mis-reported during discussions, which is reassuring to both parents and HCPs.

Figure 9-3 CMO 8 - Reliable Information



The rival theory, relating to the trustworthiness of data, reflects important concerns about professional responsibilities, but within this study it was not possible to assess whether these concerns were justified in practice.

9.3 Programme Theory 9 – Teamworking and partnership

One of the key principles of person-centred care is that it involves clinician-patient relationships based on honesty, trust and developing rapport (Scholl et al., 2014). Although traditionally these relationships have developed during face-to-face encounters, the variety of ehealth approaches described in the literature review give some insights into the ways that different communication patterns can affect how relationships develop when there is a technical interface, be it telephone (intermittent contact, real-time voice but no visual input), video calls (intermittent contact, real-time voice and visual information but remote locations), email or other electronic communication using text only (rapid communication any time, without voice or visual input), or m-health (remote monitoring, continuous or intermittent).

The provisional theory derived from the first MyQuality study (Harris, Beringer & Fletcher, 2015) and the literature review was as follows:

> **Collaboration**: Individuals who choose to share their recorded MyQuality information with their healthcare professionals will demonstrate a willingness to share the challenge of improving their quality of life by engaging in dialogue. This may reduce the sense of isolation and support resilience for individuals and families and will support collaborative working practices with HCPs.

In addition to demonstrating a willingness to work in partnership, I have chosen to expand this initial theory with concepts about the ongoing nature of this partnership. In this study MyQuality was to be used alongside conventional face-to-face encounters in healthcare, augmenting the intermittent in-person contacts with the facility for more regular electronic contact and monitoring reports. One theory was that the additional timely information exchange would support and enhance the usual patient-professional relationship, but it was also possible that technology would intrude on conventional social interaction and disrupt established patterns of behaviour. This second rough programme theory was as follows:

> **Rewarding relationships:** Giving and receiving healthcare has rewards and benefits for both participants. Interactions between healthcare practitioners and patients are social encounters between individuals with differing perspectives and skills, and give value in themselves irrespective of health outcomes. These effects may change for both parties if face-to-face healthcare encounters are supplemented or replaced with e-health interaction.

This section will explore the dynamics of the partnerships and communication experiences of the participants in this study, to clarify these theories from the perspectives of both patient/parent users and HCP users of MyQuality.

9.3.1 Context – isolation

Many parents whose children have complex needs are relatively socially isolated due to the constant demands of providing healthcare for their children. The rarity of many underlying conditions means that there may not be a natural community of families in the similar circumstances nearby. Many families of children with LLC develop supportive relationships with healthcare professionals over time, fostered by continuity of care. These clinician-patient (or clinician-family) relationships form part of Scholl's principles of providing person-centred care (Scholl et al., 2014), valued for introducing "humanness" into professional encounters.

Similarly, there are challenges for professionals when supporting patients with rare conditions for which the evidence base for treatment and support is often lacking. Professionals may find it impossible to rely on previous experience or a body of expertise to support complex clinical decision-making, which can feel threatening in an increasingly litigious medical environment. The development of collaborative working practices with patients and their families, supported by clinician-patient relationships built on solid foundations of honesty, trust, respect and developing rapport with patients, can support HCPs to work with families to make difficult decisions in their best interests.

At times, parents made specific reference to these challenges for both parents and as HCPs, and the need to learn together:

> Charlotte’s mother: “I don't know if I’m missing anything but (daughter)'s normal isn’t normal to everyone else is it, so you know, are there things that I'm missing?”
>
> Sophie’s mother: “I know - especially with (Dr A), … she's the lead, with a lot of experience. But she's also always wanting to learn as well.”

The nature of relationships between HCPs and patients is subject to professional regulation, with clearly defined roles and responsibilities for both parties, but both are also human beings. Clinical encounters in the field of children’s palliative care bring together people who are facing existential issues at times of emotional vulnerability. Parents may be facing the potential death of a child, and HCPs the potential death of a patient – not equivalent losses, but both are difficult experiences. This process can test the ability of both the professionals and parents to navigate the uncertain waters ahead.

Healthcare professionals referred to the additional depths of insight gained through inspection of MyQuality data, and how this helped them to make sense of challenging clinical circumstances.

> Community paediatrician: “[child’s mother] really has helped me (understand where she’s coming from) … When I looked at them (*MyQuality graphs and diary notes*) retrospectively knowing how the last few months have been, the comments were really helpful, because they highlighted the difficult days, the good days, when - they highlighted not just the graph, but the qualitative information adds meat to the bones, and it gave me a really nice chronology to see how things had been.”

9.3.2 Context – continuity of care

The chronic nature of many life-limiting conditions means that many patient-professional partnerships are longstanding. As such, relationships develop over repeated clinical encounters. For clinicians this provides opportunities to gain a deeper understanding of the patients and parents that they work with, which can foster the development of supportive partnerships over time as they share challenges and receive feedback from patients.

> Daisy's father: "Her surgeon was, initially, early on in our relationship, he was a bit dismissive of me, he… At a certain point [he] realised that what I was saying was relevant and I wasn't wasting his time unnecessarily and now he listens to me…. because he knows I'm not messing about. But it's taken a while for us to get to that sort of a relationship."

The small numbers of children with LLC means that specialist teams may have smaller caseloads, accentuating relationships with this group of children and their families compared to paediatrics as a whole:

> Community nurse: "I think we're invested in our patients. We want to get them as stable as we can. I can see some, like, medical colleagues, they dip in and out of these patients and they've got so many, whereas we have that smaller caseload of these patients that we know really well over a long period. We're invested into getting it right. We have so much contact with the family, with the carers, with the school, like – it's not just an appointment once every 6 months … and we see the effect that these symptoms have on their whole lives, you know, the siblings, the extended family, the schooling, their opportunities. We see how debilitating these symptoms can be …"

The duration of contact and the level and breadth of detailed knowledge of the children and their families can surpass some of the normal barriers of privacy that would exist in more superficial or transient healthcare encounters. MyQuality can accentuate this if the daily diary feature is used to clarify health or emotional details that might not usually be sought during a standard encounter. In this study, all seven regular users supplemented the numerical data with additional descriptions or emojis to represent mood or responses to events.

> Community Paediatrician: "She [patient's mother] does it (*MyQuality)* religiously, it looks like every day. And she writes notes in as well, because I've seen her diary notes. She gives me little comments and things. It's useful to see, I just find myself a little bit frustrated when it comes to [child], because there's not very much I can do about any of it."

At times this level of additional information felt uncomfortable, and HCPs needed to readjust their perspectives about what unsolicited information was being offered via MyQuality and what that meant about their working relationship:

> Consultant paediatrician: “I find it interesting to look at it (*diary notes and graphs*), but … you do feel a little like you’re spying on them! [LAUGHS] And yet [mother] puts that information in for me to see.”

Constructive working relationships between patients and HCPs are helped by the recognition of clear expectations and understanding the boundaries of responsibilities of both parties.

> Community nurse 1: “Ultimately, for all the patients that we manage it’s their mum or their dad as the primary carers. And if they are as positive as they can be and in a good place it will ultimately affect the care that they are giving, and their child will then be in the best place, so surely that would be our aim? … Everything we do is about supporting them in their role and supporting them to be the best carer that they can for really complex children where they do have to be a nurse, mum, and everything else. If they actually feel like a mum, then we've done our job!”
>
> Community nurse 2: “we're constantly trying to refocus them into the – ‘you are mum’, you're not a nurse, you are not decision-making all the time if you don't want to be. That's what we are here for, so you can just be Mum, or Dad.”

9.3.3 Mechanism – understanding patterns together

Bringing together the expertise of patients, parents and HCPs can help to address complex symptom management in a person-centred manner. Using the communication resources harnessed by MyQuality (in terms of the interactive display and shared access to diary notes and monitoring progress over time) allows the more thoughtful consideration of possible ways to resolve challenging clinical problems.

Parents in this study expressed their concerns about the responsibilities they were undertaking and appreciated the opportunity to share information which could act as a “backup” for them, reducing their isolation as guardians of their children’s health and wellbeing.

> Adam’s mother: “it would be nice to sit with [Dr A] and look through it (*the MyQuality graphs*) with her, get her input and see if there's something I'm

> missing. Because sometimes you can look at things and you can't necessarily see it, but someone else looking can go - well actually, that tallies with that. You don't always see it yourself even if it’s right in front of you.”

MyQuality supports the sharing of information, with the added advantage that this can be translated into a format that is more readily interpreted by professionals.

> Hospice doctor: “they (*parents*) are choosing to share it (*MyQuality data*) with you, so they are offering you that information and people - if you do make the time to sit with them that's what they do all the time anyway. But the tool (*MyQuality*) perhaps enables you to pick out the patterns a bit more.”

The ability to see and make sense of underlying trends can provide an objective perspective on events for parents, supporting them to make sense of their reflections on events. This additional knowledge and understanding (see section 7.4) can then be refined by working together with a HCP with whom they already have a supportive, trusting relationship, with the ability to advocate on their behalf.

> Hospice doctor: “the tool (*MyQuality*) perhaps enables you to pick out the patterns a bit more … obviously first and foremost what the parent/carers say is the most important thing, … - but just sometimes they are so involved in it that they can't see the patterns, or they need someone who is just a bit more remote to say “hang on a minute, you're saying this and this means this but I'm really not sure that that's true”… Because just occasionally I think the emotional side gets in the way, or it’s the way that things have been done for so long that they (*parents*) just can't quite see it objectively.”

> Community nurse: “I don't think we pretend that we know everything, but actually knowledge is power in terms of recognising, and then advocating on behalf of the patients … So it may well be that we use that (*MyQuality*) information to go to the child's clinic appointment with the consultant and say we recognise in discussions with mum that this is what's happening, and actually we're quite concerned about that. And actually this hasn't helped, and …”

9.3.4 Outcome – safety backup and reassurance

This teamworking could have advantages in harnessing necessary expertise, providing timely care provision for the child and reassurance for the parents:

> Sophie’s mother: “I might write something (*on MyQuality*), or plot something, that [Dr X] might think "I want to talk to her about that" whereas I might not have picked up on it necessarily…. Which I think is very helpful. Because although I'm very in tune with [daughter], I might miss something. So it’s almost knowing that I've got someone watching – like a backup system … They can pick up on stuff earlier I think.”
>
> Katie’s mother: “(MyQuality) is also reassuring in the sense that “I am not alone here, other people can see what’s going on.”

The reassurance provided by sharing MyQuality data was also noticed by HCPs:

> Consultant paediatrician: “And lately, the last few months, seem to have been relatively calm on a [child] front. You can see that from those graphs can't you, because she started really high, her scoring, and then she's kind of levelled out on most things. And then every now and again one of them will blip up, like her pain, she might have had a bad day with pain or a bad day with sleep, and I can see that. She fluctuates a lot, but it gives us a feel for, you know, what the week's been like for them.”

In turn, the reassurance provided by sharing data enhanced closer working by both parties and helped to foster supportive collaborative working patterns.

> Daniel’s mother: “I hope they respect us as much as we respect them. It feels like it’s a team, not just us against them. I'd say maybe we more SHARE the evidence, rather than show. So it’s more of a joint approach.”
>
> Daisy’s father: “the paediatrician has been more involved, more connected in the last 6 months. I did discuss it (*MyQuality*) with her and what I thought it showed, and she talked to me about those issues. I've had two meetings with her this year, one a couple of months ago which was really helpful.”

The nature and timescale of this study did not provide examples of broader or long-term rewards of care relationships so it was not possible to confirm or further refine this CMO configuration, but this is an area that would be important to explore in future work.

Experienced HCPs could see how this approach could help them to advocate on their patients’ behalf more effectively, as in this example from a community nurse:

> Community nurse: “What happens at the moment, is I can go to the consultant (*about a child’s symptoms*) and they say right I'll arrange a clinic asap. So they (*the parents*) have to bring them into hospital, it’s a medical environment. Whereas actually if we can go to the consultant and say THIS is your information (*from MyQuality*), this is what mum’s reporting. It’s good reliable information. Action from that will prevent unnecessary visits to hospital or clinic or wherever.”

Some parents could see the potential to collaborate using MyQuality with various specialists, developing new facets to a partnership approach to supporting children with complex needs.

> Daisy’s father: “Can I just mention that - the measurements - what I sort of struggled with is that they are a bit subjective, which I understand is part of the point. But if I were a neurologist, I would be looking for something a bit more specific I would imagine? Do you know what I mean - a bit more exact as a measurement?
>
> Interviewer: “So do you think - if the neurologists came and said "I want you to measure this or I want you to put such-and-such on your MyQuality"…
>
> Daisy’s father: “I'd be happy to do that. Because they know what they are talking about, what they are looking for in terms of monitoring her, her development and stuff. So I wouldn't have a problem with that… I mean I look after her every day so I get a good picture of how things are with her and whether they're getting better or worse or whatever.”

Collaboration could create new opportunities for joint working and demonstrate a healthy respect for each other’s areas of expertise.

9.3.5 Rival theory – Absent Connections

At times it can be difficult for HCPs to find rewarding outcomes of relationships with patients, particularly if they feel they may be underperforming, outside their comfort zone, and not living up to self-imposed expectations. Scholl (2014) identifies some essential characteristics of the clinicians, such as empathy, compassion and respect, as key to the provision of person-centred care, and these apply to supporting the self as well as to dealings with others. Many HCPs come into this area of work wanting to “make a difference”, and the feeling that you can’t, or don’t know how to, can damage professional confidence and self-esteem. On a personal level, no-one wants to “get it wrong” in these circumstances.

MyQuality can highlight the details and challenges in patients’ lives. In this excerpt, HCPs contemplated the motivations of colleagues who did not feel confident to deal with the complexities of supportive care, where avoiding difficult questions could be a coping strategy for a difficult area of work:

> Nurse, team B, reflecting on why some colleagues might not be keen to engage with MyQuality: “They’d rather not know! … I think there's a confidence issue … like, you can tell me (*about a problem*), but I don't know what to do. And the more you tell me, that means I've got to do something about it, and if I don't know what to do I'd rather not know, thank you.”

Several of the HCP teams recognised that working in partnership with patients and their parents was key to the effective delivery of care. The absence of a constructive relationship could hamper the provision of support by HCPs to children with complex needs:

> Community nurse 2: “the biggest fear is "I don't know that child, I've never met them before" and nurses particularly, I'm sure it’s the same for other professionals, are loathe to give advice or even see a patient child (*that they don’t know*). … they don't want to make decisions about them because they haven't got a relationship with them.”

Some teams, or groups of professionals, appeared to be more comfortable than others to admit the limitations of their knowledge or experience and seek advice.

> Community nurse 3: “we support ourselves within our team – (*asking*) has anybody got any ideas of what we can do about this, where do we go next. … I think there are very few people who would call themselves experts without needing anybody else to support them with that. That's where team working is at its best, when people acknowledge that it takes all your professionals to come together to do the right thing.”
>
> Community nurse 1: “what we've seen recently is that medical professionals are not so good at using peer support … Even for palliative care, they're not that great at supporting each other, whereas that's the first thing we do (*in our team*), we say "I don't know what to do, can you help me?".”

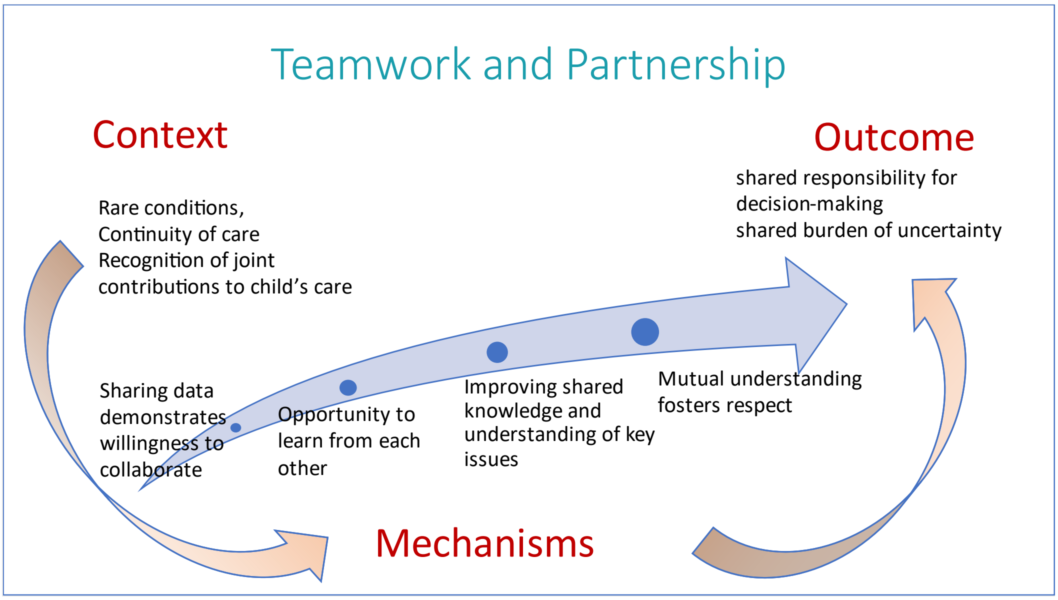
It was not possible to get much detailed feedback from those HCPs who did not engage with MyQuality to test the theory that MyQuality could highlight difficult challenges that were sufficient to deter HCPs from engaging with families, but this concept suggests further work about the resilience of staff working in this field would be welcome. This would tie in with some of the adverse outcomes identified by HCPs in chapter 8 concerning the resilience of staff and threats to the sustainability of services.

9.3.6 Revised programme theory

Collaboration, teamworking, and sharing the responsibility for planning care and support for children with LLC can help to alleviate some of the burden of responsibility felt by parents and HCPs alike when faced with difficult management scenarios. The programme theory was refined as follows:

> **Teamwork and Partnership**: As LLC are uncommon, patients, parents and professionals may be isolated and inexperienced about the management of problems (context). Individuals who share their data with HCPs demonstrate a willingness to collaborate. This allows them to bring their respective observations and expertise together to improve knowledge and understanding of key issues, fostering mutual respect (mechanism). This can support timely and responsible clinical management, sharing decision-making and the burden of uncertainty, and providing psychological reassurance to both parties that they are doing their best (outcome).

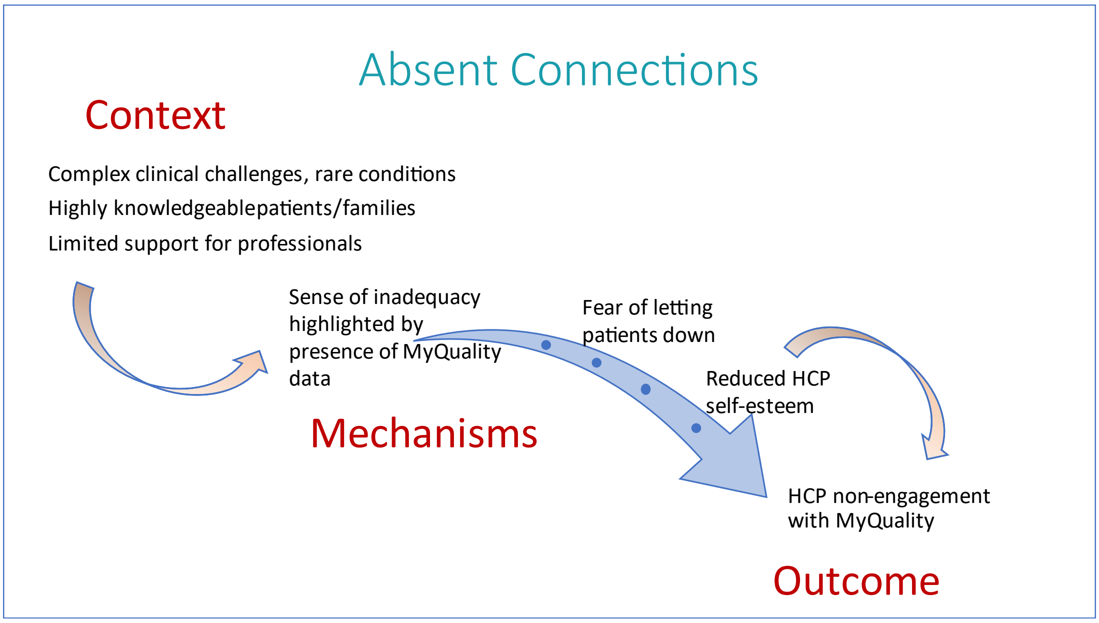
Figure 9-4 CMO 9 - Teamwork and Partnership



The absence of productive relationships could result in MyQuality data being seen as a burden or threat:

> HCPs who work with highly knowledgeable and experienced patients or their parents (context) may struggle to fulfil their role as a professional carer (outcome) if they feel that MyQuality highlights challenges they cannot address (mechanism).

Figure 9-5 Rival CMOc - Absent Connections



9.4 Communication Processes and MyQuality – overview and consolidation

This chapter considers the centre of Feldman-Stewart and Brundage's model which considers the communications process itself, including the primary goals, enabling factors, and message delivery (Feldman-Stewart & Brundage, 2009). It covers theories to explain how MyQuality supports goal-setting by sharing dialogue about priorities for care, having appropriate and reliable information to make informed decisions, and collaborating as a team. Overall, these factors support communication as outlined in Fig 9-6.

Figure 9-6 Overview CMO for processes of communication

Context	Mechanism Resource	Mechanism Response	Outcome
Multiple complex clinical concerns	Process of choosing priorities identifies goals	Patient/parental perspective highlighted	Shared awareness of goals and priorities supports a patient - centred focus
+			
Rare and/or unpredictable nature of health and social support needs	Reliable information collected from “normal” settings	Information is trusted	Enhanced decision - making, shared responsibilities
	Data-sharing provides a focus for collaboration	Mutual understanding fosters respect	Shared burden of uncertainty

9.5 Amalgamation of all CMOc’s into an over-arching programme theory

Thus far, the integration of feedback from both parents and HCPs about using data from MyQuality, combined with observations about website use, has allowed the development, consolidation, and refinement of theories to explain when, for whom, how and why MyQuality can support communication between HCPs and patients.

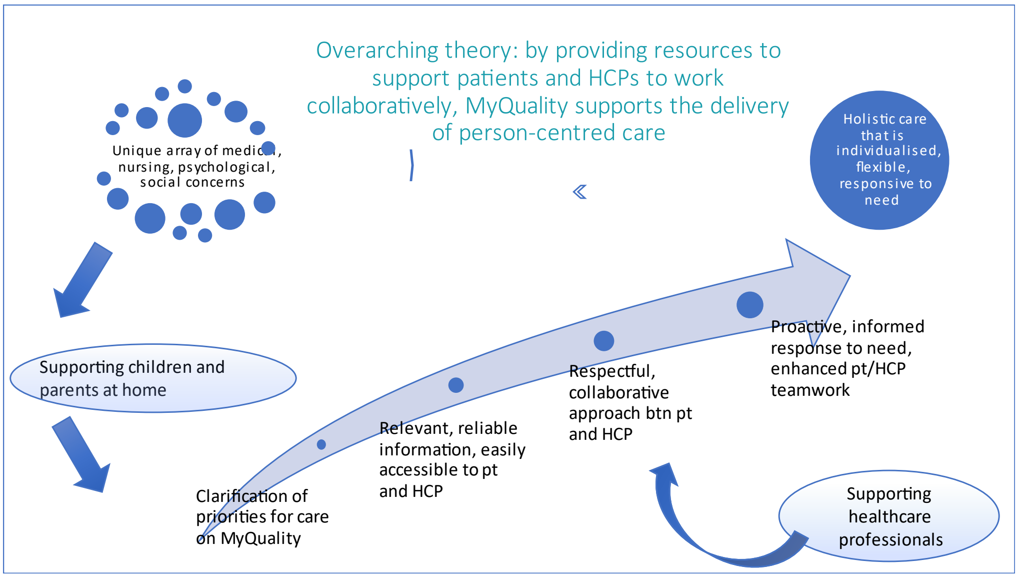
Whether or not they share their data, parents have described how they can benefit from the facilitation and convenience of documentation, reflecting and highlighting the issues that matter to them. Parents described improved understanding of their child’s health from the outputs of the graphic display, and the value of recording real life in numbers and words to provide a testament to the narrative of their child’s life. All of these can simplify the some of the challenges of caring for a child with complex healthcare needs, allowing more time to be spent with their children in the mode of “parent” rather than carer.

MyQuality can encourage healthcare professionals to hear and respond to the concerns of patients and their parents, and create the environment for more efficient, informed communication and constructive partnership.

Whilst the findings have been presented thus far in granular detail, the interplay between patients, HCPs and the communication process is vital in order for

MyQuality to support the delivery of person-centred care. Figure 9-7 visualises how these areas work together.

Figure 9-7 Overview model of PT about MyQuality and PCC



9.6 Summary of CMOc's

These chapters have demonstrated the mechanisms by which MyQuality can aid communication processes to deliver person-centred care, illustrated with evidence provided during interviews with key stakeholders when exploring, testing, and refining programme theories. Considering these in granular detail enabled enhanced understanding of the individuals' and teams' responses to this process, and this depth of understanding can facilitate the appropriate implementation, use, and evolution of MyQuality in the provision of healthcare. The next chapter will consider the implications of this approach for patients and their parents, HCPs, healthcare organisations and policy on a wider level.

10 Discussion of Findings

This thesis concerns the research question "How does an ehealth intervention such as MyQuality affect the delivery of person-centred care for children with life-limiting conditions?", with an emphasis on exploring the impact of ehealth on the dynamics of patient/parent-professional communication. Having consolidated the findings from the literature, website use and reflections from both personal and professional users of MyQuality to develop theories about how and why MyQuality enables communication and the delivery of person-centred care, this chapter will discuss these findings in the wider context of relevant middle range theories.

