Acceptance and Commitment Therapy for adults with visible differences: Advancing understanding and developing a self-guided intervention

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Published works and critical commentary submitted in partial fulfilment of the requirements of the University of the West of England, Bristol, for the degree of Doctor of Philosophy by publication (DPhil).

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2 Declaration of authorship and training

I confirm that the work presented in this doctoral thesis, including the chosen publications and accompanying commentary (except where stated) is the original work of the author.

I confirm that none of the published body of work included within this portfolio of selected publications has been submitted for another academic award either in this or any other institution.

I confirm that the necessary training requirements (60-120 credits, of which at least 60 are at level M) have been met through accredited learning.

Fabio Zucchelli, June 2022

3 Abstract

With the centrality of physical appearance in society, having an atypical appearance or ‘visible difference’ as the result of a health condition or injury can cause psychosocial challenges. While some adjust without need for psychological support, many affected individuals struggle with appearance-focused social anxiety, low self-esteem, depression and/or impaired quality of life. Acceptance and Commitment Therapy (ACT), an established transdiagnostic third-wave cognitive-behavioural approach aimed at cultivating psychological flexibility, holds conceptual promise as a method to help affected individuals develop more fulfilling lives unencumbered by appearance concerns. Despite published reports of real-world clinical use of ACT for people adversely affected by visible differences, prior to the research presented in this submission, barely any empirical studies had been published on the topic.

The five first-authored publications presented in this submission collectively sought to advance the empirical and theoretical understanding of how ACT can help individuals adversely affected by visible differences, with the applied goal of developing a testable ACT-based intervention. This work was framed by a pragmatic research paradigm, in which the research agenda is bound to its potential for beneficial social impact. Accordingly, my co-researchers and I progressed to develop a self-guided intervention aimed at maximising its reach to affected individuals. Owing to the methodological flexibility afforded by the pragmatic approach, I used a combination of qualitative and quantitative methods across the five studies, with each being selected based on the studies’ specific goals.

To build a theoretical foundation and provide direction for this work, I first conducted a narrative review of the relevant extant literature and laid out the conceptual rationale for ACT as an approach for the psychosocial difficulties associated with visible difference (**paper 1**). To better understand the subjective experience of ACT and to understand the clinical considerations of the population, in **paper 2** I interviewed individuals with visible differences who had been through a specialist-delivered one-to-one ACT intervention. This study offered new insights into the interpersonal and intrapersonal processes involved in individual ACT therapy. By interpreting participants’ interview data through the lens of ACT theory and established body image models, my analysis also shaped a framework through which to examine the role of potential change processes in relation to appearance-focused behavioural outcomes.

In **paper 3** I applied this framework to test two key processes of psychological inflexibility— experiential avoidance and cognitive defusion— as mediators of the relationship between individuals’ appearance evaluation and their behavioural coping strategies. The findings largely

supported the hypothesis that these two psychological flexibility processes explain coping behaviours beyond negative appearance evaluations. With a view to developing a novel ACT intervention for the group, these findings offered the first empirical signal that exercises to cultivate acceptance and defusion (the inverse of experiential avoidance and fusion respectively) could disrupt unhelpful behavioural repertoires.

Led by published guidance on developing complex interventions, I adopted a combination of evidence-based, population-centred and modality-specific approaches to develop the intervention. The preceding papers each contributed to the evidence base underpinning the intervention. Owing to the growing ubiquity of smartphones and the increasing use of mobile health apps, I conceived the intervention as a mobile self-guided app, which informed the modality-specific considerations of development.

Following a population-centred approach, I presented stakeholders with the idea of an ACT-based mobile intervention, and when satisfied with its conceptual appeal, progressed to a formal research process in which we gained input from user representatives and specialist clinicians on the key considerations of mobile delivery and the intervention's design. Using a range of qualitative data collection methods, we analysed the combined data and published the findings in **paper 4**. Stakeholders' input offered vital orientation for the intervention's further development, such as the need to design the intervention to safeguard users' wellbeing, and preferences for relatable, interactive and actionable content.

Guided by stakeholders' feedback, the evidence base and published guidance on designing mobile interventions, I then developed a low-cost prototype mobile intervention. In **paper 5**, I led a single group feasibility study to test the intervention's proof-of-concept in a group of adults with a range of visible differences. This involved utilising mixed methods to collect data on participants' programme usage and adherence, and the intervention's acceptability, preliminary effectiveness and clinical safety. Overall findings established feasibility of the intervention, while also offering important direction for further modification into a full-scale native app. Since publishing paper 5, we have secured external funding to build and evaluate the intervention.

Alongside the five publications, this critical commentary presents the studies in terms of their scientific and real-world context, and their collective contribution to the scientific field of psychological intervention for individuals with visible differences. It also offers a critical examination of the five publications individually and collectively, as well as the surrounding extant literature.

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4 Introduction

In this section I will set out the parameters of my DPhil submission; namely, the guiding criteria for its assessment, my aims and objectives of the submission, and the corresponding publications to which I will refer throughout this critical commentary.

4.1 Doctoral requirements of the DPhil by publication award

In this commentary I demonstrate that my work meets the doctoral-level criteria required of postgraduate researchers by UWE Bristol, whereby they:

1. Have conducted enquiry leading to the creation and interpretation of new knowledge through original research or other advanced scholarship, shown by satisfying scholarly review by accomplished and recognised scholars in the field;
2. Can demonstrate a critical understanding of the current state of knowledge in that field of theory and/or practice;
3. Show the ability to conceptualise, design and implement a project for the generation of new knowledge at the forefront of the discipline or field of practice including the capacity to adjust the project design in the light of emergent issues and understandings;
4. Demonstrate a critical understanding of the methodology of enquiry;
5. Have developed independent judgement of issues and ideas in the field of research and / or practice and are able to communicate and justify that judgement to appropriate audiences;
6. Critically reflect on their work and evaluate its strengths and weaknesses including understanding validation procedures.

In Appendix 5 I provide a summary of how I meet these descriptors.

4.2 Aims and objectives

4.2.1 Aims

In this submission I aim to demonstrate a significant contribution to knowledge in the field of psychological intervention for individuals adversely affected by visible differences, by advancing understanding of the application of ACT for this population and developing an evidence-based self-guided intervention.

4.2.2 Objectives

To meet this aim and fulfil UWE’s doctoral descriptors, this submission will:

- Present five peer-reviewed academic works as first author that pertain to the field of psychological intervention for appearance concerns associated with visible difference.

- Synthesise the collated works via a critical commentary to demonstrate how they collectively advance empirical understanding on the contribution of Acceptance and Commitment Therapy for this population.
- Critically examine the contextual and methodological challenges of the submitted works and the extant literature within which they are situated.

4.3 List of publications

Table 1 shows the five peer-reviewed publications that comprise the research outputs included in this submission.

Table 1. List of submitted publications.

Paper number	*Citation*
1	**Zucchelli, F**., Donnelly, O., Williamson, H., & Hooper, N. (2018). Acceptance and Commitment Therapy for people experiencing appearance-related distress associated with a visible difference: A rationale and review of relevant research. *Journal of Cognitive Psychotherapy, 32*(3), 171-183. https://doi.org/10.1891/0889-8391.32.3.171
2	**Zucchelli, F**., Donnelly, O., Sharratt, N. D., Hooper, N., & Williamson, H. (2020). Patients' experiences of an Acceptance and Commitment Therapy-based approach for psychosocial difficulties relating to an appearance-affecting condition. *The European Journal of Counselling Psychology, 9*(1), 28-38. https://doi.org/10.46853/001c.22012
3	**Zucchelli, F**., White, P., & Williamson, H. (2020). Experiential avoidance and cognitive fusion mediate the relationship between body evaluation and unhelpful body image coping strategies in individuals with visible differences. *Body Image, 32*, 121-127. https://doi.org/10.1016/j.bodyim.2019.12.002
4	**Zucchelli, F.**, Donnelly, O., Rush, E., Smith, H., Williamson, H., & the VTCT Foundation Team (2021). Designing an mHealth intervention based on Acceptance and Commitment Therapy for people with visible differences: Participatory study gaining stakeholders' input. *JMIR Formative Research, 5*(3). https://doi:10.2196/26355
5	**Zucchelli, F.**, Donnelly, O., Rush, E., White, P., Gwyther, H., Williamson, H., & the VTCT Foundation Team (2022). An Acceptance and Commitment Therapy prototype mobile program for individuals with a visible difference: Mixed methods Feasibility Study. *JMIR Formative Research*, *6*(1), e33449. http://doi:10.2196/26355

Note: The studies are ordered chronologically by their start date (rather than publication date).

5 Background

In this section I will provide an empirical overview of the fields spanned by the submitted publications. To place visible difference in context, I will first summarise the broad field of appearance psychology, and then define visible difference and outline the common psychosocial challenges encountered by affected individuals. I will then introduce Acceptance and Commitment Therapy (ACT) and consider its relevance to visible difference. As paper 1 reviews similar material, I will minimise duplication and focus instead on areas less explored in the publication. To place the submitted research in the context of my position as a researcher and as a person, this section will first introduce my relevant background.

5.1 Professional and personal context

The research presented in this submission is informed by a combination of my professional and personal experiences. Indeed, the process of writing this commentary has offered a rare opportunity to pause and reflect on my motives for initiating the research, and to examine the ways in which my formative years as a researcher, and as an individual, have influenced the way I conducted it.

Although I had become superficially familiar with ACT while working in NHS mental health services in various capacities for seven years after my undergraduate degree (2006-2013), it was only when I worked through Russ Harris' *The Happiness Trap*, not as a professional, but as a person seeking guidance on how to live more fully, that I connected wholeheartedly with the ACT model. Similarly, it was only through my personal experiences of mental health challenges that I apprehended and became passionate about the need to learn from individuals with lived experience to understand any phenomena. This was something I was fortunate to live out while working as a mental health Employment Specialist at the Recovery College in Central and North-West London NHS Trust, where trained service users co-produced and co-delivered mental health educational courses.

It was also at the Recovery College where I first published an academic paper, as first author of a case study report (Zucchelli & Skinner, 2013). Around this time my interest in pursuing an academic career grew, and I undertook an MSc in Sport and Exercise Psychology at UWE Bristol (2013-14), while also working as an Assistant Psychologist at the Research and Development department at Avon and Wiltshire NHS Partnership. In 2015 I joined the Centre for Appearance Research (CAR) at UWE Bristol as an honorary Research Assistant, and became absorbed in the field of visible difference as well as the wider body image research landscape, learning from the many world-leading researchers at CAR.

In 2016 I gained a short-term position at CAR as a Research Associate working with Professor Phillippa Diedrichs on the global Dove Self-Esteem Project. In this role I learned much about the process of designing, implementing and evaluating scalable low-level psychoeducation interventions. I then gained further contracts at CAR as a Research Associate from 2016 onwards, funded by a combination of competitive internal research funding and, since 2017, a donation from the Vocational Training Charitable Trust (VTCT) Foundation. It was in these roles that I conducted the research that forms the submitted works.

During the period in which I conducted the submitted research, I also maintained my interest in promoting good mental health outside of my research career. From 2018-2020 I trained and worked as a volunteer on the Bristol Mind helpline for callers experiencing emotional distress. I also pursued an ever-increasing personal interest in mindfulness and its Buddhist connections by engaging with the Bristol Insight Meditation organisation, maintaining a daily practice and attending various meditation retreats.

5.2 The psychology of appearance

Within the context of prevailing sociocultural pressures to meet narrow and unrealistic appearance ideals (Schaefer et al., 2015), appearance concerns are strikingly commonplace among the general population. In the UK, around two-thirds of adults and children report feeling negative about their appearance most of the time (House of Commons, 2020). At a population level, appearance concerns generally remain stable from adolescence through to midlife (Wang et al., 2019), though the nature of concerns may shift over time (Gagne et al., 2012).

Appearance concerns also pervade across ethnic groups and cultures (e.g., Cheng et al., 2019; Schaefer et al., 2018) and appear especially prevalent in women (Wang et al., 2019), individuals of higher weight (Diedrichs & Puhl, 2016), those identifying with non-binary genders and sexual minority orientations (Austin et al., 2013; Goldhammer et al., 2019), and individuals with visible physical disabilities (House of Commons, 2020). Processes of stigma, discrimination and sexual objectification of women likely underpin these findings (e.g., Kowalski & Peipert, 2019).

The overall body image field has been dominated by a focus on body weight and shape in the general population, perhaps unsurprisingly given the prominence of these features in contemporary appearance ideals, and the growing global incidence of eating disorders (Wu et al., 2020). Many of the established psychological models of body image focus on weight and shape concerns as key elements of the aetiology of eating disorders (e.g., the Tripartite Influence model; Thompson et al., 2004; and the Dual Pathway Model; Stice et al., 2011).

Within this context, validated measures of body image often focus on weight and shape (e.g., the Body Image Avoidance Questionnaire; Rosen et al., 1991; and the Body Image-Acceptance and Action Questionnaire; Sandoz et al., 2013), to the exclusion of other sources of appearance concerns such as facial appearance, which holds particular salience during social interactions, is often the focus of visual attention during conversations (Zebrowitz & Montepare, 2008) and is critical to identity formation (Rumsey & Stock, 2013). Similarly, skin is given credence in Western-dominated appearance narratives, in which even, blemish-free skin tones are prized (Bundy, 2012).

5.3 Visible difference

A wide range of health conditions, diseases and injuries can affect individuals' appearance in a way that diverges from the societal norm (Rumsey & Harcourt, 2012). The resulting atypical appearance is often referred to as a visible difference, which has increasingly replaced the more stigmatised term 'disfigurement' as the preferred term by those affected (e.g., Changing Faces, 2022a). Precise definitional boundaries for visible difference are difficult to identify given its subjectivity; for example, what exactly constitutes the appearance 'norm'. Nevertheless, there are various causes of visible difference that can help exemplify its scope.

Some individuals are born with a visible difference. Visible birthmarks in the form of haemangiomas (or strawberry birthmarks) affect 1% of children, and vascular lesions such as port-wine stains affect around 1 in 1000 (Sandler et al., 2009). Other congenital conditions specifically affect craniofacial development. The most common is cleft lip and/or palate, affecting around 1 in 700 people (Mossey et al., 2009). This involves a 'split' in the affected area(s) of the face, which is surgically repaired in many high-income nations within the child's first year, leaving visible scarring into adulthood. Other rarer congenital craniofacial conditions include but are not limited to craniosynostosis (causing an atypically shaped skull), haemifacial microsomias (atypically shaped and/or incomplete growth of facial features, e.g., of the ear in microtia), and Treacher Collins syndrome (underdevelopment of the cheek and jaw bones). A group of other congenital conditions result in underdeveloped, missing or atypically developed limbs, such as syndactyly (fingers or toes that have not separated) and polydactyly (where extra digits have formed).

Certain appearance-affecting conditions can manifest either from birth or later in life. The congenital condition neurofibromatosis type 1 affects nerve growth and can lead to the formation of nerve tumours. Unlike some congenital conditions whose effect on appearance lessens over time following treatment or at least remain fairly stable, neurofibromatosis type 1 typically progresses and becomes more visible (Ferner, 2007). Other conditions such as facial palsy can present from birth, as in Moebius syndrome, or can be acquired (e.g., Bell's palsy). Many dermatological conditions such as psoriasis, acne, eczema, vitiligo, and alopecia areata (in which hair follicles stop producing hair on the scalp and body) are a cause of acquired visible difference. Others are present from birth, in the case of epidermolysis bullosa, which is causes easily blistered and scarred skin.

Many other forms of visible difference are acquired during life. Injuries sustained following traumatic events such as road traffic accidents or burns can often lead to visible scarring. This may occur pre-memory (often defined as 'congenital'; Harris, 1997) or later in life. Around 1 in 250 individuals report experiencing burn injuries every year in the UK, with around 5% of those requiring inpatient treatment (National Burn Care Review Committee Report, 2001). Surgical and medical treatment for disease can also cause varying degrees of scarring and changes to appearance, for example following surgery for head and neck or breast cancer, or hormone treatment for prostate cancer. With medical advances, increasingly more people are returning to life with visible changes to their appearance following treatment for life-threatening diseases such as cancers. Medical treatment can also lead to appearance changes in the form of amputation and prosthetics, stoma formation or external medical devices.

In total, approximately 1 in 60 people are estimated to develop a visible difference during their lifetime (Changing Faces, 2017). From the above non-exhaustive list of visible difference causes, it should be acknowledged that each also bring about specific medical and functional challenges for affected individuals. The severity of these challenges may vary between causes, but very few— if any— can be classified as purely 'cosmetic'. For example, alopecia areata is often viewed even by health professionals as medically benign (Zucchelli, van Dalen, et al., under review), despite being associated with heightened comorbidity with other autoimmune diseases such as thyroid disease, lupus, vitiligo and atopic conditions such as psoriasis and asthma (Huang et al., 2013).

5.4 Appearance concerns associated with visible difference

With appearance concerns commonplace in the general population amid sociocultural appearance pressures, it is understandable that many individuals have difficulty adjusting to an appearance that diverges from the 'norm'. In the interest of parsimony, the reader is directed to the introduction of paper 1 presented in this submission for a more comprehensive overview of appearance concerns in the visibly different population.

In brief, research across a wide range of causes of visible difference has demonstrated a marked prevalence of appearance concerns and associated psychosocial outcomes including social anxiety and isolation, low self-esteem, poor quality of life, depression and anxiety compared to matched controls (Clarke et al., 2013; Dalgard et al., 2015; Hotton et al., 2020; Rumsey & Harcourt, 2004; Toussi et al., 2021). As highlighted by Kent (2002), these outcomes have historically been explained through disparate psychological theories of social anxiety (Leary & Kowalski, 1995), body image disturbance (Cash & Grant, 1996), social skills deficits (Rumsey et al., 1986), and Goffman's (1968) sociological model of stigma. In a seminal theoretical work, Kent (2002) drew from qualitative interviews with individuals who have vitiligo to integrate these four models. He proposed impression management as the unifying process across the models to explain psychosocial outcomes in individuals with visible differences. He also identified loss of valued activities as a common cost of unhelpful coping strategies aimed at impression management.

Goffman's (1963) stigma model, in which stigma is understood as the interaction between possession of a characteristic like visible difference and the societal devaluation of this characteristic, offers a highly relevant sociological account of the experiences of social devaluation, avoidance and rejection reported by some with visible differences (e.g., Changing Faces, 2022b; Houston & Bull, 1994). It also explains individuals' explicit and implicit negative attitudes towards those with visible differences (Creadore et al., 2021; Grandfield et al., 2005; Stone & Wright, 2012).

Building from Goffman's stigma model, Kent (2002) incorporated Leary's account of social anxiety, which emphasises fear of negative evaluation as a universal and innate cognitive mechanism based on a desire to avoid social exclusion and rejection (Baumeister & Leary, 1995; Leary & Kowalski, 1995). When one's characteristics are stigmatised, high expectations of negative evaluation and hypervigilance towards such evaluation may logically follow. Leary also proposed that individuals' degree of self-efficacy pertaining to impression management would predict the extent to which they experience social anxiety. The social skills training approach presented by Rumsey et al. (1986) and Partridge (1998) can be viewed as a means of enhancing this form of self-efficacy. According to this account, chronic fear of negative evaluation experienced by individuals with visible differences can take up such a high attentional load in social settings that this in itself can cause hypervigilant, preoccupied, or otherwise socially stilted behaviours. This may act as a self-fulfilling prophecy in which other people respond to these behaviours negatively. Social skills training delivered through instruction, role play, discussion and feedback is designed to facilitate confident, proactive social behaviours that interrupt this vicious cycle, and improve confidence in managing one's impressions.

Cash's (1996) cognitive-behavioural model of body image disturbance, which was intended to apply to the general population but did consider the experiences of individuals with visible difference in its conception, adds further depth to the integrated model. Cash's model acknowledges sociocultural influences like the media in the development of poor body image, and contested that encountering situations such as those where one's appearance is on display serve to trigger poor body image. Consequently, people generally respond with coping strategies aimed at reducing unwanted internal experiences. Two of these strategies presented by Cash pertain to impression management: Appearance-fixing, such as attempts to conceal or modify areas of the body; and avoidance of appearance-exposing situations. Reliance on these strategies as means of avoiding negative impressions can lead to disengagement from valued activities and a narrowing of behavioural repertoires.