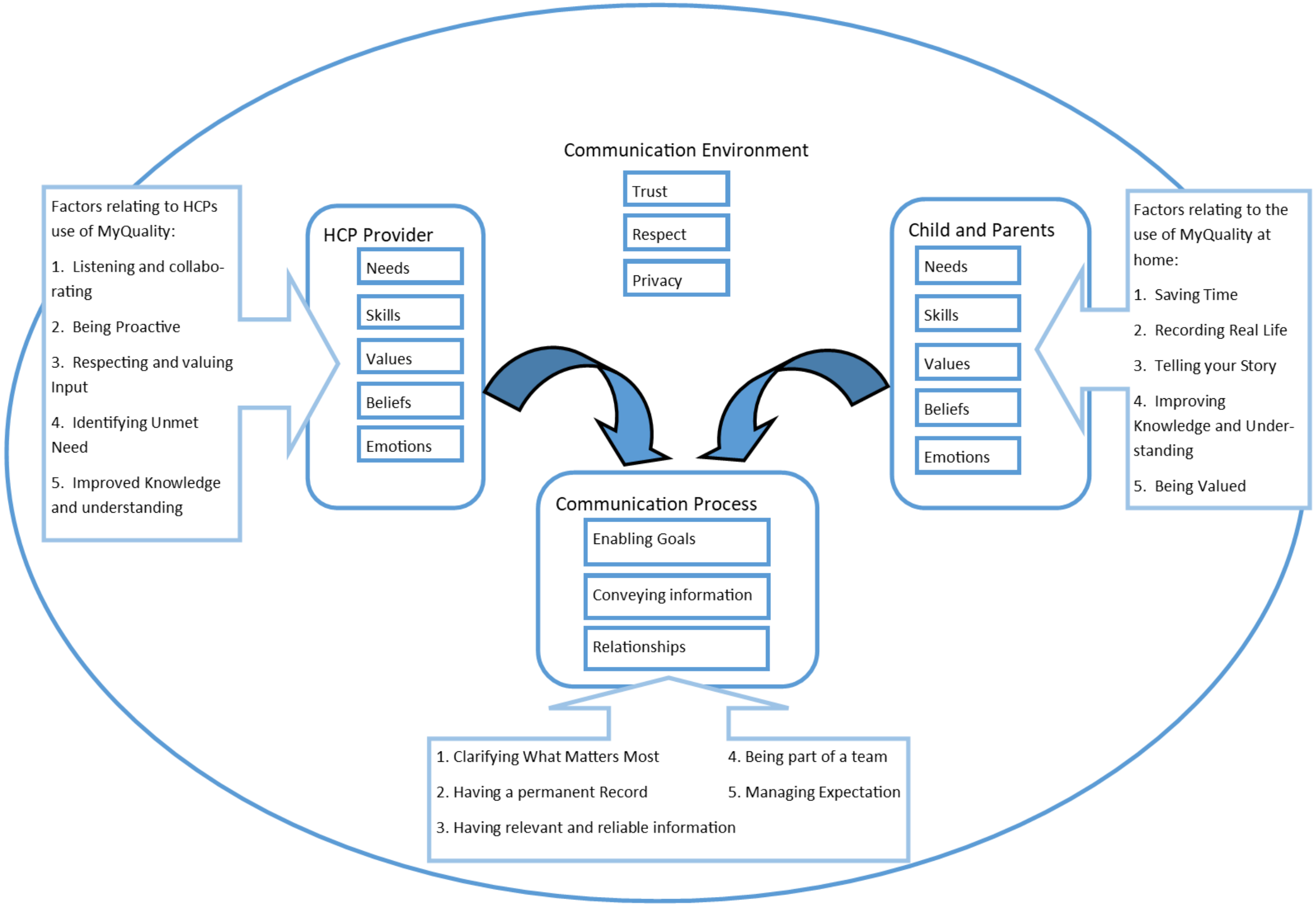
10.1 Middle range theory

Thus far the thesis has focussed on developing explanatory theories that pertain specifically to the use of MyQuality, as an example of an ehealth intervention using individualised outcome measurement. It is also possible to look at these results from a more abstract perspective by engaging the insights provided by relevant middle range theories. This process will enhance the understanding of identified mechanisms and facilitate exploration of the wider implications of the programme theories unearthed about MyQuality which may be applicable in other circumstances or settings.

10.1.1 Patient-Provider Communication

In their model of patient-provider communication involving PROMs Feldman-Stewart & Brundage (2009) outline four components: the patients, the healthcare provider, the communications process, and the environment. These are illustrated in Fig 10-1, with the model adapted to reflect the findings in this study. The first two components relate to the theories outlined in chapter 7 concerning patients and their parents, and chapter 8 about HCPs. The third component concerns the communication goals and conveying of messages as described in chapter 9. Their fourth section relates to the environment in which the communication occurs, which features in many of the contexts outlined in the previous sections and affects both micro- and meso- level programme theories already described, but also references wider influences on behaviour in society.

Figure 10-1 Final model - MyQuality and Communication



A key constituent of this communications model is the importance of recognising the needs, skills, values, beliefs and emotions of the participants. In the case of the patients and parents or carers interviewed in this study, all were driven by the need to support their ill child and family to the best of their ability and to make use of opportunities to provide their children with as “normal” a life as possible, treasuring opportunities for meaningful and rewarding time together. They valued their children’s existence and the quality of their family life, believing that as parents or carers they could make a difference. All reflected on their roles as a parent of a child with complex needs, illustrating many of the dimensions described by Woodgate et al. (2015). Parenting was seen as not simply an activity, but as a fulfilling aim in life - several alluded to being “the best mother/parent that I can be”. In order to do so parents acquired a range of specialised skills and took on considerable responsibility for their child’s wellbeing but described challenges in having this expertise and commitment recognised and valued by others. Elements of the needs, skills, beliefs, values and emotions of patients and their parents were included in the first four programme theories.

10.1.2 Self-Determination Theory

Many of these features reflect aspects of Deci and Ryan’s Self-Determination Theory (SDT), in particular the Basic Psychological Needs sub-theory (Ryan & Deci, 2017). Basic psychological needs are broadly defined as critical resources underlying individuals’ natural inclination to more towards increasing self-organisation, adjustment and flourishing (Vansteenkiste, Ryan & Soenens, 2020). The three basic psychological needs identified by Deci and Ryan are autonomy (the feeling of being the origin of one’s own behaviours), competence (feeling effective), and relatedness (feeling understood and cared for by others) (Ng et al., 2012). These three needs represent “psychological nutriments that are essential for ongoing psychological growth, integrity, and well-being”. Other elements of SDT explore the motivations and goals of human behaviour (Deci & Ryan, 2008).

Autonomy refers to the experience of volition and willingness, and the need to self-regulate one’s experiences and actions. This is not the same as independence or self-reliance. The hallmark of autonomy is that one’s behaviours are self-endorsed, or congruent with one's authentic interests and values. When acting with autonomy, behaviours are engaged wholeheartedly, whereas one experiences incongruence and conflict when doing what is contrary to one's volition (Ryan & Deci, 2017). Autonomy support includes affording individuals choice and encouraging self-regulation.

Competence concerns the experience of effectiveness and mastery (Vansteenkiste, Ryan & Soenens, 2020). People need to feel able to operate effectively within their important life contexts. Competence is supported when individuals act within defined structural parameters and receive positive informational feedback, but wanes in contexts in which challenges are too difficult, negative feedback is pervasive, or feelings of mastery and effectiveness are diminished or undermined by interpersonal factors such as person-focussed criticism and social comparisons (Ryan & Deci, 2017).

Relatedness involves feeling socially connected. People feel this most typically when they feel cared for by others, but this also includes a sense of belonging and feeling significant among others. By both feeling connected to close others and by being a significant member of social groups, people experience relatedness and belonging, through contributing to the group or showing benevolence (Ryan & Deci, 2017; Ng et al., 2012). Inability to relate to others comes with a sense of social alienation, exclusion and loneliness (Vansteenkiste, Ryan & Soenens, 2020).

Supports for autonomy, competence and relatedness are not only theorised to facilitate more self-determined and high-quality functioning in the short term, but are also understood to promote the development of more effective self-functioning, resilience, and enduring psychological health for the long term (Ryan & Deci, 2017). Satisfaction of an individual's needs for autonomy, competence and relatedness is a necessary condition for a person's growth and integrity and fosters overall well-being (Ryan, Huta & Deci, 2008). These contribute to eudaimonia, a term described by Aristotle (Rowe, Broadie & others, 2002) as a life lived well, or the realisation of valued human potentials. Eudaimonia is not a feeling or a state of being, but a way of living that includes virtues such as courage, generosity, wisdom, and being fair and just to others. Aristotle's eudaimonia is characterised by reflection and deliberation concerning an individual's actions and aims, and behaving voluntarily toward ends that represent the realisation of our highest human natures (Ryan, Huta & Deci, 2008).

10.1.2.1 Self-determination theory and support for children and their parents (PTs 1-4)

Many of the mechanisms identified in the programme theories about MyQuality address one or more of these basic psychological needs. When considering how the use of MyQuality supports patients and parents at home, the provision of simple and efficient methods of documentation (PT 1 & 2) under the control of the MyQuality user (autonomy) which support improved knowledge and understanding (PT 4) of the child's care and needs (competence), with clear reflection and articulation of a narrative (PT 3), can improve confidence and resilience for parents. This study did not set out to measure parental psychological health, resilience or overall wellbeing, but the features described as outcomes of these activities (greater control, improved confidence, more "quality time" to be a parent rather than a carer) portray the values and beliefs of parents that they can improve the quality of life for their children and family. These are reflected in the professed aims to do their best for their children, providing meaning and purpose to life in the eudaimonic tradition.

The first PT, "Simplifying Intensive Parenting", describes the mechanisms whereby MyQuality, through the provision of an easy and convenient method of documentation, supports parents to save time by becoming more organised and methodical in the time-consuming record-keeping required to ensure safe care for their ill child. This process creates opportunities to spend more time on "normal" family roles such as being a parent rather than a carer. This supports the parental basic psychological need of relatedness, and the process bolsters parental feelings of competence and autonomy. It also reflects the parental need to document their child's daily life, in the belief that this aspect of parental duty will enhance their safety and is a parental responsibility.

The second PT, "Recording 'Real Life'" recognises the value of creating a true and holistic record of the varied nature of every child's and parent's experiences. When choosing what to record, the personal users exercise their autonomy. This documentation process extends to include the use of the diary function and creates an opportunity for reflection, contributing to the processes described in the third theory, concerning sense-making. This can support an evolving narrative which shapes the relationships and perspectives of how the child and family interact with the world around them. The need to "Tell my story, have my say" was articulated by many parents and reflects relatedness, competence and autonomy.

The final theory examines "Improving Knowledge and Understanding" by parents regarding their child and his/her condition, which enhances competent parenting. The belief that this is a parental role and important skill, needed for the safe care of their child and valuable to them as parents, places this explanatory element of the use of MyQuality by personal users into Deci's overarching theory, highlighting aspects of competence and autonomy.

10.1.2.2 Self-determination theory and support for HCPs (PTs 5 & 6)

Those HCPs who engaged with MyQuality (autonomous decision) found new opportunities to learn and improve understanding of the child's needs (competence) and to collaborate and develop relationships based on mutual respect (relatedness). These positive approaches to meeting their psychological needs led to responses such as more focussed engagement and active listening (PT5) and proactive management (PT6), this enthusiasm representing a sense of subjective vitality associated with eudaimonia (Ryan, Huta & Deci, 2008). This endorsement for the use of MyQuality to enhance the ability of HCPs to support parents was noted particularly from the range of professionals who worked in community settings, where there may be more opportunity for practitioners to work autonomously and to build and maintain long term relationships with their patients and families. The act of listening by physicians has previously been shown not only to improve the quality of data gathering, diagnosis and therapeutic interventions, but is also associated with creating and maintaining good doctor-patient relationships, and can act as a healing and therapeutic agent in itself (Jagosh et al., 2011). In this way, the theories about how MyQuality supports listening and proactive patient management tie in with the theories about communications processes in the next section.

Those who did not engage most frequently cited the potential loss of control over their workload (a threat to autonomy) or a risk of being overwhelmed by a range of issues which they did not feel competent to address. These reactions were noted from multiple professional groups, but primarily from those based in institutions rather than working in the community. The potential for damage to relationships by "letting people down" or favouring some over others as with the risk of an inequitable service due to a digital divide could upset the desired interactions with others (relatedness). These threats to the psychological needs of HCPs could lead to emotional responses of fear or apprehension, with the potential for negative effects on their psychological wellbeing and personal resilience, ultimately leading to burnout of individuals and unsustainable clinical services (Kavalieratos et al., 2017; Donohue et al., 2018).

10.1.2.3 Self-determination theory and communication processes (PTs 7, 8 & 9).

The third group of programme theories is focussed on the processes of communication themselves rather than the individuals who participate in it and includes the identification of goals and conveyancing of messages. The ability to agree on goals (PT 7, "Clarifying What Matters Most") supports the autonomy of both the individual patients and their parents, and the healthcare practitioners' ability to provide support most effectively. The provision of "Reliable Information" (PT 8) enhances competent decision-making, and "Teamwork and Partnership" (PT 9) addresses the psychological needs for relatedness of both parents and HCPs. Babenko (2018) has highlighted the particular importance of relatedness (rather than autonomy or a sense of competence) as a key underpinning of physicians' professional wellbeing, a critical component of quality patient care.

Although the focus on basic psychological needs can illuminate aspects of the Feldman-Stewart & Brundage model of communication, it is important to recognise that this model also highlighted the various other needs, skills, beliefs, values and emotions of participants as well. The variable levels of practical needs and emotional states over time depending on the course of a child's deterioration in health means that different levels of engagement with MyQuality, varying with circumstances, would be expected. This is what was observed both in the initial

MyQuality study (Harris, Beringer & Fletcher, 2015) and with patient/parent participants in this study.

For HCPs, external factors such as the dynamics within and between team members and different organisations further complicates the assessment of why individual HCPs choose to engage with MyQuality. This study is too small to draw conclusions based on numerical assessments, but it is notable that those who did choose to use MyQuality were in primary support roles such as community nurses, community paediatric teams or hospital outreach teams. HCPs in secondary or tertiary support roles were collectively more reluctant to engage or to identify suitable participants, perhaps because of the additional tiers of relationships such as those between different provider teams, or tensions between clinical demands and other professional obligations. Competing priorities, potential reductions in autonomy, perceived threats to their assertions of capability, and a more complex array of relationships at levels more abstracted from direct patient care may have diminished their motivation to adopt MyQuality as a tool to improve communication or reduced the flexibility in their working patterns to permit this. These potential causes deserve further exploration in the future, but have been noted in similar populations of hospice and palliative care providers (Kavalieratos et al., 2017).

10.2 Patient Empowerment

The first MyQuality study (Harris, Beringer & Fletcher, 2015) suggested that patient empowerment could be a key factor to explain how MyQuality improved communication and the delivery of person-centred care, and demonstrated statistically significant improvements in empowerment scores before and after MyQuality use in a cohort of hospice patients and families. However, that observational study took place in 2013/14, did not include a control group, was the first research study to take place in that setting. The introduction of MyQuality to the hospice in 2013 provided different resources compared to the current study. Key health systems contexts have changed over time (such as access to a different range of provider services), and the issues surrounding digital communication have evolved significantly over recent years. Furthermore, the measurement of empowerment in itself was insufficient to confirm the role of empowerment processes in communication, which include access to knowledge and information, self-determination and autonomy, and sharing control of dialogue and decision-making (Skinstad & Farshchian, 2016). In light of these factors, exploration of the role of empowerment was an important aspect of this study.

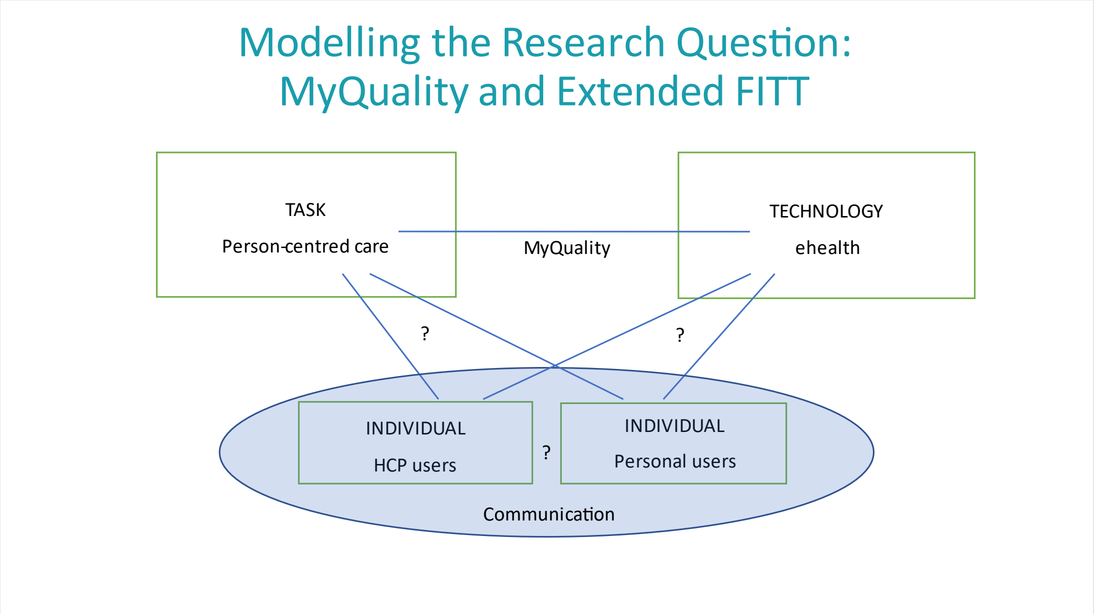
As shown in chapter 6, the levels of empowerment as measured by FES in patient/parent users of MyQuality did rise slightly, but this did not reach statistical significance when the results of all participants were assessed together. However, many of the interviews with parents recounted demonstrations of empowerment in action, where the “evidence” and insights provided by MyQuality use led to a change in their self-reported behaviour and interactions with HCPs. Interestingly, the three families where the FES scores increased over time (Katie, Daniel, Sophie) were the same three families whose HCPs engaged most with data outputs, seeing the reports from the graphs themselves and often making the effort to view these in advance of clinical encounters. Whilst the other three (Adam, Daisy and Matthew’s parents) shared their insights from MyQuality with HCPs, this tended to be at the instigation of the parent by demonstrating graphs in clinic or raising issues that they had identified as patterns themselves, rather than through interest demonstrated proactively by the HCPs. The difference in empowerment levels between those whose HCPs had actively engaged with MyQuality data compared to those whose HCPs hadn’t engaged was statistically significant. This positive reinforcement of MyQuality use through HCP endorsement more closely mirrors the activity observed in the hospice in the original study, which could explain the discrepancy in FES scores between the two studies, and echoes the findings of Miyamoto et al. (2016) and Graffigna et al. (2016).

There was no statistically significant difference between the baseline FES scores of those who engaged with MyQuality to a great extent, on a temporary basis, or who struggled to use it, suggesting that it was not a prior level of empowerment that provided a key context for engagement.

10.3 FITT Theory

The FITT theory (see section 2.4) provides a model for the interactions between individuals, technology and task. MyQuality contains features designed to support a person-centred approach to care (see Fig 2.4), and this aspect of the FITT relationships has not been further assessed in this work. The relationship between the individual users and the technology, the impact on communication, and the interactions between communication processes, individuals and the delivery of person-centred care will be explored more fully in this discussion.

Figure 10-2 Model of research question



When considering the complexities of MyQuality, issues about nature of the technology and its implementation were frequently raised by both HCPs and parents, a finding reflected in other reviews. Schreiweis et al., (2019) categorised the barriers into three main groups: individual barriers, technical barriers, and organisational or environmental barriers. It is interesting to note that the potential technical and organisational barriers such as security risks, system language, reliability of the service and level of IT support, accessibility and ease of use were much less dominant in the interview findings in this study than the issues relating to individuals, such as the perception of clear benefit of use, aspects of trust and control, enhancement of collaboration, the quality of user experience, issues related to ehealth literacy and cognition, and individual motivation. This discrepancy may simply reflect this study's focus, which did not consider in great depth the technical issues or implementation processes required to adopt MyQuality at scale.

The extended FITT model (Kujala et al., 2020) has provided a structure to investigate the implementation of ehealth in practice and further explore the role of the individual, including their response to the nature of the ehealth task, a focus not included in Schreiweis et al. (2019)'s work. FITT explored these issues in three domains: the fit between the task (delivery of PCC) and the technology (MyQuality), outlined in chapter 2; the fit between the technology and the individuals using it, both patients/parents and HCPs; and the fit between those individuals and the task (PCC). These latter groups will be discussed below.

10.3.1 FITT: Technology and individuals

10.3.1.1 Access

Use of the website depended on the personal user having access to the internet and the necessary software, but as levels of access to IT infrastructure have increased throughout society this represented less of a barrier to its use than in the past. For those with adequate online access there were no instances where participant patients or their parents were unable to successfully set up their priorities, add numerical or text data, locate the graphs or identify individuals with which to share data in this study or the previous 2013/14 evaluation. Although getting feedback from those who decided not to engage with MyQuality and did not participate in this study was difficult, HCPs involved in the identification of potential participants reported only one instance of non-engagement related to limited access to online technology in this study. In contrast, some HCPs did experience technical difficulties accessing MyQuality as some provider organisations prohibited staff access to websites not on an approved list, and it was necessary to arrange for MyQuality to be added to these lists.

10.3.1.2 Integration with existing systems

More significant barriers to implementation were noted by HCPs than by patients, a finding echoed in Schreiweis et al. (2019)'s systematic literature review. In practical terms, as MyQuality is a stand-alone site, HCPs reported that they were less likely to access this as it meant logging into a new system with a new password. Data from MyQuality was not automatically linked to, or accessible from, central healthcare records, necessitating additional work to integrate MyQuality data into NHS patient notes. The need to remember separate passwords and navigate separate websites meant that in reality HCPs tended not to access MyQuality frequently, which further reduced familiarity with the system.

10.3.1.3 Analysis of outputs

A further concern related to the implementation of MyQuality with HCP teams related to their expressed concerns about interpretation of the data outputs when examining the graphs of their patients. Those who implemented MyQuality most successfully adopted collaborative approaches with their patients and their parents to explore the graphs together, suggesting that implementation advice in the future should focus more on these techniques, and reassure HCPs that the graphs are a tool to stimulate discussion rather than to demand analysis. This method has been used in other settings (Chung et al., 2015) where HCPs used graphs to ask "tell me what this information is telling you" to clarify levels of patient understanding and concern.

10.3.1.4 Automated email alerts

The final area of concern relating to technology, which was identified by most teams, was the use of "email alerts". This feature of MyQuality was initially developed following discussion with patients and their parents who wanted the reassurance that unusually abnormal results would be flagged to their HCPs, and by hospice managers who were keen to ensure provision of timely support and appropriate prioritisation of workload by staff. Despite the enthusiasm of managers, HCP users of MyQuality had raised these concerns during early stages of its development and the website had evolved to address these difficulties. The email alerts were adjusted to reflect individual priorities, so that a child with input from multiple clinical teams could direct an email alert to the most appropriate specialist. When setting up the email alerts, the clinicians would have to approve this process in order for the email alert facility to fire.

To illustrate this, consider the case of a child who sees a local community paediatrician, various specialists about respiratory and seizure management, and is registered with the hospice, and wishes to use MyQuality so that all can get an overview of progress at home. Once priorities were identified by the personal user, the relevant HCPs would be invited to access the data. If the patient/parent wanted to set up an email alert about seizures this could be directed specifically to the neurologist for example, rather than to a range of specialists or generalists who might feel that they were not the best source of advice on seizure management. The identified recipient, in this example the neurologist, would need to signal that they were happy for email alerts about seizures to come to them. HCPs who did not feel it appropriate to receive email alerts were encouraged to discuss appropriate sources of urgent advice with the patients/parents as an alternative to the email alert system (e.g., to contact hospital switchboard to reach the on-call neurologist, or a local paediatrician or emergency ward).

Despite these additional measures to allow HCPs to exercise control over the source and nature of email alerts, this function of MyQuality generated more concern than any of the others amongst HCP users, to the extent that it proved a significant limiting factor in the uptake of MyQuality by HCPs. Rather than seeing timely alerts of deterioration as a useful aspect of the intervention, the lack of control and sense of urgency associated with email alerts provoked concerns about the management of their time, responsibilities and jurisdiction, all threats to elements of autonomy and competence.

10.3.2 FITT: Disrupting roles and responsibilities

The modified FITT model (Kujala et al., 2020) includes individuals, both professionals and patients, but does not stipulate interactions between them. Clarity of roles, responsibilities, and expectations with regards to technology is key to implementation and uptake of this process.

When both patients and HCPs will be using technology, the initiation of its use can affect subsequent practice. If tracking is initiated by patients who then share their data with professionals, attempts at collaboration often fail to engage service providers, leading to frustration for patients (Chung et al., 2016). If initiated by HCPs, this could be seen as another obligation which could add to patient and carer workload (Piras, 2019), one that HCPs are reluctant to impose and personal users may resent.

The situation becomes more complicated when patients invite several HCPs from different specialities, locations and professional groups to access data. This adds another layer of complexity as confusion over the accountability and responsibilities of different HCPs may lead to further work to ensure that all needs are met in the most efficient and effective manner, as articulated on p216. This is likely to become an increasing problem as the roles of generalists (such as a GP or community paediatrician) become eroded through the increasing involvement of discrete professional subspecialists and multidisciplinary teams, with resulting lack of continuity of care and more complex referral patterns (Gilburt, 2016).

In this study there were several instances where HCP teams felt that the lack of clear boundaries and expectations was sufficient to dissuade them from using MyQuality. Some of these related to concerns about the expectations of patients, as seen in the examples given by HCPs about being faced with issues that were “outside their remit”, or the concern that patients might expect their HCPs to be closely monitoring their data. Other examples related to the expectations of fellow HCPs about the level of support or communication between teams that could be expected in response to MyQuality data, raising some challenging moral questions for them about the extent of their duty.

Some comments from HCPs suggested that the issues related to personal perceptions of duty, competence and professionalism. Whilst some reported the fear of being overwhelmed by problems that they could do nothing about, others seemed comfortable to report that 80% of the issues raised by parents “could not be fixed”, but that did not dissuade them from engaging with MyQuality; instead, they valued the insights into the family’s perspectives.

One of the observations during this study was the lack of understanding by both patients and HCPs of the other's expectations. Given the potential for dissatisfaction and conflict in children's palliative care (Whiting, 2013; Parsons & Darlington, 2021) and the emotionally charged nature of these circumstances, this is not surprising. Some parents were unsympathetic to the challenges faced by HCPs in sifting out large volumes of patient-generated material that may or may not have been relevant, feeling that it ought to be their role to do this (see p208) without any appreciation of the additional challenge this could pose for HCPs in terms of time and resource management, or any sense of how autonomous practice was limited by professional or organisational obligations. Some HCPs responded very defensively to the concept that parents might expect them to be reviewing MyQuality frequently, or responding to email alerts, when the parents professed to have no such expectations and emphasised that they would pursue their routine channels of communication in case of concern or emergency. In both situations, the lack of appreciation from the interviewees about the perceptions of the other users led to reluctance to engage fully with MyQuality and suggests that a collaborative discussion about mutual expectations would be a valuable first step if MyQuality were to be introduced to support clinical care.

The proposal for a pre-emptive discussion to clarify expectations and responsibilities may appear to be at odds with the ethos underpinning MyQuality: the free public accessibility and the intention to enhance the voice of the patient within clinical encounters could be replaced by an erosion of the autonomy of the personal user to engage with MyQuality on their own terms. It is important to note that there is no obligation for MyQuality data to be shared between personal users and their HCPs. As demonstrated by PTs 1-4, there are benefits of MyQuality use to personal users that do not depend on shared access to data; instead, this discussion about mutual expectations would be most appropriate when exploring the use of data in collaboration. This process would demonstrate reciprocal respect by both patients/parents and HCPs for their respective challenges. The benefits of establishing mutually agreed expectations would outweigh the risks of disengagement, leading to shared benefits and supporting collaborative endeavours to provide the complex support required for the child and parents.