Over the past 30 years clinicians and researchers have developed and evaluated interventions that target these psychosocial challenges in individuals with visible differences. To avoid repetition, the reader is again directed to paper 1 for further elaboration on this area. In brief, although updated systematic reviews are warranted to capture efforts over the past eight years, existing reviews suggest that interventions have been led by cognitive-behavioural therapy (CBT) protocols, often in tandem with social skills training (Bessell & Moss, 2007; Muftin & Thompson, 2013; Norman & Moss, 2015). There is only limited evidence for the effectiveness of this approach, though this may in part be due to a lack of rigour and methodological homogeneity across included studies, and small sample sizes. The interventions also varied in delivery method, ranging from intensive specialist-led interventions applied individually (e.g., Papadopoulos et al., 2004) to group therapy (e.g., Kleve et al., 2002), a blend of self-help and therapist support (e.g., Bessell et al., 2012) and fully self-administered low-level interventions (e.g., Newell & Clarke, 2000).

The range of possible intervention modalities has been formalised into the Centre for Appearance Research tiered framework for interventions for people with a visible difference (Jenkinson et al., 2009; modified by Harcourt et al., personal communication, July 10, 2018; see figure 1). As recognised in guidelines on care pathways for common mental health conditions (National Institute for Health and Care Excelllence, 2011), the intensity and delivery method of intervention should accord with individuals' degree of psychological need and personal preference. Built into the framework are the dimensions of clinical need and the reach of interventions (i.e., how many people they could benefit), whereby higher clinical need concords with lower reach, and lower need matches greater reach.[1]

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[1] The framework also acknowledges the practical and ethical limitations of placing responsibility solely on the affected individual as the agent of change. As we have learned from Goffman and latterly Cash and Kent's work, it is imperative to target public attitudes towards visible difference through concerted campaigns, such as those by the UK charity Changing Faces, in order that the sociocultural context within which people experience their visible difference is more accepting, and ultimately provides less ground for self-stigmatisation and hypervigilance about others' reactions. Clearly this is still a work in progress, so it remains vital to offer active intervention for affected individuals. Even when doing so, it is important to validate people's experiences through psychoeducation and a general recognition of the role of stigma in shaping their distress (e.g., Clarke et al., 2013).

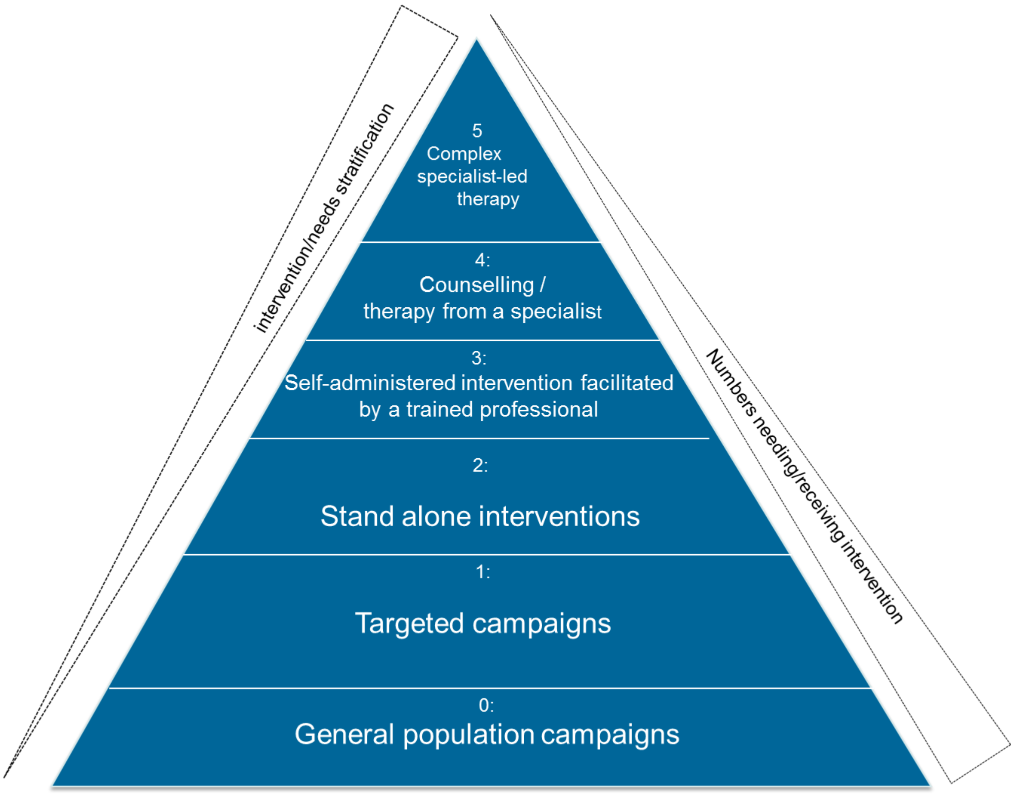

Figure 1. The Centre for Appearance Research tiered framework for interventions for people with a visible difference (Jenkinson et al., 2009; modified by Harcourt, personal communication, July 10, 2018).

5.5 Acceptance and Commitment Therapy

Before summarising the relevance and potential of Acceptance and Commitment Therapy (ACT) as an alternative approach for individuals adversely affected by visible differences to a traditional CBT model, I will first present a brief background to ACT. In doing so I will present the aspects of ACT not covered in paper 1, namely, a more comprehensive overview of the psychological flexibility model, and the scientific and philosophical underpinnings of ACT.

ACT can be understood as the therapeutic endeavour of enhancing individuals' capacity for psychological flexibility as a means of behaviour change (Hayes et al., 2012). This is the ability to contact the present moment with openness and awareness, and, as the context allows, act in a way aligned to one's values (Hayes et al., 2004). The most adopted model of psychological flexibility, the "hexaflex" (shown in figure 2), posits six interconnected processes, all of which are designed to counteract their inverse psychological *in*flexibility process. More recently, ACT protocols such as Focused ACT have grouped the six processes into three "pillars" of *openness*, *awareness* and *engagement* / *values-guided action* (Strosahl et al., 2012).

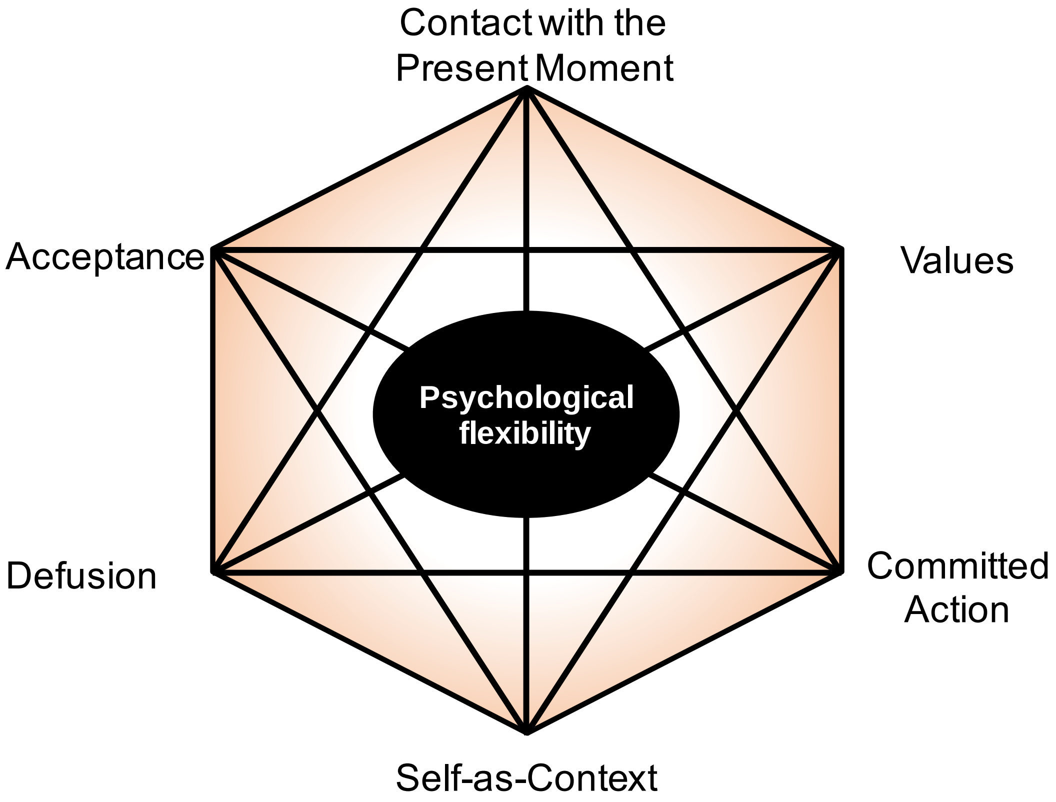

Figure 2. Hexaflex model of psychological flexibility.

The first process, acceptance, describes the capacity to open up to unwanted internal states with curiosity towards the physical sensations that accompany any state, rather than trying to control, avoid or suppress such states (i.e., experiential avoidance). Cognitive defusion (or just *defusion*) shares the attitude of the *openness* pillar in undermining the “literality” or “absolute truth” of unhelpful thoughts that, if taken literally (as in *fusion*), can lead to unhelpful behavioural responses. Various defusion techniques exist, but all share the property of viewing thoughts more as verbal constructions than objective reality.

Two processes focus on the cultivation of the *awareness* pillar: Contact with the present moment and self-as context. The former counteracts the innate human tendency to shift temporal perspective into the past and future, by orienting attention to the here-and-now, and the latter refers to a felt sense of an enduring self capable of observing all inner experiences rather than identifying with them. These awareness processes are perhaps most obviously connected to mindfulness, a construct derived from Hindu and especially Buddhist practices. In Western psychology, the term is commonly defined as “the awareness that arises from paying attention, on purpose, in the present moment and non-judgmentally” (Kabat-Zinn, 1994, p.4). However, the openness processes of acceptance and defusion can also be seen in Bishop et al's (2004) more comprehensive and operationally precise definition of mindfulness: The ability to self-regulate attention so that it is intentionally present-oriented and self-aware, and, importantly, orient this attention with an attitude of openness, curiosity and acceptance. For this reason, many ACT techniques draw from mindfulness practices.

An aspect unique to the psychological flexibility model in ACT is that of its *values-guided action*, or *engagement* pillar. In ACT, the other aspects of *openness* and *awareness* are cultivated as means of serving valued action rather than as ends in themselves. Value clarification means that an individual has a clear sense of what matters to them in how they live, or, in other words, what kind of person they want to be. Committed action is the behavioural enactment of these values in both premeditated and ad hoc behavioural decision-making.

ACT is often described as a "third wave" cognitive-behavioural therapy alongside approaches like dialectical behavioural therapy (DBT; Linehan et al., 1999), compassion-focused therapy (CFT; (Gilbert, 2009), mindfulness-based stress reduction (MBSR; Kabat-Zinn, 2003) and its adapted relative mindfulness-based cognitive therapy (MBCT; Segal et al., 2004). All are distinguished from "second wave" traditional cognitive(-behavioural) therapies by their focus on the function of internal experiences and behaviour, rather than their content. They also typically incorporate mindfulness practices as a means of becoming aware of internal experiences and hence being capable of adjusting their function (Cullen, 2008).

The roots of ACT also grew from the "first wave" of behavioural therapy, and specifically Skinner's radical behaviourism (e.g., Skinner, 1957). As part of this approach, cognitions are understood as privately observable behaviours, which, like overt behaviours, can be influenced by changing the context (namely antecedents and consequences) around them. As private behaviours, it follows, cognitions cannot directly cause overt behaviours, as proposed in traditional CBT. The originator of ACT, Steven Hayes, argued that traditional CBT approaches make the logical error of assuming that because, when asked, people typically purport their thoughts, feelings and beliefs as causes of their behaviour, cognition is therefore the proximal and outright cause of behaviour, and to control behaviour we must control our cognitions (Hayes, 1987).

Hayes instead posited attempts to control cognitions, reinforcing their function as aversive, as counter-productive to valued action, and often maintaining harmful behavioural repertoires. Zettle and Hayes (1982, p.107) lifted a single component of Beck's cognitive therapy (1979) called "comprehensive distancing", in which individuals are taught to psychologically distance themselves from their thoughts, feelings and beliefs, to demonstrate that by doing so, one can gain control over one's overt behaviour simply by viewing private events with more detachment.

Central to this hypothesis were insights drawn from basic science involving behavioural analysis of human language, and specifically our ability to extrapolate verbal representations of experiences as a means of making sense of the world. Relational Frame Theory (RFT; Barnes-Holmes et al., 2002) developed as an account of human language, in which our ability to construct and respond to bidirectional relations between stimuli (whether physical or abstract) is presented as the building block of language and higher cognition, having served to confer survival adaptation in our species. Stimulus equivalence (Sidman, 1971), in which objects are judged to be equivalent, is an example of one of the many “relational frames” (i.e., ways in which stimuli can be related) called co-ordination. Stimulus equivalence underpins the utility of comprehensive distancing (and defusion) by explaining how abstract representations of actual experiences, via cognitions, can become subjectively real, and hence can induce equivalent suffering and further attempts to avoid such cognitions from recurring. By thinking about a feared situation, for example, and imagining the embarrassment of people at a party commenting and laughing about one’s visible difference, this abstract representation can be felt as if it were really happening. This “literality” defines fusion, and underscores attempts to avoid and control unwanted cognitions (experiential avoidance). In this way, experiential avoidance and cognitive fusion together are posited as the central and ubiquitous causes of human suffering (Hayes, 2004).

Situated in the broader field of contextual behavioural science (Hayes et al., 2012), ACT is based on a functional contextualist paradigm, (or organising philosophical structure; Feilzer, 2010), which draws from pragmatism and contextualism (Hayes et al., 1999). Pragmatism holds the pursuit of beneficial goals to human progress, in the context in which we live, as the primary goal of science (Rescher, 2012), while contextualism contends that any act can only be understood with reference to its context, namely its history and current conditions (Fox, 2006). Amalgamated from these approaches, functional contextualism pragmatically places the ability of any action or idea to reach its intended goal as the sole criterion of interest (Hayes et al., 1999). In this way, functional contextualism is a-ontological; it does not profess to any claims about reality. In ACT, this manifests in a focus on the “workability” of behaviour, namely, the extent to which behaviour serves valued ends, rather than seeking to adjust cognitions and behaviour to accord with any essentialist reality (as is the approach in traditional CBT; Hooper & Larsson, 2015, p.23).

The overarching goal of functional contextualism is to predict and influence behaviour with consideration of its context (Biglan & Hayes, 1996). Specifically, its aim is to do so with maximal precision, scope and depth. Scope refers to as broad a range of applications of an underlying theory as possible, such as the way in which ACT has been applied to areas as diverse as occupational services, chronic pain, gastrointestinal conditions, mood disorders and beyond (Ferreira et al., 2018;

Hooper & Larsson, 2015, p.24). Indeed, a recent review of meta-analyses found strong evidence of ACT's efficacy for anxiety, depression, substance use and pain (Gloster et al., 2020). Depth pertains to the ability of a theory to be empirically triangulated in its coherence across levels of analysis, from social sciences to neuroscience and biology. Precision implores parsimony in analytical concepts used to explain phenomenon; for example, experiential avoidance need not be adjusted in its definition whether applied to obsessive behaviours or appearance concerns.

Together, the goals of functional contextualism play out in ACT through its transdiagnostic approach to mental health, whereby the central components of psychological flexibility remain consistent across its broad clinical (and non-clinical) applications. While adaptations to the specific challenges faced in different problem areas are often required, for example acknowledging the societal context of intrusion encountered by many with visible differences, the hexaflex itself remains unchanged. Owing to this transdiagnostic approach, ACT is capable of conferring simultaneous across-domain benefits (Gloster et al., 2020; e.g., depression, anxiety and quality of life in individuals with long-term conditions; Brassington et al., 2016; and smoking cessation and weight loss; Spas et al., 2015).

5.6 ACT and visible difference

Having separately summarised visible difference and the ACT model, I now turn to the conceptual and empirical suitability of ACT to the psychosocial challenges commonly encountered by individuals with visible difference. This is one of the primary objectives of paper 1, so the reader is directed to this paper for an in-depth overview and discussion of this question. In summary:

- As a transdiagnostic approach to mental health, ACT is suited to simultaneously addressing the various possible psychosocial challenges by individuals with visible differences, such as appearance-focused social anxiety, depression, generalised anxiety and low self-esteem.
- By focusing on individuals' capacity for valued living rather than reducing perceived psychopathological symptoms, ACT offers a positive orientation to therapeutic progress aligned to their deeply held desires.
- The pragmatic focus in ACT on changing the function of cognitions rather than their form circumvents the need to challenge the veracity of cognitions with reference to any essentialist reality, which may prove problematic when individuals' lived experience provides evidence for thoughts such as "People will stare, because I look strange" or "People judge me negatively because of my appearance".
- While barely any empirical research had been published on the application of ACT to visible difference (especially prior to paper 1), there is growing evidence for the effectiveness of ACT for related psychosocial challenges like social anxiety (e.g., Craske et al., 2014; Kocovski

et al., 2013) and body dissatisfaction (Griffiths et al., 2018). The protocols for these interventions can offer direction for ACT applied to individuals adversely affected by visible difference.

The ACT formulation and therapeutic approach towards appearance concerns associated with visible difference shares characteristics with existing population-specific CBT approaches (e.g. Bessell et al., 2012; Clarke et al., 2013), while also diverging in consequential ways. In terms of formulation, like the traditional CBT approaches, the ACT model is largely consistent with Kent's (2000) integrated model of appearance concerns in visible difference. Namely, a context of social stigma and negative reactions from others is understood as encouraging preoccupied attention, motivated by a fear of negative evaluation and impression management, towards threat-focused stimuli including other people and one's own appearance. As a result, individuals have fewer attentional resources available to respond to the social environment with openness and spontaneity. Individuals may develop socially awkward overt behavioural repertoires as a result, which only serve to reinforce negative reactions from others. This is akin to the ACT for social anxiety formulation presented by Kocovski et al. (2013).

Focused on impression management, individuals are likely to respond to appearance-salient situations, including associated appearance-focused unwanted internal experiences, by trying to reduce or get rid of such unwanted experiences. In ACT terms, this desire to get rid of or reduce unwanted experiences is the hallmark of experiential avoidance, while fusion with unwanted appearance-focused thoughts also reinforces the believability of such thoughts and hence their aversive quality. In keeping with Cash et al. (2005), this desire is typically borne out by avoiding and/or leaving appearance-salient situations, and engaging in time-consuming, expensive or impractical strategies aimed at 'fixing' one's appearance (such as concealing or covering sites of difference). As recognised by Kent (2000), this has the consequence of individuals missing out on valued activities.

Similarly, in both ACT and traditional CBT formulations, the short-term relief associated with avoidant and appearance-fixing behaviours is understood to negatively reinforce the behaviours through the removal of stressful stimuli (R. J. Newell, 1999). However, the solutions proposed in the models differ. In traditional CBT, the solution is to reduce discomfort associated with appearance-exposing situations, via cognitive restructuring and improving confidence through social skills training. In ACT, relief from distress is superseded as a behavioural contingency by values; that is, acting in accordance with one's personally meaningful life orientations becomes the conscious motive for one's behaviours, which can be achieved alongside unwanted experiences. This is enacted through values clarification and action planning (which comprise the valued action pillar), which anchor the openness and awareness pillars.

To facilitate valued action, individuals are helped to cultivate openness through acceptance (the antithesis of experiential avoidance which underpins the aforementioned unhelpful coping strategies), and to detach from the literality of their unwanted thoughts through cognitive defusion. An awareness of one's internal experiences, namely becoming consciously aware of what it is one has been reactively avoiding and believing, so they can change our relationship to such content, is a necessary precursor to the capacity for openness. Being present and noticing an enduring sense of self provide such awareness, often cultivated through mindfulness practice.