10.3.3 FITT: Individuals and Task

The intention behind MyQuality was to improve the delivery of person-centred care at the level of the direct interaction between patients and parents and their healthcare professionals, with the aim of improving the outcomes and experience of care. Effective communication underpins this process, hence the focus on communication in this study. However, Street et al. (2009) noted that while talk itself can be therapeutic, clinician-patient communication often influences outcomes through more indirect routes. They emphasised maximising the therapeutic effects of communication via intermediate outcomes such as trust, mutual understanding, adherence to treatment, social support and self-efficacy. Street hypothesised that shared understandings, enhanced therapeutic alliances, increased patient empowerment and agency and resultant improved decision-making could lead to improved outcomes (Street et al., 2009). Many of these interim outcomes, such as developing trust, feeling “known”, being involved, and improving knowledge and understanding have been identified by parental participants of this study. The HCPs who engaged with the process have described an improved awareness of their patients’ perspectives, more holistic “whole life” insights into the impact of the child’s condition, and demonstrated respect for the experience and expertise of parents.

As has been described, the measurement of person-centred care is difficult (De Silva, 2014) and there is no direct measure of the extent to which MyQuality can be considered successful in this regard. However, through its impact on the dynamics of communication MyQuality may promote a shift towards inclusivity and equity in the professional-patient relationship, a key component in the models of person centred care (Meskó, Radó & Gy\Horffy, 2019).

10.4 Asking the Realist question – what works for whom, under what circumstances, and why?

This study has generated understanding of how ehealth approaches such as MyQuality can support those living with LLCs, and their HCP teams, to communicate and support a person-centred model of care.

For parents of children with LLC, MyQuality use supported life at home through efficient and meaningful documentation of daily life, facilitating reflection and improving understanding about the day-to-day variability in their child’s needs, increasing the parents’ sense of autonomy and competence whether or not they shared information with HCPs.   The personal relevance of the documentation process enabled a “whole life” perspective rather than a biomedical viewpoint, thus enhancing a person-centred approach.

HCPs reported MyQuality data helped them to understand their patients’ needs and support these proactively, but only if adequately trained and resourced to meet those identified needs. The patient-controlled content and access triggered concerns for some HCPs about the extent and remit of their role, and trustworthiness of data. For HCPs working in community-based roles, access to MyQuality data provided useful thinking time and feedback on patient/parent-identified issues, important factors which supported their own needs, skills and values.

Sharing MyQuality data enabled more efficient prioritisation of needs during subsequent healthcare encounters, shared decision-making based on reliable information, and facilitated development of parent/HCP partnerships, thus supporting PCC. Sharing information and a proactive approach by HCPs to collaborative working relationships was associated with greater empowerment for parents.

The combination of a biopsychosocial focus, an enhanced understanding of the unique needs of each child, and facilitation of supportive clinician/parent relationships demonstrates how MyQuality may enable the delivery of person-centred care.

10.5 Recommendations for practice

This thesis matters because it critically evaluates an attempt to improve person-centred care for children with LLC, and the parents who support them. The numbers of children with complex needs are likely to increase in the future, the pressures on healthcare providers as individuals and organisations are likely to increase, and there is a national imperative that people should be supported as individuals rather than simply processed as commodities within health and social care. Furthermore, there is a moral imperative to honour the right of every child and family to the best quality of life possible for their circumstances, and to respect the value of their lives however difficult or short they may be.

This evaluation demonstrates how and why ehealth can support the delivery of person-centred care for this group, and also highlights many of the challenges and barriers. Specific recommendations for practice in the field of children's palliative care are as follows:

- Offer resources to patients to efficiently document and share records of daily life which are sensitive and meaningful to them, convey information simply, and amplify the priorities of the patient and family within healthcare dialogue.
- Create opportunities to observe patterns, record these in a consistent manner, and learn from experience in order to respond to need in a proactive, timely manner.
- Include parents as members of the "Team Around the Child" and respect their expertise.
- Integrate ehealth outputs with appropriate instruction and support for staff, and link these with NHS patient records for maximal ease of access and regular use.
- Support HCPs to develop resilience through additional training and peer networks.

If that sounds like a big task, the motivation comes back to the needs of the child and family. As Sophie's mother put it:

I think the reason why I DO do it (use MyQuality), and other people will do it, is that you feel that you've getting something positive out of it. If it was something that I had to do, almost like homework at school, or another chore, I'd be less inclined. Because yeah, we do have a lot to do, but I feel there's a benefit to doing it, for me and for (daughter)… and they know that'd I'd do everything in my power to help (daughter).

11 Discussion of Thesis

Street et al. (2009) stressed that "more rigorous approaches to integrating theory, context and measurement are needed if we are to make significant gains in our understanding of how clinician-patient communication contributes to healing and well-being". This chapter will reflect on the research processes of this PhD journey and make suggestions for the future.

11.1 The research process – strengths and limitations

When I embarked on this PhD, I had a passion to explore the dynamics of interactions between HCPs and their patients in order to support PCC, but no idea how to go about this. When I finally realised that a realist approach would address my question, I overlooked Pawson's remark that the realist method is not for novices (Pawson et al., 2004) only to discover this truth for myself over the ensuing years. The strengths of the realist approach lie in its "real-world" approach to complexity, and the depth of explanatory detail it provides, as outlined in chapter 3. The challenges I faced are outlined in this section.

11.1.1 Delineating the scope

Realist evaluation provided a useful framework for me to unpack the complexity associated with the architecture of MyQuality as an intervention, and the features of the environment in which it was implemented. My previous clinical experience had given me first-hand insights into the impact of personal interactions between clinicians and patients, the dynamics of teamwork, and the influences of organisations, policies and cultures on care provision. However, it soon became clear that consideration of these multiple interacting factors would be impossible within the practical constraints of this study. Limiting the scope was at times an uncomfortable process as I recognised that I was ignoring some key elements in the real-life drivers of behaviour, but I was reassured to hear Pawson's assurance that "we can never obtain perfect knowledge of all the dynamics of policies and programmes" … and that any evaluation will only take a limited and specific cut at the issues (Pawson, 2013a, p46). He recommends focussing on a small number of programme theories to produce a "partial exploration of a partial set of ideas". I made a pragmatic decision to focus primarily on the micro-level interactions in this study but recognised the multitude of unaddressed factors that contribute to the bigger picture.

Despite refining the scope of the research question, it was still very tempting to be led into unexplored areas as new mechanisms or theories appeared over time. The constant need to restrict and justify the focal range was a necessary but frustrating aspect of undertaking a realist evaluation.

11.1.2 Maintaining transparency

Coming from a positivist tradition, I was familiar with a systematic approach to seeking and analysing evidence, transparent reasoning and reporting, and reproducible results. I soon found that whether I considered evidence from literature or from primary sources during the interviews, my best attempts to demonstrate transparency were made much more difficult by the nature of realist enquiry. The robust quality of realist evaluation is based on following realist principles rather than a set of protocols, but that makes it challenging to reproduce (Wong et al., 2017).

The literature searching was an iterative process that began in 2016 and was revisited regularly as new concepts appeared over the course of the study. Whilst it started with the aim of exploring a few landmarks in the literature maze around ehealth, PCC and communication, the CLUSTER searching approach (Booth A, 2018) provided a large number of potential paths to follow, some of which linked together in a useful navigational roadmap while others became confusing distractions. Despite the best of intentions, it was difficult to demonstrate transparent decision-making through this process due to the fluctuations about relevance as theory concepts evolved with time, and the influence of intuition as part of the abductive process. This challenge was compounded when searching for relevant mid-range theories (Booth & Carroll, 2015). The difficulties in reporting realist searches have been highlighted recently, and suggestions have been made to report these in a more systematic manner (Booth, Briscoe & Wright, 2020).

The use of direct quotes to illustrate contexts, mechanisms and outcomes was intended to relay the sources of explanatory concepts (Gilmore et al., 2019), but inevitably there were elements of my own interpretation which influenced these. Words on paper cannot convey the full nature or depth of feeling relayed through tone of voice, body language, nor key contextual observations during the interviews. There will have been elements of my own processing of the “fuller picture” that will have influenced how the data fed into the theory concepts, which I have tried to convey in chapters 7, 8 & 9. Participants were given the opportunity to respond to my summaries of their comments via email to minimise erroneous interpretation of their comments.

The evolution of theory in this thesis from the literature and interviews with participants was not a linear process as the sequential chapters might suggest. The theories were refined or refuted based on repeated interviews and return visits to the literature and were also shaped by contributions from the PPI meeting. Those reported here have been tested and refined as far as resources would permit, and no doubt will evolve in the future.

11.1.3 Recruitment of participants

For practical reasons, the study was geographically restricted to the southwest region of England to facilitate face-to-face meetings with HCPs and families. This is also the area in which I had previously worked as a clinician, so I had a convenient network of colleagues. Despite this I faced significant challenges with gatekeeping at multiple levels: organisations shielding their staff from the distractions of research; consultants shielding their patients or their team members from additional obligations associated with participation in the study; and parents shielding their children from unfamiliar research staff. The latter was particularly notable with the advent of Covid, when the excuse given for non-participation was that parents were shielding their children from infection and thus did not visit the hospice or want visitors in their homes. Only one new participant was recruited after the pandemic began, and despite assurances that interviews and questionnaires could be carried out remotely it was difficult to establish a productive relationship and MyQuality engagement was only temporary. Staff were forced to adopt different working patterns and faced many more pressing demands on their time as the pandemic progressed, and no further new participants were identified. Although the number of participants was smaller than initially envisaged, the reality of research in a pandemic made me revise my expectations in preference to a fruitless pursuit of participants from an understandably wary population.

In addition to the reduced sample size, I had initially hoped for feedback from a more diverse population, including teenagers or young adults who would use MyQuality themselves (rather than proxy report from parents). Many children with LLC are either very young or have cognitive dysfunction, meaning that they rely on others to speak for them, but I had hoped that recruitment from the group of oncology patients might offer opportunities to get input from articulate young people about the MyQuality process. Unfortunately, gatekeeping by clinical staff prevented recruitment from this group.

I also recognise that this study lacks a broad cultural mix of participant families. The study population included many different types of family setup (single parents, married couples, stepparents, foster parents, extended families with grandparents, same-sex couples, and a guardianship). There was a mixture of ages, urban/rural locations, a variety of employment backgrounds, but all bar one were of white British origin and spoke English as their first language. The southwest includes several urban multicultural conurbations, but historically many families from minority ethnic groups have been reluctant to engage with hospice services, preferring to seek support within extended family networks rather than from outside providers. It was more difficult to engage with this group and the findings in this study are missing a multi-cultural perspective.

Recruitment and retention of professionals as participants was guided by Solberg's seven R-factors (Riis et al., 2016): Relationship (recruiters are known for their involvement in medical services and for doing practical research); Reputation (participants need to believe that the relationship between researcher and participants will not be abused); recognising the need for research Resources and the requirements on participants for study-related activities and minimising these;

Rewarding participants; Reciprocity (negotiated mutual obligations for recruiters and participants); Resolution (recruitment persistence and a willingness to make repeated contact); and Respect: recruiters need to genuinely respect participants, their work and their constraints. Given that I was already known to, and in many cases had worked with, the HCP teams involved in this study I felt that many of these R's were already satisfied, apart from Rewards. The advent of the Covid-19 pandemic and the great disruption in work patterns that followed made it much more difficult to persist with recruitment under new and difficult circumstances. Resources were very stretched, priorities changed, and I felt the need to respect my front-line colleagues by not adding to their workload through my research. I remain indebted to those who did make time for follow-up interviews during 2020 under these challenging circumstances.

11.1.4 Limited teamwork

The process of abduction has been likened to creative imagination, building on gut feelings, hunches, and informed reconceptualization (Jagosh, 2020) and is a key component of the retroductive process. In many realist evaluations this is enhanced by teamwork with a variety of stakeholders who provide a range of insights and perspectives, whereas in the context of a PhD study the researcher works more independently. Although some of the decisions made regarding data extraction, theory development and refinement were made in partnership with the supervisory team or PPI group, most were made by this researcher alone, thus limiting opportunities for discussion about configurations of theories, underlying assumptions, or decisions regarding the interpretation of data. At times decisions about how factors influenced each other (particularly whether they were acting as contexts or mechanisms) were difficult and may seem worthy of challenge, but debate on these issues would be welcomed as an opportunity to add further insights and understanding.

11.1.5 PPI involvement

Involvement of patients and public is an accepted feature of good research practice (Staniszewska & Denegri, 2013; Garces et al., 2012) and in this study included the YPAG at the stage of study design. The intention had been to repeat the YPAG meeting later in the study to comment on theories as they developed, but the logistics of this were difficult once Covid-19 intervened. In addition, plans were in place to meet with a group of parents of children with LLC in early April 2020 to discuss the theories gleaned from the literature, but this too was abandoned as most parents were suddenly faced with home-schooling and isolation with their children with complex needs, so re-instating this with a remote meeting proved difficult. There was a very useful on-line meeting with two bereaved parents who provided valuable feedback during the theory development process (see 4.5.3), but in total the amount of PPI input was rather less than had been originally envisaged.

11.1.6 Clarity of researcher role

As outlined in section 4.6.5, I was very aware that I wore multiple "hats" during the PhD process and at times it was difficult to isolate my "researcher" brain from that of clinician, website developer or colleague of those I was interviewing. Over time I learned to adapt my invitational interview approach ("what can I do for you?"), engrained from 25 years of working with patients, to one with a realist research focus. There were times when an open unstructured approach provided many avenues for exploration ("so what is a typical day like for you?") to understand the contextual influences on the choices made by families or HCPs, but this would then be supplemented by questions that would lead into the testing or refinement of theories. Reviewing some of the early interview transcripts has revealed the extent of this learning process, and perhaps some opportunities to maximise the focused feedback from participants were missed during the early stages due to inexperience with realist interviewing techniques in contrast to clinical interviews.

Role clarity was also important during the analysis phase, to ensure that the focus remained firmly on the search for mechanisms and theory generation, and that rival theories were explored even if they might refute the original design or implementation of MyQuality. This was helped by writing a research diary, where the process of journaling my progress assisted rational interpretation rather than emotional responses. My ability to separate my research, clinical and developer roles was strengthened over the course of this study by regular supervision and discussion of findings.

11.2 Areas for future research

This study has exposed areas where knowledge is lacking but could not be addressed within the constraints of this PhD. In particular, the challenges to the personal resilience of some healthcare professionals when faced with MyQuality deserves in-depth consideration for multiple reasons: it was not a universal response, and some HCPs were clearly more threatened by this concept than others; appropriate training or support may address elements of this issue in due course; and the longer-term implications for recruitment and retention of healthcare professionals could affect service delivery in the future.

In addition, the structure of MyQuality put the control over content and access firmly within the remit of the personal user rather than the professional. This distortion of the usual HCP-professional relationship was not explicitly mentioned by those who did not engage, instead discussing the limits of their resources and remit, but may be fundamental to their perceptions of their professional roles or identity (Currie et al., 2012; Saks, 2016). This concept feeds into the relationships and dynamics of interactions in the delivery of a person-centred model of care and is worthy of further exploration.

Two further areas beyond the remit of this thesis include minimising the risk of inequitable services due to inequalities in access and use of digital technology, and exploration of the ethical and medicolegal aspects of patient-generated data for health service providers.

11.3 Contribution to new knowledge

Despite the challenges described above, this thesis has made a contribution to new knowledge. The programme theories outlined in chapters 7, 8 and 9 and their resonance with models of communication and middle range theories described in chapter 10 shed new light on the motivations, subsequent reasoning and behaviour of the key participants in the communication processes encompassed by MyQuality. These in turn address some of the intermediate processes in the delivery of person-centred care.

This study has offered qualitative and quantitative evidence to support the development of theories to explain how and why MyQuality contributes to a person-centred approach, making a novel contribution to knowledge in the field of ehealth. This is the first study to address this area in such depth within the field of children's palliative care.   It is also unique in bringing together the reflections of parents and clinicians engaged in the same process, providing a dual perspective to enhance the theory-building process.

The detailed exploration of the impact of MyQuality use for parents of children with LLC has provided new insights into their needs, values, beliefs, skills and emotions and how these can affect communication. Although there is a considerable body of literature already about their wide-ranging roles and responsibilities, participants shared many of their deeper hopes, fears and concerns about their interactions with HCPs and the unvoiced tensions between being "a good parent" and "a good patient".

The use of the FITT theory to consider the interrelationships between the technology, the individuals and the task has facilitated a greater understanding of the complexities of implementation of such a process in practice.   To the researcher's knowledge, the FITT theory has been applied to understand the implementation of ehealth in institutional settings previously, but has not previously been used to consider ehealth implementation across a wide range of individuals, teams and settings, for a more conceptual task (PCC) than previous examples such as documentation, access to radiology, or self-management (Ammenwerth, Iller & Mahler, 2006; Kujala et al., 2020).

The insights regarding the reluctance of HCPs to engage with MyQuality add a new dimension to the debate about the delivery of person-centred care, and the resources needed to facilitate this.

11.4 Wider implications, concluding reflections.

This study sheds light on some important issues for healthcare provision in the 21st century. There are tensions between the emphasis on the delivery of person-centred care and the pressures on resources which demand cost- and time-efficient methods of care delivery (Mesko et al, 2017). Advances in medical knowledge have driven a trend towards increasing subspecialisation, with less recognition of the value of continuity of care and the skills of generalists. The public's access to information in the age of the internet has changed their approach to professional expertise (Donnelly, Shaw & van den Akker, 2008) and this has shaped the expectations of healthcare (Snow, Humphrey & Sandall, 2013). Although the increased use of technology and ehealth had started well before the advent of Covid-19, the pandemic accelerated the change and disrupted many alternative patterns of healthcare provision and societal interaction.

Since March 2020 when the first wave of Covid-19 affected the UK, a major change related to the concept of safe environments for personal interactions such as healthcare provision. The public's view of physical encounters in spaces such as hospital wards, hospices, outpatient clinics altered as shared spaces were viewed as potentially risky to highly vulnerable individuals, such as those with life-limiting conditions. This changed the risk/benefit calculations about the use of technology such as ehealth, which now needs to be measured against the adverse costs of isolation and lack of hands-on support.

The pandemic has also raised new issues about healthcare professionals, notably the increasing acknowledgement that caring takes its toll on individuals and on the system as a whole. Whilst the public may show hope-filled images of intangibles such as angels and rainbows, organisational policies increasingly reflect greater recognition and acceptance that staff are not infinitely resilient and require adequate support and resourcing to work most effectively (Mills et al., 2018; Zannatta et al, 2020). This study showed the potential for a small ehealth intervention to threaten to disrupt the coping mechanisms of many motivated, well-intentioned staff; larger-scale changes may generate impossible demands and be unsustainable unless issues around staff support to foster a resilient workforce are addressed.

MyQuality preceded the pandemic by many years but was designed recognising these cultural behaviour shifts of the 21st century. Although focussed on a specific population, this study illustrates how some users adapted and maximised the benefits from this approach, whilst others appeared threatened by the changes. Although MyQuality as it currently exists is unlikely to be scaled up for general use, the principles behind it such as giving patients (and their carers) a more active role in their own healthcare, recognising their expertise, individual skills, and adapting support to meet their needs more broadly, could apply to a much wider population than those requiring children's palliative care. The aging population and decline in the scope of "cradle-to-grave" statutory health and social care support means that increasing numbers will require supported self-management (Mesko et al., 2017). eHealth could contribute to this process, but will need to be incorporated into models of healthcare provision at a broad level (Calvillo, Roman & Roa, 2015). Fundamental to these processes is a change in the perceptions of the roles and responsibilities of HCPs and patients, with empowered patients engaging and taking responsibility for their healthcare to a greater extent than in the past, sharing the process in empathetic discussions with healthcare professionals who will act as guides or coaches. These therapeutic partnerships would be characterised by trust and mutual respect, with communication a reciprocal process rather than a hierarchical one (Meskó, Radó & Gy\Horffy, 2019; Calvillo, Roman & Roa, 2015).

More significant changes in the fundamental principles of healthcare may be imminent, with ehealth in its wider concept creating a transformative force for the future of medicine (Moerenhout, Devisch & Cornelis, 2018). The smartphone has been likened to the printing press in its power to change access to knowledge, communication and autonomy (Topol, 2015), and the combination of the "quantified self" movement and "Big Data" provide new reference frameworks for concepts of health and wellbeing for individuals and populations. As the developed world faces the combined challenges of an aging population, rising chronic disease and escalating healthcare costs, there will be increasing pressures for healthcare to move from a reactive or curative approach to managing illness towards a more proactive, preventative paradigm where risk identification and prevention of chronic disease are the main targets for healthcare (Moerenhout, Devisch & Cornelis, 2018). This concept has been termed “Precision Medicine” (Hood, Balling & Auffray, 2012) and consists of Predictive, Preventive, Personalised and Participatory medicine. It brings together a systems biology approach, combining biological information such as genomic, physiological and lifestyle data and integrating this with environmental information from Big Data contributions to population health. The Participatory element underlines the role of the individual as an active participant and requires an increase in individual responsibility and a shift away from paternalistic models of the past. Within the confines of the world of children’s palliative care, MyQuality is supporting the first steps in that direction.

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Appendix A – Recruitment Information for Teams

MyQuality study – professionals' information sheet

What is the purpose of this project?

This project is about improving communication in healthcare.

My name is Dr Nicky Harris, and I have developed a website called MyQuality to help people with medical conditions and the health and social care professionals involved in their care to focus on what really affects someone's quality of life, and to share that information more effectively. As a paediatrician working in a children's hospice, I introduced the website to many families of children with life-limiting conditions and it has evolved in response to their feedback and user experience. However, using websites in this way in medicine is a fairly new development. Not enough is known about whether using a website makes a difference and if there are any effects on how patients and their families and professional staff work together.

Why have I been asked to take part?

You have been invited to take part because you support children and families living with life-limiting or long-term health conditions. In addition, a child, young person or family using MyQuality may have identified you as someone involved in their care, and would like to give you shared access to their MyQuality information.

Do I have to take part?

No, your participation is entirely voluntary. If you do decide to take part and then change your mind you will still be able to leave the project at any time, without giving any reason. To leave the project, simply contact one of the researchers (details below). However, we would really appreciate your views, so we hope that you will want to take part.

What will happen if I agree to take part?

You will be encouraged to use the MyQuality website, and invited for an interview.

- You will be invited to access MyQuality (www.my-quality.net) and register on the site as a professional user. The website has instructions about how to use it, but I can also give you a demonstration and describe some case studies to illustrate how it might be relevant to your team's work.
  I would welcome you to speak to patients and families on your caseload who might benefit from using MyQuality, and will provide you with information for them about this study.

- I will invite you to take part in a telephone interview a few months after you start to participate in this project. The interview will take about 30 minutes. I will request your verbal consent to record this so that I can concentrate on listening to you. Your interview comments will be treated as confidential and will not be shared outside the research team.

During the interview, I will ask about your experience of accessing and using MyQuality information that individuals or families have shared with you. I will be interested in your views even if you access MyQuality for just a short time or stop using it altogether.

Support for you

I understand that talking about health issues faced by specific families, and the challenges for professionals attempting to address them, may be upsetting. If you become distressed during the interview I will listen quietly if we are on the phone, and offer you the option to stop the interview or to continue, in your own time. Although the interview will be recorded, the conversation will remain completely confidential. If you share information which suggests that a child or family may be at serious risk to themselves or to others, we will discuss how this should be managed in line with local safeguarding procedures.

Are there any risks associated with taking part in this study?

There are no risks to physical health from taking part in this project.

There are always some risks when using electronic as opposed to paper records to monitor progress or guide healthcare decisions. When entering information onto a website on the internet, there is a risk that confidentiality may be breached by malicious means, or that the website may fail and lose data. MyQuality is hosted on a server in the UK, and all efforts are made to maintain the highest standards of cyber security using the latest firewall and encryption techniques. Data is backed up on a daily basis. Despite this, no website can give an absolute guarantee of security and confidentiality, but we will do our utmost to safeguard your information. If your organisation uses paper records, we recommend periodically printing a copy of the graphs produced by your MyQuality users and including these in your paper files, much as you would print out relevant email correspondence.

MyQuality does not link with NHS electronic records; it is a stand-alone system. It is readily accessible via the internet, but some NHS organisations may have limits placed within their internal IT networks which prevent access to all websites. If you take part in this project, or you find that MyQuality is a useful adjunct to your usual clinical service, please encourage your local IT support team to add it to the list of permitted sites on your network.

Will my participation be confidential?

All the information from this study will be anonymised. I will remove any details that may identify you from our records, and replace these with a unique research code. All the records will be kept securely in line with research guidance from University of the West of

England, and all electronic records will be password-protected and saved on the university servers with up-to-date firewall protection.

I will be able to see what is entered on the website, and how often this is accessed. This will allow me to understand how people use MyQuality, but this information will be anonymised and will not identify any individual professionals or personal users of the site. This data will not be shared with anyone outside the research team.

Should you decide to withdraw from the study, any information you have given up to that point will be kept securely, and may be used to help understand more about how MyQuality is used.

When I analyse the results from this work, only members of the supervisory research team will have access to the study data. Drafts of the results summary will be carefully reviewed to ensure that no inadvertent identifiable details are released before any results are made public.

After the project has ended, I intend to archive the anonymised transcripts from the interviews. These may be of interest to researchers in the future, or needed for educational purposes. They will only be accessible to approved researchers, and your identity will not be revealed.

Who is funding and carrying out the project?

The project is being carried out as part of PhD research within the Faculty of Health and Allied
Sciences at the University of the West of England, Bristol. The MyQuality website is owned by MyQuality Limited, and managed on a no-profit basis. It is free to use and available online at http://www.my-quality.net. There is no external sponsor, and no commercial interest in this project.

What will happen to the findings from the project?

The findings will be part of a PhD thesis, for submission to the University of the West of England. A short version of this will be available to all participants in the project. I hope to publish the findings in a professional journal and at conferences or training sessions in due course, with the aim of improving care in the future.

Who has reviewed the project?

This project has been reviewed by the Health Research Authority Integrated Research Application System, which approves health and social science research in the United Kingdom and by the faculty research ethics committee of the Faculty of Health and Allied Sciences, University of the West of England.

What should I do if I wish to take part in this project?

Please contact Dr Nicky Harris (details below).

What if I have a problem with the project?

If at all possible, we would like you to speak to one of the researcher team first as this will help us correct any problems quickly. Dr Nicky Harris would be the first line of call. The

Director of Studies overseeing this project is Dr Toity Deave, and additional supervision is provided by Dr Antonia Beringer, and Dr Andy Gibson.

This project is part of PhD research in the Faculty of Health and Allied Sciences at the University of the West of England (Bristol). If you would rather speak to someone outside the project team, please contact Dr Tim Moss, Postgraduate Dean, Faculty of Health and Allied Sciences at UWE.