In terms of their therapeutic approach, there are vital differences between ACT and CBT in both their therapeutic processes and goals. The key divergence in process lays in the focus on cognitive restructuring (i.e. changing cognitions' content) in traditional CBT, and a focus on changing one's relationship to cognitions (i.e. changing their function) in ACT. Regarding therapeutic goals, the overarching target of CBT is reduction of distress (typically anxiety in this population), exemplified by regular recording of distress markers throughout the intervention. Conversely, the transdiagnostic goal of ACT is a more fulfilling life, in which any accompanying distress is accommodated.

These differences mean that apparently identical therapeutic techniques (as distinct from their underlying therapeutic processes) in ACT and CBT are utilised for different functions. Namely, social skills training is a key behavioural technique in both approaches for the population. In CBT, the training is aimed at providing self-management skills to gain confidence and find social situations more comfortable, whereas in ACT it is offered as a values-based set of skills to facilitate valued action. For example, if someone held a value of adventure, and one of their value-based goals was to go travelling, social skills training would be framed as a means of facilitating this goal by enabling them to meet and establish relationships with new people. In both CBT and ACT, social skills training are practiced through graded exposure. As discussed in paper 1, unlike in CBT, graded exposure in ACT does not involve self-rating of distress markers, but rather is viewed as a pragmatic means of moving towards valued goals. Indeed, in a common ACT metaphor, when one dials down distress, willingness (or acceptance) automatically dials down as a result (Hayes et al., 2004).

As an addendum to paper 1, I should clarify that by arguing for the suitability of ACT for the population, and in some cases doing so with reference to limitations of traditional CBT, it is not my contention that ACT is undeniably the superior approach. Rather, I contend that ACT offers a viable alternative worthy of investigation given its conceptual fit. That there exists a lag between practice and research, whereby many health professionals already use ACT in this clinical field (Harcourt et al., 2018; Stock et al., 2020; Shepherd et al., 2020), only further compels this need.

6 Research Approach

In this section I will consider the research approach I adopted across the submitted works. To do so, I will outline my worldview regarding the formation of new knowledge, how this fits with relevant theoretical and practical imperatives, and the methods I used to conduct the research. I will also summarise the empirical frameworks that shaped my approach to intervention development in the latter phase of the works.

6.1 Pragmatic research paradigm

Consistent with the pragmatic truth criterion of the contextual behavioural science underpinning ACT, I followed a pragmatic research paradigm in the presented body of research. In their application to social research, paradigms can be functionally defined as a set of conceptual and practical heuristics based on shared beliefs and values that direct researcher's decisions towards identified research questions (Kaushik & Walsh, 2019). A pragmatic research paradigm privileges the real-world consequences of actions, including research as a series of actions, in addressing social problems, over the pursuit of either a positivist or subjectivist version of truth (Feilzer, 2010). This follows the philosophy of pragmatism, which accepts a plurality of different possible realities and truths as existing in the world, which can be viewed as objective and/or subjective 'layers' (Dewey, 1925, p.40; (Feilzer, 2010). In this way, it has been argued that pragmatism is nonparadigmatic as it does not assert a prescriptive ontology or epistemology, but rather sees them as unfixed functions of human action in the world (Greene et al., 2001, p.28; Weaver & Olson, 2006).

This emphasis on addressing real-world challenges also fits the remit of the broader research programme on visible difference at the Centre for Appearance Research (CAR) since 2017, within which most of the presented works were conducted. The programme, funded by a donation from the Vocational Training Charitable Trust (VTCT) Foundation, aimed to address research priorities coproduced with a group of over 20 charities and organisations, *the Appearance Collective*, who serve individuals with a range of causes of visible difference (e.g., Alopecia UK; Cleft Lip and Palate Association; Changing Faces; Facial Palsy UK; Dan's Burns Trust; Psoriasis UK; Vitiligo Society UK). One such priority was to develop effective psychological support for individuals with visible differences who struggle with appearance concerns. Stakeholder involvement of this type in setting research priorities is crucial to understanding and addressing the most pressing real-world problems faced by those who can benefit from the research (The James Lind Alliance, 2022)

Within this wider priority, in the case of my body of research, the social problem identified was the need to better understand ACT as a therapeutic approach for individuals with visible differences, in the context of practitioners already adopting ACT for the population with no population-specific undergirding research; apparent conceptual limitations of the dominant traditional CBT approaches used; and a dearth of accessible psychological interventions available to the population.

In the same way that the ‘workability’ of an individual’s actions define therapeutic progress in ACT, the utility of research in addressing its specified problem is the primary driver of pragmatic research (Rorty, 1999, p.26). Pragmatic research is therefore unattached to any particular methodology, instead advocating for the most appropriate methods for the specific research question posed (Tashakkori et al., 1998). With a view to exploring multiple possible layers of reality, pragmatic research often utilises abductive reasoning, in which researchers “move back and forth between induction and deduction – first converting observations into theory and then assessing those different theories through action” (Morgan, 2007, p.71). This process is often best suited to a mix of qualitative and quantitative methods.

This is not to claim that all those involved, including researchers and participants, will not bring their own unique worldviews and experiences into research; indeed, pragmatism calls for a reflexive approach compelling researchers to consider how their values influence their research questions, methods and data interpretation (Feilzer, 2010). This follows the assertion of pragmatism that all actions, including researchers’ decisions, cannot be separated from the social, environmental and intrapersonal context in which they are situated (Morgan, 2014, p.26).

6.2 Research methods

Following the pragmatic research approach, I employed a mix of qualitative, quantitative and research synthesis methods in the presented body of research, selected based on their suitability to each specific research question and the presumed layers of reality to which they pertained.

To examine the existing literature of relevance and develop a theoretical rationale for the application of ACT to individuals with visible differences, I used narrative research synthesis methods (paper 1). Where the research question concerned the explicitly subjective experience of participants who had gone through ACT (as in paper 2), I conducted semi-structured interviews and analysed the data via interpretative phenomenological analysis (IPA; Smith & Osborn, 2003), a qualitative method based on the study of subjective human experience (see section 7.2 for more detail). From this more inductive reasoning approach involving detailed exploration of a small sample partly designed to postulate applicable theoretical models for testing, I then used cross-sectional quantitative methods best suited to deductively testing out the fit between the psychological flexibility and Cash’s (1996) body image disturbance models (fully described in section 7.3). In contrast to the subjective layer of reality explored in paper 2, the survey study of paper 3 was more concerned with an objective layer presumed to hold relative stability across the population of individuals with visible differences (without presuming invulnerability to context). The approach for paper 3 also aligns to the contextual behavioural science goal of predicting behaviour with theoretical precision, by mapping key psychological flexibility constructs to unhelpful body image coping behaviours, and scope, by recruiting a representative sample of visible difference.

When my research goals evolved into the development of a low-level ACT intervention, I adopted more collaborative, participatory qualitative methods in which stakeholders including user representatives and clinical experts could contribute to shaping the intervention. With many design questions and participant preferences to consider in this process, I adopted a suite of qualitative data collection methods, which I analysed collectively using template analysis (Brooks et al., 2015), a qualitative method suited to the iterative design process that abductively moves between inductive and deductive reasoning (see section 7.4 and paper 4 for more detail). In this way, the layer of reality I sought to explore was an entirely pragmatic one: Namely, what ACT intervention can we collaboratively construct that could meet the needs and preferences of individuals with visible differences?

Once my research aim progressed to testing the feasibility of a prototype ACT intervention (for paper 5), I applied mixed methods. I chose quantitative methods to collect intervention usage data, repeated outcome measures and acceptability ratings, because these were best suited to the presumed objective reality of how participants used the intervention, and whether there existed a ‘signal’ for its effectiveness. I used qualitative interviews to address the more subjective aspect of participants’ experiences and perceptions of the intervention in terms of its acceptability, clinical safety and potential for a positive impact on their daily lives. I also sought to maintain the reflexivity encouraged in pragmatic research (as well as qualitative research; Braun & Clarke, 2006) in the programme of research by keeping reflexive logs during all qualitative data collection and analyses.

6.3 Intervention development frameworks

As the presented works encompass the development of an ACT-based intervention for individuals adversely affected by visible differences, I will now summarise the frameworks that have informed this endeavour. The intervention I sought to develop is best understood as a complex intervention, as defined under UK Medical Research Council (MRC) guidance (Craig et al., 2008).[2]

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[2] A complex intervention is one that comprises a number of interacting components, which all ACT protocols do via cultivation of multiple psychological flexibility components, as do existing visible difference interventions that include practical social skills training alongside intrapersonal training (e.g. Bessell et al., 2012). Complex interventions also promote new behaviours from those receiving the intervention (Craig et al.,

In an MRC-funded publication, O'Cathain et al. (2019a) presented a taxonomy of nine approaches to developing complex interventions, which can be applied to frame my methods. One approach identified is theory and evidence-based development, marked by a systematic combination of published research evidence and theories. Another is a target population-based approach, in which interventions are centred on the views and actions of those who will use the intervention. A third approach is modality-specific, where the form of intervention (e.g., digital) shapes or at least informs the development process. Within O'Cathian et al's MRC intervention development taxonomy, such approaches may also be combined in a coherent way that suits the objectives of the research.

One of the most cited theory and evidence-based frameworks for complex interventions is the original MRC guidance on developing and evaluating complex interventions (Craig et al., 2008). This sets out a series of phases that may be conducted in a linear or reticulated sequence. The two phases most relevant to my presented works are the development and feasibility phases. In the development phase, pertinent existing evidence is identified and used as the basis for identifying and/or developing a theory of behaviour change tailored to the intervention context. Such groundwork was presented in my narrative literature review (paper 1), and I also drew from existing theory when interpreting qualitative findings in paper 2. Next in the development phase the identified theory may be tested via early models of change processes and outcomes, as conducted in my cross-sectional quantitative study presented in paper 3. The feasibility phase, encompassing papers 4 and 5, involves assessment of the intervention's acceptability, adherence, mode of delivery as well as piloting future trial designs. This original MRC guidance, however, offers minimal detail on the intricacies and practicalities of these phases. It also overlooks the utility of stakeholder involvement in developing an intervention.

Bleijenberg et al. (2018) produced an independently funded expanded account of the MRC development phase, parsing it into planning and design subphases. The planning subphase includes determining population needs and examining current practice and context, which I carried out through informal stakeholder involvement prior to the work presented in paper 4 (see section 7.4.1.). The design subphase involves creating a full intervention prototype, with decisions having been made regarding the content, intensity, mode of delivery and dose (which was the remit of paper 4). By reviewing existing published guidance, the authors also suggest methods for identifying

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2008), as ACT programmes invariably do by helping individuals to reorient their behavioural repertoires in line with their values.

and testing underpinning theories, including cross-sectional quantitative studies to elucidate possible causal mechanisms (as conducted in paper 3).

Though published after I began the early development work presented, O'Cathain et al. (2019b) produced MRC-funded guidance specifically on the development phase of complex interventions. Importantly, the authors acknowledged and built in the importance of involving stakeholders— those who will deliver, use and benefit from the intervention— to better understand design challenges and users' context, and to generate ideas for the intervention. O'Cathain's (2019b) guidance also notes the importance of iteratively refining an intervention in collaboration with stakeholders to optimise its acceptability and feasibility. These imperatives were central to my design work with stakeholders presented in paper 4, and are shown in the authors' abridged logic model below in figure 3, which shows the core principles, actions to consider, outputs and short-term effects in developing complex interventions.

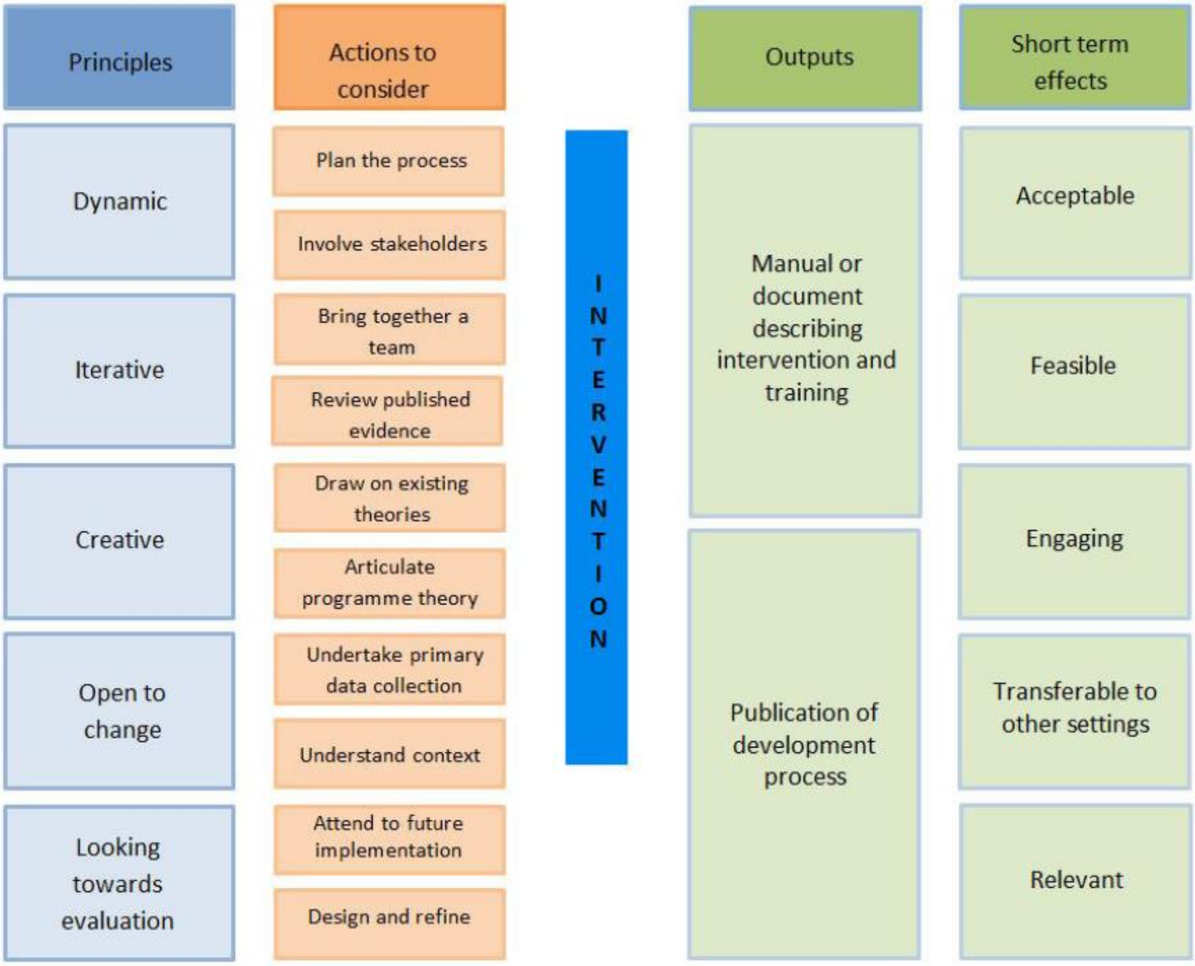

Figure 3. Abridged logic model for complex intervention development (O'Cathain et al., 2019b), to show elements most relevant to the presented works.

Further guidance on optimising the early development phase of complex interventions is offered by Czajkowski et al. (2015), who present the ORBIT model for developing behavioural treatments for chronic diseases. Though my research was not focussed directly on behaviour modification to prevent and treat disease, the ORBIT model offers instructive detail applicable to the broad gamut of behavioural interventions. One example is the guidance on common research and/or design methods suitable to the different phases of development. These phases are shown in figure 4. Examples of methods suited to the *Define* and *Refine* subphases of the 'design' phase that I adopted include focus groups and interviews (presented in papers 4 and 5). For the *proof-of-concept* subphase of the 'preliminary testing' phase, I applied the recommended treatment-only design, and in the (*feasibility) piloting* subphase I used mixed methods (both in paper 5).

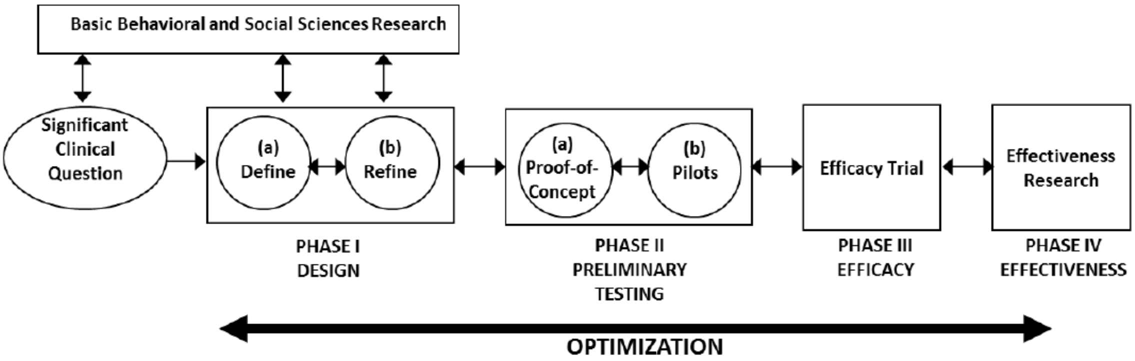

Figure 4. The ORBIT model for behavioural treatment development (Czajkowski et al., 2015).

In contrast to these theory and evidence based approaches, population-based approaches place the perspectives and needs of the target population at the front-and-centre of the development process (O'Cathain et al., 2019a). In this way, this approach can be seen as part of the broader participatory action methodology, in which research is conducted by researchers in democratic collaboration with people who may benefit from it. That is, the research is conducted *with* people rather than *on* them (Bradbury & Reason, 2003). This approach is also steeped in a pragmatic paradigm in which the urgent issues encountered by a population set the research agenda for pursuing the practical solutions (Reason & Bradbury, 2001). The participatory action research approach has been used to create a model tailored for intervention development (the Participatory Intervention Model; Nastasi et al., 2000), which informed my development work, for example where I prioritised stakeholders' empowerment and ownership by seeking and incorportating intervention content from them (as reported in paper 4). The population based approach also embraces empirical methods, typically adopting "mixed methods research to systematically investigate the beliefs, attitudes, needs and situation of the people who will be using the intervention" (Yardley et al., 2015; p.1).

Once mobile health (mHealth) became the targeted mode of delivery in my presented works, I also drew on intervention-specific published guidance for developing mHealth interventions. Further details of the recommendations I adopted from this literature are given in paper 5. The methods underlying these published guidance papers encompassed analysis of user experience (Alqahtani & Orji, 2020), and app developers, therapists and academics (Pierce et al., 2016; Roth et al., 2014).

Following O'Cathain et al's (2019a) MRC-funded intervention development taxonomy, my presented works adopted a combination of the theory and evidence-based, population-based and modality-specific approaches. My focus on ACT as the underpinning behaviour change model for the intervention (paper 1 onwards) and my empirical efforts to establish and test the potential processes of change in the population (in papers 2 and 3) were explicitly theory and evidence based. This intervention development groundwork presented in papers 1 to 3 therefore aligned to the original MRC guidance (Craig et al., 2008). In contrast, my early planning and design work presented in paper 4 was more clearly population-based. In paper 5, I applied elements of both approaches in testing the feasibility of an ACT-based mHealth prototype. For papers 4 and 5, I also drew on intervention-specific approaches. Though I began the development work presented in paper 4 before O'Cathain et al's two updated MRC guidance articles were published (2019a; 2019b) and so was not intentionally guided by these as-yet-unpublished documents, the work in papers 4 and 5 essentially unknowingly followed this more expansive updated MRC guidance.

6.4 Ethical considerations

Paper 1 involved evidence synthesis methods, and hence posed no ethical concerns. For papers 2-5, I gained approval from the UWE Bristol Faculty Ethics Committee prior to commencing recruitment. When managing data, I followed the Data Protection Act 1998 (for paper 2) and the Data Protection Act 2018 (for papers 3 to 5).

In paper 2, I interviewed service users of the North Bristol NHS Trust Outlook Service. I had intended to interview service users from more than one Trust, which would have required NHS Health Research Authority (HRA) approval. However, as I was unable to arrange a cross-site study, the study no longer met HRA approval criteria, primarily because the study involved no change to treatment protocols for service users involved. As such, I liaised with the Trust to register the study as a service evaluation. In terms of ethical considerations during data collection, I periodically offered participants the chance to take a break if the interview evoked distress, though many described the process as rewarding and uplifting. In designing the surveys for papers 3 and 5 for participants with visible differences, I drew from published ethics guidelines for internet-mediated research (British Psychological Society, 2017), which was helpful in making the content simultaneously ethically sound and more user-friendly, such as minimising participant information to a readable level.