Researcher contact details

Name	Preferred contact method	Additional contact details
Dr Nicky Harris PhD Candidate and lead researcher	Email nicky.harris@uwe.ac.uk	write: Dr Nicky Harris, Blue Lodge, Glenside Campus, Blackberry Hill, Bristol BS16 1DD [redacted]
Dr Toity Deave Director of Studies Associate Professor for Family & Child Health	Email: Toity.deave@uwe.ac.uk	Centre for Child and Adolescent Health, University of the West of England Bristol Oakfield House, Oakfield Grove, Clifton, Bristol BS8 2BN Tel: 0117 331 4085
Dr Antonia Beringer PhD Supervisor Senior Research Fellow/Senior Lecturer	e-mail: antonia.beringer@uwe.ac.uk	Centre for Health and Clinical Research, Faculty of Health and Applied Sciences, Glenside Campus, Blackberry Hill Bristol BS16 1DD Tel: 0117 32 88209
Dr Andy Gibson PhD Supervisor Associate Professor Patient and Public Involvement	Email: Andy.gibson@uwe.ac.uk	Faculty of Health and Applied Sciences, Glenside Campus, Blackberry Hill Bristol BS16 1DD

CONSENT FORM FOR PROFESSIONALS IN HEALTH AND SOCIAL CARE

MyQuality
My life, my measure

UWE Bristol
University of the West of England

CONSENT FORM

Title of project: MYQUALITY – WHAT MATTERS TO YOU

Please initial each box if you agree

<table>
<tr><td colspan="2">I have read the Information Sheet dated 15th November 2017 about this research study and have had the opportunity to ask questions.</td><td></td></tr>
<tr><td colspan="2">I understand that taking part in this research is voluntary and that I am free to stop the interview or withdraw at any time, without giving a reason.</td><td></td></tr>
<tr><td colspan="2">I understand that the interviews and/or group discussions will be audio recorded, and I agree that this can happen</td><td></td></tr>
<tr><td colspan="2">I understand that the feedback and comments that I share during the discussion or interview may be used anonymously in the study reports, but I will be asked for my permission first.</td><td></td></tr>
<tr><td rowspan="2">I understand that once the study is complete, my information will be kept securely at the University of the West of England.</td><td>My information will be kept for 7 years in line with the 1998 Data Protection Act, and then destroyed.
OR</td><td></td></tr>
<tr><td>I agree for my information to be kept in the Data Repository in UWE for future use.</td><td></td></tr>
<tr><td colspan="2">I understand that my personal details will be kept confidential</td><td></td></tr>
<tr><td colspan="2">I agree to take part in this study</td><td></td></tr>
</table>

Your Name (please print): ______________________________

Signature: ______________________________

Date: ______________________________

Researcher's Signature: ______________________________

Research Number: ______________________________

MYQUALITY consent v3_ 15/11/2017 IRAS 213423

Identification of Potential Participants in the MyQuality Study

Participant criteria:

A: Health

1. Children or young people with palliative or complex health care needs receiving support from your team
2. Families of children or young people fitting criteria above
3. Life expectancy at least 3 months from time of entry into study

B: Communication

4. Regular access to a computer and the internet
5. Able to speak/read English to a sufficient level to have a discussion/interview, and complete an empowerment scale. If the child/young person is unable to do this, a parent/guardian can participate on their behalf.

C: Demographics

6. Normal place of residence is in the South West of the UK
7. Child/young person is under 25 years old*.
    a. Young children, and those aged up to 18 whose illness or disability means that it is difficult to use a website, may be participants in the study with their parents/guardians using the website on their behalf. Their parents/guardians will be interviewed and will complete a Family Empowerment Scale.
    b. Children under 12 years old may wish to use the MyQuality website themselves, but we recommend that this takes place only with close parental involvement. Parental consent, and the child's assent, will be required to proceed with the study. Both will participate in the interviews and be invited to complete a Family Empowerment scale.
    c. Children/young people between 12 & 18 may choose to use the website independently of parental oversight, but will need parental consent to take part in the study, in addition to confirming their own assent to participate. They will be interviewed with or without their parents present (by mutual agreement) and complete a Youth Empowerment Scale.
    d. Young people aged 18+ are responsible for their own use of the website, and their own consent, and will complete the Youth Empowerment Scale. If cognitively unable to do this, parent/guardians may use the website on their behalf, be interviewed, and complete a Family Empowerment Scale.

Exclusion Criteria:

1. Children or young people with life-threatening illness, where there may be a risk of death but where palliative care services are not typically involved in a child's care. (eg acute illness, or mental health conditions such as anorexia or severe depression.)
2. Individuals with a poor command of English. The website, interviews and questionnaires are all in English and there is no funding to employ translation services.
3. Individuals over 25 who access palliative care services are welcome to use MyQuality but this will be outside the bounds of the study.

Appendix B – Patient Information leaflets and consent forms

MyQuality study – information sheet for parents or carers using MyQuality

What is the purpose of this project?

This project is about improving communication in healthcare. You might speak to a healthcare professional to share your concerns, but sometimes those conversations aren't easy – it might be difficult to say what is on your mind, or to know how to share those issues with professional staff. They might not understand the things that matter most to you or your child.

My name is Dr Nicky Harris, and I have developed a website called MyQuality to help people focus on what really matters to them, and share that information with their healthcare team. However, using websites in this way in medicine is a fairly new development. Not enough is known about whether using a website makes a difference and if there are any effects on how patients and their families and professional staff work together.

Why have I been asked to take part?

You have been invited to take part because you have a child or young person who is living with a significant health condition.

Do I have to take part?

No, participation is entirely voluntary. If you decide to take part and then change your mind you will be able to leave the project at any time, without giving any reason. To leave the project, simply contact one of the researchers (details below). However, I would really appreciate your views, so I hope that you will want to take part.

What will happen to me if I take part?

I will explain the study to you and seek your consent to take part. I will need to collect a few details such as your and your child's name, date of birth, address and a contact telephone number.

There are three parts to this study: a questionnaire, the website, and an interview.

- Before using the website, I would like you to complete a questionnaire about how you feel about sharing your concerns about your child and family's health and wellbeing with the professionals who support you. This should take no more than 10-15 minutes.

- MyQuality website: You will have an introduction to MyQuality. There is information on the website itself to explain how to use it, or you may ask for a demonstration by a member of the research team. The website can be used to describe, prioritise and monitor the health concerns that you feel are most important for your child and family. You may choose to share this information with one or more of your healthcare professionals or keep it entirely private, it is up to you. You may use the website as much or as little as you wish.

- At least a month after starting to using the website, I will contact you about to arrange an interview, and repeat the questionnaire. The interview can be a face-to face discussion or over the telephone, whichever is more convenient. The discussion will take about 30 minutes and will be recorded, so that I can concentrate on listening to you, and also to have a record of what has been said so that I don't miss anything important.

The interview will be about using the website, and how that may (or may not) have affected your views about what matters most to you and your child, and how you work with the professionals who support you. I will be interested in your views even if you use MyQuality for only a very short time, or stop using it altogether. If you continue to use it for a lengthy period of time, I would like to contact you after 3-6 months and request a second interview to see how views and experience change over time.

The interview comments will be treated as confidential and will not be shared outside the research team. The only time I may need to share information is if, during conversation, I believe that you, your child or someone else may be at risk from harm. This is extremely unlikely to happen and may mean asking for help from people outside the research team, but will be done to protect the interests of those at risk of any harm.

Are there any risks from taking part in this project?

There are no risks to physical health from taking part in this project.

Taking part may result in you focussing on the health and quality of life of your child or family in a way that is new to you. Should you find this is causing you distress, you can stop using MyQuality at any point. However, I would recommend that you speak to a member of your professional team, or the research team, in confidence, about the issues that have brought this about as you may find that discussion can be a useful way forward. Similarly, should you become upset when discussing these issues in a research interview, I will offer to delay or stop the interview should you wish, and listen to your concerns.

When entering personal information onto a website on the internet, there is always a risk that confidentiality may be breached by malicious means, or that the website may fail and lose the data you have entered. MyQuality is hosted on a server in the UK, and all efforts are made to maintain the highest standards of cyber security using the latest firewall and encryption techniques. Data is backed up on a daily basis. Despite this, no website can give an absolute guarantee of security and confidentiality, but we will do our utmost to safeguard your information.

Are there any risks if I don’t take part in this project?

No, the care and support provided by professionals for your child and family will continue as before.
You may use MyQuality without taking part in the project, or you may choose not to use it at all. However, previous study participants have reported that they found being part of a research project interesting and useful, so we do hope that you will take part.

What will happen to the information you keep about me?

Once you decide to take part, I will ask for your written consent to keep any information that you give us, to comply with regulations concerning research and data protection. This information may include questionnaire responses, interview recordings, or the data entered on the website.

With your permission, we will write to your child’s GP to say that you are taking part in this project. The GP will not have access to any information that you share with us as part of this study.

All the information will be anonymised. I will remove any details that may identify individuals from our records, and replace these with a unique research code. All the records will be kept securely in line with research guidance from University of the West of England, and all electronic records will be password-protected and saved on the university servers with up-to-date firewall protection.

I will be able to see what is entered on the website. This will allow me to understand how people use MyQuality, to check how many people use the site and how often they do so, but this information will not include names or contact details.

If you decide to leave the study, any information given up to that point will be kept securely, and may be used to help to understand more about how MyQuality is used.

When I analyse the results from this work, only members of the supervising research team will have access to the information. Drafts of the results summary will be carefully reviewed to ensure that no inadvertent identifiable details are released (for instance if your child has a very rare condition or a unique set of social circumstances that someone outside the research team might recognise) before any results are made public.

After the project has ended, I intend to archive the anonymised reports from the interviews, questionnaires, and a summary of the website data with the UWE Research Data Repository. This information may be of interest to researchers in the future, or needed for educational purposes. It will only be accessible to approved researchers, and your identity will not be revealed.

What will happen to the findings from the project?

The findings will be part of a PhD thesis, for submission to the University of the West of England. A shortened version of this will be available to all participants in the project. I hope to publish the findings in a professional journal and at conferences or training sessions in due course, with the aim of improving care in the future.

Who is funding and carrying out the project?

The project is being carried out as part of PhD research within the Faculty of Health and Allied Sciences at the University of the West of England. The MyQuality website is owned by MyQuality Limited, and managed on a no-profit basis. It is free to use and available online at http://www.myquality.net. There is no external sponsor, and no commercial interest in this project.

Who has reviewed the project?

This project has been reviewed by the Integrated Research Application System by the Health Research Authority, which approves health and social science research in the United Kingdom. This process is overseen locally by the ethics sub-committee of the Faculty of Health and Allied Sciences, University of the West of England.

What should I do if I wish to take part in this project?

Please contact Dr Nicky Harris (details below).

What if I have a problem with the project?

If at all possible, speak to one of the researchers first as this will help us correct any problems quickly. Dr Nicky Harris would be the first line of call. The Director of Studies overseeing this project is Dr Toity Deave, and additional supervision is provided by Dr Antonia Beringer, and Dr Andy Gibson.

This project is part of PhD research in the Faculty of Health and Allied Sciences at the University of the West of England (Bristol). If you would rather speak to someone outside the project team, please contact Dr Tim Moss, Postgraduate Dean, Faculty of Health and Allied Sciences at UWE.

Researcher contact details

Name	Preferred contact method	Additional contact details
Dr Nicky Harris PhD Candidate and lead researcher	Email nicky.harris@uwe.ac.uk	write: Dr Nicky Harris, Blue Lodge, Glenside Campus, Blackberry Hill, Bristol BS16 1DD [redacted]
Dr Toity Deave Director of Studies Associate Professor for Family & Child Health	Email: Toity.deave@uwe.ac.uk	Centre for Child and Adolescent Health, University of the West of England Bristol Oakfield House, Oakfield Grove, Clifton Bristol BS8 2BN Tel: 0117 331 4085
Dr Antonia Beringer PhD Supervisor Senior Research Fellow/Senior Lecturer	e-mail: antonia.beringer@uwe.ac.uk	Centre for Health and Clinical Research, Faculty of Health and Applied Sciences, Glenside Campus, Blackberry Hill Bristol BS16 1DD Tel: 0117 32 88209
Dr Andy Gibson PhD Supervisor Associate Professor, Patient and Public Involvement	Email: Andy.gibson@uwe.ac.uk	Faculty of Health and Applied Sciences, Glenside Campus, Blackberry Hill Bristol BS16 1DD

CHILDREN AND YOUNG PEOPLE - ASSENT TO PARTICIPATE

MyQuality
My life, my measure

UWE Bristol | University of the West of England

CONSENT FORM

Title of project: MYQUALITY – WHAT MATTERS TO YOU

Please initial each box if you agree

I have read the Information Sheet dated 15th November 2017 about this research study and have had the opportunity to ask questions.		
I understand that taking part in this research is voluntary and that I am free to stop the interview or withdraw at any time, without giving a reason.		
I understand that the interviews and/or group discussions will be audio recorded, and I agree that this can happen		
I understand that the feedback and comments that I share during the discussion or interview may be used anonymously in the study reports, but I will be asked for my permission first.		
I understand that once the study is complete, my information will be kept securely at the University of the West of England.	My information will be kept for 7 years in line with the 1998 Data Protection Act, and then destroyed. OR	
	I agree for my information to be kept in the Data Repository in UWE for future use.	
Permission to inform my GP about my intention to take part in this study	I give permission for my GP to be informed OR	
	Do not inform my GP	
I understand that my personal details will be kept confidential		
I agree to take part in this study		

Your Name (please print): ____

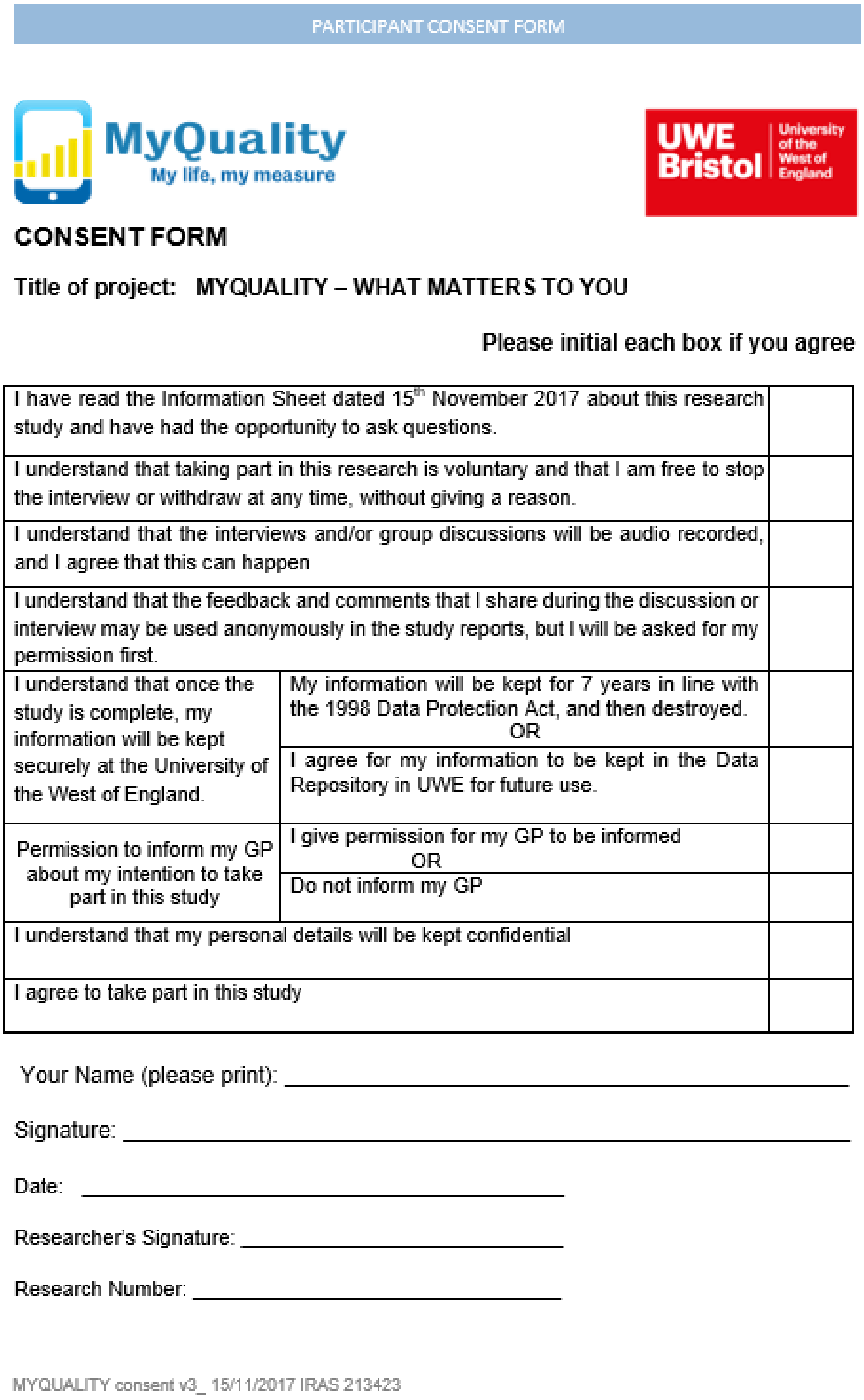
Signature: ____

Date: ____________________________________

Researcher's signature _________________________

Research number ___________________________

MYQUALITY consent v3_ 15/11/2017 IRAS 213423



PARTICIPANT CONSENT FORM

MyQuality
My life, my measure

UWE Bristol University of the West of England

CONSENT FORM

Title of project: MYQUALITY – WHAT MATTERS TO YOU

Please initial each box if you agree

I have read the Information Sheet dated 15th November 2017 about this research study and have had the opportunity to ask questions.		
I understand that taking part in this research is voluntary and that I am free to stop the interview or withdraw at any time, without giving a reason.		
I understand that the interviews and/or group discussions will be audio recorded, and I agree that this can happen		
I understand that the feedback and comments that I share during the discussion or interview may be used anonymously in the study reports, but I will be asked for my permission first.		
I understand that once the study is complete, my information will be kept securely at the University of the West of England.	My information will be kept for 7 years in line with the 1998 Data Protection Act, and then destroyed. OR	
	I agree for my information to be kept in the Data Repository in UWE for future use.	
Permission to inform my GP about my intention to take part in this study	I give permission for my GP to be informed OR	
	Do not inform my GP	
I understand that my personal details will be kept confidential		
I agree to take part in this study		

Your Name (please print): ______________________________

Signature: ______________________________

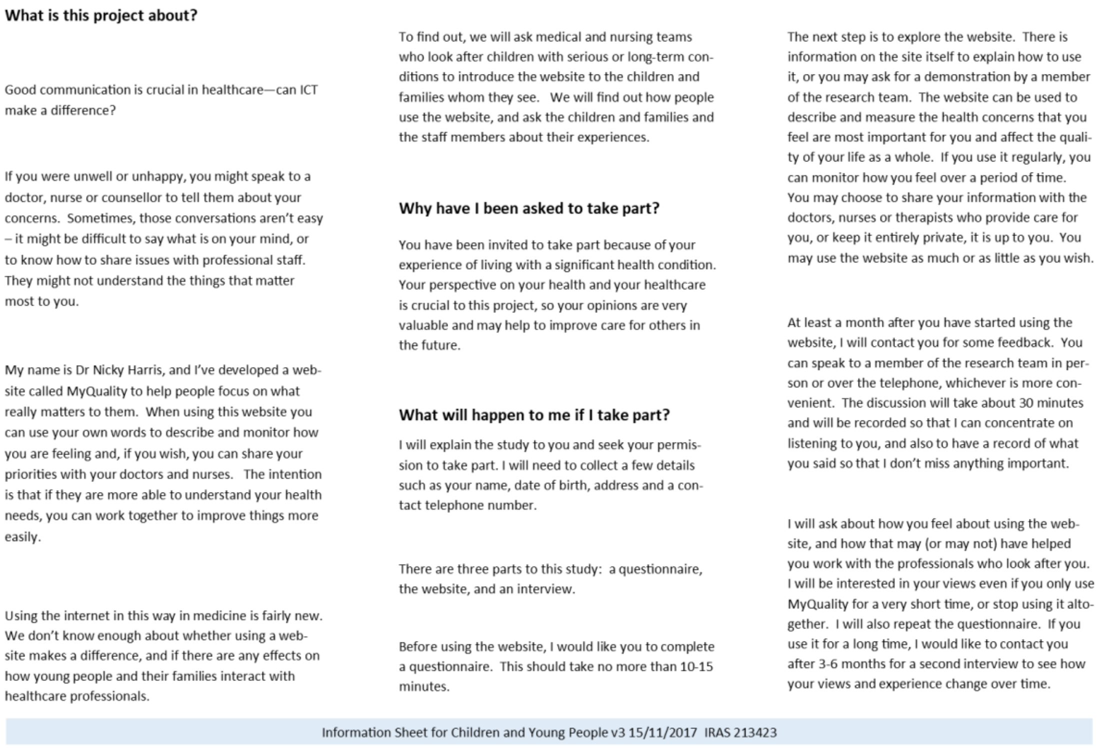
Date: ______________________________

Researcher's Signature: ______________________________

Research Number: ______________________________

MYQUALITY consent v3_ 15/11/2017 IRAS 213423

Information leaflet for Children and Young People age 12+



What is this project about?

Good communication is crucial in healthcare—can ICT make a difference?

If you were unwell or unhappy, you might speak to a doctor, nurse or counsellor to tell them about your concerns. Sometimes, those conversations aren't easy – it might be difficult to say what is on your mind, or to know how to share issues with professional staff. They might not understand the things that matter most to you.

My name is Dr Nicky Harris, and I've developed a website called MyQuality to help people focus on what really matters to them. When using this website you can use your own words to describe and monitor how you are feeling and, if you wish, you can share your priorities with your doctors and nurses. The intention is that if they are more able to understand your health needs, you can work together to improve things more easily.

Using the internet in this way in medicine is fairly new. We don't know enough about whether using a website makes a difference, and if there are any effects on how young people and their families interact with healthcare professionals.

To find out, we will ask medical and nursing teams who look after children with serious or long-term conditions to introduce the website to the children and families whom they see. We will find out how people use the website, and ask the children and families and the staff members about their experiences.

Why have I been asked to take part?

You have been invited to take part because of your experience of living with a significant health condition. Your perspective on your health and your healthcare is crucial to this project, so your opinions are very valuable and may help to improve care for others in the future.

What will happen to me if I take part?

I will explain the study to you and seek your permission to take part. I will need to collect a few details such as your name, date of birth, address and a contact telephone number.

There are three parts to this study: a questionnaire, the website, and an interview.

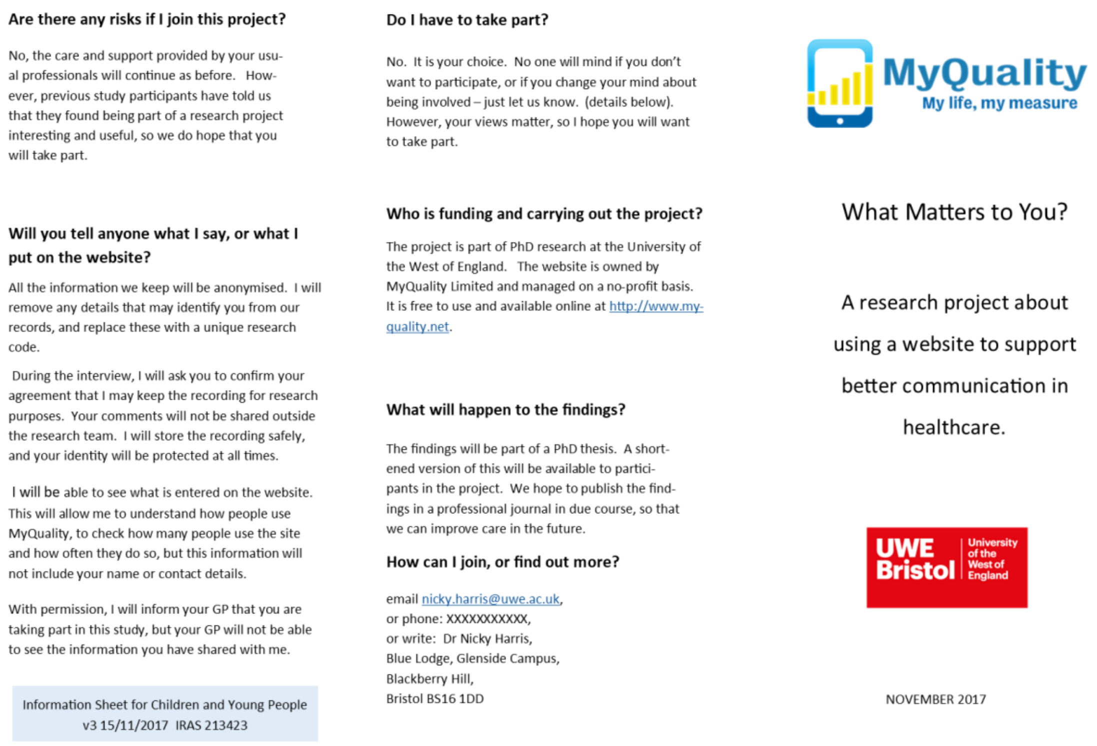
Before using the website, I would like you to complete a questionnaire. This should take no more than 10-15 minutes.

The next step is to explore the website. There is information on the site itself to explain how to use it, or you may ask for a demonstration by a member of the research team. The website can be used to describe and measure the health concerns that you feel are most important for you and affect the quality of your life as a whole. If you use it regularly, you can monitor how you feel over a period of time. You may choose to share your information with the doctors, nurses or therapists who provide care for you, or keep it entirely private, it is up to you. You may use the website as much or as little as you wish.

At least a month after you have started using the website, I will contact you for some feedback. You can speak to a member of the research team in person or over the telephone, whichever is more convenient. The discussion will take about 30 minutes and will be recorded so that I can concentrate on listening to you, and also to have a record of what you said so that I don't miss anything important.

I will ask about how you feel about using the website, and how that may (or may not) have helped you work with the professionals who look after you. I will be interested in your views even if you only use MyQuality for a very short time, or stop using it altogether. I will also repeat the questionnaire. If you use it for a long time, I would like to contact you after 3-6 months for a second interview to see how your views and experience change over time.

Information Sheet for Children and Young People v3 15/11/2017 IRAS 213423



Are there any risks if I join this project?

No, the care and support provided by your usual professionals will continue as before. However, previous study participants have told us that they found being part of a research project interesting and useful, so we do hope that you will take part.

Will you tell anyone what I say, or what I put on the website?

All the information we keep will be anonymised. I will remove any details that may identify you from our records, and replace these with a unique research code.

During the interview, I will ask you to confirm your agreement that I may keep the recording for research purposes. Your comments will not be shared outside the research team. I will store the recording safely, and your identity will be protected at all times.

I will be able to see what is entered on the website. This will allow me to understand how people use MyQuality, to check how many people use the site and how often they do so, but this information will not include your name or contact details.

With permission, I will inform your GP that you are taking part in this study, but your GP will not be able to see the information you have shared with me.

Information Sheet for Children and Young People v3 15/11/2017 IRAS 213423

Do I have to take part?

No. It is your choice. No one will mind if you don't want to participate, or if you change your mind about being involved – just let us know. (details below). However, your views matter, so I hope you will want to take part.

Who is funding and carrying out the project?

The project is part of PhD research at the University of the West of England. The website is owned by MyQuality Limited and managed on a no-profit basis. It is free to use and available online at http://www.my-quality.net.

What will happen to the findings?

The findings will be part of a PhD thesis. A shortened version of this will be available to participants in the project. We hope to publish the findings in a professional journal in due course, so that we can improve care in the future.