Before beginning recruitment for the participatory work presented in paper 4, I considered the ethical quandary of just how appropriate it would be to frame the work as a research study involving research participants. Given the ethos of the study was of collaboration with experts by experience (user representatives) and by profession (psychological practitioners), presenting collaborators with participant information and consent forms may set a tone of traditional research power dynamics with researchers placed as experts and the participants as recipients. I sought guidance from Dr Andy Gibson, Associate Professor in Patient and Public Involvement (PPI) at UWE Bristol, who acknowledged the tension but suggested it would be prudent to seek institutional ethical approval, given we intended to publish the work. During recruitment and data collection (e.g., at the user representative workshop), I made sure to use language that emphasised collaboration and participants' expert role (e.g., 'experts by experience' and 'experts by training').

The intervention feasibility study in paper 5 presented perhaps the greatest ethical challenge, given participants were accessing the fully self-guided intervention remotely, and we were unaware of any potential iatrogenic psychological effects of the intervention (itself one of the feasibility objectives). To mitigate risks of potential harm to participants, I agreed on a set of safeguarding measures with my co-authors.[3]

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[3] Safeguarding measures included a 'Get Help' button at the top of the intervention homescreen with details of relevant support contacts, daily monitoring of participants' entries in the intervention to check for any content indicative of potential risk, in which case I would send a prepared text message advising they consider accessing support and/or their involvement in the study, and similar automated text messages for participants scoring in the severe range of the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). I also conducted a pre-intervention orientation phone call with all participants, in which I double-checked their suitability for the study (e.g., whether they felt emotionally ready to engage with a self-guided programme) and directed them to the safeguarding measures.

7 Publications

In this section I will present each of the submitted publications in the order in which I conducted the corresponding research (which may differ to the chronology of publication dates). For each paper, I will provide the background to how the research was developed, describe the research process, and critically reflect on my work. I will also summarise the contribution made by each paper to the field, as well as how I disseminated the papers beyond peer-reviewed publication.

7.1 Paper 1: Laying groundwork for ACT and visible difference

Zucchelli, F., Donnelly, O., Williamson, H., & Hooper, N. (2018). Acceptance and Commitment Therapy for people experiencing appearance-related distress associated with a visible difference: A rationale and review of relevant research. *Journal of Cognitive Psychotherapy, 32*(3), 171-183. https://doi.org/10.1891/0889-8391.32.3.171

7.1.1 Background to paper 1

Prior to writing paper 1, I was involved in two research studies that directly informed my work. When first at CAR in 2016, I contributed as third author to a systematic review of ACT interventions for body dissatisfaction and weight self-stigma (Griffiths et al., 2018). In my role, I re-ran a systematic literature search and filtered the results, contribute to the manuscript, and led the submission process. We found six suitable studies, most of which focused on samples of women of higher weight. The review suggested preliminary promise for the effectiveness of ACT for body dissatisfaction and weight self-stigma despite a relative paucity of research. As we included search terms targeting visible difference and broader terms for body dissatisfaction, we could be confident that no studies investigating ACT for any form of visible difference had yet been published.

In September 2016 I gained a position as a Research Associate at CAR working on a research project led by Dr Nicola Stock on health professionals' experiences of working in NHS cleft care. I interviewed over 50 specialist NHS cleft health professionals including 19 clinical psychologists, and jointly conducted a content analysis, resulting in two publications in which I was second author (Stock et al., 2020; Stock et al., in press). A finding of interest was that around half of the psychologists favourably reported applying ACT principles with their service users born with a cleft, particularly in relation to appearance concerns with adolescents and adults. Psychologists described particular clinical utility in working on value-based action with service users, as a means of reorienting their energies towards their deeply held desires and away from a struggle with appearance concerns (Stock et al., 2020).

This combined work helped me understand the state of the evidence base, and offered an example of the clinical reality of ACT applied to individuals with visible differences. In January 2017, my line manager Dr Heidi Williamson and colleague Dr Nic Hooper secured internal funding for me to engage in formative research on the application of ACT for visible differences. It was during this time that I produced paper 1 and conducted the research for paper 2. Central to the project was close collaboration with clinical psychologists working in the field. Dr Olivia Donnelly, with whom I collaborated throughout the entire submitted body of work, led Outlook, a nationwide psychology service at North Bristol NHS Trust for individuals with visible differences. Dr Donnelly specialises in ACT, and predominantly used this approach when working with service users at Outlook. At the early stages of the project I also collaborated with Dr Elisabeth Baker based at the Royal Free London NHS Trust, who similarly used ACT to support users of plastic and reconstructive surgery services who are experiencing appearance concerns.

As a group of researchers and clinicians, we intended to build a programme of clinically applicable research on the use of ACT to the population, covering the range of levels presented in CAR's tiered intervention framework(Jenkinson et al., 2009). We met regularly as a group to steer this programme, including my work over the year.

7.1.2 Study process and critical reflection on paper 1

When seeking to formally establish the state of research on a topic, systematic reviews are considered the gold standard (Cochrane, 2022). However, from our systematic review on ACT for body dissatisfaction it was clear that a narrower review was unnecessary. As a team, we also considered conducting a scoping review, often used to map out the extant literature on a broad topic with undefined boundaries, and to inform the direction for subsequent systematic reviews (Pham et al., 2014). However, the research question was already well-defined; namely, what is the effectiveness of ACT for psychosocial challenges associated with visible differences, and how should ACT be tailored to the population?

We therefore agreed that the priority was to write a narrative literature review that summarised and synthesised the relevant literature, developed a theoretical and empirical rationale for building a programme of research on the topic, and set out future directions for this research. Adopting a pragmatic approach towards the real-world application of ACT, and with the knowledge that psychological practitioners were already using ACT for the population (personal communication during preparation of Harcourt et al., 2018; Stock et al., 2020), we also wanted to offer practical clinical guidance based on ACT theory and the specific needs of the population. To do so, I worked closely with Dr Donnelly. For example, in the paper we carefully discussed the issue of appearance concealment (e.g., covering visible difference with clothing) in terms of its workability; that is, the function of the behaviour as either workable for the person's values or unworkable, rather than the behaviour being inherently maladaptive or adaptive. During this time I also attended a two-day ACT workshop for North Bristol NHS Trust staff wellbeing led by Dr Donnelly, which greatly helped me understand ACT from an applied perspective.

On reflection, one area for methodological improvement in this study was the way that I conducted the literature search. As the search spanned multiple clinical areas, I primarily drew on the (pre-publication) systematic review on ACT for body dissatisfaction (Griffiths et al., 2018) as well as a recently published book which summarised the collective evidence base on ACT (Hooper & Larsson, 2015), including on social anxiety disorder, posttraumatic stress disorder, stigma, pain and health conditions. I performed forward citation searches from the studies identified by Hooper and Larsson (2015) to capture all up-to-date literature. In hindsight, however, applying systematic literature searches across the clinical areas, with clearly defined search terms, would have been a more rigorous approach.

My view on the most appropriate measures of psychological flexibility has also changed since writing paper 1. In the 'Future directions for research' section of paper 1, I highlighted the need to assess appearance-specific psychological flexibility (especially the key processes of experiential avoidance and defusion) via the recently developed Body Image Psychological Inflexibility Scale (BIPIS; Callaghan et al., 2015). Certainly, this measure holds greater face validity for the visible difference population than other body image (in)flexibility measures, which predominantly focus on weight and shape (e.g., Body Image Acceptance and Action Questionnaire; Sandoz et al., 2013). However, the BIPIS does not have subscales of the ACT processes or pillars, and so offers only limited measurement precision, a declared priority of contextual behavioural science.

Similarly, the Acceptance and Action Questionnaire version 2 (AAQ-II; Bond et al., 2011), which I highlighted as an established measure of psychological (in)flexibility, has been the subject of recent scrutiny. Originally developed purely as a measure of experiential avoidance (Hayes et al., 2002), its construct validity for measuring psychological flexibility is highly questionable (Francis et al., 2016). As noted by Wolgast (2014), many of the scale items also appear to conflate experiential avoidance with distress markers (e.g. "I'm afraid of my feelings") and the relevance of the item "It seems like most people are handling their lives better than I am" to psychological flexibility is unclear. Accordingly, researchers have since developed the CompACT, a more comprehensive measure of psychological (in)flexibility, including subscales of the openness, awareness and valued action pillars (Francis et al., 2016). In a comparison of discriminant validity and item performance between the

CompACT and AAQ-II, Ong et al. (2020) found that the CompACT had higher discriminant validity and more consistent item performance.

7.1.3 Contribution of paper 1

In paper 1, I laid the necessary groundwork for initiating a broad body of research on the use of ACT for individuals with visible differences, by reviewing and synthesising existing relevant empirical literature and setting an agenda for future research. In doing so, and in part informed by previous research in which I was involved, I highlighted a gap between practice and research, with many practitioners applying ACT principles to support the population, without any population-specific ACT research having been published. By reviewing and synthesising the disparate relevant literature, I enhanced theoretical understanding of how ACT may apply to individuals with visible differences, which is crucial to developing evidence-based interventions (Bleijenberg et al., 2018; Craig et al., 2008; Czajkowski et al., 2015). The theoretically informed clinical guidance we offered in the paper also provided clinicians with much-needed direction in supporting individuals at the higher end of clinical need.

7.2 Paper 2: ACT in practice

Zucchelli, F., Donnelly, O., Sharratt, N. D., Hooper, N., & Williamson, H. (2020). Patients' experiences of an Acceptance and Commitment Therapy-based approach for psychosocial difficulties relating to an appearance-affecting condition. *The European Journal of Counselling Psychology, 9*(1), 28-38. https://doi.org/10.46853/001c.22012

7.2.1 Background to paper 2

Prior to undertaking the research underpinning paper 2, Dr Donnelly had produced a working ACT practitioner guide for individuals with appearance concerns related to a visible difference, with input from Dr Baker. We agreed as a team that one of the objectives of the internal funding was to explore the experiences of service users with visible differences who have completed specialist-led ACT for appearance concerns. In doing so, we aimed to refine the practitioner guide, and extrapolate the findings pertaining to any population-specific therapeutic processes explored to then test theory, and ultimately inform the design of a lower-level intervention for the population. In this way, we sought to address a range of levels presented in CAR's tiered framework of interventions (Jenkinson, 2009). Following a pragmatic research paradigm, we agreed that a qualitative approach was best suited to this objective as it concerns the exploration of individuals' lived experience.

With the funding, we also planned to start the work outlined in the Future Directions of paper 1, namely to build towards piloting and evaluating the effectiveness of ACT for the population. To do so, in 2017 we assessed the feasibility of conducting a cross-site randomised controlled trial (RCT) at the Outlook service in North Bristol NHS Trust and Royal Free Hospital. We soon established that the referral rates of potentially suitable participants at these sites over a six-month period were too slow and unpredictable to enable a future RCT. Instead, we discussed a non-concurrent multiple baseline design as an alternative approach to RCTs, better suited to specialist psychological services with limited numbers of service users (Twohig et al., 2006), and which have been used to assess ACT interventions (e.g., Twohig & Woods, 2004; Yadavaia & Hayes, 2012).

However, for two reasons we did not progress with this method. Firstly, both clinicians were understandably concerned about the participant burden in completing outcome measures at multiple timepoints, and the potential strain this may have on the therapeutic relationship. Secondly, Dr Donnelly's practitioner guide adopted a process-based treatment approach, in which the order and selection of evidence-based procedures are tailored to the unique context of the individual to improve their quality of life (Hofmann & Hayes, 2019, p.2). This necessarily precluded a treatment protocol which could be uniformly applied to participants and hence controlled in a multiple baseline design.

Another line of research I suggested in the Future Directions section of paper 1 was the use of case studies to provide "rich idiographic detail that can aid clinicians… and stimulate research questions". Dr Donnelly was keen to write a clinical case study, but acknowledged she had limited availability to lead a write-up. I was therefore keen to incorporate the idiographic aspect into the interview study, best suited to IPA (Smith & Osborn, 2003; see paper 2 for details).[4]

7.2.2 Study process and critical reflection on paper 2

Having established a study objective, we agreed that I would conduct a qualitative interview study with users of Dr Donnelly's Outlook service to understand their experiences of therapy. To explore ACT processes beyond the specific clinician's characteristics, we agreed that I would also interview service users working with Dr Bakerat Royal Free Hospital. However, due to unforeseen circumstances, Dr Baker was unable to continue contributing to the project. From my original intention of assessing the feasibility of an RCT, through to dismissing the feasibility of a multiple baseline design, to being unable to conduct interviews across NHS sites, I was learning the logistical challenges that can be encountered when collaborating with clinicians working in specialist NHS services, and the importance of adapting the research design in light of such constraints.

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[4] To my knowledge, no such qualitative case study or case series has been published to date. Shepherd et al. (2020) published a case series of three service users with burns scarring who went through ACT, but analysis was limited to quantitative outcome measurement (and was not controlled via a multiple baseline design).

Given our circumstances, I decided to focus more squarely on individuals' lived experiences of specialist one-to-one ACT. In doing so, I recognised that any findings regarding ACT processes and how they may be extrapolated into intervention development would be tentative, given that the therapeutic alliance would necessarily contribute towards individuals' experiences, over and above ACT processes. We were also unable to conduct fidelity checks on the intervention because our ethical approval precluded any changes to routine treatment. The process-based approach adopted by Dr Donnelly also created limitations in extrapolating interview findings to inform lower-level interventions, as these are less amenable to specialist-tailored delivery. The tension between offering a low-level intervention capable of reaching a high number of people and the need to provide individually formulated intervention was one I already encountered in the interviews I had conducted with cleft health professionals, who had emphasised the importance of adapting their interventions to the needs, context and practical constraints of individuals and their families.

As I was primarily interested in understanding the subjective lived experiences of individuals who had been through one-to-one ACT therapy and was keen to gain idiographic nuance of their experiences, I chose to analyse the semi-structured interviews using IPA (Smith & Osborn, 2003). As I sought to explore individuals' experiences through their own lens, I took an inductive approach to the semi-structured interviews. For example, when asking participants about their experience of the various ACT components, I did not probe by using ACT terminology such as "values", "defusion" or "willingness" – unless mentioned by a participant. Perhaps partly as a result, I noted that participants rarely described their experiences of therapy (and outside) in terms of specific processes and methods, instead predominantly discussing such processes more broadly alongside the practitioner's interpersonal qualities. This challenge has since been raised in other qualitative ACT research, with Fogelkvist et al. (2021) reporting that individuals diagnosed with eating disorders predominantly answered their questions about the helpful aspects of therapy in terms of "common therapeutic factors rather than methodologically-specific factors" (p.190).

The double hermeneutic aspect of IPA, in which I sought to make sense of how the participants' made sense of their experiences, was necessarily influenced by an ACT lens. As participants rarely referred to ACT terminology, my interpretation of their accounts in terms of constructs such as values and openness was only tentative. Upon reflection, I note that my interpretation may have been blinkered by this ACT lens, and possibly also by loyalty towards the practitioner and unconscious concern not to present their work in ACT-inconsistent terms. Consequently, I feel I made insufficient comment on participants' description of mindfulness practice sometimes apparently more as a means of emotional regulation than openness and acceptance, and therefore the extent to which participants had truly absorbed the ACT approach. The position of ACT in relation to emotional regulation remains a subject of contention within ACT literature (e.g., Valdivia-Salas et al., 2010). [5]

As noted in the Discussion, another aspect of participants' accounts that seemingly diverged from the ACT approach was their description of cognitive reappraisal. I discussed this with my co-authors, and especially Dr Donnelly, in great depth. It was instructive to gain Dr Donnelly's perspective on how their intervention may relate to participants' accounts of cognitive reappraisal. I had also recently attended a panel event at the 2018 Association of Contextual Behavioral Science (ACBS) World Conference, entitled "If I restructure your thoughts and decrease your anxiety, can I still call it ACT?" Here, the panel also discussed the more specific question of whether inadvertent cognitive reappraisal resulting from ACT processes in therapy contradicts ACT, or whether it can be accommodated as a workable function towards values-based living. It was through my conversations with Dr Donnelly and reflections on the panel event that I ultimately posited cognitive reappraisal as a by-product of cognitive defusion and exposure exercises in the Discussion section.

With an objective of the study being to explore testable theoretical processes of change, I also interpreted the findings through this lens. To this end, I examined the findings for their consistency with the various theoretical models used to understand the experiences of individuals with visible differences (outlined in section 5.4). From this exercise, Cash et al's (2005) model of body image coping most clearly aligned to the findings, as well as the ACT model. This served as a springboard for paper 3.

7.2.3 Contribution of paper 2

To my knowledge, this was the first published study to explore in detail the lived experience of individuals who had been through one-to-one therapy (of any type) for appearance concerns related to visible difference. In doing so, the paper offered insight into clinical considerations pertinent to working with the population at a higher level of intervention. The paper also explored the ways that ACT processes such as defusion and openness may facilitate improved body confidence and engagement with valued life activities for individuals with visible differences. By interpreting the findings through the lens of established body image coping models, the paper also offered direction for testing change processes within an evidence-based framework.

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[5] Emotional regulation has been defined as "how individuals influence which emotion they have, when they have them, and how they experience and express them" (Gross, 2014; p.3-20). The element of controlling the formation and type of emotions appears antithetical to the 'control as a problem' aspect of ACT. Some participants' accounts of engaging in mindfulness practice could be seen as reflecting this attempt to control emotions (e.g. "…you have the tools to just take stock, um, just relax, calm, refocus your mind, let it go.").

7.3 Paper 3: Testing ACT and appearance theory

Zucchelli, F., White, P., & Williamson, H. (2020). Experiential avoidance and cognitive fusion mediate the relationship between body evaluation and unhelpful body image coping strategies in individuals with visible differences. *Body Image, 32*, 121-127. https://doi.org/10.1016/j.bodyim.2019.12.002

7.3.1 Background to paper 3

In August 2017, CAR secured a donation from the VTCT Foundation to undertake a broad programme of research on the psychosocial aspects of visible differences. Through this donation, I gained a Research Associate position at CAR. I conducted part of the write-up of paper 2 since joining the programme, but paper 3 was my first to be conceived and conducted through this funding.

Consistent with my pragmatic research paradigm, one of the programme's research priorities was to develop psychosocial support resources that all member organisations of the Appearance Collective could offer to those they serve, maximising the resources' potential for real-world impact in terms of reaching a high number of people. This lent itself to a lower-level psychosocial intervention, encompassing level 2 (standalone interventions) and level 3 (self-guided with trained health professional support) of CAR's tiered framework of interventions (Jenkinson, 2009). Following MRC guidance for developing complex interventions (Bleijenberg et al. 2018; Craig et al., 2008; O'Cathain et al., 2019b), by mid-2017 I was at the stage of having reviewed the relevant empirical literature (paper 1) and positing an underpinning theoretical framework to be tested (paper 2). The next stage, as per MRC guidance, was to test potential causal mechanisms of behaviour change.

7.3.2 Study process and critical reflection on paper 3

Investigating ACT-based processes of change for the target population is a deductive research question, namely one involving testing an existing theory. Quantitative methods using a representative sample are therefore the most suitable approach to the question. To determine the study design, I drew heavily on a recently published paper by Mancuso (2016), in which the author used cross-sectional mediation analysis to test the hypothesis that body image flexibility (i.e., domain-specific psychological flexibility) would mediate the relationship between body image evaluation and Cash et al's (2005) proposed unhelpful coping strategies, in a sample of adult females. While recognising the deductive limitations of cross-sectional research in which causal chains cannot conclusively be determined, it was the most practicable method in the face of limited time and resources.