How can I join, or find out more?

email nicky.harris@uwe.ac.uk,
or phone: XXXXXXXXXXX,
or write: Dr Nicky Harris,
Blue Lodge, Glenside Campus,
Blackberry Hill,
Bristol BS16 1DD

MyQuality
My life, my measure

What Matters to You?

A research project about using a website to support better communication in healthcare.

UWE Bristol University of the West of England

NOVEMBER 2017

Appendix C – Empowerment Scales and Permissions

School of Social Work
Regional Research Institute for Human Services
Research and Training Center for Pathways to Positive Futures

[redacted]

[redacted]

Dr. Nicky Harris

Palliative Care Paediatrician

Postgraduate Researcher and PhD Candidate

University of the West of England (Bristol)

May 19, 2017

Dear Dr. Harris,

This letter confirms our permission to use the **Family Empowerment Scale** to continue your research at the PhD level in consideration of the role of empowerment when using eHealth in the dynamics of the relationships between children and families who are receiving palliative care support and their health and social care professionals.

We are delighted that you are interested in using this publication and hope that you will continue to find it useful. Please cite properly, whether the citation be in printed form or on a website. We would be very interested to hear about your experiences and findings, particularly with respect to aspects of the scale that might be improved.

For further specific or technical information, contact Dr. Barbara Friesen at [redacted]

Good luck in your research.

Best regards,

Amy Bass

Publication Coordinator

Research and Training Center for Pathways to Positive Futures

Regional Research Institute
Portland State University

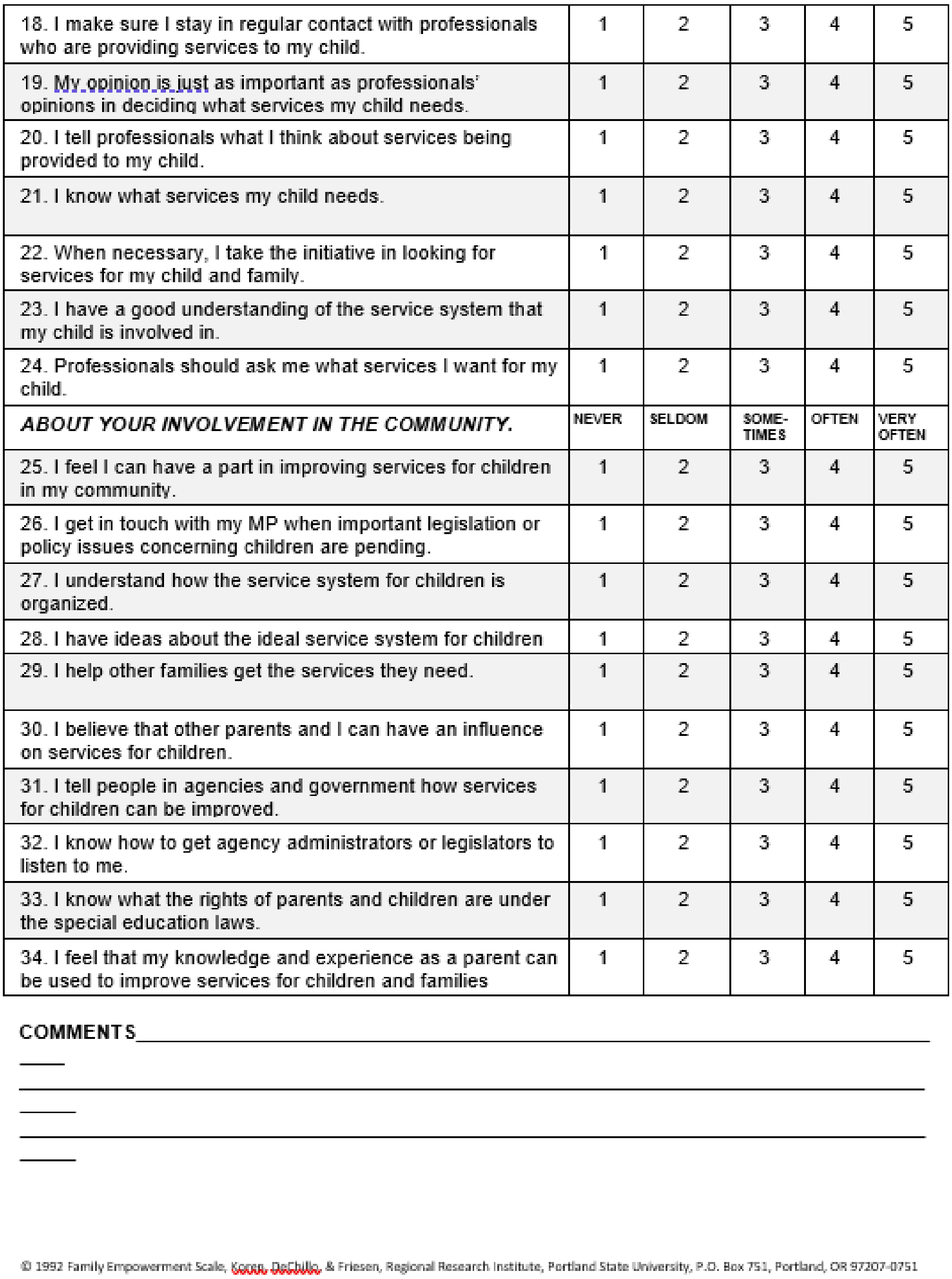
[redacted]

[redacted] rtcpubs@pdx.edu

FAMILY EMPOWERMENT SCALE

These questions ask about several areas of your life–your family and your child's services. The questions include many different activities that parents may or may not do. For questions that do not apply to you, please answer "Never". Also, we know that other people may be involved in caring for and making decisions about your child, but please answer the questions by thinking of your own situation. Feel free to write any additional comments at the end and write on the back if you need more space.

ABOUT YOUR FAMILY...	NEVER	SELDOM	SOME-TIMES	OFTEN	VERY OFTEN
1. When problems arise with my child, I handle them pretty well.	1	2	3	4	5
2. I feel confident in my ability to help my child grow and develop.	1	2	3	4	5
3. I know what to do when problems arise with my child.	1	2	3	4	5
4. I feel my family life is under control.	1	2	3	4	5
5. I am able to get information to help me better understand my child.	1	2	3	4	5
6. I believe I can solve problems with my child when they happen.	1	2	3	4	5
7. When I need help with problems in my family, I am able to ask for help from others.	1	2	3	4	5
8. I make efforts to learn new ways to help my child grow and develop.	1	2	3	4	5
9. When dealing with my child, I focus on the good things as well as the problems.	1	2	3	4	5
10. When faced with a problem involving my child, I decide what to do and then do it.	1	2	3	4	5
11. I have a good understanding of my child's disorder.	1	2	3	4	5
12. I feel I am a good parent.	1	2	3	4	5
ABOUT YOUR CHILD'S SERVICES...	NEVER	SELDOM	SOME-TIMES	OFTEN	VERY OFTEN
13. I feel that I have a right to approve all services my child receives.	1	2	3	4	5
14. I know the steps to take when I am concerned my child is receiving poor services.	1	2	3	4	5
15. I make sure that professionals understand my opinions about what services my child needs.	1	2	3	4	5
16. I am able to make good decisions about what services my child needs.	1	2	3	4	5
17.I am able to work with agencies and professionals to decide what services my child needs.	1	2	3	4	5

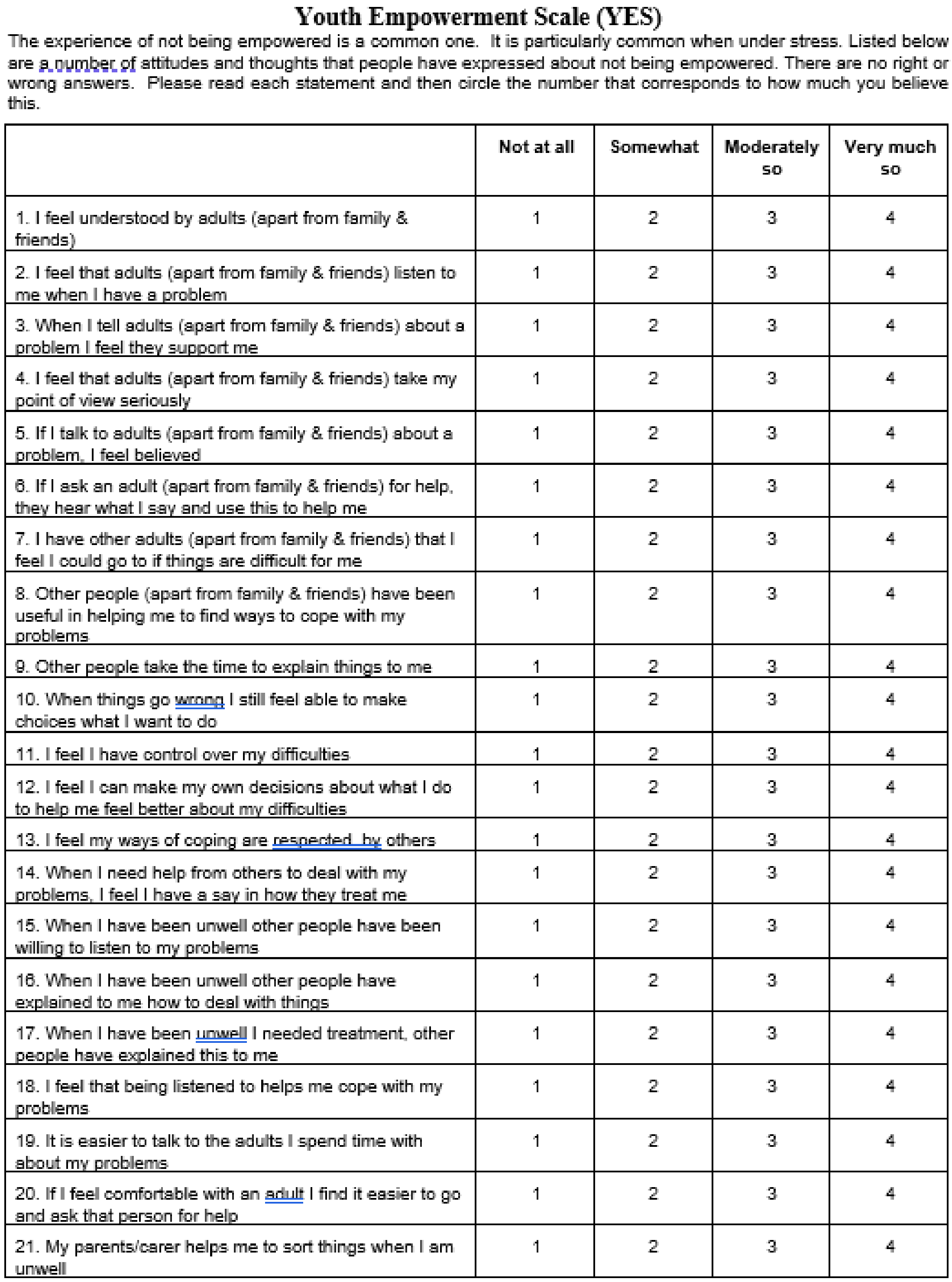


18. I make sure I stay in regular contact with professionals who are providing services to my child.	1	2	3	4	5
19. My opinion is just as important as professionals' opinions in deciding what services my child needs.	1	2	3	4	5
20. I tell professionals what I think about services being provided to my child.	1	2	3	4	5
21. I know what services my child needs.	1	2	3	4	5
22. When necessary, I take the initiative in looking for services for my child and family.	1	2	3	4	5
23. I have a good understanding of the service system that my child is involved in.	1	2	3	4	5
24. Professionals should ask me what services I want for my child.	1	2	3	4	5
ABOUT YOUR INVOLVEMENT IN THE COMMUNITY.	NEVER	SELDOM	SOME-TIMES	OFTEN	VERY OFTEN
25. I feel I can have a part in improving services for children in my community.	1	2	3	4	5
26. I get in touch with my MP when important legislation or policy issues concerning children are pending.	1	2	3	4	5
27. I understand how the service system for children is organized.	1	2	3	4	5
28. I have ideas about the ideal service system for children	1	2	3	4	5
29. I help other families get the services they need.	1	2	3	4	5
30. I believe that other parents and I can have an influence on services for children.	1	2	3	4	5
31. I tell people in agencies and government how services for children can be improved.	1	2	3	4	5
32. I know how to get agency administrators or legislators to listen to me.	1	2	3	4	5
33. I know what the rights of parents and children are under the special education laws.	1	2	3	4	5
34. I feel that my knowledge and experience as a parent can be used to improve services for children and families	1	2	3	4	5

COMMENTS____

____

____



Youth Empowerment Scale (YES)

The experience of not being empowered is a common one. It is particularly common when under stress. Listed below are a number of attitudes and thoughts that people have expressed about not being empowered. There are no right or wrong answers. Please read each statement and then circle the number that corresponds to how much you believe this.

	Not at all	Somewhat	Moderately so	Very much so
1. I feel understood by adults (apart from family & friends)	1	2	3	4
2. I feel that adults (apart from family & friends) listen to me when I have a problem	1	2	3	4
3. When I tell adults (apart from family & friends) about a problem I feel they support me	1	2	3	4
4. I feel that adults (apart from family & friends) take my point of view seriously	1	2	3	4
5. If I talk to adults (apart from family & friends) about a problem, I feel believed	1	2	3	4
6. If I ask an adult (apart from family & friends) for help, they hear what I say and use this to help me	1	2	3	4
7. I have other adults (apart from family & friends) that I feel I could go to if things are difficult for me	1	2	3	4
8. Other people (apart from family & friends) have been useful in helping me to find ways to cope with my problems	1	2	3	4
9. Other people take the time to explain things to me	1	2	3	4
10. When things go wrong I still feel able to make choices what I want to do	1	2	3	4
11. I feel I have control over my difficulties	1	2	3	4
12. I feel I can make my own decisions about what I do to help me feel better about my difficulties	1	2	3	4
13. I feel my ways of coping are respected by others	1	2	3	4
14. When I need help from others to deal with my problems, I feel I have a say in how they treat me	1	2	3	4
15. When I have been unwell other people have been willing to listen to my problems	1	2	3	4
16. When I have been unwell other people have explained to me how to deal with things	1	2	3	4
17. When I have been unwell I needed treatment, other people have explained this to me	1	2	3	4
18. I feel that being listened to helps me cope with my problems	1	2	3	4
19. It is easier to talk to the adults I spend time with about my problems	1	2	3	4
20. If I feel comfortable with an adult I find it easier to go and ask that person for help	1	2	3	4
21. My parents/carer helps me to sort things when I am unwell	1	2	3	4

Dear Nicky,

It was lovely talking to you last Friday. I have attached the following information for you about the YES as promised:

1) The YES which has 21 items. I am currently in the process submitting the two papers on the scale describing how we did the EFA paper (Journal of Adolescent Health, Impact Factor of 3.8) and the CFA paper (Psychological Medicine, Impact factor 5.4) and once these are submitted (hopefully submitted within the next 2 weeks) I will email them both to you. There is no charge for the scale we want people to use it and cite our papers.

2) The qualitative paper (using IPA) which generated and developed the items for the scale. This is the only paper that conceptualised empowerment from young people with psychosis. The issues of empowerment for young people are similar regardless of their physical and mental health/illness

3) My second paper which demonstrated the importance of empowerment, showing that it mediates the relationship between psychological processes and mental health, well-being, and recovery in young people

4) I have attached my Introduction chapter for my PhD which summaries all the definitions on empowerment, the polices on empowerment for young people and the research done to date on empowerment from adults/adolescents perspective. This will help you with the rationale as to why empowerment is important, how it is defined etc. I am currently working on a systematic review paper on empowerment and this will be completed by the summer.

If there is anything else you need please do not hesitate to get in touch. My mobile no is [redacted]

Kind regards,

Annmarie

Dr Annmarie Grealish, PhD, MSc, PGDip CBT, BSc, RMN, RGN

Lecturer in Mental Health

Florence Nightingale Faculty of Nursing and Midwifery

King's College London

[redacted]

[redacted]

[redacted]

[redacted]

Appendix D – Semi-structured Interview guide for initial interviews with families

Interviews with Individual users or Families

1. Introduction & Key Concepts:

   What support do you/your family value most from your health care professionals?

   What would you change to improve services for those receiving palliative care?

   Do you think there is a role for communications technology such as MyQuality? Can you explain why?

   If personal user: Do you have any concerns about using MyQuality?

   If family member of a C/YP user: Do you have any concerns about your child using MyQuality?

   Do you think there are any limitations to using MyQuality in your home/family?

2. Processes & Interactions:

   What are the nature of the priorities you/your family identified on MyQuality? Did you find the identification easy or difficult? Has it changed over time?

   Are there priorities that you feel you would not with to include on MyQuality? If not, why not?

   Have you had insights or information because you have been using MyQuality that you would not have had otherwise? Prompt - Examples?

   Have you set up any clinical alerts? Have these been useful? Prompt - Examples?

   Do you share your data with any members of your professional team? If so, who? If not, why not?

   Do you know if your healthcare professionals are looking at your MyQuality data? If so, how do you know?

   Are there any practical advantages or disadvantages to using MyQ? Prompts – STEEEP framework (safety, timeliness, efficiency, effectiveness, equality of access, patient-centredness)

   Have you encountered any problems or barriers to using MyQuality? Prompt – examples?

3. Reflection on communication and working relationships:

   What is your preferred communication style with your health care professionals? (prompt - F2F/phone/email/letter/text messaging/other) What factors influence this?

   What do you see as the most important differences in interaction with your health care professionals when using MyQuality, compared to your usual interactions (eg clinic visits/home visits/ward rounds etc)?

      Face-to-face vs on-line/telephone follow-up? Prompts: any change in:

         Frequency of contact

         Trust

         Openness - Is it easier or harder to enter difficult discussions?

         Privacy concerns?

         Lack of non-verbal cues to communication

   Who should decide on the priorities for support from a palliative care service?

   How can you ensure that the aims of the consultation are meaningful and relevant?

   Who should determine whether goals are realistic? What factors do you take into account to ensure that goals may be achievable?

   How do you manage differences of opinion?

   Does the use, or lack of use, of MyQuality have any effect on your ability to make decisions about treatment or interventions?

4. Reflection on potential use of MyQuality in future:

   Do you think you will continue to use MyQuality?

      If yes – how/why

      If no – why not? What would be needed to change this?

   Is it possible, or desirable, to amalgamate patient-generated data to give information to services?

   Any general observations not covered here….

Appendix E – Semi-structured follow-up interview example

The following are sample segments of interview notes, testing programme theories with families.

Motivation: (TA1)

What motivated you to use Myquality? What do you get out of using it?

Prompts: time efficiency?

Identification of priorities?

Data presentation/sharing to HCPs?

Acceptance of role in identification of priorities for care?

Patients who are motivated to use ehealth will think about their priorities and organise these methodically, to be more easily understood by others.

Expectations (TA5) of what ICT can do for your/your family's health – rival theories:

Quantification may be useful to get better understanding

vs

"medicalisation" of daily life is another chore and a waste of time.

A) *Quantification of normal life may provide useful information and insights – "knowledge is power"*
B) *Medicalisation of normal life may become too much of a burden for patients or create unrealistic expectations of support from healthcare services*

Monitoring may lead to improvements in QOL (confident, optimistic view)

Vs

Monitoring may show deterioration and I'd rather not know (vulnerable, pessimistic)

Monitoring of health priorities will lead to improvements in QOL. Positive responses will encourage ehealth use. If documentation of change shows continuing decline, this may foster a sense of hopelessness.

Do you feel that the professionals looking at your data **value** (TA7) what you are recording? How did this make you feel?

Does the use, or lack of use, of MyQuality have any effect on your ability to make decisions about treatment or interventions?

Patients who feel that their healthcare practitioner values their data will continue to monitor it, and be more collaborative in management decisions and accountable for acting on healthcare advice.

How do you manage differences of opinion?

Has using MyQuality led to any changes in the way you view yourself/your role in healthcare interactions? – examples? **(TA6)**

eHealth which enables individuals to have greater understanding and insights is empowering for users, who are therefore more likely to communicate this to others

Has using MyQuality helped you to improve QOL for your child/family? – examples

Have you encountered any problems or barriers to using MyQuality? Prompt – examples?

Can you think of any potential dangers in this approach?

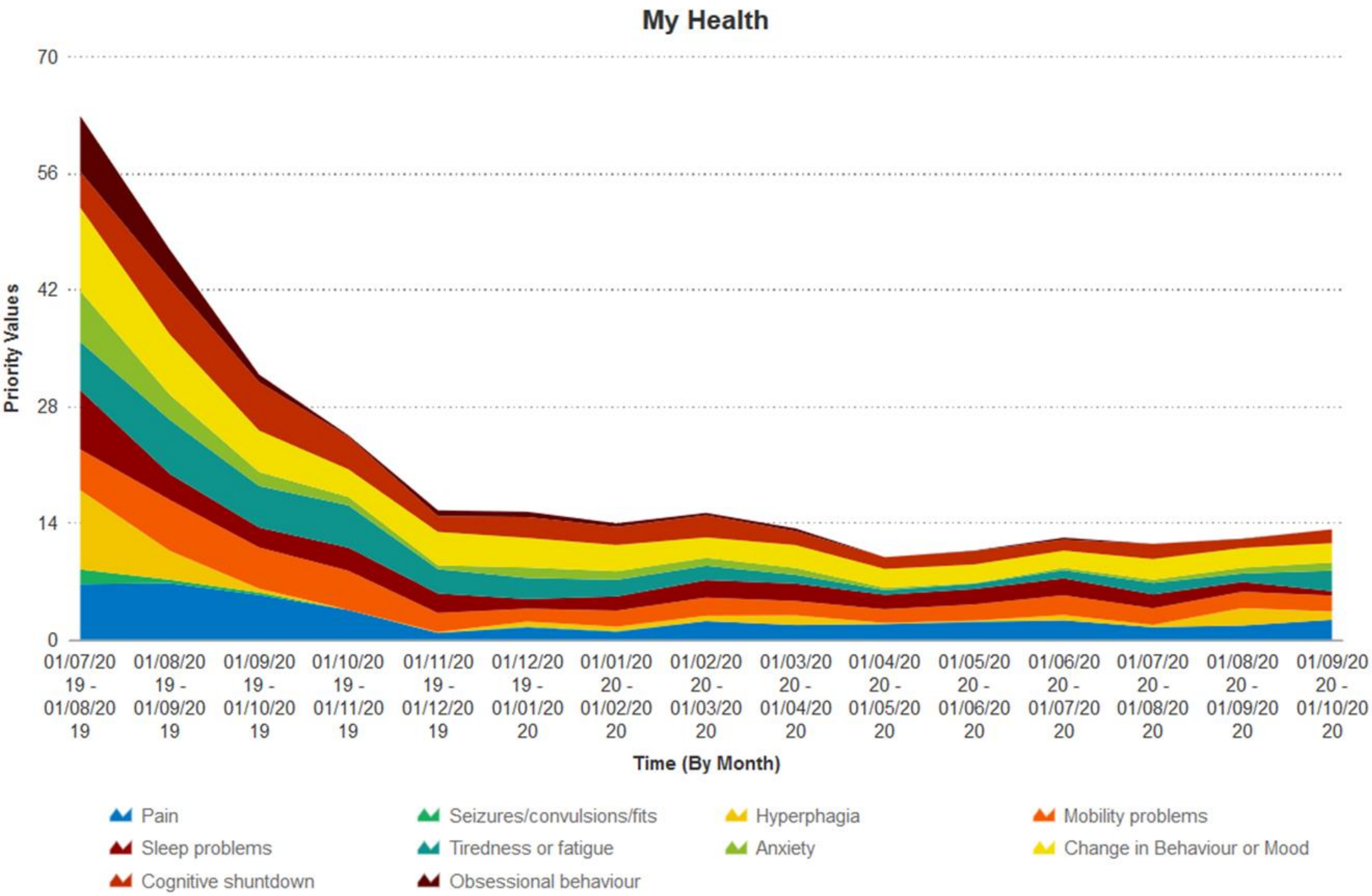
Ask: HCPs have expressed concerns that patients will manipulate their data in order to gain access to additional support (earlier admission/extra review for example). Do you think this is a justifiable concern? **(TA8)**

Healthcare professionals need to trust patients to record data honestly if they are going to make decisions based on personalised data collection

Ask: HCPs have concerns that they will be overwhelmed with patient information and demands to "fix" things that are outside their remit. Do you think this is a justifiable concern? **(TA7)**

Healthcare practitioners who feel that patient data will present issues that are outside their remit may feel overwhelmed/dismissive/threatened by eHealth

Samples of printouts of MyQuality outputs taken for discussion – the following is one example:


My Health
Priority Values
70
56
42
28
14
0
01/07/2019 - 01/08/2019
01/08/2019 - 01/09/2019
01/09/2019 - 01/10/2019
01/10/2019 - 01/11/2019
01/11/2019 - 01/12/2019
01/12/2019 - 01/01/2020
01/01/2020 - 01/02/2020
01/02/2020 - 01/03/2020
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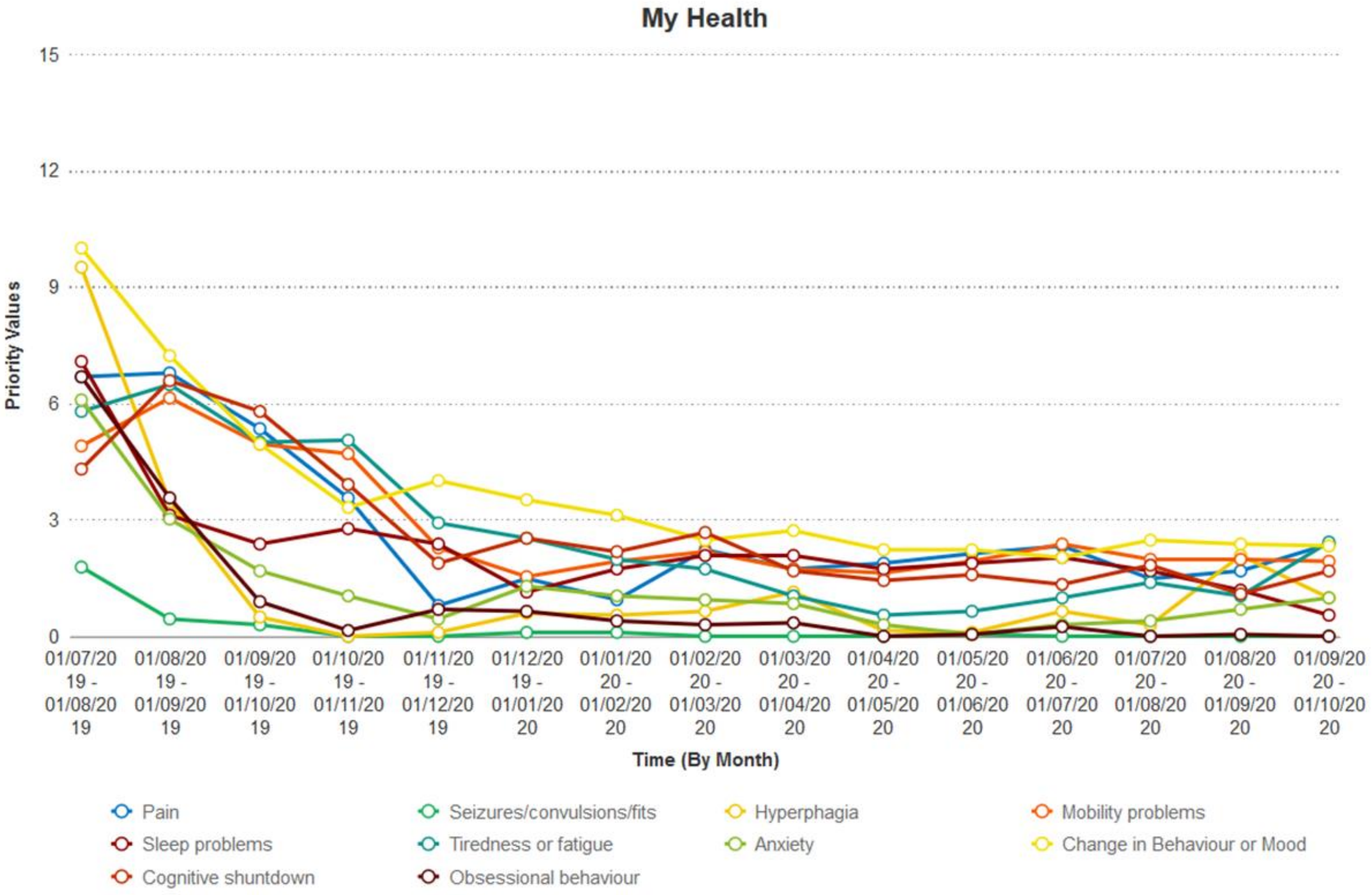
01/04/2020 - 01/05/2020
01/05/2020 - 01/06/2020
01/06/2020 - 01/07/2020
01/07/2020 - 01/08/2020
01/08/2020 - 01/09/2020
01/09/2020 - 01/10/2020
Time (By Month)
Pain
Seizures/convulsions/fits
Hyperphagia
Mobility problems
Sleep problems
Tiredness or fatigue
Anxiety
Change in Behaviour or Mood
Cognitive shuntdown
Obsessional behaviour