Unlike Mancuso (2016), I sought to delineate between experiential avoidance and cognitive fusion as processes of psychological flexibility in the tested model. Doing so, I reasoned, would help to better understand any differences in how each determine behavioural changes in terms of appearance-fixing and life disengagement, which would be instructive when designing interventions. I also chose not to test other processes such as contact with the present and values clarification. This was partly because I saw a clearer theoretical rationale for experiential avoidance and cognitive fusion as mediators of the relationship of interest (detailed in paper 3). Also, from my reading of ACT literature, these two processes are commonly presented as the cornerstone of psychological inflexibility; for example, "ACT is a functional contextual therapy approach based on Relational Frame Theory which views human psychological problems dominantly as problems of psychological inflexibility fostered by cognitive fusion and experiential avoidance." (contextualpsychology.org, cited by Cullen, 2008, p.5). This can also be seen in validated measures of psychological (in)flexibility, such as the Avoidance and Fusion Questionnaire for Youth (AFQ-Y; Greco et al., 2008). Subsequent research in visible skin conditions has also focused on fusion as a mediator, finding it mediates the relationship between psychological flexibility together with disease severity, and disability from psoriasis (Almeida et al., 2020).

When selecting measures, I considered the Body Image Psychological Inflexibility Scale (BIPIS; Callaghan et al., 2015), as I had suggested in paper 1, to test whether body (in)flexibility explained more variance than the domain-general measures of experiential avoidance and cognitive fusion. However, I was aiming for parsimony in constructs, and I was also concerned by the apparent lack of discriminant validity between the BIPIS and body image quality of life (as measured by Cash and Fleming's (2002) Body Image Quality of Life Inventory), with a Cronbach's alpha of 0.94 between the two scales (Callaghan et al., 2015). Based on participants' accounts from paper 2 describing self-initiated cognitive reappraisal, I also considered measuring cognitive distortions related to appearance as a covariate in the mediation model. However, I was unable to find a suitable measure. Jakatdar et al. (2006) had developed the Assessment of Body-Image Coping Distortions, but this centred on common weight and shape-based cognitive distortions encountered by the general female population.

Another consideration in designing the study was the potential for operational overlap between the constructs of experiential avoidance and behavioural disengagement from appearance-salient activities. This would open the possibility of offering only tautological conclusions from findings. That is, if experiential avoidance was found to mediate the relationship between appearance evaluation and behavioural disengagement (as established in the results), the question may be posed as to what is actually demonstrated by one form of avoidance mediating another. This was a question my co-authors and I discussed before deciding on the study design. Ultimately, to test the model, we felt it worthwhile to distinguish between experiential avoidance as an attitude of unwillingness, marked by private behaviours aimed at avoiding unwanted private experiences, and overt behaviours aimed at avoiding situations in which appearance cues are salient, which together indicate limited life engagement. This distinction between experiential avoidance and behavioural disengagement was borne out in the findings, in which the Brief Experiential Avoidance Questionnaire (BEAQ; Gámez et al., 2014) and the Body Image Life Engagement Questionnaire (BILEQ) held a Cronbach's Alpha of 0.61, indicating no multicollinearity (typically indicated with correlations of >0.8; Vatcheva et al., 2016).

Aiming at recruiting a representative sample, I approached all member organisations of the Appearance Collective to promote the study. On reviewing the spread of the various visible difference causes in the final sample, this spread largely mirrored the extent to which each organisation had promoted the study. For example, the charity Alopecia UK repeatedly advertised the study, and alopecia was the most highly represented cause of visible difference in the sample at nearly 20%. Conversely, charities who support burn survivors were less engaged, and this group were underrepresented (at 6.8%). On reflection, I could have made greater efforts to recruit a more representative spread of visible difference causes.

7.3.3 Contribution of paper 3

Though limited by its correlational nature, paper 3 offered an important theoretical development to underpin an ACT-based intervention and to support the real-world application of ACT for those struggling with a visible difference. Namely, findings were consistent with the idea that practical exercises to reduce fusion may help individuals engage in fewer unhelpful body image coping behaviours. Findings were also consistent with acceptance— the antithesis of experiential avoidance— as a therapeutic tool to help people engage in more activities across life domains despite evoking body image threats (such as meeting new people or applying for a job). By testing a mediation model, the paper added greater specificity to the extant literature (e.g., Shepherd et al., 2019) regarding the role of psychological flexibility processes in relation to appearance-based behavioural outcomes.

7.4 Paper 4: Designing a self-guided ACT intervention

Zucchelli, F., Donnelly, O., Rush, E., Smith, H., Williamson, H., & Team, T. V. F. R. (2021). Designing an mHealth intervention based on Acceptance and Commitment Therapy for people with visible differences: Participatory study gaining stakeholders' input. *JMIR Formative Research, 5*(3). https://doi:10.2196/26355

7.4.1 Background to paper 4

With the aim of developing a novel self-guided psychological intervention under the broad VTCT Foundation research programme, in January 2018 I secured 12 months of internal funding as lead applicant to initiate the design of a mobile ACT intervention.

To select an initial mode of delivery to present to stakeholders, I referred to Michie et al's (2014) evidence-based APEASE framework for selecting behaviour change intervention modalities (which considers: Affordability; Practicality; Effectiveness/Cost-effectiveness; Acceptability; Side-effects/Safety; and Equity). Given the increasing ubiquity of smartphone ownership across socioeconomic profiles (Correa et al., 2020; Statista, 2022) and its increasing use for health self-management over traditional web-based formats (Torous et al., 2017; see paper 4 for more detail), I chose mobile delivery.

I stated four objectives of my research under the funding. First, I sought to gain stakeholder input, including patient involvement (PI) from user representatives, on the mobile mode of delivery and to design the intervention. The second objective was to design the architecture and content of the intervention. This required expertise from app development specialists, so I budgeted for an external software developer, *Dataphiles Ltd*, with whom CAR had collaborated on previous web-based interventions (Bessell et al., 2012; Williamson et al., 2019) to produce mock-ups of the programme. A third objective involved applying for an external grant to develop a minimum viable product once the design had sufficiently progressed. Lastly, I aimed to publish a peer-reviewed paper detailing the design process. As highlighted by O'Cathain et al's (2019b) principles of intervention development (see figure 3), publishing development work is imperative to allow others to assess the quality and rigour of the process, and to draw links from the design phase to any future outcomes of the intervention.

As briefly outlined in the *History of the Initial Design* Methods subsection in paper 4, in February 2018, I presented the project to members of the Appearance Collective organisations as a real-life demonstration of public and patient involvement (PPI), at a PPI workshop run by CAR. These members were crucial to implementing the long-term vision of the project, as they would act as service providers or at least gatekeepers to an intervention. My colleagues Professor Diana Harcourt, Dr Heidi Williamson and Dr Nicola Stock co-facilitated the session with me. We split the group into three simultaneous activities, with each group moving between the three activities: A focus group (covering members' needs regarding psychosocial interventions for their beneficiaries, their current practices, the context within which they operate, and their views on a mobile mode of delivering an intervention); a usability session using a partial (static) mock-up presented on smartphones; and content generation in the form of micro-mindfulness exercises. Together, these activities spanned the planning and designing phases of intervention development (Bleijenberg et al., 2018).

Overall, stakeholders indicated interest and enthusiasm for the concept of an ACT-based mobile intervention, while also providing us with valuable learning points on how to engage stakeholders for this project. For example, I refined the focus group topic guide from this informal work for the subsequent formal user representative focus group, and noted the difficulty of assessing usability of a non-clickable mock-up without continuous guidance and feedback from a facilitator. Following this early stakeholder engagement, I moved forwards to a more formal and rigorous participatory research design process, which constituted paper 4.

7.4.2 Study process and critical reflection on paper 4

This study, which gained input from user representatives and specialist psychological practitioners to consider the appropriateness of mobile delivery as an intervention modality for the population, and to design a mobile self-guided intervention, mapped on to the design phase of intervention development presented by Bleijenberg et al. (2018). Following Czajkowski et al's (2015) ORBIT intervention development model, I adopted an iterative design protocol that cycled between designing and refining the prototype based on key stakeholders' preferences and ideas.

From a pragmatic research paradigm perspective, the wide-ranging research aims detailed above were best suited to multimodal qualitative methods. The broader, more explorative question (i.e., understanding the suitability of mobile delivery) was best addressed with focus groups and semi-structured interviews, while the more responsive, detailed feedback and idea generation suited one-to-one usability testing with a talk aloud procedure and written feedback (O'Cathain et al., 2019b). Using a multimodal qualitative methodology also facilitated data source triangulation, enabling a more comprehensive understanding of phenomena of interest (Carter et al., 2014). For example, the focus group format utilised with user representatives stimulated identification and sharing of various perspectives concerning mobile delivery and design preferences (Morgan, 1996), while one-to-one interviews, usability testing and written feedback offered greater privacy to share sensitive topics and personal experiences (Carter et al., 2014).

In hindsight, another research method I could have considered incorporating into this work is the Delphi protocol, whereby researchers systematically form a consensus on a topic (such as key components of an intervention) from a group of informed individuals. This method typically involves recruiting expert professionals, but where appropriate can also include experts by lived experience (e.g., service users in Lakke et al., 2012; and e-health users in Schneider et al., 2012).

A methodological challenge came in determining the extent of stakeholder input, which can range from coproduction to consultation, throughout the design process. In coproduction, stakeholders and researchers (or other developers) generate ideas and make decisions together about intervention design (O'Cathain et al., 2019b). In consultation, researchers consult with stakeholders often through qualitative methods to better understand the context that an intervention will operate in, but the researchers ultimately make the design decisions (INVOLVE, 2018). As a whole, our design process involved more consultation than coproduction. However, the precise role of user representatives and psychological practitioners varied depending on the design element. For example, as the intervention was *a priori* ACT-based, and given the importance of retaining fidelity to the therapeutic model for future effectiveness (Bellg et al., 2004), it appeared more appropriate to coproduce the ACT-focused content with clinical specialists (with Dr Donnelly making design decisions in reference to the group' input), and to consult with user representatives on its precise delivery. Similarly, content like real-life examples and the functionality of the programme was better suited to coproduction with user representatives (with Emma Rush, founder of Vitiligo Support UK, making design decisions based on the group's input), and consultation with clinicians.

As highlighted in the *Limitations* section of paper 4, the sample size of user representatives was low. Although our plan was to work with a relatively small group who could commit to the ongoing iterative design process, we planned for a larger group than six, and especially a larger group than four at the user representative workshop. From experience at the earlier stakeholder meeting in February 2018, it appeared important to conduct one-to-one usability sessions to give participants sufficient live feedback, and to allow a talk-aloud protocol. This necessitated one researcher per participant, and I was able to recruit and train seven researchers to help. Unfortunately three user representatives dropped out at short notice. In hindsight, though creating its own risk of having too few researchers if all participants did attend, it may have been prudent to 'over-recruit' participants for the workshop in anticipation of likely dropout.

Consideration should also be given to how the findings may have been influenced by the type of stakeholders involved— and not involved— in the formal research process. Though it was important to gain the perspectives of specialist psychological practitioners with clinical expertise in applying

ACT to the population, their professional context will have had a bearing on the data. Most worked in specialist health psychology and mental health services in the NHS, and delivered predominantly higher-level intervention at steps 4 and 5 of the CAR intervention framework (Jenkinson, 2009). With these clinicians used to careful risk management, this may have given the qualitative findings a more cautious perspective than is representative of the lower step 2 needs level (standalone support) targeted by the intervention.

Similarly, the absence of software development and/or user experience design experts in this research process may have limited its capacity to comprehensively understand the design challenges involved, as recommended by O'Cathain et al. (2019b). While Dr Williamson and I were able to engage in two 'discovery' sessions with the software developer *Dataphiles* to produce the first partial mock-up, our limited funding precluded their ongoing involvement in the iterative design process. Similarly, I had gained valuable input from Dr Praminda Caleb-Solly, a user experience expert from UWE Bristol, and worked with her MSc cohort using the intervention as a case study for their design assignment. Although I learned a great deal about digital user design principles from these interactions, it nevertheless left an expertise gap in ascertaining the technical feasibility of various design preferences and ideas presented by the user representatives and clinicians.

7.4.3 Contribution of paper 4

This paper was the first published to explore mobile health as a mode of delivering psychological support to individuals with visible differences. Given the current popularity of mobile apps, this contributes an important development to the visible difference field. The strengths and challenges of mobile health identified for the population give other researchers, clinicians and intervention developers a greater understanding of individuals' needs in the context of contemporary health technology. More directly, these findings, together with stakeholders' design preferences and ideas, informed the continued development of an ACT-based prototype mobile intervention for individuals with visible differences. Furthermore, the paper offers those in the field of complex intervention development an example of how evidence-based, population-based and modality-specific approaches can be coherently synthesised based on the needs of a specific project O'Cathain et al. (2019a).

7.5 Paper 5: Feasibility testing a prototype mobile ACT intervention

Zucchelli, F., Donnelly, O., Rush, E., White, P., Gwyther, H., Williamson, H., The VTCT Foundation Research Team at the Centre for Appearance Research. (2021) An Acceptance and Commitment Therapy prototype mobile program for individuals with a visible difference: Mixed methods feasibility study, *JMIR Formative Research* 6(1). https://doi:10.2196/33449

7.5.1 Background to paper 5

From March 2019, I continued to design a prototype of the intervention from the combined stakeholder input described in paper 4, with further input from Dr Donnelly and Emma Rush. The prototype was also directly informed by the original research conducted for papers 2 and 3. For example, I incorporated the theme from paper 2 suggesting participants valued compassionate modelling from a therapist, together with themes from paper 4 emphasising user representatives' preference for "that human element" and the need to mitigate dropout. I did so by filming short scripted introductory videos at the start of each intervention session with Dr Donnelly, who acted as the 'app guide' throughout the programme by also appearing in photographic form alongside speech bubbles responding to users' entries. Many of the participants from paper 2 also consented to anonymised quotes from their interviews being presented as illustrative case examples in the prototype.

Drawing on the empirical finding from paper 3 that experiential avoidance and especially cognitive fusion may mediate appearance-focused behaviours, I incorporated a series of specific defusion and acceptance exercises into the prototype (e.g., for defusion: "I'm having the thought that…"; naming thoughts as stories; and viewing thoughts as passengers; and for acceptance: Allowing intense experiences, and mindful mirror practices). I also applied findings from paper 4, where stakeholders expressed a need to design the intervention for learning, by explicitly matching all exercises to their corresponding skills (e.g., defusion or acceptance), and inviting users to self-rate and track their skills over each session.

Back in October 2018, while still conducting the participatory design work in paper 4, I co-wrote an Innovate UK grant application to develop the intervention into a minimum viable product, in collaboration with Dr Williamson and *Dataphiles*. Our application was unsuccessful, though the reviewers' feedback was generally positive, exemplified by one comment, "in particular the early engagement of end users is to be congratulated". However, with the scheme focused in part on technological innovation, the reviewers felt the project was lacking in this regard.

As the VTCT Foundation research programme funded my research time but no software development costs, I explored ways of creating a functional prototype at negligible cost. I had met

Professor Michael Levin in July 2018, co-director of the Utah State University ACT research group, when he presented his research findings at the ACBS World Congress in Montreal, Canada, in a symposium titled “Barriers and innovations in self-guided ACT interventions”. Having briefly discussed developing low-cost mobile prototypes with him at the conference, I followed this up via email to explore possibilities. He outlined various options including free-to-use app development platforms such as App Inventor and their strengths and weaknesses. He also described his successful experience of using *Qualtrics* for hosting a prototype of a daily ACT skills self-guided mobile intervention for college students (Haeger et al., 2020).

Following Prof. Levin’s advice, I decided to use *Qualtrics* as the prototype platform. To assist in translating the prototype content I had created in wireframing software into Qualtrics, I advertised a voluntary placement at CAR for UWE Bristol MSc Health Psychology students. Holly Gwyther took this position, and ably helped me painstakingly learn the technical limits of Qualtrics to create a prototype between June 2019 and March 2020.

The resulting feasibility study published in paper 5 was delayed by the COVID-19 pandemic, which also exacerbated my personal challenges of parenting a first baby, born in May 2020. In June 2020 the first national lockdown came to an end, and in discussion with my co-authors including the lead user representative Emma Rush, we decided to begin recruiting in July 2020.

7.5.2 Study process and critical reflection on paper 5

Having developed a prototype, we sought to test its feasibility in adults with visible differences who experience appearance concerns. The scope of the study, which was not yet in the piloting stage involving formal testing of recruitment rates and required sample sizes for a full RCT, fitted within the early feasibility stage of the MRC framework (Craig et al., 2008) and the *proof-of-concept* element of the preliminary testing phase in the ORBIT model (Czajkowski et al., 2015). Our hope was to establish the intervention’s proof-of-concept, thereby strengthening any funding applications to develop a full app which we could then test via an RCT either preceded by a pilot RCT, or with an internal pilot (e.g., Anderson et al., 2020). To address our objectives, we used quantitative methods with nested qualitative interviews, which strengthened the study by allowing data triangulation to help explain phenomena. Chiefly, the semi-structured interviews helped understand *how* the programme may have helped participants beyond the findings from quantitative outcome measures.

In terms of the interviews, as highlighted in the *Limitations* of paper 5, my position as lead developer of the intervention and my previous contact with participants may potentially have influenced participants’ accounts. As I noted in my reflexive log, I was careful to emphasise my openness to constructive feedback and to hearing any negative experiences, and I made a concerted effort to probe any comments suggestive of such views. If funding had been available for a colleague to conduct the interviews, I remain ambivalent as to whether this limitation would have outweighed the strength of my knowledge about the programme and my ability to probe and collect more in-depth information.

The process of producing paper 5 also taught me about ‘scope creep’ as a pitfall in approaching data analysis. Following the findings in paper 3, I had originally aimed to test acceptance and defusion as mediators of change in appearance-fixing and life engagement behaviours in the feasibility study. However, in discussion with my co-authors and especially Dr Paul White, an applied statistician, it became apparent that doing so fell beyond the scope of the feasibility objectives. I had also intended to add single item measures of life engagement and appearance-fixing to the single item measures of psychological flexibility processes at the start of each session, but my co-authors felt that these would cause unnecessary participant burden and may diminish adherence. Missing these outcome markers precluded session-by-session mediation analysis (e.g., Niles et al., 2014), which would have been more appropriate for the single-group design and small sample size than traditional mediation methods (as in paper 3). After taking advice from Dr White, I conducted a correlational analysis between pre-to-post changes in avoidance, fusion, appearance-fixing and life disengagement to test consistency with the mediation hypothesis. These showed mixed findings, perhaps unsurprisingly given the small sample size. Ultimately, though, the manuscript’s reviewers echoed Dr White’s initial concerns, recommending we remove these findings as they were beyond the study’s scope.

Practically speaking, using Qualtrics as the intervention platform was crucial as it allowed me to test the feasibility of a prototype without external funding, but it also created limitations. Although well optimised for mobile use, the platform is nevertheless limited in its visual appeal and functionality, which restricted the scope of the acceptability research objective where visual appeal and usability play a role (Alqahtani & Orji, 2020). Qualtrics also doesn’t facilitate ecological momentary assessment, which can be helpful both as a self-monitoring feature for users and in generating more user data for analysis (e.g., Levin et al., 2019). We were therefore unable to explore the utility of this feature.

7.5.3 Contribution of paper 5

Building from the research presented in papers 1-4, this paper established for the first time the feasibility of both ACT as a novel intervention approach in the field of visible difference, and mobile delivery as a novel modality for psychosocial self-management in the population. In so doing, it offers promise of a new evidence-based approach for providing standalone psychological self-management for adults with visible differences.

7.6 Dissemination of papers

In addition to publishing the presented research, I also disseminated the findings to a range of audiences in academia and beyond. To maximise the potential for real-world impact, I shared findings in various formats to stakeholders including charity and NHS staff, people with visible differences and their families, and clinicians. The supplementary table 1 in Appendix 3 shows the forums through which I disseminated each paper presented in the commentary.

8 Discussion on the combined works

In this section I will review the presented publications as a collective body of work by summarising its overall contribution to the field, discussing the methodological considerations from the work, its scope, and how it has informed subsequent projects and my development as an independent researcher.

8.1 Contributions to the field of psychological intervention for visible difference

The presented publications span five years of work in which I led a research project aimed at advancing understanding on the application of ACT for individuals with visible differences, and latterly developing an evidence-based self-guided intervention. To advance understanding, in paper 1 I provided a theoretical and empirical rationale for the suitability of ACT for the population, highlighted a practice-research gap, and set out a multipronged research agenda. In paper 2 I explored individuals' subjective experience of one-to-one ACT therapy, offering insights into potentially pertinent therapeutic processes, and mapping findings onto a conceptually consistent evidence-based model (Cash et al., 2005). In paper 3, framed by Cash's model, I tested key psychological flexibility processes as mediators of appearance-based coping behaviours, which advanced the empirical basis of ACT as an appropriate approach for individuals with visible differences.

Recognising that appearance concerns exist on a spectrum of clinical need in the population and that clinicians who reported adopting ACT for the group were predominantly working at high-level needs settings, in paper 1, with Dr Donnelly, I also offered evidence-based clinical guidance for working one-to-one with individuals, and in paper 2 explored the individual therapy considerations of ACT for individuals with visible differences.

With real-world impact at the forefront of my pragmatic research agenda, I worked with key stakeholders to design a self-guided ACT intervention intended to reach a high number of people with lower levels of appearance concerns. This intervention was developed through a mixture of evidence-based, population-based and modality-based approaches (O'Cathain et al., 2019a), including drawing from the work undertaken in papers 1-3. The participatory design process presented in paper 4 culminated in a prototype mobile intervention, which I feasibility-tested in paper 5. Combined, these works have contributed a prototype ACT mobile intervention to the field, novel both for its therapeutic approach and modality. Importantly, it has been shown to have proof-of-concept for adults with visible differences who have appearance concerns, with great potential for real-world impact if modified to reflect participants' feedback, fully developed and made openly available to users. This has been recognised through funding from the VTCT Foundation for us to complete this work, to commence in January 2023.

8.2 Methodological considerations

8.2.1 Methodological strengths

A strength of the combined works was the methodological range and adaptability to the specific research questions posed at each stage of the project. This was facilitated by a pragmatic research paradigm, which accords with the pragmatism of contextual behavioural science as well as the priority for real-world impact held by CAR and the Appearance Collective within the VTCT Foundation research programme. Fully embracing this approach meant that I was able to tailor not only the data collection methods but also data analysis approaches to the research question. For example, in three different qualitative studies I adopted three different qualitative analysis approaches, namely IPA, framework analysis and thematic analysis (papers 2, 4 and 5 respectively). For the more deductive research goals, such as testing proposed mechanisms of change (paper 3) and level of user engagement, preliminary effectiveness and clinical safety (paper 5), I applied quantitative methods, again using different analytical approaches suited to each question.

8.2.2 Qualitative considerations

Reviewing my qualitative work across papers 2, 4 and 5, there are certain methodological considerations worthy of reflection. In doing so, I will draw on O'Brien et al's (2014) standards for reporting qualitative research.

An important consideration is the research paradigm, or worldview, adopted by the researcher, and how this shapes data collection and analytical methods. As discussed in section 6.2, the overarching pragmatic research paradigm I adopted across the studies allowed me to consider the most relevant worldview for each research question depending on the type of presumed reality, on a spectrum of the objective to subjective, indicated by the research question. On reflection, my worldview was something I underreported in papers 4 and 5. In both cases, I held a pragmatic, a-ontological position whereby I made no judgement about the underlying truth of participants' accounts, instead focusing purely on their reports as bound to their subjective experience of using an intervention and providing ideas of how it could be improved.

Another question faced by any qualitative researcher is when to stop recruiting, and how this decision is made. A common principle applied to this decision is data saturation, which describes an assumed stage from which any further data collection provides redundant information, on the basis that participants have already reported all meaningful accounts of a phenomenon (Lincoln & Guba, 1985). Although often used as a marker of methodological rigour, it assumes a realist, positivist worldview, whereby researchers' interpretation is assumed to 'excavate' knowledge rather than knowledge being generated through their interpretation (Braun & Clarke, 2019). The phenomenological account of IPA used in paper 2 is more akin to an interpretive/constructivist worldview, which concerns the multiple realities of participants (Merriam, 2009), and its idiographic approach is also at odds with the data saturation principle. In paper 5, I invited all participants to interview, so had exhausted recruitment possibilities. However, as discussed in section 7.4.2, on reflection, widening recruitment of user representatives for paper 4 would have given a broader set of perspectives and ultimately enhanced the data quality.

In terms of maximising the trustworthiness of findings, one technique often utilised in qualitative research is member checking, involving sharing results (typically in lay summary form) with participants to check for accuracy and resonance with their experiences (Birt et al., 2016). I chose not to use member checking in paper 2, as my analysis was necessarily interpretative and bound to my subjective and theoretical positionality. The dynamic, iterative nature of the design research in paper 4 made member checking difficult as the data covered multiple time points and feedback on different versions of the intervention. However, as part of the participatory action research process, on each iteration of the design, I sent participants summaries of their feedback and how we would modify the design as a result (see example in Appendix 3, supplementary figure 1). While not strictly member checking given it was done prior to the formal analysis, I invited participants to respond with any concerns or queries. As I increasingly recognised the value of member checking over time, also through collaborating on other qualitative projects, I made sure to conduct and report member checks in paper 5.

Another technique for conferring trustworthiness is keeping a clear audit trail, which I was able to do by using Nvivo 12 software in all qualitative studies, something I have continued to do since the presented works. Triangulation can also enhance trustworthiness by widening the scope of analysis (Carter, 2014). I applied triangulation of data sources in paper 4, and triangulation of researchers' perspectives in papers 2, 4 and 5.

8.2.3 Quantitative considerations

Regarding my quantitative work in papers 3 and 5, a central consideration relates to the scales I used to measure the psychological flexibility processes and appearance-focused behavioural outcomes. As the ACT model predominantly targets overt behavioural changes (via valued action) rather than affective outcomes, it seemed important to use scales measuring appearance-focused overt behaviours. The challenge was finding a fully validated behavioural measure. There are very few established outcome measures for appearance concerns in the visibly different population, and the few that do exist do not clearly measure overt behaviour. For example, while the Derriford Appearance Scale 24 (Carr et al., 2005) does include some behavioural items (e.g., "avoid communal changing"), there is no behavioural avoidance subscale.

I was aware of my CAR colleagues' work on the Dove Self-esteem Project in which they developed a measure of appearance-related life disengagement, the BILEQ, for an RCT testing an intervention for girls and parents (Diedrichs et al., 2016). As agreed by colleagues in the VTCTF research team at CAR who included the BILEQ in CAR's set of preferred outcome measures, the scale holds strong face validity for adults with visible differences. I was also aware of Prof. Diedrichs' intention to fully validate the scale in adults. However, this work remains incomplete, with only the adolescent version of the scale (Body Image Life Disengagement Questionnaire; BILD-Q) validated to date (Atkinson & Diedrichs, 2021). There clearly remains a need to fully test the psychometric properties of the adult BILEQ/BILD-Q in a visibly different population.

My selection of psychological (in)flexibility process measures was primarily based on their published psychometric qualities. For example, unlike the AAQ-II, the BEAQ I used in papers 3 and 5 has shown strong discriminant validity from emotional distress measures (Rochefort et al., 2018; Tyndall et al., 2019). However, a recent study has questioned this strength, suggesting that the BEAQ overlapped more than other measures of psychological inflexibility or experiential avoidance with emotional distress (Ong et al., 2020). The CompACT, of which I used the valued action subscale in paper 5, has been shown to hold stronger discriminant validity than other established measures of psychological (in)flexibility, and the valued action subscale specifically performed most consistently across clinical and non-clinical populations (Ong et al., 2020). As a reminder of the importance of contextual specificity, however, adaptation of the CompACT was required for it to perform adequately in a Portuguese sample (Trindade et al., 2021).

There is also a broader challenge in measuring psychological flexibility and its constituent processes with traditional trait self-report measures given its dynamic, context-specific nature whereby the extent to which an individuals' behaviour displays flexibility can only truly be understood with reference to its context (Hayes et al., 2006; Kashdan & Rottenberg, 2010). Researchers have begun to develop more contextually located measures of psychological flexibility, by stipulating conditions under which the psychological flexibility skills are most helpful (e.g., using mindfulness during turbulent times) and giving a 7-day timeframe, with promising early psychometric results (e.g., Psy-Flex; Gloster et al., 2021). The Psy-Flex also consists of single items for each constituent process, and combined with the 7-day window, may be especially useful as a session-by-session process measure in the ACT mobile intervention going forward.

In terms of deciding on my quantitative research designs, I drew on a combination of relevant published studies, my statistical capabilities and discussion with co-authors (especially Dr White, an experienced statistician). However, with the knowledge and skills I now possess— partly through first-hand experience and partly through ongoing learning such as via conferences like the ACBS World Congress in June 2021— I would likely approach the research questions somewhat differently. I would have considered including all psychological flexibility processes in paper 3 and using structural equation modelling to parse out the significant interconnected paths between variables, instead of a traditional mediation analysis. Similarly, I would have considered a more idiographic form of analysis such as idiographic network analysis (e.g., Fisher et al., 2017) to identify within-participant changes alongside group changes in paper 5. This approach would suit the increasing recognition of the idiographic nature of applied contextual behavioural science (Hofmann & Hayes, 2019).

8.2.4 Stakeholder involvement

The stakeholder involvement process presented in my work focused on two key stakeholder groups: User representatives with lived expertise of visible difference, and specialist clinicians with professional expertise. The involvement of the former can be understood as PPI, in which representative patients and/or members of the public actively contribute to research alongside researchers (INVOLVE, 2018).

In my work, the boundaries between PPI and formal research were not always clear. For example, in the first stakeholder meeting with Appearance Collective members in February 2018 (which led to the formal process presented in paper 4), we conducted focus groups and usability sessions, which are common research methods for intervention development. Stakeholders' input at the meeting also directly informed the intervention's development. However, we did not gain ethical approval for this work, as it was fundamentally a PPI exercise and we did not use their input as 'research data' (INVOLVE, 2016). It was only when we felt there was sufficient interest in the mobile mode of delivery from the various organisations, garnered largely from the meeting, that we felt it worthwhile to record stakeholder input more formally as 'research'.

Alongside the ethical imperative of user representatives being involved in creating an intervention aimed at serving their interests, it is assumed that PPI offers an important additional source of knowledge that helps optimise interventions and the research processes used to assess them (Gibson et al., 2017; O'Cathain et al., 2019b). However, it is also important to monitor and assess this in any project, to help form an evidence base for best practice in PPI, and facilitate planning for future projects (Staniszewska et al., 2011).

To this end, in late 2018 Dr Williamson and I met UWE colleagues and PPI experts Dr Andy Gibson and Dr Jo White to discuss evaluation of our PPI in this project. Dr Gibson had co-developed an evaluation framework for PPI, the Public Involvement Impact Assessment Framework (PiiAF; Popay et al., 2014), which we planned to utilise in assessing the impact of our PPI. Examples of how we did so included adding questions (not reported in paper 5) at the end of each intervention session asking participants to rate the helpfulness of design aspects that were directly informed by PI, such as having a human app guide, and instant feedback to users' selections in the form of 'pop-up messages' from the app guide. We also gained ethical approval for Dr Jo White to conduct semi-structured interviews with the user representatives, informed by the PiiAF (see Appendix 3, supplementary figure 2 for interview schedule), which she conducted in early 2019. I intend to collate data from the feasibility study, the interviews and future development and testing work to write a paper evaluating the impact of the PI process.

8.3 Scope of the combined works

8.3.1 Scope of clinical need

Although logistically unable to address each level of the CAR tiered framework for interventions (Jenkinson, 2009), my combined work did address the higher, specialist-led level and lower, standalone intervention levels. One issue that I grappled with throughout the project was the apparent tension between the need to tailor individualised, process-driven and/or psychological formulation-driven interventions to individuals' contexts, and the aim of producing a self-guided intervention capable of reaching as many people as possible to maximise its real-world impact.

There has been increasing recognition of the need for an idiographic, bottom-up treatment approach in ACT. Ideally, this involves functional analysis of an individuals' context on their behaviour and the how they can develop psychological flexibility processes (Hofmann & Hayes, 2019). This approach is partly feasible in self-guided interventions, such as in ACT It Out session 2, where users are guided through a process of creative hopelessness to understand their unique behaviours and environments that maintain their suffering. However, especially without advanced software programming and no health professional support alongside the intervention, the programme's idiographic tailoring has remained limited.

Fundamentally, though, the process-based focus of ACT is well suited to scalable, low-level interventions (Hofmann & Hayes, 2019). With psychological flexibility targeted as a transdiagnostic change process rather than requiring a specific diagnostic-based treatment protocol (as in a more top-down, nomothetic approach), users should theoretically benefit from developing this capacity regardless of their specific psychosocial challenges and form of visible difference.

8.3.2 Scope of the target population

As outlined in section 5.4, the extant literature on a range of causes of visible differences highlights marked commonalities in terms of psychosocial challenges faced by affected individuals, such as appearance-focused social anxiety, body dissatisfaction and impaired quality of life. However, over the course of the combined works, I have become increasingly cognisant of the unique medical, functional, and interpersonal challenges that different causes of visible difference can present. For example, although in the user representative focus group, participants expressed a preference for real-life examples across the spectrum of visible differences in an intervention to highlight common experiences, participants' feedback in the feasibility study suggested that for some, only examples in which the case shared important features with their condition resonated with them.

Such shared features included the site of difference (e.g., a facial difference compared to a more disguisable area), functional impairments which may affect communication (such as those encountered with facial palsy or cleft lip and palate) and fluctuating conditions (e.g., skin diseases like psoriasis and eczema). Overall, while retaining a pragmatic focus on producing knowledge and usable interventions for individuals across the range of visible differences to optimise the reach and impact of the works, I also recognise the benefit of paying close attention to the meaningful differences between causes and have brought this into subsequent work (discussed in section 8.4).

A clear limitation of the combined works is an underrepresentation of marginalised demographic groups, including minority ethnic groups. In the exclusively qualitative works (papers 2 and 4), all participants were White, while in paper 3 only 2.3% (5/220) were Asian/Asian British and 1.8% (4/220) were Black/Black British. In the feasibility study, only 3% (1/36) were Asian/Asian British and 3% identified as Black/Black British. With Black ethnic groups comprising 3.3% of the national UK population, this suggests they were somewhat underrepresented in the combined works, while Asian ethnic groups were markedly underrepresented given Asian groups make up 7.5% of the UK population (UK Government, 2020).

Just how 'representative' a group of exclusively White user representatives (as in paper 4) can be of all individuals with a visible difference is highly questionable. In recruiting participants, including user representatives, I made efforts to recruit those from minority ethnic groups, such as explicitly asking in adverts for individuals from ethnic minority groups. However, on reflection I should have given higher priority to representation of individuals from minority ethnic groups in my work. As I have done in subsequent work, I could have closely monitored the sample's distribution of ethnicity throughout data collection, and targeted any underrepresented groups through tailored adverts as data collection progressed.

Similarly, the highest percentage of men in any of my studies was 22% (in paper 3). This echoes figures in modern health behaviour and psychology research (e.g., Maher et al., 2014). More specifically in the field of visible difference, the largest population study to date involving 1,265 participants with visible differences recruited 28% men, and out of those recruited from the community (as in my studies) rather than clinics, this fell to 18% (Rumsey et al., 2014). In terms of psychosocial intervention research in visible difference, across all intervention studies included across two systematic reviews (Bessell & Moss, 2007; Norman & Moss, 2015), 35% of 563 participants were male. There are likely multiple reasons for men engaging less in this research, including suggestions from research that distress may be less prevalent in men with visible differences such as alopecia (Macbeth et al., 2022) and facial palsy (Hotton et al., 2020). However, these findings may themselves be limited by male underrepresentation in medical help-seeking actions, and a desire to minimise body image and mental health concerns (Jankowski et al., 2018). Overall, again it is questionable just how representative the participants I recruited are of the visibly different population, with many causes of visible differences showing no gender predilection, and some such as burns scarring being more prevalent in men (Perkins et al., 2021).

Lastly, my primary research reported in papers 2-5 has focused exclusively on the age group of adults with visible differences. This was a function of logistical and ethical barriers. Firstly, age-appropriate measures of psychological (in)flexibility have been developed and validated separately in adults and children/adolescents. For example, the AFQ-Y and its brief 8-item version (AFQ-Y8; Greco et al., 2008) was developed and validated specifically for children and adolescents as a comprehensible measure for children aged 8+. Conducting the survey study reported in paper 3 across all age groups would therefore have required two separate surveys. While technically feasible, the time and resources required to manage the logistics of gaining parental consent and adapting the survey for children was prohibitive. Such a study may well be of value in the future with dedicated resources to help inform an ACT intervention for young people.

Relatedly, as ACT It Out was designed as a standalone self-guided intervention to maximise access to potential users, this would need to be reconsidered for children and adolescents, for whom greater clinical oversight and guidance would be necessary (e.g., in *Young Person's Face IT*, adapted from *Face IT at Home* for adults; Bessell et al., 2012; Williamson et al., 2019). The content of ACT It Out would also require tailoring to young people's context, such as the primacy of peer relationships in adolescence, a focus on transitioning into adulthood, and developmental considerations. These have been incorporated into evidence-based protocols for young people, such as the *Discoverer, Noticer, Advisor and Values* programme (Hayes & Ciarrochi, 2015; Marino et al., 2019).

8.4 Developments from the combined works

8.4.1 Projects stemming from the combined works

Directly building on paper 5, CAR have recently secured further funding from the VTCT Foundation to continue our research programme, with one workstream focusing on the development and evaluation of psychological interventions in visible difference. Importantly, the funding includes software development costs. To inform the development of a full native mobile app, I am in the process of compiling all participant feedback from paper 5 and reviewing the technical and financial feasibility of the suggested changes. In planning the next phases of the project, I have set out a rough diagram showing the tasks expected to develop the intervention and make it accessible to users (see Appendix 3, supplementary figure 3).

My work on ACT It Out has also directly informed the proposed next phase of a separate project at CAR, focusing on understanding psychosocial adjustment to physical scarring and limb loss among military veterans to inform support services (UNITS). In a survey study of military veterans with appearance-affecting injuries, body image flexibility and self-compassion were both found to be associated with a host of body image and quality of life outcomes (Keeling et al., in preparation). Dr Keeling subsequently invited me to join the project team in an application to the Forces in Mind Trust to fund a project named 'UNITS Phase 2: Acceptance and Commitment Therapy-based support for appearance-altering injuries'. My brief is to help adapt ACT It Out for a military population and in video format (as advised through PPI).

I am also currently contributing to another VTCT Foundation programme project at CAR, which stemmed from the PhD work conducted by Dr Nick Sharratt, exploring intimacy and romantic relationships in individuals with visible differences. After completing his PhD, Dr Sharratt began developing a self-guided intimacy intervention. To do so, he conducted a Delphi study with psychological practitioners, who favoured ACT as an approach for the problem area in the population. From further PPI work, he developed a podcast-style 6-session intervention. Following Dr Sharratt's departure from CAR, Maia Thornton has taken over the project. I am advising on the intervention content from the knowledge I have gained through the presented works.

The ACT It Out project, intimacy work and UNITS programme are all aimed at level 2 on the CAR tiered framework, providing standalone self-administered interventions with a wide population reach. One delivery method more akin to level 3 on the CAR tiered framework (self-management with health professional support) is training paraprofessionals to provide low-level psychological support to affected individuals. These are health professionals without specialist psychological training who are routinely involved in the care of affected service users.

To this end, my work presented in papers 1 and 2 forged the path for a pan-European project funded by Erasmus+, entitled ‘Act Now - A training program development for healthcare professionals to use the principles of Acceptance and Commitment Therapy (ACT) to facilitate patient adjustment to the challenges of living with a visible difference’. Based on my work, I was invited along with Dr Williamson to be a partner on this project, with Dr Donnelly as a co-developer and evaluator of the training programme. After conducting a training needs survey of multidisciplinary health professionals from the five delivery nations, together we developed a one-day training programme, and trained project partners from these nations to deliver the training in their respective countries. The programme was delivered to 137 multidisciplinary health professionals across the five countries, and Dr Williamson and I also delivered the training to 12 members of the Appearance Collective in February 2020. All training materials are now publicly available online (https://actnow-erasmusproject.eu/training-resources/). I also led the evaluation of the programme via trainees’ self-reported knowledge, attitude and perception surveys taken before, after and at 3-month follow-up. I have led on the write-up of this project for academic publication, which is still under preparation.