My Health
15
12
9
6
3
0
Priority Values
01/07/2019 - 01/08/2019
01/08/2019 - 01/09/2019
01/09/2019 - 01/10/2019
01/10/2019 - 01/11/2019
01/11/2019 - 01/12/2019
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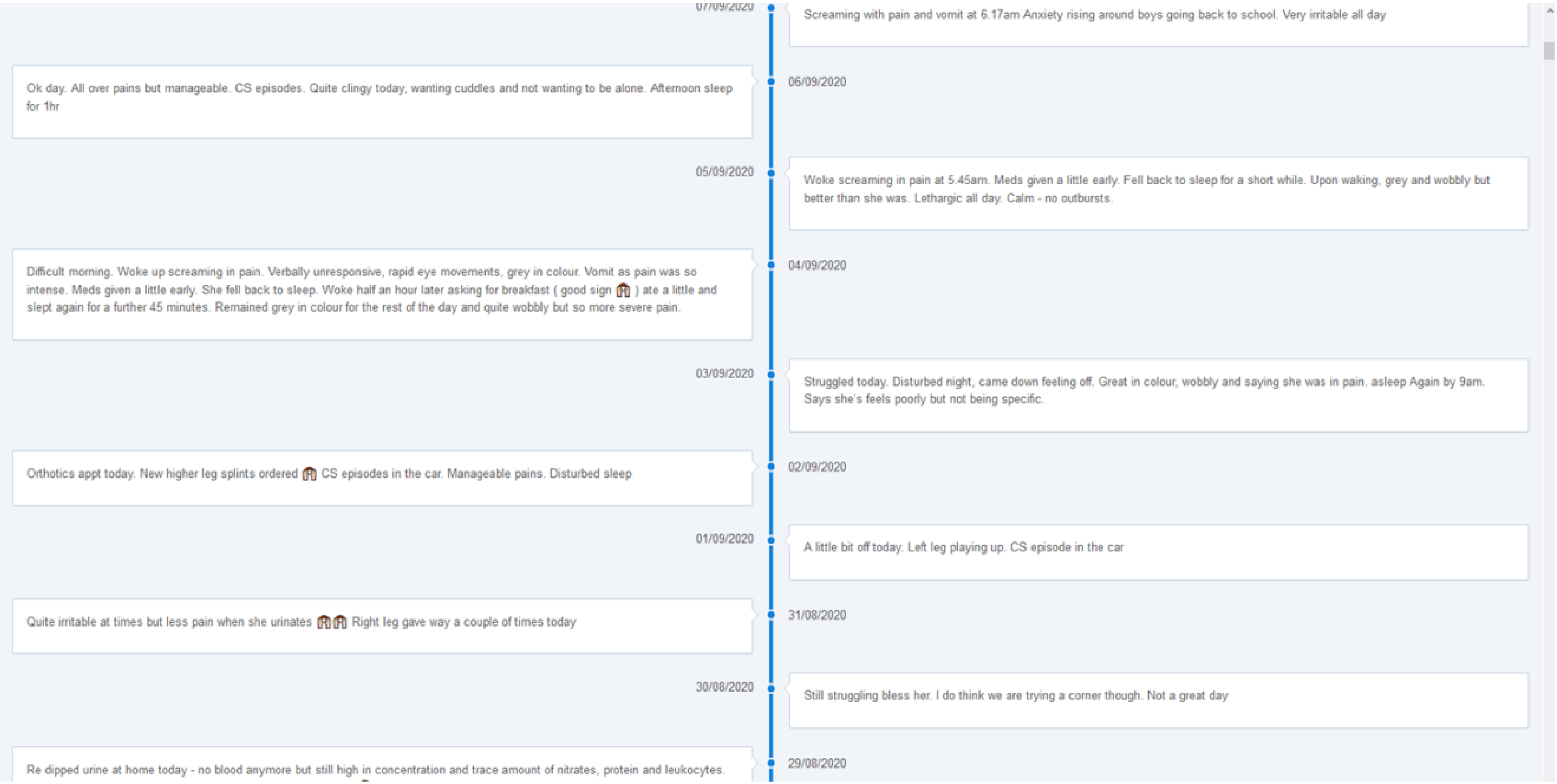
01/08/2020 - 01/09/2020
01/09/2020 - 01/10/2020
Time (By Month)
Pain
Sleep problems
Cognitive shuntdown
Seizures/convulsions/fits
Tiredness or fatigue
Obsessional behaviour
Hyperphagia
Anxiety
Mobility problems
Change in Behaviour or Mood



07/09/2020

Screaming with pain and vomit at 6.17am Anxiety rising around boys going back to school. Very irritable all day

06/09/2020

Ok day. All over pains but manageable. CS episodes. Quite clingy today, wanting cuddles and not wanting to be alone. Afternoon sleep for 1hr

05/09/2020

Woke screaming in pain at 5.45am. Meds given a little early. Fell back to sleep for a short while. Upon waking, grey and wobbly but better than she was. Lethargic all day. Calm - no outbursts.

04/09/2020

Difficult morning. Woke up screaming in pain. Verbally unresponsive, rapid eye movements, grey in colour. Vomit as pain was so intense. Meds given a little early. She fell back to sleep. Woke half an hour later asking for breakfast (good sign 🙏) ate a little and slept again for a further 45 minutes. Remained grey in colour for the rest of the day and quite wobbly but so more severe pain.

03/09/2020

Struggled today. Disturbed night, came down feeling off. Great in colour, wobbly and saying she was in pain. asleep Again by 9am. Says she's feels poorly but not being specific.

02/09/2020

Orthotics appt today. New higher leg splints ordered 🙏 CS episodes in the car. Manageable pains. Disturbed sleep

01/09/2020

A little bit off today. Left leg playing up. CS episode in the car

31/08/2020

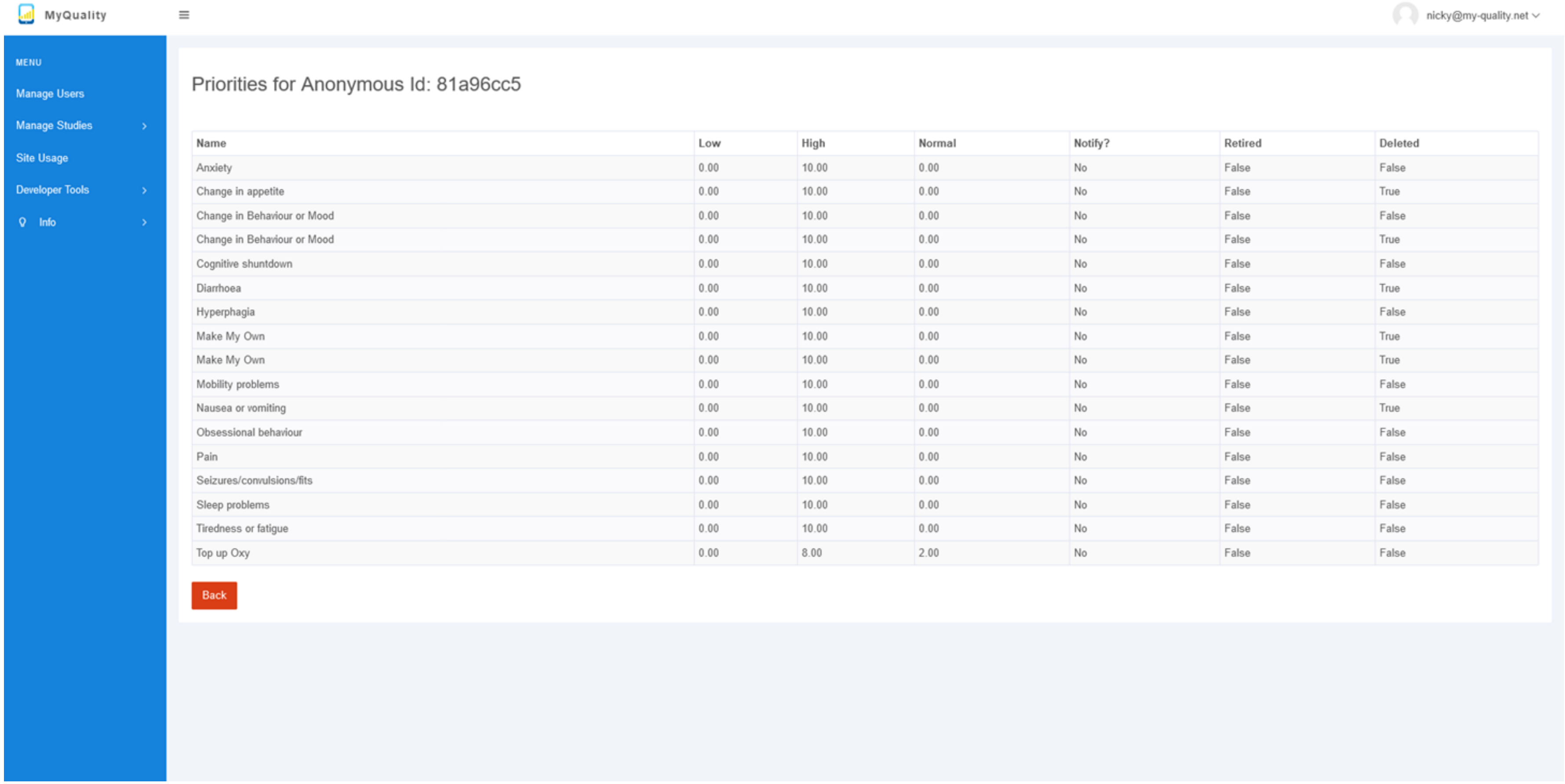
Quite irritable at times but less pain when she urinates 🙏🙏 Right leg gave way a couple of times today

30/08/2020

Still struggling bless her. I do think we are trying a corner though. Not a great day

29/08/2020

Re dipped urine at home today - no blood anymore but still high in concentration and trace amount of nitrates, protein and leukocytes.



Priorities for Anonymous Id: 81a96cc5

Name	Low	High	Normal	Notify?	Retired	Deleted
Anxiety	0.00	10.00	0.00	No	False	False
Change in appetite	0.00	10.00	0.00	No	False	True
Change in Behaviour or Mood	0.00	10.00	0.00	No	False	False
Change in Behaviour or Mood	0.00	10.00	0.00	No	False	True
Cognitive shuntdown	0.00	10.00	0.00	No	False	False
Diarrhoea	0.00	10.00	0.00	No	False	True
Hyperphagia	0.00	10.00	0.00	No	False	False
Make My Own	0.00	10.00	0.00	No	False	True
Make My Own	0.00	10.00	0.00	No	False	True
Mobility problems	0.00	10.00	0.00	No	False	False
Nausea or vomiting	0.00	10.00	0.00	No	False	True
Obsessional behaviour	0.00	10.00	0.00	No	False	False
Pain	0.00	10.00	0.00	No	False	False
Seizures/convulsions/fits	0.00	10.00	0.00	No	False	False
Sleep problems	0.00	10.00	0.00	No	False	False
Tiredness or fatigue	0.00	10.00	0.00	No	False	False
Top up Oxy	0.00	8.00	2.00	No	False	False

List of 17 priorities now, appetite, diarrhoea, N&v, extra behaviour deleted + two MYO ie total 11

Sharing with Practitioners (details redacted): 1 nurse, 1 doctor, 1 team link, no change from initial arrangement at start of study.

Appendix F – HCP interview guide

Example notes for interview with consultant paediatrician:

3 patients identified:

[redacted]

Challenges in recruitment? Challenges in use of MyQ?

Communication preferences – (telephone? “No news is good news?”)

Key themes to come out from patients:

Supporting greater understanding of your/your child’s needs (multiple complexities and how they interact, patterns of change, personalised monitoring, clarification of priorities for care

Theory 2 – responsibility to remember everything, aided by recording in real time.

Theory 4 – graphic display to understanding, cause and effect, confidence

Fulfilling your role as parent/carer – being a better parent. Getting more organised, burden of responsibility, being vigilant for problems, feeling confident and reassured, being in control, telling your story

Theory 1 – priority-setting to support greater patient-centred focus

Theory 2 – responsibility to remember everything, aided by recording in real time.

Theory 3 – consistent record, reliability of recall

Theory 4 – visual graphic display to understanding, cause and effect, confidence

Working with HCPs – collaboration, having relevant information, power discrepancies, clarifying roles and responsibilities, trust, the importance of being heard. Medicalisation of normal life (3A)

Theory 5 – sharing – willingness for dialogue, timely management

Theory 6 – shared decision-making

Theory 7 – greater responsiveness to need

Theory 8 – relevance of data recording

Key themes from HCPs

Lots of comments about how MyQuality is a really good idea:

Convenience of remote access

Real time recording

More reliable than memory

Workload/caseload management more efficient

Can see what works and what doesn’t

Potential barriers:

Managing workload – symptom control and scope of this, email alerts (9A, 11)

Managing expectation eg email alerts and immediate response, medical vs nursing vs no oversight, dealing with different agendas (pt and HCP), realistic goal setting (9B, 10,11)

Co-ordinating with other service providers – back door second opinions, role of various providers, co-ordinating responses to problems (12, 13)

Territorial issues – who does what, saying no to email alerts, defining your service vs others (11b)

Resilience, emotional responses – eg sense of vulnerability or potentially being overwhelmed by nature and volume of information

Needing to trust pts/families as equal partners (risk of manipulation of data entry, or different prioritisation that is “medically incorrect”

Avoiding the digital divide – equitable services

The following are segments of interview notes, testing programme theories with HCPs.

What is important to you about linking with your patients using MyQuality? What do you value about it?

Theory:

7. Professionals who work in the field of children's palliative care who *make time* to look at the MyQuality data produced by their patients/families will have a **greater understanding (Res)** of the nature and variability of their challenging symptoms, and a **timely awareness (Res)** of change which should result in a **greater responsiveness to patient need (Resp)** and timely modification of treatment advice as appropriate. (F2,3)

Do you think there are any limitations to using MyQuality in your service/with your families?

What are your concerns about using MyQuality as a professional?

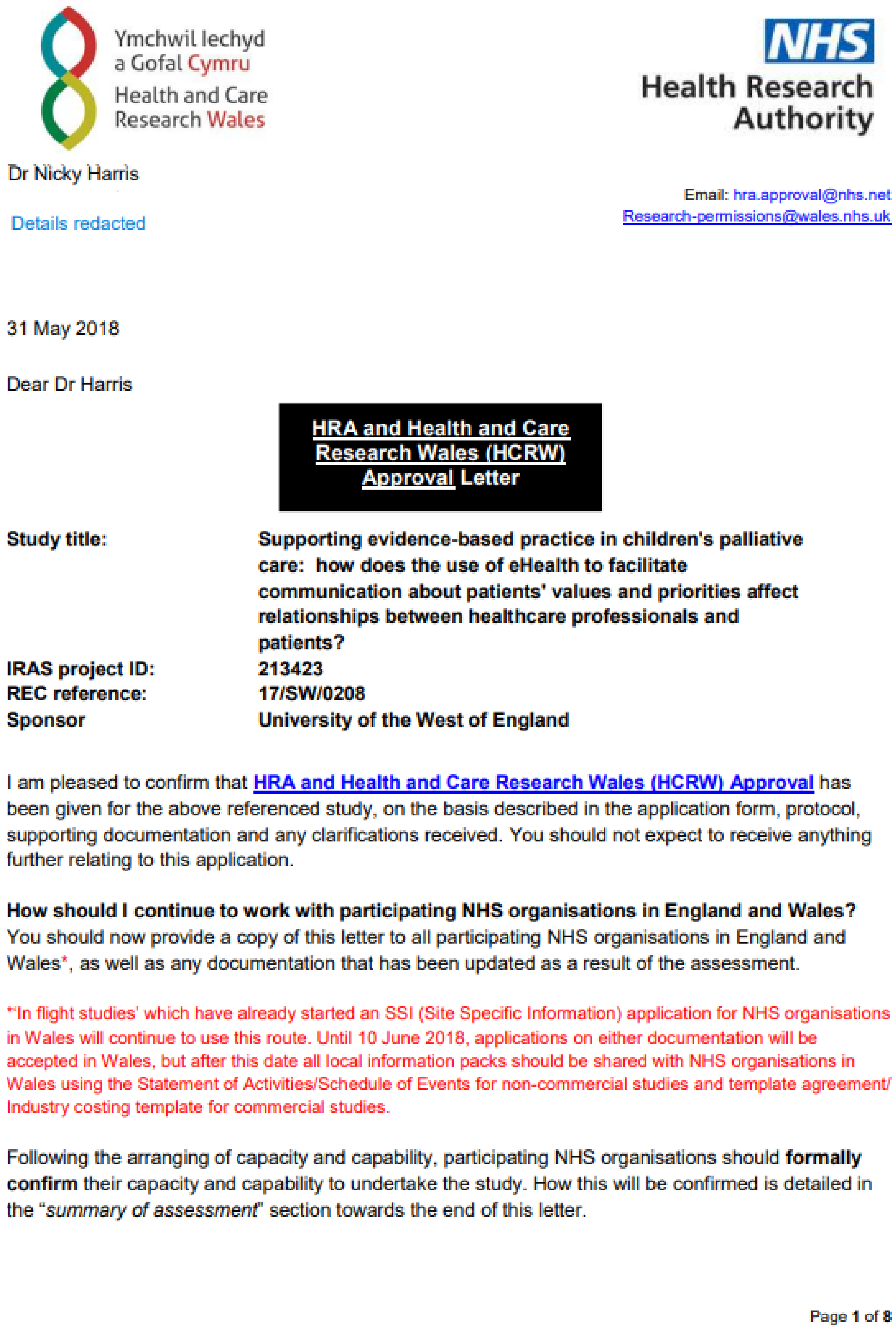
7A: Rival theory: Professionals who work in the field of children's palliative care who make *time* to look at the MyQuality data produced by their patients/families will have a greater understanding of the nature and variability of their challenging symptoms, which may include *problems that are not easy to solve, or reveal unmet need and highlight inadequate resourcing* for support. This may cause them to feel **overwhelmed by the scale and nature of the difficulties (Resp)** the families face. This can lead to a fearful approach to engaging (ST) with MyQuality data and reduce staff resilience (LT).

7B: Rival theory: Professionals who work in the field of children's palliative care who make time to look at the MyQuality data produced by their patients/families may comprehend the scale and variability of the challenges families face. If they *attempt to meet these needs without adequate resourcing* to do so, they face an **increasing and potentially unsustainable workload,** which will ultimately lead to higher levels of burnout over time.

What are your concerns about your patients and their families using MyQuality?

(prompt?: consider issues about managing expectation)

Appendix G – Ethical Approvals – copy of HRA approval letter, amendment, and details of ethical considerations for study design and conduct.



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr Nicky Harris

Details redacted

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

31 May 2018

Dear Dr Harris

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Supporting evidence-based practice in children's palliative care: how does the use of eHealth to facilitate communication about patients' values and priorities affect relationships between healthcare professionals and patients?**
IRAS project ID:	**213423**
REC reference:	**17/SW/0208**
Sponsor	**University of the West of England**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales*, as well as any documentation that has been updated as a result of the assessment.

*'In flight studies' which have already started an SSI (Site Specific Information) application for NHS organisations in Wales will continue to use this route. Until 10 June 2018, applications on either documentation will be accepted in Wales, but after this date all local information packs should be shared with NHS organisations in Wales using the Statement of Activities/Schedule of Events for non-commercial studies and template agreement/ Industry costing template for commercial studies.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

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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.18.07.194*
Title of project:	*MyQuality – Measure What Matters*
Date of original approval:	*6 July 2018*
Researcher:	*Nicky Harris*
Supervisor (if applicable)	*Toity Deave*

1. Proposed amendment: Please outline the proposed amendment to the existing approved proposal.

Extension of timeframe for follow-up interviews – the original application included an option of a third interview, to revisit participants who continue to use MyQuality for 6 months after their initial pair of interviews. Some participants have been using it regularly for longer (in some cases up to a year longer) but not had a 6 month follow-up interview. This would take the form of telephone interview, not face-to-face as with previous interviews.

2. Reason for amendment. Please state the reason for the proposed amendment.

Recruitment and interviewing stopped with lockdown from March 2020.

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.

1. Infection risk – face to face interview option as described in the original application will not now be offered. Interviews will be conducted over the telephone (or video-calling if technology & broadband allows.)
2. Their personal or child's circumstances may have changed – initial contact will be made via email to confirm that they are happy to proceed with a follow-up interview, to allow time for participants to consider their options and decline/withdraw if further follow-up is not desired.

To be completed by supervisor/ Lead researcher:

Signature:	
Date:	

To be completed by Research Ethics Chair:

Send out for review:	☐ *Yes* ☐ *No*
Comments:	
Outcome:	*X Approve* ☐ *Approve subject to conditions* ☐ *Refer to Research Ethics Committee*
Date approved:	*13/10/2020*
Signature:	*Julie Woodley via email*

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.

Design and conduct of the proposed study

The study is a realist evaluation, drawing on a mixture of qualitative and quantitative approaches. The design of the study will require patients (or their carers) and the professionals providing them with support to use the website, complete questionnaires and participate in interviews or discussions. Qualitative research in the health services raises ethical issues about the risks to participants, including causing anxiety and distress, the potential for exploitation, misrepresentation, and breaching confidentiality (Richards & Schwartz, 2002).

A framework for ethical decision-making in healthcare derives from the work of Beauchamp & Childress (2001) which brings together the concepts of autonomy, beneficence, non-maleficence, and justice, and these will need to be applied from the initial recruitment phases of the study through to its completion.

Autonomy refers to the concept that an individual is free to make choices about themselves, and in the healthcare context confirms an individual's authority to determine what decisions are made about interventions or processes. In a research scenario, the principle of autonomy underpins the importance of gaining informed consent and confirming the right of potential study recruits to decline to participate or to withdraw from a study.

Beneficence (doing good) and non-maleficence (avoiding harm) are key factors to be considered in many medical interventions, as there is frequently a need to balance the potential benefits from a procedure against the possible risks, and most interventions are not entirely risk-free. In a research context, the balance of benefits and risks may be quite different from a healthcare context, as both elements may be difficult to quantify or predict. In some cases the benefit to the individual may be minimal beyond the sense of altruism, but may bring some benefit to the population or to knowledge as a whole, and this needs to be weighed against unknown risks. It is important to provide accurate information and have honest discussions about research studies with participants in order to obtain truly informed consent to participate.

Justice refers to fairness and the equitable distribution of resources, supported by a utilitarian philosophy to find "the greatest good for the greatest number". The resources may include access to money, time, staff, facilities or medications in a healthcare context, and in research justice addresses the need to use resources responsibly. This concept is relevant in discussions about research prioritisation, cost-effectiveness, and efficient dissemination of outputs. This aspect is key to the current movement towards greater sharing of the products of research via open-access publishing, and research and data repositories.

Alternatives to the Beauchamp and Childress approach to ethical challenges in healthcare exist, and may subdivide many of the issues raised above into separate areas for consideration – for instance some define truth-telling and the preservation of confidentiality as two distinct areas for clarification and elaboration within any research proposal, and others have a dozen or so highlighted areas for careful consideration. Confidentiality is a key concern, particularly in a field with small numbers of individuals with rare conditions and a small professional workforce, where even limited data such as a date of birth, a diagnosis, or place of residence or site of work could reveal a participant's identity. However, Beauchamp and Childress provide a framework for deliberation of issues that is well-recognised by other researchers, ethicists, and clinicians. This framework needs to be applied to the issues raised in this particular study, which I will outline below.

Recruitment

Teams providing supportive and palliative care to children and young people will be approached by me, with a no-obligation discussion about the nature of the study and an invitation to take part (autonomy). Should they agree, recruitment of patients will take place through contact with these teams, who will act as participant identification centres. Exclusion criteria will apply, as it would be inappropriate to contact those whose life expectancy is anticipated to be shorter than 3 months (non-maleficience). For practical reasons the study is limited to those living or working in the southwest of England (justice – use of resources), and it would be impractical to approach those without access to a computer, or whose spoken English is insufficient to undertake an interview in English.

Study participants will be recruited via front-line providers of children's palliative care services, who will be seeking their permission to send their contact details to me (confidentiality). This information will be transferred either via personal discussion (face to face or on the telephone) or by using a secure email service such as nhs.net, which is sufficiently encrypted to be used for sending confidential patient information within or around NHS and voluntary sector providers and is the "industry standard" practice.

All study participants will be given information to help them make an informed decision about whether or not they would like to take part and will be made aware that there is no obligation to participate (autonomy). The information sheets and consent forms have been adapted to address a range of situations: participation by adults and children over the age of 12 using the website to self-report; parents consenting on behalf of their children; parents or carers using the website as a proxy for their children (who may be unable to participate themselves due to young age or cognitive impairment); and professionals taking part in this project. These documents have been subject to inspection by the YPAG and were adapted where necessary to incorporate their feedback (non-maleficence).

Retention of participants

Study processes may add an extra burden to busy families and to professional users, but these will only occur once informed consent has been given. Participants who provide consent but then change their mind are free to withdraw from the study at any time (autonomy) by informing me by email or text or telephone. The website can be used as much or as little as the individuals see fit, to suit their personal circumstances (beneficence). Should participants feel that the burden of using MyQuality is too much for them, they may stop using the website but report their experiences through the interview processes, as this perspective will be valued as part of this research.