At the higher end of clinical need, my combined works and collaboration with Dr Donnelly have also led to further discussions with other members of the Outlook service at North Bristol NHS Trust, Dr Vera Fixter and Ellie Davis, about the potential for evaluating an ACT-based group therapy protocol for individuals with appearance-affecting conditions that they have developed and intend to run at Outlook. We discussed possible funding sources for this collaborative work, such as the NHS Research Capability Funding scheme. We retain an interest in pursuing this avenue.

Through my work on the combined studies, Dr Nicola Stock, Dr Matthew Hotton and Dr Laura Shepherd from the NHS Cleft Psychology Clinical Excellence Network Research Subgroup invited me to contribute to a project spearheaded by the Subgroup, exploring the association between psychological flexibility and wellbeing in parents of children with cleft lip and/or palate. I am currently the lead investigator on this project, which is in its data collection stage. This work has allowed me to contribute to developing a better understanding of how ACT processes may play out in particular appearance-affecting conditions, and specifically parental modelling of psychological flexibility.

8.4.2 Researcher development from the combined works

Over the course of conducting the presented research, I developed a range of hard and soft researcher skills which I have continued to apply and build on in subsequent work. In terms of soft skills, through my work particularly in papers 4 and 5 I learned the importance of forming and maintaining strong working relationships with a range of stakeholders to maximise the quality and relevance of research. I learned ways of keeping stakeholders engaged in the project, including by giving periodic updates on the project's progress and how their involvement has informed the next phase of research.

By leading each study from conception to dissemination, I also developed project management skills and a clearer understanding of the resources, level of communication and timescales involved in conducting and publishing research. Through co-writing a grant application following paper 4 to Innovate UK with the support of the University's Research, Business and Innovation team, and receiving the reviewers' feedback, I also learned about the process of grant writing and the importance of closely matching the grant's criteria. This was helpful when co-writing successful applications to the VTCT Foundation's small grants fund for a study investigating men's experience of alopecia, and to Pfizer for a study establishing the socioeconomic burden of alopecia.

As noted in section 8.3.2, a limitation of my combined work was the underrepresentation of ethnic minority groups and men. I have taken this challenge more seriously in subsequent work and learned practical methods for maximising diverse and representative recruitment. For example, in both alopecia studies I have been involved in since completing the combined works, my collaborators and I have dedicated significant time and resource to gaining PPI from a diverse group of individuals, with whom we discussed ways of making the research relevant and appealing to a different ethnic groups, sexual orientations and genders. I have developed a particular interest in engaging men in visible difference research (perhaps partly fuelled by currently being one of only two men out of 30+ CAR members!). With Dr Nick Sharratt, I led a training workshop in April 2021 for members of the Appearance Collective on understanding men's support needs and preferences, drawing on our findings from the alopecia study and a literature review of research on men with visible differences.

Across papers 3, 4 and 5, I used Qualtrics survey software both for traditional online surveys and to host a prototype mobile app, and through collaboration with Dr Caleb-Solly, learned the value of understanding user experience. I have become increasingly interested in user design as a means of optimising user experience and engagement, both from potential users of a mobile app intervention, and from survey participants. I have since applied my Qualtrics skills in four survey studies. I have also recorded a series of training videos for UWE undergraduate and Masters' dissertation students on engaging participants using Qualtrics, which have been accessed online by students over the past two years.

In terms of hard research skills, the quantitative analyses I conducted with the guidance of Dr Paul White in papers 3 and 5 have nurtured a greater understanding of the statistical methods available and how to carry them out. For example, since using multiple imputation for missing data in paper 3, I have done so again in subsequent studies, and I have used the mixed model analysis approach I first used in paper 5 in another study. My work on papers 2, 4 and 5 also developed my qualitative research skills, especially in terms of understanding the importance of reflexivity across the entire study span. In subsequent work, I have given more time and energy into reflexive practice throughout the qualitative process, including in the write-up. I am also now a far more confident mixed methods researcher, and through paper 5 came to understand first-hand how qualitative and quantitative methods can be used in a complimentary, integrated way. This is something I took forward into a study on men's experiences of alopecia, involving a mixed methods online survey followed by interviews with a subsample (Zucchelli, Mathews, et al., under review; Zucchelli, Sharratt, et al., under review).

Over the course of conducting the presented works, the ethical considerations I faced (presented in section 6.4) sharpened my interest in research ethics more broadly. Since 2019 I have been a scrutineer for UWE Bristol's Health and Applied Sciences Faculty Research Ethical Committee, responsible for scrutinising staff and high-risk student research project applications to ensure they meet UWE's ethical standards for research. Through the committee, I have attended continued professional development workshops and webinars on ethical topics. A particularly pertinent webinar to the ethical challenges highlighted in paper 4 was "Research ethics and co-production/public involvement" in March 2022, where PPI experts from UWE Bristol addressed the potential boundary issues between co-production and qualitative research. I also attended the online Research Ethics Conference in June 2021, hosted by the University of Exeter.

Along with the hard and soft researcher skills I developed through the combined works, I have also developed more fundamentally in terms of my research approach and worldview, which I have taken into future research (while recognising its ever-evolving nature). As described in section 6.1, the pragmatic research paradigm I adopted throughout the presented works was driven by a combination of the pragmatic orientation of contextual behavioural science as well as the research environment of the VTCT Foundation programme and CAR more broadly. This context has undoubtedly shaped my approach to research beyond the presented works. The methodological adaptability associated with the pragmatic approach also suits my personal worldview, as over recent years particularly I have grown increasingly less wedded to any particular psychological subdiscipline or socio-political ideology, and more open to framing and addressing any presenting issue through what appears the most suitable framework. On reflection, this outlook parallels psychological flexibility, and especially the broader version espoused by Kashdan and Rottenberg, (2010), whereby "When someone is described as being psychologically flexible, they are more apt to be versatile... That is, they show an awareness of what a situation requires and an ability to organize and prioritize strategies that “fit” the situation rather than relying on dominant, default strategies.” (p.12).[6]

Conducting a series of studies with a unified aim has also given me a greater appreciation of the ‘bigger picture’ of a pragmatic research project. I have learned about the process of moving from theoretical advancement into practical application, the need to understand through stakeholder engagement the logistical parameters and feasibility of putting ideas into practice, and to sustain a sharp focus on real-world impact as the guiding principle. Spending time reflecting on the five studies as a single research project, their interconnection, and how in hindsight I may have done things differently, has especially helped me to see the bigger picture of research. Writing this commentary is therefore a task that I am very grateful for undertaking, as in itself it has greatly developed me as an independent, reflexive researcher.

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[6] This conception of psychological flexibility also ties into my ongoing contemplative practice and interest in Buddhism. An apocryphal story from the Zen Buddhist tradition neatly summarises the pragmatism of psychological flexibility. In the story, a student asks their master “What is the purpose of lifetime of practice?”, to which the master simply replies "An appropriate response”.

9 Appendices

9.1 Appendix 1: List of tables and figures

Table 1. List of publications in DPhil submission.

Figure 1. The Centre for Appearance Research tiered framework for interventions for people with a visible difference (Jenkinson et al., 2009; modified by Harcourt, personal communication, July 10, 2018). *Reuse permitted via email from Prof. Harcourt (April 20, 2022).*

Figure 2. Hexaflex model of psychological flexibility. *Copyright, Steven C Hayes, used with permission.*

Figure 3. Abridged logic model for complex intervention development (O'Cathain et al., 2019b), to show elements most relevant to the presented works. *Reuse and adaption permitted in accordance with the Creative Commons Attribution 4.0 Unported (CC BY 4.0) license.*

Figure 4. The ORBIT model for behavioural treatment development (Czajkowski et al., 2015). *Permission to use issued by American Psychological Association, license no. 5274331189003.*

9.2 Appendix 2: Abbreviations

AAQ-II	Acceptance and Action Questionnaire version 2
ACBS	Association of Contextual Behavioral Science
ACT	Acceptance and Commitment Therapy
AFQ-Y	Avoidance and Fusion Questionnaire for Youth
AFQ-Y-8	Avoidance and Fusion Questionnaire for Youth 8-item version
APEASE	Affordability, Practicality, Effectiveness/Cost-effectiveness, Acceptability; Side-effects/Safety, Equity
BIPIS	Body Image Psychological Inflexibility Scale
BEAQ	Brief Experiential Avoidance Questionnaire
BILD-Q	Body Image Life Disengagement Questionnaire
BILEQ	Body Image Life Engagement Questionnaire
CAR	Centre for Appearance Research
CBT	Cognitive Behavioural Therapy
CFT	Compassion-Focused Therapy
CompACT	Comprehensive assessment of Acceptance and Commitment Therapy processes
COVID-19	Coronavirus Disease 2019
DBT	Dialectical Behavioral Therapy
HRA	Health Research Authority
IPA	Interpretative Phenomenological Analysis
MBCT	Mindfulness Based Cognitive Therapy
MBSR	Mindfulness Based Stress Reduction
MRC	Medical Research Council
NHS	National Health Service
ORBIT	Obesity-Related Behavioral Intervention Trials
PPI	Patient and Public Involvement

PiiAF	Public Involvement Impact Assessment Framework
Psy-Flex	Psychological Flexibility
RCT	Randomised Controlled Trial
RFT	Relational Frame Theory
UNITS	Understanding psychosocial adjustment to physical scarring and limb loss among military veterans to inform support services
UK	United Kingdom
UWE	University of the West of England
VTCT	Vocational Charitable Training Trust

9.3 Appendix 3: Supplementary tables and figures

Supplementary Table 1. Dissemination of papers beyond academic publication.

Dissemination forum	*Paper(s) presented*	*Mode of delivery*	*Audience*
Mindfulness and body image episode, "including an interview with Fabio Zucchelli from CAR who talks about the current research in the area." (from synopsis) *CAR Appearance Matters Podcast*, January 2017.	Paper 1	Recorded oral	Public
The perspective of adults with psychosocial difficulties arising from a visible difference: Findings from a qualitative interview study. *15th World Congress of the Association of Contextual Behavioral Science*, Seville, June 2017.	Paper 2	Live oral	Academic & clinical
Convened symposium on third-wave CBT interventions for patients with visible differences at *Appearance Matters 8 Conference*, Bath, June 2018, involving: The perspective of adults with psychosocial difficulties arising from a visible difference: Findings from a qualitative interview study.	Paper 2	Live oral	Academic & clinical
Psychological flexibility: Its influence on how people with appearance-affecting conditions deal with daily body image stressors. *The VTCT Foundation Showcase Conference*, Royal College of Surgeons, London, July 2019.	Paper 3	Live oral	Charity & NHS staff
Psychological flexibility, visible difference and vitiligo. Vitiligo Society Annual Open Day Conference, London, December 2018.	Paper 3	Live oral	People with vitiligo, family & charity staff
Workshop (x3): Moving Towards what you want from life and away from appearance concerns. *Alopecia UK Big Weekend*, Bristol, September 2019.	Papers 1, 2 & 3	Ran workshop	People with alopecia & family
Testing two components of psychological flexibility as mediators between body evaluation and unhelpful body image coping strategies in adults with visible differences. *Appearance Matter 9*, Online, July 2021.	Paper 3	Live oral	Academic & clinical
Developing a mobile app intervention based on ACT for adults with a visible difference affected by appearance distress. *Appearance Matters 8 Conference*, Bath, June 2018.	Paper 4 (user rep findings only)	Poster	Academic & clinical
Developing a mobile app intervention based on ACT for adults with a visible difference affected by appearance distress. *Association of Contextual Behavioral Science Annual World Conference*, Montreal, July 2018. Received the Junior Investigator Award for Best Poster.	Paper 4 (user rep findings only)	Poster	Academic & clinical
Designing ACT It Out, a prototype mobile health application for adults with visible differences. *The VTCT Foundation Showcase Conference*, Online, July 2020.	Paper 4	Live oral	Charity & NHS staff

Designing and testing a mobile ACT intervention for adults with visible differences. *Association of Contextual Behavioral Science Annual World Conference,* Online, June 2021.	Papers 3, 4 & 5	Live oral	Academic & clinical
Living well with appearance concerns through psychological flexibility. Lipodystrophy UK online event for World Lipodystrophy Day, March 2021.	Papers 3, 4 & 5	Recorded oral	People with lipo-dystrophy & family
Designing and testing the feasibility of an Acceptance and Commitment Therapy prototype mobile app intervention for adults with visible differences. Appearance Matter 9, Online, July 2021.	Papers 4 & 5	Poster	Academic & clinical

Supplementary Figure 1. Example of summary feedback emailed to user representatives (sent August 2018).

Eight key points from your input into 'ACT It Out' app: Training Sessions 1 & 2

What you said		**How we'll change the app design**
1. The app needs to explain earlier, quicker and clearer how it will help you.	→	Create a short summary at the very start, showing how the app will help. This may be a video, and/or real-life quotes of how ACT and apps helps people.
2. There should be easily accessible links to support resources (e.g. from charities).	→	Add a visible "Get Help" symbol on-screen, with links to support resources.
3. Videos and/or stories from people with appearance-affecting conditions would make the app more relatable.	→	Give a series of short videos and/or written stories from people with appearance-affecting conditions.
4. A human guide in the app would make it more relatable.	→	Provide a human guide throughout the app. This may be done as a mix of videos and/or photos.
5. You're expected to do too much writing in the app	→	Wherever possible, give lists of ready-made answers rather than having to write your own answers; e.g. offer a list of emotions to choose from. (Adding notes will remain an options as well, for those who find it useful).
6. There isn't enough instant feedback from the app.	→ → →	(a). Wherever possible, for each answer available to select, give a 'pop-up' message, e.g. if you select "embarrassed" as an emotion, a message could pop up saying "Embarrassment is a natural reaction when we think others are judging us." (b). (As suggested by you) Give more screens in which the human guide offers feedback and encouragement. (c). (As suggested by you) Where appropriate, give short quizzes on what you've just learned, and give feedback on your answers.
7. Certain icons (e.g. "Learn", "Apply") look like buttons when they're not, and some icons need to be clearer.	→	Make it more obvious which icons are not buttons, and label icons to make them clearer.
8. It can be difficult to choose just one value to focus on.	→	Help guide your choice of value(s) by first asking which life area you want to work on most: (a) Relationships, (b) Health, (c) Work / Education, or (d) Leisure.

Supplementary Figure 2. Interview schedule for evaluating PPI process during research project.

Interview Schedule for Experts-by-Experience

1. Can you tell me about how you first became involved in the ACT App project?

2. Can you describe how exactly you have been involved in the project?

3. What form did your involvement take? (e.g. meetings, e-mail, Skype etc; one-to-one sessions, focus groups etc)

4. To what extent do you feel you were able to influence the planning of this project?

   - please could you provide examples

   (Prompt: for instance, were you asked if you thought that the idea of an app was a good idea?/were any particular suggestions you made taken on board in planning how you might be involved or what you would like to contribute?

5. Do you know what, if anything, has changed about the app itself, as a result of yours or other public contributors' inputs?

   If yes:
   - please give examples
   - please explain how were you made aware of this impact

6. What was it about your experience, knowledge or skills that you think was valued by the research team?

7.. Were there cases where changes which were suggested were not taken on board?

   If yes:
   - please give examples
   - - please explain how were you made aware of this
   - How do you feel about any changes you suggested not being taken on board?
   - If your suggestions were not taken on board were the reason for this explained to you?

8. What different ways of contributing to the project were offered to you? For example, if you could not make a meeting were you invited to contribute in another way?

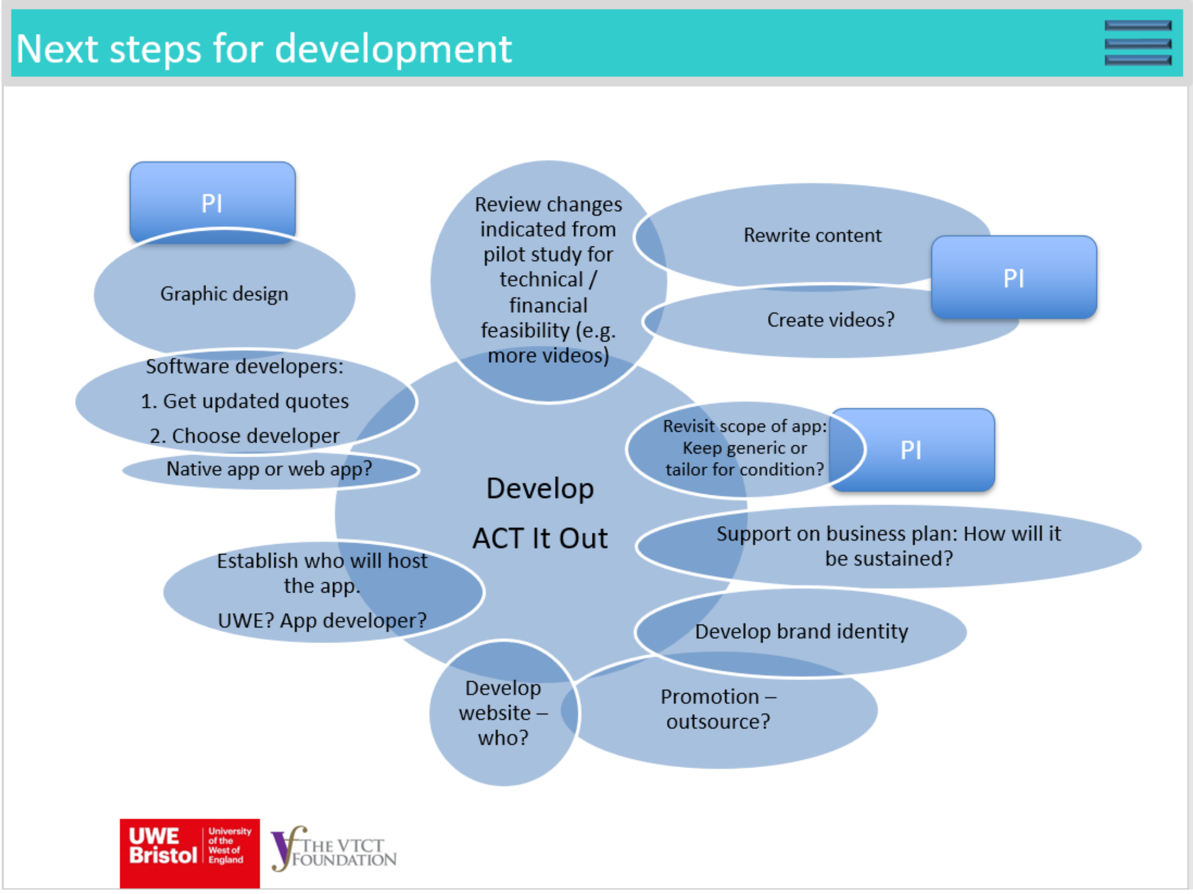
9. Were there ways you would have preferred to contribute which were not offered to you?

10. How much flexibility has there been in how the project team have worked with you? (e.g. how able and willing were the team to accommodate any changes you suggested? Was it possible to reschedule plans if this would improve the scope to be involved? How did time and money influence the scope for decision making?

    - please could you provide examples of any flexibility or inflexibility?

11. Based on your experience so far, do you have any thoughts about what could be done better in terms of members of the public such as yourself being involved in a similar project?

Supplementary Figure 3. Proposed next steps for developing a full native app version of ACT It Out.



Next steps for development

PI

Graphic design

Software developers:
1. Get updated quotes
2. Choose developer

Native app or web app?

Review changes indicated from pilot study for technical / financial feasibility (e.g. more videos)

Rewrite content

Create videos?

PI

Revisit scope of app: Keep generic or tailor for condition?

PI

Develop

ACT It Out

Support on business plan: How will it be sustained?

Establish who will host the app.

UWE? App developer?

Develop brand identity

Develop website – who?

Promotion – outsource?

9.4 Appendix 4: Academic CV

Fabio Zucchelli
fabio.zucchelli@uwe.ac.uk

Current post(s) at the University of the West of England, Bristol:

- Research Fellow at the Centre for Appearance Research.
- Associate Lecturer in the Psychology Department.

Qualifications:

Ongoing	University of the West of England (UWE), Bristol DPhil (Doctorate in Philosophy by publication) – enrolled Jan 2021
2012-2014	University of the West of England (UWE), Bristol MSc Sport and Exercise Psychology (Distinction; Overall mark: 78)
2003-2006	The University of Reading BA (Hons) Psychology and Philosophy (1st class)

Current roles

VTCTF Research Fellow at the Centre for Appearance Research

- Leading externally funded project to understand the socioeconomic costs of alopecia areata.
- Leading on project to design, develop and evaluate a mobile app intervention for people with a visible difference experiencing appearance anxiety.
- Co-running externally funded qualitative research project exploring men's experiences of having alopecia and the available psychosocial support.
- Co-conducting systematic review on positive body image interventions for young people.
- Co-running largescale study evaluating multiple key outcome measure in a sample of adults with visible difference.

Associate Lecturer in the Psychology Department

- Leading two Level 1 Psychology seminar groups through the academic year.
  - Preparing for seminars by liaising with module lead and preparing material.
  - Delivering seminars and dealing with students' queries and concerns.
- Delivering specialist lectures (e.g. male body image; mental wellbeing).
- Carrying out marking for assignments in Level 1 Psychology programme.
- Supervising Masters' and undergraduate dissertations.

Previous appointments and experience

2016-2017	Research Associate at the Centre for Appearance Research, funded by QR funding (working on a feasibility study of Acceptance and Commitment Therapy for patients with appearance-affecting conditions) and a Vice Chancellor Early Career Researcher Award (working on a national cleft project).
2015-2016	Research Associate at the Centre for Appearance Research, funded by the Dove Self-Esteem Project (working on an Impact Case Study for REF 2021).

2015-2016 Research Coordinator at Avon and Wiltshire NHS Partnership Research & Development team.

2014-2015 Assistant Psychologist at Avon and Wiltshire NHS Partnership Research & Development team.

Teaching specialisms

- Appearance Psychology and research (e.g. general body image, alopecia, cleft, vitiligo)
- Mindfulness and third-wave psychological approaches (e.g. mindfulness-based interventions, Acceptance and Commitment Therapy, self-compassion).
- Sport and Exercise Psychology
- Positive Psychology
- Research Methods (qualitative and quantitative)
- Ethics in conducting research

Teaching experience

- UWE Psychology Level 1 Introduction to Psychology seminars (including online/blended learning delivery) and associated marking (2 groups throughout academic year 2019-22).
- Supervised two Masters' dissertation and one undergraduate dissertation to successful completion (2019-21) & co-supervised Master's dissertation to completion (2018-19).
- Delivered lecture on male body image for UWE Level 3 Appearance & Embodiment module (2020-22).
- Created and delivered video learning material on using Qualtrics for undergraduate and MSc Dissertation modules, now featured on the module Blackboard pages (2020-2022).
- Invited guest lectures at the University of Kent on Level 3 Psychology in Action module; Mindfulness and Body Image (Feb 2017, Jan 2018, Jan 2019 & Jan 2020).
- Contributed online lecture content for Level 1 Intro to Psychology module on Mental Wellbeing (2020-21).
- UWE Health Psychology Professional Doctorate workshop on Positive Psychology (May 2019).
- UWE Psychology Level 1 Research Design and Analysis module seminars (Nov-Dec 2018).
- UWE Psychology Level 1 Critical Thinking module seminars; Research Ethics (Nov 2018).
- Marked reflective assignments in UWE Sport & Exercise Psychology MSc (May 2017).
- UWE Psychology Level 3 lecture on Body Image & Embodiment module (Oct 2016 & Oct 2017).
- UWE Psychology Level 3 lecture on Sport & Exercise Psychology module (Feb 2017).
- Co-facilitated motivational interviewing workshops on Sport & Exercise Psychology MSc (Jan 2017).
- Completed 'Prepare to Teach' day training at UWE Bristol (2017).

Publications

Guest, E., **Zucchelli, F**., Costa, B., Bhatia, R., Halliwell, E., & Harcourt, D. (in press) A Systematic Review of Interventions Aiming to Promote Positive Body Image in Children and Adolescents. *Body Image*

Stock, N.M., **Zucchelli, F.,** Hammond, V., Hudson, N., Sell, D. (in press). Facilitators and barriers to delivering an optimal specialist service in the United Kingdom: An example from cleft lip and palate care. *British Journal of Healthcare Management*.

Johnson, A., Wilk, L., **Zucchelli, F.,** & Sharratt, N. (2022) Why a Charter for Best Practice for NHS wig provision? *Dermatological Nursing, 21*(1).

Zucchelli, F., Donnelly, O., Rush, E., White, P., Gwyther, H., **Williamson, H.,** The VTCT Foundation Research Team at the Centre for Appearance Research. (2021) An Acceptance and Commitment Therapy prototype mobile program for individuals with a visible difference: Mixed methods feasibility study, *JMIR Formative Research 6*(1), e33449.

Zucchelli, F., Donnelly, O., Rush, E., Smith, H., Williamson, H., & The VTCT Foundation Research Team. (2021). Designing an mHealth intervention for people with visible differences based on acceptance and commitment therapy: Participatory study gaining stakeholders' input. *JMIR Formative Research*, *5(3).*

Sharratt, N. D., Williamson, H., **Zucchelli, F**., & Kiff, J. (2020). Becoming known: Disclosure and exposure of (in)visible difference. *Stigma and Health.*

Zucchelli, F., Donnelly, O., Sharratt, N., Hooper, N., & Williamson, H. M. (2020). Patients' experiences of an acceptance and commitment therapy-based approach for psychosocial difficulties relating to an appearance-affecting condition. *European Journal of Counselling Psychology*, *9(1)*, 29-40.

Zucchelli, F., White, P., & Williamson. H. (2020) Experiential avoidance and cognitive fusion mediate the relationship between body evaluation and unhelpful body image coping strategies in individuals with visible differences. *Body Image.*

Stock, N., **Zucchelli, F**., Hudson, N., Kiff, J., & Hammond, V. (2019). Promoting psychosocial adjustment in individuals born with cleft lip and/or palate and their families: Current clinical practice in the United Kingdom. *Cleft Palate-Craniofacial Journal*, 1-12.

Stiernman, M., Maulina, I., Zepa, I., Jagomägi, T., Tanaskovic,, N., Knežević, P., **Zucchelli, F**. …Persson, M. (2019). Translation and pilot study of the Cleft Hearing Appearance and Speech Questionnaire (CHASQ). *European Journal of Plastic Surgery*, 1-10.

Zucchelli, F., Donnelly, O., Williamson, H., & Hooper, N. (2018). Acceptance and commitment therapy for people experiencing appearance-related distress associated with a visible difference: Rationale and review of relevant research. *Journal of Cognitive Psychotherapy*, *32(3)*, 171-183.

Griffiths, C., Williamson, H., **Zucchelli, F**., Paraskeva, N., & Moss, T. (2018). A systematic review of the effectiveness of Acceptance and Commitment Therapy (ACT) for body image dissatisfaction and weight self-stigma in adults. *Journal of Contemporary Psychotherapy*, *48(4)*, 189-204.

Zucchelli, F., Rumsey, N., Humphries, K., Bennett, R., Davies, A., Sandy, J., & Stock, N. M. (2018). Recruiting to cohort studies in specialist healthcare services: Lessons learned from clinical research nurses in UK cleft services. *Journal of Clinical Nursing*, *27(5-6)*, e787-e797.

Zucchelli, F. (2017). Beard transplants and facial hair trends: Why men are motivated to have surgery. *Journal of Aesthetic Nursing*, *6(1)*, 30-31.

Zucchelli, F., Skinner, S. (2013) Central and North West London NHS Foundation Trust's (CNWL) recovery college: the story so far. *Mental Health and Social Inclusion, 17(4)*, 183-189.

Conference Presentations

Oral presentation: Zucchelli, F. Testing two components of psychological flexibility as mediators between body evaluation and unhelpful body image coping strategies in adults with visible differences. Appearance Matter 9, Online, July 2021.

Poster presentation: Zucchelli, F., Sharratt, N., Montgomery, K., & Chambers, J. Men with alopecia: Understanding their experiences, support needs and engagement preferences. Appearance Matter 9, Online, July 2021.

Poster presentation: Sharratt, N., Zucchelli, F., Johnson, A., & Chambers, J. Public experiences of consultations with health professionals: How can GPs and Dermatologists 'do better' by patients with alopecia? Appearance Matter 9, Online, July 2021.

Poster presentation: Guest, E., Zucchelli, F., Costa, B., Bhatia, R., Halliwell, E., & Harcourt, D. A systematic review of interventions aiming to promote positive body image in children and adolescents. Appearance Matter 9, Online, July 2021.

Poster presentation: Zucchelli, F., Donnelly, O., Rush, E., White, P., Gwyther, H., Williamson, H., & The VTCT Foundation Research Team. Designing and testing the feasibility of an Acceptance and Commitment Therapy prototype mobile app intervention for adults with visible differences. Appearance Matter 9, Online, July 2021.

Oral presentation: Zucchelli, F. Designing and testing a mobile ACT intervention for adults with visible differences. *Association of Contextual Behavioral Science Annual World Conference,* Online, June 2021.

Oral presentation: Zucchelli, F. The co-design of ACT It Out, a prototype mobile health application for adults with visible differences. *The VTCT Foundation Showcase Conference*, Online, July 2020.

Oral presentation: Zucchelli, F. Psychological flexibility: Its influence on how people with appearance-affecting conditions deal with daily body image stressors. *The VTCT Foundation Showcase Conference*, Royal College of Surgeons, London, July 2019.

Oral presentation: Zucchelli, F. Psychological flexibility, visible difference and vitiligo. Vitiligo Society Annual Open Day Conference, London, December 2018.

Poster presentation: Zucchelli, F., Williamson, H., Donnelly, O., Rush, E., Caleb-Solly., P. & The VTCT Foundation Research Team. Developing a mobile app intervention based on Acceptance and Commitment Therapy for adults with a visible difference affected by appearance distress. *Association of Contextual Behavioral Science Annual World Conference*, Montreal, July 2018. Received the **Junior Investigator Award** for Best Poster from the Association of Contextual Behaviour Science.

Oral presentation: Zucchelli, F. Developing a mobile app intervention for adults with a visible difference affected by appearance distress, the *VTCT Foundation Showcase Conference*, Royal College of Surgeons, London, July 2018.

Convened and chaired symposium on third-wave cognitive behavioural interventions for patients with visible differences at *Appearance Matters 8 Conference*, Bath, June 2018. Conducted oral presentation in this symposium: Zucchelli, F. & Donnelly, O. The perspective of adults with psychosocial difficulties arising from a visible difference: Findings from a qualitative interview study. *Appearance Matters 8 Conference*, Bath, June 2018.

Poster presentation: Zucchelli, F., Williamson, H., Donnelly, O., Rush, E., Caleb-Solly., P. & The VTCT Foundation Research Team. Developing a mobile app intervention based on Acceptance and Commitment Therapy for adults with a visible difference affected by appearance distress. *Appearance Matters 8 Conference*, Bath, June 2018.

Oral presentation: Zucchelli, F. & Donnelly, O. The perspective of adults with psychosocial difficulties arising from a visible difference: Findings from a qualitative interview study. *15th World Congress of the Association of Contextual Behavioral Science*, Seville, June 2017.

Poster presentation: Hope-Bell, J., Donnelly, O., Hooper, N. & Zucchelli, F. (2017). The effectiveness of Acceptance and Commitment Therapy (ACT) in improving stress and wellbeing for employees in a hospital setting. *15th World Congress of the Association of Contextual Behavioral Science*, Seville, June 2017.

Poster presentation: Griffiths, C., Williamson, H., Zucchelli., F & Moss, T. (2017). A systematic review of the effectiveness of Acceptance and Commitment Therapy (ACT) for body image dissatisfaction and weight stigma in adults. *15th World Congress of the Association of Contextual Behavioral Science*, Seville, June 2017.

Oral presentation: Zucchelli., F., Persson., M., Sharratt., N. & Strauss, R. Healthcare professionals' experience of using the Cleft Hearing, Appearance and Speech Questionnaire (CHAS-Q). COST Action 'Appearance Matters' Scientific meeting, Ljubljana, Slovenia, April 2017.

Oral presentation: Zucchelli, F., Stock, N.M. and The Cleft Collective team (2017). Successful recruitment in large research studies: The experiences of Research Nurses, *Annual Conference of the Craniofacial Society of Great Britain and Ireland*, Newcastle, February 2017.

Oral presentation: Zucchelli., F. & Stock., N.M. Preliminary findings from an interview study with cleft psychologists, to members of the UK Cleft Lip and Palate (a) Psychology Clinical, (b) Speech and Language Therapy and (c) Clinical Nurse Specialist Excellence Networks at *the Annual Conference of the Craniofacial Society of Great Britain and Ireland*, Newcastle, February 2017.

Public Engagement

Invited guest on BBC Radio Cumbria to discuss the psychosocial impact of male hair loss, July 2021.

Zucchelli, F. Living well with appearance concerns through psychological flexibility. Lipodystrophy UK online event for World Lipodystrophy Day, March 2021.

Represented the Centre for Appearance Research on an expert panel at the online screening of "Scars" documentary. February 2021.

Co-delivered training based on Acceptance and Commitment Therapy for health professionals who support individuals with appearance-affecting conditions at an Appearance Collective Training Workshop, Kingston Smith, London, February 2020.

Zucchelli, F. Workshop (x3): Moving Towards what you want from life and away from appearance concerns. *Alopecia UK Big Weekend*, Bristol, September 2019.

Represented the Centre for Appearance Research at *Bristol Fashion Week 2018,* The Mall, Bristol, July 2018.

Zucchelli, F. Acceptance based interventions for body image and appearance distress, at 'Your Body and You'; An evening on mindfulness, acceptance and body functionality to promote body positivity, *Body Positive Café at the Fringe Arts Bath Festival*, Bath, May 2018.

Co-facilitated Appearance Collective Training Workshop on Public Involvement in research on visible difference, Kingston Smith, London, January 2018.

Zucchelli, F. Using mindfulness and self-compassion to improve training and body image with Fabio Zucchelli. http://www.lionheartrad.io/47-fabio-zucchelli/, Invited guest on *the LionHeart Radio podcast* (US), June 2017.

Zucchelli, F. Mindfulness and body image episode, including interviews with Melissa Atkinson and Fabio Zucchelli about CAR's research on mindfulness-based interventions for body image and Acceptance and Commitment Therapy for adults with a visible difference. *CAR Appearance Matters Podcast*, January 2017.

Funding

Awarded £1,672.20 internal university funding to publish Erasmus+ project data, January 2022.

Awarded £33,800 as co-applicant to Pfizer Grant on a project quantifying the socioeconomic burden of alopecia, August 2021.

Awarded £11,616 as co-applicant to Vocational Training Charitable Trust Foundation's New Ways of Working Grant on a project evaluating a remote cross NHS-site intervention for facial palsy services, March 2021.

Awarded £18,751 as co-applicant to Vocational Training Charitable Trust Foundation's Small Grants Programme for a project exploring men's experiences of having alopecia and available psychosocial support, January 2020.

Awarded £24,000 as co-applicant of Erasmus+ programme to develop, deliver and evaluate an international training programme for health professionals, August 2018.

Awarded £15,000 internal university funding to develop a mobile app intervention for people with a visible difference and appearance anxiety, January 2018.

Co-applicant on unsuccessful bid for £53,720 to Innovate UK Digital health technology catalyst round 3: Feasibility studies, January 2019. (Scored 63/100 (70+/100 receives funding)).

Current research interests

- Psychological interventions for people with visible difference.
- Men's experience of having an appearance-affecting condition (especially alopecia).
- Training health professionals in supporting patients with visible differences.

- Body image and sport / exercise.
- Mindfulness and body image.
- Psychological flexibility and body image.
- Positive body image interventions.

Roles and responsibilities within the University

- Scrutineer for the HAS Faculty Research Ethical Committee: Responsible for scrutinising staff research project applications to ensure they meet UWE's ethical standards for research.

- Impact lead for VTCTF research programme: Responsible for ensuring research is conducted and disseminated to maximise real world impact, and prepare for potential future REF Impact Case Study submissions.

- CAR Website: responsible for updating CAR's UWE webpages, in liaison with the UWE Web Team.

- Arranging and coordinating the 'Ignite' presentations and the conference feedback survey at Appearance Matters conferences (2018, 2020 & 2021).

- Peer-reviewing manuscripts for scientific journals (Body Image, Psycho-Oncology, The Cleft Palate-Craniofacial Journal, Frontiers in Global Women's Health).

Professional Training

- NIHR ARC West online training on designing survey questionnaires.
- Motivational Interviewing for psoriasis 1-day workshop.
- Member of Bristol Acceptance and Commitment Therapy peer consultation / skills practice group.
- Writing for Publication 2-day workshop.
- Preparing to Teach workshop at UWE.
- Using NVivo for qualitative research 2-day workshop at UWE.
- Good Clinical Practice Training.

9.5 Appendix 5: Summary evidence of meeting UWE Bristol doctoral descriptors

Below I summarise how I meet the UWE Bristol doctoral descriptors across this submission:

1. *Has conducted enquiry leading to the creation and interpretation of new knowledge through original research or other advanced scholarship, shown by satisfying scholarly review by accomplished and recognised scholars in the field*

By addressing a gap in the research literature, I conducted one secondary research study (paper 1) and four primary research studies (papers 2-5) which led to the generation of new knowledge. Examples of this new knowledge include psychological flexibility processes being shown to play a mediating role in appearance-focused coping behaviours in a representative sample of adults with visible differences (paper 3), and establishing the feasibility of an ACT mobile intervention for the population (paper 5).

I was the lead author on each of the submitted works, which were all published in peer-reviewed journals. This demonstrates satisfied scholarly review by accomplished and recognised scholars in the field.

2. *Can demonstrate a critical understanding of the current state of knowledge in that field of theory and/or practice*

For each publication, I undertook a literature review on the current state of knowledge in the field to inform the study’s design and critically evaluate the extant literature.

In the critical commentary I provide a more in-depth and contemporary critical examination of the surrounding literature, primarily in the fields of visible difference, ACT and intervention development.

3. *Show the ability to conceptualise, design and implement a project for the generation of new knowledge at the forefront of the discipline or field of practice including the capacity to adjust the project design in the light of emergent issues and understandings*

I led each study throughout the conception, implementation and dissemination stages, as evidenced by my position as lead author in all papers. I drew on the expertise of my academic, clinical and user representative collaborators to help shape the individual research studies as well as the wider research agenda. In papers 2, 4 and 5 especially, with the input of my collaborators I adjusted the project design in light of emergent issues.

For example, after being unable to recruit participants across NHS sites for paper 2, I shifted the focus of the study from primarily understanding the real-life application of ACT processes to individuals’ subjective experience of therapy. In paper 5, in consultation with my collaborators, we decided when to begin and end recruitment amid the COVID-19 pandemic to minimise influence from national lockdowns on the data.

4. *Can demonstrate a critical understanding of the methodology of enquiry*

I adopted a range of robust research methods and analytical approaches across the five studies, with each selected based on their suitability for the specific research question. In each paper I outline the rationale for my chosen methods in the context of published literature, and discuss the methodological limitations of my work.

In this critical commentary I have also critically discussed in more detail the methodological underpinnings that informed my work, including the broad pragmatic research paradigm and the intervention development frameworks.
5. Has developed independent judgement of issues and ideas in the field of research and / or practice and are able to communicate and justify that judgement to appropriate audiences
Although I consulted with collaborators in each study, I conducted the literature review for each independently and led the dissemination of all five papers through peer-reviewed publication as well as public engagement and conference presentations (as presented in Appendix 3, supplementary table 1). With a pragmatic research agenda, it felt important to disseminate findings to stakeholders including members of Appearance Collective organisations and individuals with visible differences (e.g., at the Alopecia UK Big Weekend and Vitiligo Society UK conference).
6. Can critically reflect on their work and evaluate its strengths and weaknesses including understanding validation procedures
In each paper I outlined my understanding of the study's methodological strengths and limitations. Writing the critical commentary has also given me greater scope to critically reflect on my works individually (primarily in the Publications section) and collectively (e.g, in my discussion of the methodological considerations and scope of my combined works in the Discussion section).

10 References

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