Data Collection

There will be three types of data collected as part of this study: website use, interview transcripts (for personal and professional users), and empowerment questionnaires (for personal users only).

To ensure confidentiality is maintained, all participants will be given a study number, and website data will be downloaded with a unique, randomly-generated computer code as an identification number. Access to the master copy that links individuals to their study numbers and website anonymization code will be limited to the research student, and this will be kept securely in a separate file on the university server, away from the main data storage. The interviews will be transcribed verbatim, removing names and identifying comments. Given the potential number of individuals with rare conditions, these identifiable characteristics will include any reference to age, diagnosis, location of home or supportive care, or details of dates of involvement in the study. Health and social care professionals who participate in the interviews will also be given personal identification codes, distinct from any reference to their name or location of work. Questionnaire responses will be scanned, stored and analysed with the study numbers only, with no publicly identifiable information.

The entry of data on the website may require individuals to consider questions about their quality of life or symptom management in a new way, on a daily basis. Previous experience (Harris, Beringer & Fletcher, 2015) suggests that website information could provide reassurance about improvements and act as a positive reminder of progress over time, and this was frequently viewed as a beneficial outcome by study participants. However, the graphic display produced by the website may shed a different light on deterioration of physical, emotional, psychological or other stressors in life, and render some coping mechanisms (such as denial) more difficult. Should this occur, people may need to stop using MyQuality. It will be important to recognise the potential psychological burden for users, so these challenges have been acknowledged in the study information leaflets (non-maleficence). Individuals are encouraged to seek support if necessary and to discuss any issues with their health and social care professionals.

The interview process itself may potentially have both beneficial and harmful effects. Interviews of patients or their family/carers may allow the opportunity for discussion and reflection on their own circumstances, which can be of therapeutic value (beneficence). However, it also demands time, and may be perceived as stressful by participants. To mitigate this, the interviews will take place in the environment of the interviewee's choosing, and include open-ended questions to allow for a relaxed, conversational style of discourse. The interview schedule is semi-structured to allow the opportunity to consider areas for discussion that are related to the research question but not specifically designated on an interview guide. Techniques such as mind-mapping to contextualise the support and communications network, and reassurance that there are no "right or wrong" answers, should help to relieve anxiety (non-maleficence).

The only exception to this, and stipulated in the information sheets, is the duty to prevent harm to vulnerable individuals. The interview process will allow children or families to discuss personal issues in a private space, including their fears, frustrations, and challenges. If issues arise in interviews that signify a danger to the patient or family, there is a clear commitment to pass these concerns onto the relevant agencies for the purposes of safeguarding against harm. Aside from this, participants can be reassured of the confidentiality of the interview discussion, and that the researcher will not relay information to other parties.

Data analysis

When the research data are analysed, the results will only be shared within the university supervisory team, via secure encrypted networks such as the internal university network (confidentiality).

Once the study has been completed, the initial report’s findings will be shared with study participants. The perspectives provided by lay observers to this work are valued, so early password-protected drafts of reports will be shared with the Young People’s Advisory Group and with parent participants in the PPI process, to review the conclusions, and advise on public access to our work. Professionals will receive their initial reports via nhs.net. It will be important that they feel confident that they would not be able to identify participants from any information that could be made generally available. Publication of results will not take place until this assurance has been received.

Appendix H – PPI group summary notes, questions for discussion in italics

1. **Overview:** The purpose of this PhD is to understand how it might be possible to improve the care for children with life-limiting illness and their families by using modern communications technology. It starts with a few assumptions:

- Parents (or those acting in a parent role) are experts in their child's day-to-day care, and provide for their physical, emotional and social needs.
- Professionals may have expertise and experience in aspects of a child's medical or nursing care, educational or practical needs, and may be able to support the child and family.
- Effective communication is the bedrock of children's palliative care
- The use of modern technology to facilitate communication between the parents and professionals should maximise the ability of both parties to support the child, the family, and themselves as they carry out their respective roles.

Q1 – are these assumptions correct/reasonable/sufficient?

The "modern communications technology" being explored is the MyQuality website –(www.my-quality.net if you want to have a look at it yourself). This is an interactive website for patients to use (or their parents/carers for children) when working with the professionals involved in their care. They can record the issues that matter most to them on a day-to-day or week-to-week basis, describe them in their own language, prioritise them, monitor them, and share this data with their healthcare professionals should they choose to do so. The purpose of website is to facilitate communication of a child or family's perception of the factors that influence their quality of life, and to share this with their health/social care team. The website does this in several ways:

- Allowing the patient or family to identify and describe their priorities gives them freedom to choose, and personalise, what aspects of daily life they wish to emphasise. A scoring system helps users to rate the impact of the problem on their day in a simple manner, relevant to what is normal for them/their child.

- It can be used daily, to give a regular reliable up-to-date record of change over time, instead of depending on memory when sharing information

- It can used done anywhere, which allows observations from home or their usual environment rather than something limited to encounters with professionals

- The information gets converted to a graph to show how things change over time, and a visual picture may be a quicker and simpler method to describe change than by putting things into words

- It is possible to set up an automatic alert system in advance, as a "safety net" in case some symptoms get to a point where professional advice would be advisable.

- A daily diary allows the user to annotate their scoring both with detailed description, and with thoughts about possible explanations for the numerical scores that appear on the graph.

- Personal users can choose to share their information, should they wish, with one or many members of the professionals involved in their care who have registered on the website.

2. This project: The aim of this research project is to consider not IF people will use this website, but to better understand how parents and professionals communicate and work together, and how the use of a website like MyQuality might influence that process.

I am trying to answer that question using a Realist Evaluation, which is a research approach to consider what works, for whom, under what circumstances, and how or why, when a new intervention (such as using the website) is introduced. It was developed particularly for interventions where people, and decision-making, determine how things work (or don't work) in practice.

This process starts by looking at available information to understand what we already know, and what can we learn from similar projects elsewhere. That information includes published research, but also relevant experience from a variety of perspectives. The next step is to consider potential theories about what underlying factors may be influencing the decisions people make about whether, how and why they use the website.

These theories are explored in an experimental way by asking people who have used MyQuality about their experience and getting their feedback about whether the theories are correct, need modification, or are wrong or missing something. Over time, the theories can be explored with a range of users and will evolve as there is more and more feedback, to allow the researchers to understand more about key contributing factors or circumstances, and underlying hopes, fears and expectations about this process. By the end of the research project, I hope to understand what it is about MyQuality that works (or doesn't work), and to have further insights into the challenges about effective communication between families and professionals in this field and how to begin to address these.

So far there have been 20 interviews with 14 families.

- All 14 families were interviewed at the beginning about their hopes and concerns about this approach to care.
- 6 families used the website extensively and gave lengthy feedback about their experiences.
- 3 did not complete the study as their children's health deteriorated and they subsequently died, and further follow-up interviews were not possible or appropriate.
- 5 families were keen to start but never really got going with the website and declined a second interview, though some did feedback their reasons for this via email.

In addition, 10 professional teams (46 participants) from a mixture of hospital, hospice and community settings participated in interviews or focus groups at the start of the process. Follow-up interviews with healthcare professionals are ongoing.

The family interviews come from 13 families with children who were either too young to use the website themselves or had health conditions which meant that they were unable to do so. In addition, there was one family with a 14 year old girl who was interested in using the website herself, but after initial enthusiasm she did not input any readings and then lost interest. I had initially hoped for insights from young people as part of this research process, but persuading professionals to refer them to me to participate in this project has been difficult.

Several themes have emerged consistently from the interviews with parents who have used the website about their children. Broadly, these are in two categories – supporting the website user in their role as parent to their child; and supporting teamwork between patient/parents/carers and healthcare professionals. These are outlined below.

3. Themes from interviews from patients/parents

1. supporting the personal user as a patient/parent/carer to "be the best they can be"

- Getting more organised
    - Keeping a reliable record (better than your memory or sheets of paper)
    - Being able to document and then "park" events, and then get on with life
    - Regaining a sense of control over chaos, when so much is going on

- Developing a greater understanding of your child's needs
    - Monitoring that is flexible, personalised and relevant to your circumstances
    - Recognising what is "normal" for you/your child
    - Improved understanding of multiple health complexities and how they interact
    - Looking for patterns of change, cause and effect

- Supporting you in your role
    - Telling your story, having your say about what is important to you
    - Clarifying your role in your child's care team
    - Knowing that you are making a difference to the care your child receives
    - Recognition of your contribution and input by others

- Sharing the burdens and responsibilities of caring for another person
    - Being part of a team providing care
    - Trusting others with your information, and trusting that they value it
    - Communicating effectively – timely, relevant information
    - Learning together about what is best for you/your child/your circumstances
    - Sharing risk and responsibility

- Gaining confidence
    - Feeling part of a team, less isolated
    - Feeling less vulnerable (by having more "information")
    - Backup system for your own observations
    - Being vigilant for problems

- Seeing the bigger picture
    - Holistic care of a person or family, not just individual symptoms

2. Teamwork between patients/parents/carers and healthcare professionals

- Working collaboratively
    - Sharing information
    - Opportunities to listen to each other
    - Sharing risks and responsibilities
    - Supporting each other

- Forging relationships based on shared experiences
    - Trusting others
    - Learning together, admitting limitations of knowledge
    - Respecting each other’s roles and contributions towards a common goal
    - Reducing or reshaping power discrepancies in healthcare

- Improving co-ordination of care
    - Effective use of time to disseminate information
    - Consistent reference records across all involved teams

- Speaking the same language, correct for time and place
    - Reduction in recall bias/memory gaps
    - Clarification of priorities for care
    - Real-time input
    - Real-world environment (as opposed to observation in hospital)
    - Relevant information for your circumstances

Most of these points were raised by most of my family interviewees at some point, but I struggled to categorise them. Some (eg trust, teamwork etc) recur in several sections, but with a slightly different slant. I had previously divided the themes into “your role as a parent of a child with significant health issues”, “your role as an individual”, and “your role as part of a team with professionals”, but was not sure that it was appropriate. Other categorisations may be better (practical/efficiency benefits, emotional/psychological benefits, and clinical benefits for example?) but that may seem to clinical, and I want to retain a holistic feel so I am open to other suggestions.

Q2: *a) I would value your reflections on whether these categories make sense to you.*

b) Are there other factors about your role in being a parent that are not mentioned?

c) Are there other factors about being part of a team that are missing?

d) would any of this cause offense to parents – eg references to feeling vulnerable or isolated or overwhelmed, or the implication that communication could be improved?

4. Theory Development – patients/parents

The Realist Evaluation approach involves the development or refinement of theories about how or why something works, trying to understand underlying mechanisms that may be playing a part in people's responses and leading to the results that you hope to see. The following are some of the theories that pull these interview findings together.

For reference: HCPs = healthcare professionals, LLI = Life limiting illness

1. **Clarifying what matters most**: Families or children living with LLI may contemplate and identify the key issues that they would like their healthcare practitioners to address and record these on the MyQuality website. In doing so, they will clarify their priorities for support and be able to emphasise these issues to their HCPs in clinical encounters, which will increase the focus on their priorities for care and give a more patient-centred focus for the delivery of care by HCPs.

2. Having a **reliable record**: Families of children living with LLI carry a considerable burden of responsibility to be the eyes, ears and voice for their children. If they can monitor, quantify and document their symptoms on a daily basis using MyQuality, they will develop a real-time visual record which will support their recollections, reflections and understanding of their child's needs and how these may change over time, unaffected by the benefit of hindsight, or loss of recall. This will improve their confidence when reporting their child's circumstances to HCPs.

3. Having **relevant information**: Families of children with LLI may record information on MyQuality whilst they are away from healthcare support (i.e. outside hospital, hospice, community nursing or GP settings). They will be prospectively documenting their child's health in a "normal life setting", resulting in a more realistic, continuous record of health concerns. This can increase the relevance and reliability of their observation and interpretation of change over time and support increased confidence during discussion with HCPs and more accurately informed collaborative decisions.

4. **Improving Knowledge**: Patients or their families who interrogate the graphic display generated by regular inputting of data into MyQuality will explore patterns of problems or symptoms, potential causes and effects of any change, and develop a greater understanding of their child's symptoms and behaviour. This can reduce a sense of uncertainty or helplessness, and support resilience for them as carers.

5. **Being part of a team**: Families of children with LLI who choose to share their recorded MyQuality information with their healthcare professionals will demonstrate a willingness for dialogue about improving the quality of life of the child/family by working collaboratively with their HCPs, and facilitate timely and responsible symptom management through regular honest recording of change over time.

Q3: These theories are derived from evidence from the literature and interviews with patients and families.

a) Do these theories make sense to you?

b) Is there anything that leaps out at you that is missing about the mechanisms that may be at work?

Most of these theories relate to the individual component parts of MyQuality and the data that arise from the process. There may be an argument that the outcome from using this approach is greater than the sum of its parts. One of the comments made by several interviewees was the feeling that they wanted to "do their job, be the best mum I can be".

Do these theories adequately pick up this sentiment?

Eg: literature describes several components of parental tasks required:

- Healthcare provider: nurse, physio, OT, technician (re catheters, NG tubes, feeding and suction equipment, BiPap etc), and adjuster of medication etc.
- Case manager: daily role to assess, prepare, implement, co-ordinate, monitor and evaluate their child's complex care routines and treatments.
- Student: parents are in a continual learning process to educate themselves about their child and the condition, care and treatment options.
- Teacher: parents know their child best and thus become a key source of information for HCPs, extended family, friends, school and community, and to help other parents
- Detective: figuring out various aspects of their child and child's care as treatments and medical procedures often hit and miss, every child is unique. Interpreting non-specific signs and symptoms difficult.
- Guard: watching over and protecting their children. Monitoring health status, maintaining vigilance for change, protecting psychosocial wellbeing.
- Advocate: standing up for children to make sure their needs are met and their interests and self-worth respected.
- Being a good parent to ALL your children: maintaining relationships, balancing needs of multiple family members
- Juggler: managing unexpected crises, repeated need to "triage" daily priorities
- Decision-maker: for day-to-day decisions re risk management and prioritisation within family life, and for major or life-changing decisions re life/work/relationships
- Self-care: to manage physical and emotional consequences of parental role

Multiple papers reflect the need to support parents as part of holistic care, and that this leads to better outcomes for ill child and for long-term family adjustment.

Is an additional theory more specifically about being a parent warranted here?

Eg: facilitating being "a good parent": Parents of children with LLI who choose to use MyQuality are taking a proactive step to address the multiple tasks involved in parenting. This can be empowering for parents, leading to improved psychological wellbeing and more efficient and effective communication with HCPs.

Am I still missing something about an aspect of trying to regain control? Also, something about being recognised and valued and respected as a parent –

Eg: Endorsement of parental contribution: Parents of children with LLI who choose to use MyQuality are asserting their control over the nature of data collected and recorded, thus affirming their central role as prime guardians of their child's wellbeing. When HCPs view this data, they acknowledge, respect and value this contribution to improving the child's health, which contributes to support of self-esteem and resilience of parents.

Again, thoughts about appropriate wording etc always welcome!

Appendix J – Rae's reflective matrix

Position of the subject of objectivation	Overall Social Space	Within Field of Specialists	Within academia
Pre-research	How do researchers' broader motivations affect the reason to conduct research in the first place, the choice of topic and research question, and the choice of methodology?	What is the relationship between the researcher and the health care field? How is the topic relevant to health care?	Where do the researcher's interests (and conflicts of interest) lie within the relevant literature and its interpretations?
Data Collection	What are the shared and divergent understandings between the researcher and participants with regard to research generally, and to the health-related topic? Are there any differences of a social nature eg gender, education, or experience? To what extent are meanings negotiated between the researcher and participants, and how is this influenced by life experiences? Is the researcher prepared to undergo change as a result of interaction with the research? What is the potential for change in the participant?	Do the researcher and participants share the same language? Are there any power differentials between the researcher and the participant, based on positions held (present and past), health discipline, or education?	Are questions or prompts inadvertently shaped by popular (perhaps fleeting) scholarly opinion?
Data analysis		How does the researcher's experience with the field shape the analysis? Are some data dismissed as being commonplace whereas they may warrant deeper interrogation? To what extent does the researcher consider the balance of analytical authority to rest with the participant or with the researcher?	How does the researcher moderate any drive for outcomes that might inadvertently lead to data omissions or fabrications?

Appendix K – Samples from reflective notes

Pre-Research phase:

Feb supervision discussion: potential for conflict of interest so will need to illustrate how I have approached dual role issues. Agreed parameters with supervisors about how to deal with negative feedback – does this study require stopping rules that are more stringent (and how to do this with quali data?) How best to support self and remain objective if findings are challenging my initial assumptions?

Data collection phase:

Transcribing first interview – interesting to look back on the recording and consider a) how it differs from what I remember about the interview in my head b) how different the content feels when I am in a different emotional state (not anxious!) and c) how I have covered a lot, most of what was in the interview guide but also lots that isn't – so easy to get confused with my medical hat/researcher hat alternating as the child's details are discussed. How can I not offer an opinion on ketogenic diet when asked? Staying in researcher mode is much harder than I had anticipated. Also, I found it felt insensitive to be asking my research questions at times in the context of a constantly coughing child in the corner of the room, but if that is "normal" then I must ignore it. Tricky.

Doing transcribing of patient interviews and I'm aware that 2 major issues don't really fit into these theory areas – desire for control, and co-ordination of care. This is in some of the empowerment literature but I need to think about theory areas and where this fits in. It is easy to get distracted by the literature and themes that others have identified, but they don't necessarily fit with my quest for a focus on communication and working relationships.

Attended qualitative research group meeting re reflexivity (I am only scratching the surface of reflection really) and considering what I am bringing to this exercise re my first study and conclusions from it, and am I being open minded enough about rival theories, alternative explanations, and what are my drivers for empowerment and patient-centred care – how much baggage of my own re expectations and assumptions am I bringing to the analysis? Particularly came into focus with (family X) as they didn't "get" the impact in the same was as (A, B or C's) families did. Also reflecting that I am perhaps not digging hard enough for the detail in the interviews – eg specifically what was the impact of various elements of MyQ design in their reaction to the processes – "what is it about XXX questions". Daily diary? Sharing access? What precisely are they getting from the graphs? Why do they use the bits they use, and what does that mean for them?

Follow-up interview with printout of graphs: intended as a visual aid for discussion but too easy to morph into a clinic review (medical hat), or an IT session (developer hat). And SO tempting to feed this back to HCPs but I just have to trust the parents to do that themselves.

Follow-up interview with HCP confirms unanticipated, unwanted outcome. Am I adding to my colleagues' woes?

Data analysis phase:

Wondering while in the car – my questions about control and empowerment assume that there is a problem with lack of control and disempowerment. While that resonated with me, how universal is it? Or am I still working through my own issues here?

Had a good go at putting theories onto NVivo and then doing some initial coding against interviews – very frustrating. May end up thinking about adaptation to LLI and how might MyQuality be able to restore some sense of control/dignity/role/support for parents. The role of a good parent or good patient? Interesting, but not at all what the theories are about. There is an interesting mix of old-fashioned ground-up theory extraction, with RE theory testing, and I'm not sure how to totally square that circle. Need to incorporate something about telling your own story, and practical coping benefits of recording/understanding, and redefining and affirming your role as primary carer for a child with LLI. Need to incorporate this with member-checking

Got to thinking while walking the dog – its almost like the parents are addressing some of their higher needs in Maslow's hierarchy (ie we know that they can feed their children and keep them safe, and interact with society on their behalf, but it's the higher needs of making a contribution and finding a purpose that MyQ might tap into.) The HCPs have the opposite issue – MyQ is exposing the vulnerability to factors lower down the triangle ie role, and even questioning their competence and volition – so many feeling quite threatened and vulnerable in their comments. Found some interesting bits on google re Maslow's triangle in other settings (eg teaching, employment, etc) and some stuff from laconte which addresses fears and barriers to meeting those needs – need to consider this dimension.

Brainstorming concepts about HCPs, juggling the needs of patients and families. If a family shows them too much about the detail (weight) of what they are dealing with, will HCPs sink? If they have to work in a different way with other teams, will they remain buoyant or will they be undermined? All about staying afloat. Ties in with resilience and the need to support teams to evolve with change. Parents are using MyQ to *help* them stay afloat, not to add to the burden. Ties in with not only surviving, but thriving (wrong word but a growth concept). Thriving ties in with self-determination.

Brainstorm whilst reading Times supplement about the future of healthcare (Aug 12th) and the role of symptom trackers, AI, and public willingness to share information and use them (and pt empowerment). But all is very focussed on either getting a diagnosis, or monitoring/managing a condition – not a holistic approach. Is the nature of holistic care something that HCPs haven't really incorporated esp in disease specialties? Is this what is so frightening? Does this explain why generalists – community nurses and paeds - are happier with the concept of "what matters to you" more than specialists, even those in palliative care – due to the lack of boundaries? [redacted] in particular have been suspicious about patients using this to "game the system" – and unboundaried use might allow this to happen more readily? … The trust/distrust issue and the boundaries/holistic care issue are two different mechanisms here. So how do you genuinely embed the principles of holistic care into professionals who apparently espouse the call but whose words do not match their actions?

Appendix L – Sample of if-then-because statements

Programme Theories: – if – then – because, or Intervention – Context - Mechanism (Resource – response) – Outcome (short term ST or long term LT) – negative outcome

For patients/families:

1. When users decide to register on Myquality, they acknowledge their role in deciding to think about their priorities for care and document these with clarity. This may result in focussed contemplation of hopes, fears and expectations from care (ST) and clarity in discussions (LT) with their healthcare team (S1)(F1)
2. If users put details on the on the website they are committing to engaging in a new manner which will enable a change in the dynamic (ST) of the consultation rather than acceptance of the status quo. (S1, S3) (F2,3)
3. When users chose which priorities to enter (rather than being chosen for them as in proms) which gives them control and can be empowering when discussing care with HCPs, leading to more person-focussed discussion (ST) and support the delivery of patient-centred care (LT) (S1) (F1)
4. If users set priorities then they will feel clearer about what they want from a consultation and more confident and empowered when talking to HCPs which will support equilibrium in conversation (S1) (F1)
5. When users clarify numerical scales with free text, they are sharing their knowledge and fears about present and future symptom control, which can illuminate understanding and misconceptions resulting in relevant personalised discussions with HCPs (S1) (F1)
6. If users choose to enter data onto the website regularly, they can save time and energy compared to using paper diaries which can release time for more pleasant activities and contribute to improving QOL (S1) (F2,3)
7. When users choose who can see the data that they enter onto the website, they can protect their privacy and confidentiality by controlling who has access to it, which can be empowering and encourage more honest and open recording of personal information. This will facilitate discussions which support person-centered care. (S1) (F7)
8. If individual users can see change over time, they may see patterns that illustrate cause and effect which leads to greater understanding of their child's condition, so they will be more confident that they know what is going on with their child and better able to make decisions (ST) about interventions or not which should result in more patient-centred care (LT) (S1, S2) (F4,F6)

Appendix M – Nvivo codebook samples

Nodes\\theory areas – as of April 2020

Name	Description
1 - patient-centred focus	If families or children living with life-limiting illness who contemplate and identify the key issues that they would like their healthcare practitioners to address and record these on the MyQuality website, they will clarify their priorities for support and be able to emphasise these issues to their HCPs in clinical encounters which will increase the focus on their priorities for care and give a more patient-centred focus for the delivery of care by HCPs.
10 - managing expectation	Families who monitor, quantify and document their symptoms on a daily basis using MyQuality may expect that these are viewed regularly by their HCPs which may increase pressure on HCPs to respond to short-term rather than longer-term changes. HCPs may find it difficult to ignore the expectations of patients/families and feel that they are letting their patients down if they are not constantly aware of MyQuality feedback. This could lead to work overload, poor decisions, and burnout
11 - email alerts	Email alerts that are set up by families for specific priorities may "effortlessly" generate additional workload for HCPs
12 - multiple providers	Many children with LLI see multiple HCPs and may be sharing their data with many individuals or providers. When a potential change is highlighted, there may be confusion about which other individuals or teams have contacted a family or responded to the information, which may lead to duplication of contact, or a lack of contact (ST) with a family. This is wasteful of time, money and may be dangerous (LT) without clear lines of communication within and between teams, as well as directly to the families
13 - second opinion	Many children with LLI see multiple HCPs, If they share their information with a clinician not normally involved in their day-to-day care, this can create a "back door" route for new referrals or increased workload which is not recognised through official channels, or an informal "second opinion" request by patients or other HCPs. This may lead to an unresourced expectation of input from teams, or delivery of conflicting advice (ST).
2 - improving confidence	Families of children living with life-limiting illness carry a considerable burden of responsibility to be the eyes, ears and voice for their children. If they can monitor, quantify and document their symptoms on a daily basis using MyQuality, they will develop a real-time visual record which will support their recollections, reflections and understanding of their child's needs and how these may change over

Name	Description
	time, which will improve their confidence when reporting their child's circumstances to HCPs.
3 - accuracy of observation	Families of children with life-limiting illness may record information on MyQuality whilst they are away from healthcare support will be prospectively documenting their child's health in a "normal life setting", resulting in a more realistic, continuous record of health concerns unaffected by the benefit of hindsight, or loss of recall.
4 - understanding	Patients or their families who interrogate the graphic display generated by regular inputting of data into MyQuality will explore patterns, cause and effect, and develop a greater understanding of their child's symptoms, which can reduce a sense of uncertainty or helplessness and support resilience for them as carers.
5 - willing shared input	Families of children with life-limiting illness who choose to share their recorded MyQuality information with their healthcare professionals will demonstrate a willingness for dialogue about improving the quality of life of the child/family by working collaboratively with their HCPs, and facilitate timely and responsible symptom management through regular honest recording of change over time.
6 - HCPs collaborate	Professionals who work in the field of children's palliative care who agree to look at the MyQuality data produced by their patients/families will demonstrate a willingness to incorporate patient feedback and collaborate with them in healthcare discussions, leading to mutually agreed management plans and understanding of risk, benefits and priorities for care.
7 - HCPs timely response	Professionals who work in the field of children's palliative care who make time to look at the MyQuality data produced by their patients/families will have a greater understanding of the nature and variability of their challenging symptoms, and a timely awareness of change which should result in a greater responsiveness to patient need and timely modification of treatment advice as appropriate.
8 - HCPs value data	HCPs who advise their patients to monitor specific issues will encourage patients and families to feel that there is value in the monitoring process and be motivated to continue recording and produce relevant data for collaborative healthcare encounters in the future.
9 - identification of unmet need	Families and children with LLI who identify key issues that do not align with the key issues identified or expected by HCPs may create an increasing workload. This can be recognised as an unmet need and generate a demand for increased resourcing to meet those needs

Nodes\\Sphere of influence

level of personal/team interaction with MyQuality

Name	Description
S1 individual pt or family	personal users decide to register, identify and describe priorities, daily monitoring, viewing graphs, decisions about sharing,
S2 individual HCP	HCP decides to register, looks at data, uses diary notes or receives email alerts
S3 interactions between users and HCPs	sharing data (electronic or verbal), email alerts
S4 in-team effect	MyQ information used to influence workload or decide case management within teams
S5 team policy - teams and families	team management decisions re using MyQ data on a regular basis re management of families or patients in general
S6 care co-ordination between teams	issues relating to co-ordination of multiple teams involved with one family
S7 commissioners and managers	MyQ relating to identification of unmet need or strategic development of services

Nodes\\MyQuality function

feature of MyQuality use

Name	Description
F1 individualised outcome measurement	relates to the process of considering, identifying, describing personalised outcome priorities for care
F2 daily monitoring	real-time data entry/ information
F3 remote access	relates to valuing accessibility of information
F4 graphic display	visualisation and interpretation of graphs
F5 email alerts	creation of or response to email alerts
F6 diary notes	use of or analysis of diary notes to personalise, supplement or understand records more easily
F7 data sharing	use of MyQ data shared with HCPs - electronically or via paper or discussion

Appendix N – sample of data extraction table on excel

Title	**Type of intervention**	**population**	**aim**	**Implementation or methods**	**key findings**	**comments**	**relevance to MyQ project**	**limitations**
Tracking health Data is not enough….	mhealth	adults using health monitors eg fitbit & similar	users' views of mhealth technology. Can technology be intergrated into healthcare. Can behaviour change be sustained?	focus groups of users	practical technology, easy to use NB. Integration with general health information v useful, needed to be more than just a record of activity. Control of type and amount of data collected and how this was shared. Link data contextually to help understanding eg with education or analysis of data built in. Interaction with health care professionals to confirm understanding and significance of data and receive individual support and guidance	Participants wanted data in context to make sense of it - time for reflection and action on information obtained NB. Patient design framework to bring together data, alerts, education, feedback, goal setting. Also a patient-provider framework to put teamwork at the centre to share collaborative reflection and action. Raises relevant questions about the role of providers and how to support them to incorporate this data into working practices	users views. Similar feedback to original SHINE MyQ population. Interesting to reflect on lack of educational links in MyQ.	normal adult population v different to children with LLI
eHealth system for collecting PROMS ...	eHealth to collect PROMs in real time	cancer patients in Australia	test feasability and acceptability of PROMPT-Care re support for clinical decisions, self-management, etc	mixed methods - web use, interviews of patients and staff	using website v feasable. Very few reports were discussed with patients by medical staff, even though patients thought this might be useful (GP or oncologist). Concerns form staff about problems that were "outside their remit" or concerns about potentia to increase clinical workloads and extend consultation times. Raised issues about staff training bening essential.	insights into website design being important, and training issues for staff. No detailed mention of relationship or communication issues. Limited addition to CMO constructions	v similar in outline to original MyQ project. Not as interactive - one-way transfer of information only, and PROM rather than PGOM.	outpatient review; fortnightly snapshot only; short-term use;
understanding potential uptake of a proposed mHealth programme	mHealth	childhood illness in Peru, resource poor setting	to explore potential facilitators and barriers to implementation of text messaging and information service	interviews, 25 semi-structured interviews with parents of children <5 yrs	facilitators: potential for 2-way communication; clear, direct and timely information; voice call features eg emergency hotline; security of information. Prompted by doubt of own abilities to effectively manage the illness at home. Useful to supplement limited encounters or inadequate encounters with healthcare system; and overcome barriers such as time or distance from healthcare providers, or difficulty obtaining appointments. Barriers: preference for in-person healthcare visits, esp from fathers; cost (of making phone calls); lack of confidence in text messaging capabilities; dealing with unknown providers who may or may not be giving accurate information; lack of trust re alterior motives for this programme.	in discussion - empowerment, and 2-way communication made them feel that someone cared about their child. Wanted targeted and tailored content.	users views and concerns shed light on potential CMO influences.	survey on hypothetical programme, implementation of existing programme and response to it not done.

Appendix P – details of patient participants

(Content redacted to protect patient confidentiality. For further information please contact the author)

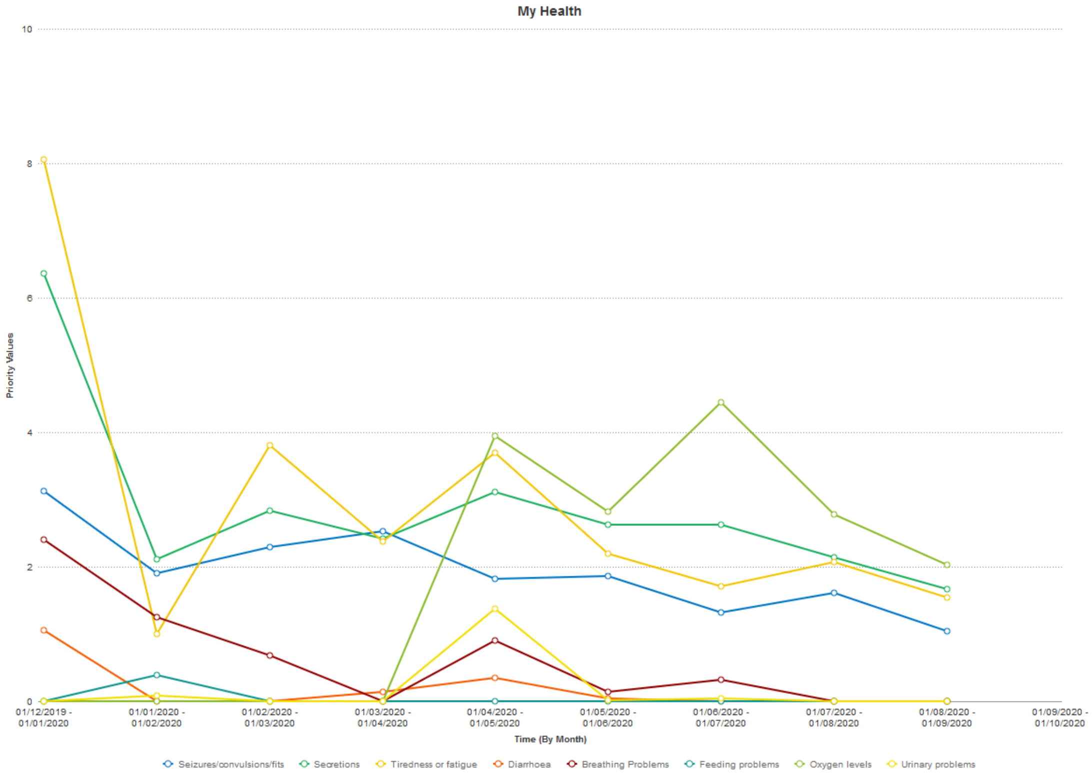
Appendix Q – website use – table from spreadsheet – extensive users

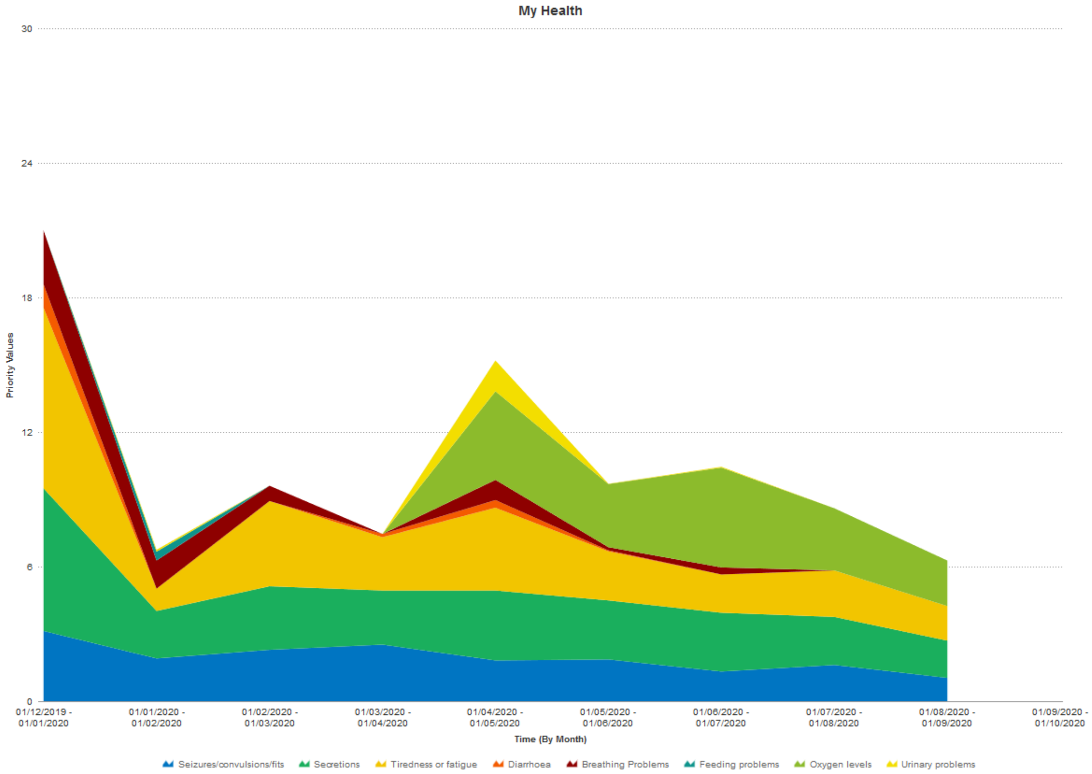
		nature of data entry					
child's name	**person entering data**	**extensive - regular/batch**	**number of priorities**	**comments (list names of priorities)**	**free text (F) or from list (L)**	**changed over time?**	**comments re priorities**
Adam	mother	extensive	10	bruising or bleeding, appetite, behaviour,diarrhoea, friends and relationships, mobility, N&V, seizures, skin, sleep	L	Y	priorities edited over time
Daisy	father	extensive	9	breathing, secretions, constipation, feeding, mobility, mouth, muscle weakness, sleep, tiredness	1F, 8L	Y	chest secretions and sleep added one month after the others
Daniel	both parents	extensive	7	dystonia x 3 for different times of day, dystonia breakthroughs, seizures, sleep overnight, pain	6F, + pain from list	y, pain deleted	pain priority retired
Katie	mother	extensive	11	Anxiety, behaviour, cog shutdown, hyperphagia, mobility, obsessional behaviour, pain, seizures, sleep, tiredness, top up oxy	4F (cog, hyperphagia, top up oxy and obession, 7 from list	y	6 deleted priorities - appetite, behaviour (extra), diarrhea, N&V, + 2 MYO
Matthew	mother	extensive	2	seizures, frequency of suctioning	1L 1F	Y	also had constipation added and deleted x4, and urinary probs added and deleted x2
Charlotte	mother	extensive	5	breathing probs, constipation, dystonia, N&V, secretions	2F, 3L	Y	all 5 were modified and deleted in the first week - partly personalisation process?
Sophie	mother	extensive	8	breathing, diarrhoea, feeding, oxygen levels, secretions, seizures, tiredness, urinary probs	2F, 6L	Y	mum very keen to personalise priorities to reflect her needs, edited every few weeks

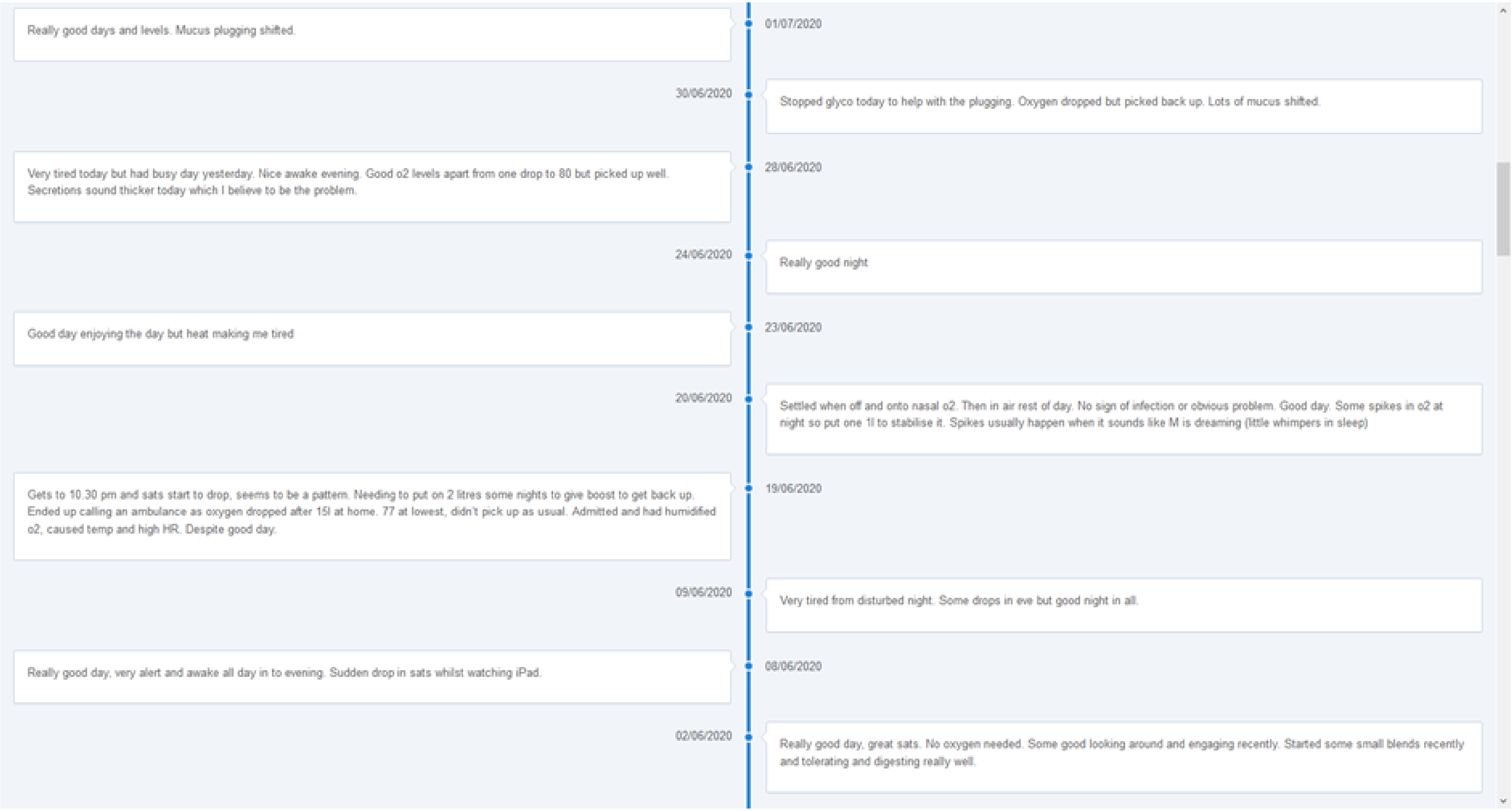
	Numerical ranges		diary notes		extent of use -			
child's name	**ranges - default (Likert)**	**ranges - personalised (P)?**	**diary used Y/N**	**comments**	**#days**	**# entries**	**chart views**	**other changes**
Adam	x		Y	extensive use, detailed descriptions	214	937	194	12 logins, 40 priority edits, 10 priority adds, 1 description, 2 sharer added
Daisy		7 given personalised normal ranges	Y	extensive use of diary entries,	70	410	82	32 logins, 9 priority adds, 13 priority edits, 2 sharer added,
Daniel	L for all except dystonia breakthrough	P ranges for dystonia breakthrough	y	daily diary otes to supplement score and to record ketones	744	10577	2672	819 logins, 8 priority adds, 1 delete, 58 priority edits, 1 priority retire; 6 sharers added, 4 removed, 29
Katie	L for all except top up oxy	1 only - 0-8, normal 2	y	detailed notes, including emojis	624	3800	1286	10 logins, 17 priority adds, 6 deleted, 22 edits,3 sharers added, 15 diary views
Matthew		P	Y	mostly about seizures and bowels and occ temps etc, but a few about degree of distress creating strong visual image of what was happening at home.	57	509	150	9 logins, 8 priority adds, 6 priority deletes, 13 priority edits, 1 sharer added
Charlotte		P x5	Y	used about once a week, most days this was left blank. Recording dose changes or clinical condition, nothing non-medical	37	342	99	4 log ins, 10 priority adds, 5 deletes, 10 edits, 1 sharer added
Sophie		P x 8	yes	used most days, mostly recording medical events but also general activities, good things as well as difficulties.	124	707	200	25 logins, 8 priority adds, 15 edits, 4 sharer added, 1 removed

	graph patterns?	**email alerts**		**sharing via MyQ**		**other sharing**		**general comments**
child's name	**Y/N/?/n/a**	**Y/N/?/n/a**	**email alerts triggered?**	**Y/N/?/n/a**	**to whom**	**Y/N/?/n/a**	**with whom**	
Adam	N	Y	N	Y	hospice duty team, hospice nurse	Y	information discussed in MDT meetings	had used it briefly prior to study, having seen advert about it at hospice. Tends to download in batches so although there is a lot of data and a lot of looking at graphs some of this is retrospective interest rather than concurrent with treatment concerns. Invited for late follow-up interview but no reply.
Daisy	?	N		Y	CCN and school nurse	Y	comm paediatrician during clinics	short gap in recording for 2 weeks towards the end when life became very hectic (mother moved in) but restarted of his own volition. Re patterns - he thought he could see some, I couldn't really, but the most striking thing was how stable most things were on average. Big day to day variation.
Daniel	?	N		Y	Hospice duty team, and consultant paed	Y	social services	extensive backdating at the start, then ongoing regular use on a daily basis. Lots of complex review of graphs (519 times, mostly since Oct 2020)
Katie	y	n		y	hospice, consultant and CCN	y	regional consultant via discussion	
Matthew	N	N		N		in discussions with cons paed		early days characterised by experimenting with formatting of priorities, all prioity editing done at the beginning, along with most of the deletions. Had 4 priorities for 2 weeks (including urinary and constipation), then reduced this to two for duration of the study.
Charlotte	Y?	n		Y	cons paed			
Sophie	?N	Y for 2	n	Y	cons paed, CCN, specialist nurse	Y in clinic in person	cons paed	

Appendix R – Samples of MyQuality Graphs produced by participants







01/07/2020

Really good days and levels. Mucus plugging shifted.

30/06/2020

Stopped glyco today to help with the plugging. Oxygen dropped but picked back up. Lots of mucus shifted.

28/06/2020

Very tired today but had busy day yesterday. Nice awake evening. Good o2 levels apart from one drop to 80 but picked up well. Secretions sound thicker today which I believe to be the problem.

24/06/2020

Really good night

23/06/2020

Good day enjoying the day but heat making me tired

20/06/2020

Settled when off and onto nasal o2. Then in air rest of day. No sign of infection or obvious problem. Good day. Some spikes in o2 at night so put one 1l to stabilise it. Spikes usually happen when it sounds like M is dreaming (little whimpers in sleep)

19/06/2020

Gets to 10.30 pm and sats start to drop, seems to be a pattern. Needing to put on 2 litres some nights to give boost to get back up. Ended up calling an ambulance as oxygen dropped after 15l at home. 77 at lowest, didn't pick up as usual. Admitted and had humidified o2, caused temp and high HR. Despite good day.

09/06/2020

Very tired from disturbed night. Some drops in eve but good night in all.

08/06/2020

Really good day, very alert and awake all day in to evening. Sudden drop in sats whilst watching iPad.

02/06/2020

Really good day, great sats. No oxygen needed. Some good looking around and engaging recently. Started some small blends recently and tolerating and digesting really well.

Appendix S – FES results

Section 1 – family

study number	FES number	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Q11	Q12
e51	1	3	3	4	2	4	2	5	5	5	5	5	3
C57	1	4	4	5	4	3	4	4	4	5	5	2	3
D56	1	3	3	4	3	4	3	3	4	4	3	3	4
E59	1	3	3	3	3	3	3	5	5	5	4	5	3
f60	1	4	4	4	4	3	4	4	3	4	5	4	3
F61	1	4	4	5	3	4	5	3	4	5	4	5	5
D52	1	5	4	4	3	3	4	5	5	4	5	3	4
B62	1	4	4	4	3	4	5	4	4	4	4	4	4
E64	1	4	3	5	4	3	3	2	5	5	5	5	3
C57	2	4	4	4	3	5	3	3	4	4	4	4	3
C67	1	4	3	5	4	2	3	5	4	4	4	2	4
F60	2	4	3	4	2	3	4	3	3	5	4	3	3
B62	2	4	4	4	3	4	4	5	5	5	4	5	4
E64	2	4	5	5	4	4	4	4	5	4	4	5	4
B70	1	4	4	4	3	2	2	5	4	5	4	3	5
C67	2	4	3	4	3	3	4	4	4	3	4	4	3
G71	1	4	4	4	2	4	4	3	4	3	4	4	4
C68	1	5	5	4	5	5	5	5	4	5	5	5	5
G72	1	5	5	5	4	5	4	4	5	5	5	5	5
G72	2	5	5	5	4	5	5	4	5	5	5	5	5

Section 2,
services

G73	1	3	3	3	3	3	3	2	3	3	3	3	3
study number	FES number	Q13	Q14	Q15	Q16	Q17	Q18	Q19	Q20	Q21	Q22	Q23	Q24
e51	1	2	1	2	4	4	3	5	5	5	5	5	5
C57	1	4	4	4	4	3	5	4	4	3	5	4	3
D56	1	4	4	4	4	4	4	4	4	4	3	3	3
E59	1	4	4	4	4	5	5	5	5	4	4	4	5
f60	1	5	2	4	4	4	4	5	3	4	5	3	5
F61	1	5	5	5	5	5	4	5	5	5	5	5	5
D52	1	5	3	3	4	5	5	5	4	4	3	3	4
B62	1		4	5	4	5	5	4		4	4	5	5
E64	1	4	4	4	3	3	5	5	4	4	4	5	4
C57	2	4	3	4	5	4	4	3	4	3	4	3	5
C67	1	4	4	5	5	5	5	5	4	5	4	4	5
F60	2	3	4	5	4	4	5	4	5	3	4	3	5
B62	2	4	4	5	4	5	5	4	4	4	4	4	5
E64	2	5	5	5	5	5	5	5	5	5	5	5	5
B70	1	4	2	5	5	5	5	5	5	3	5	2	4
C67	2	4	4	4	4	5	5	5	4	4	3	4	4
G71	1	5	4	4	4	4	3	5	3	4	3	3	4
C68	1	5	5	4	5	5	4	5	4	4	4	5	5
G72	1	5	5	5	5	5	4	5	4	4	4	5	5
G72	2	5	5	5	5	5	5	5	5	4	5	4	4
G73	1	2	2	2	3	3	3	3	2	3	2	2	2

Section 3, community

study number	FES number	Q25	Q26	Q27	Q28	Q29	Q30	Q31	Q32	Q33	Q34
e51	1	1	1	1	1	2	1	1	1	1	4
C57	1	3	2	2	3	4	3	2	2	3	3
D56	1	3	3	3	4	2	3	2	3	3	3
E59	1	3	2	3	3	3	4	4	3	2	3
f60	1	3	2	2	4	3	3	2	3	3	4
F61	1	3	4	4	5	4	4	5	5	4	5
D52	1		3	3	3	2	5	2	3	2	5
B62	1	1	1	4	2	1	4	1	4	3	3
E64	1	4	3	4	3	4	4	4	3	3	5
C57	2	3	2	2	4	3	3	3	2	2	3
C67	1	2	1	3	3	2	2	2	1	3	3
F60	2	4	2	2	4	3	2	2	2	3	4
B62	2	3	2	3	4	3	4	2	1	3	3
E64	2	4	4	4	4	4	5	4	4	3	5
B70	1	3	1	2	3	3	3	2	2	5	5
C67	2	2	1	3	3	2	3	3	2	4	4
G71	1	1	1	2	4	1	3	1	1	2	4
C68	1	3	1	3	3	2	3	2	1	2	4
G72	1	5	1	2	3	4	4	2	1	1	5
G72	2	5	1	3	3	4	5	3	1	1	5
G73	1	2	1	2	2	1	3	1	2	3	3

study number	FES number	avg sec 1	avg sec 2	avg sec 3	avg overall
e51	1	3.83	3.83	1.4	3.12
C57	1	3.92	3.92	2.7	3.56
D56	1	3.42	3.75	2.9	3.38
E59	1	3.75	4.42	3	3.76
f60	1	3.83	4.00	2.9	3.62
F61	1	4.25	4.92	4.3	4.50
D52	1	4.08	4.00	2.8	3.68
B62	1	4.00	3.75	2.4	3.44
E64	1	3.92	4.08	3.7	3.91
C57	2	3.75	3.83	2.7	3.47
C67	1	3.67	4.58	2.2	3.56
F60	2	3.42	4.08	2.8	3.47
B62	2	4.25	4.33	2.8	3.85
E64	2	4.33	5.00	4.1	4.50
B70	1	3.75	4.17	2.9	3.65
C67	2	3.58	4.17	2.7	3.53
G71	1	3.67	3.83	2	3.24
C68	1	4.83	4.58	2.4	4.03
G72	1	4.75	4.67	2.8	4.15
G72	2	4.83	4.75	3.1	4.29
G73	1	2.92	2.42	2	2.47

Appendix T – Dissemination of work associated with this thesis

Publications based on Thesis Material

Harris N, Noyes J, Fraser L, Lapwood S, Harrop E, Blackburn M, Price J, Chambers L, Bluebond-Langer M: *Managing and sharing research data in children's palliative care: Risks, benefits and imponderables* J Adv Nurs 2020 Nov; 76(11):2794-2797 doi:10.1111/jan.14527

Harris N, Blackburn M, Noyes J, Aldrige J, Lapwood S, Dunbar H, Price J, Mitchell J, Chambers L, Bluebond-Langer M: *Undertaking Doctoral Research with Children and Young People with Life-limiting or Life-threatening Conditions* Journal of Advanced Nursing 2019 75(12), doi:10/1111/jan.14082

Presentations or Posters based on Thesis Material

Logistics of Language – contexts, mechanisms, outcomes, and bits in-between. Oral presentation for CARES online conference, March 2022

Knotty Problems in Realist Evaluation – untangling theory development at multiple levels Online presentation for NottsRealist network, March 2022

eHealth Technology and Children's Palliative Care – presentation at launch of OsloMet Research Programme, CHIP homeTec, December 2021

Person-centred care using eHealth technology in children's palliative care – what works, for whom, under what circumstances, and why. UWE HAS Graduate Showcase Annual Conference, June 2021.

eHealth technology and the delivery of person-centred children's palliative care – opportunities and obstacles. Oral presentation for University of York/Martin House Research Centre Biennial Research Conference, April 2021.

The MyQuality Project South West Regional Children's Palliative Care Network, Feb 2021

Insider/Outsider Positionality in Realist Research – Immersed, Informed, and Objective? Poster presentation for International Conference on Realist Research, Evaluation and Synthesis 2020, Dublin (postponed to Feb 2021 online)

The fine art of theory development in realist enquiry - creating an image of "what lies beneath" Presentation to 2020 CARES Summer Online Symposium, August 2020.

eHealth in Children's Palliative Care: empowerment or Entrapment? Association of Paediatric Palliative Medicine Research Symposium, Nov 2019, London.

Ethics in Four Dimensions – Oral presentation to HAS Faculty Annual conference, UWE, June 2017