

**Digital Mental Health in the Wild:**  
**An Adapted Grounded Theory Study**

Thesis submitted in accordance with the requirements of the University of Chester for the  
degree of Doctor of Philosophy by:

**Aislinn Dawn Bergin**

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### **Dedication**

I want to dedicate this PhD to my best-friend, Sandra O’Conner. Without you I would never have done this – you made me say ‘yes’ – and I wish you were here to see how far I’ve come.

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### **Abstract**

This study explores Digital Mental Health (DMH), referring to the use of digital technologies in mental health, from the perspective of users and system builders – individuals ‘in the wild’. Using an adapted constructive Grounded Theory Methodology (Charmaz, 2014), it qualitatively explores DMH and how it is applied to everyday life. Interviews with users, developers and academics were supported by data collected from extant documents and observations. Findings addressed the complexity of development and use, where differences in priority between the technical and clinical paradigms in development challenged the usability and usefulness for consumers of DMH. Changes implemented within, and the transience of, DMH resources were constructed by users as potentially distressing and difficult for system builders to mitigate. DMH is a new and emerging way to self-manage mental health. However, whilst it provides options, it does not inform as to how to choose and, whilst it supports change, it is not in itself motivating. In understanding the role of DMH it is essential to consider it alongside existing mental health prevention and management. DMH is constructed not as use of a single resource, but rather a toolkit for self-management where resources are used in different ways and at different times. Some will be integral whilst others may be used more occasionally. Many of the participants identified the difficulties and challenges of managing their mental health with only traditional tools and interventions available, and how DMH offered additional ways of doing so. DMH offers users autonomy and a way to explore their experiences in a simulated environment, contributing to its purpose as a supplement to existing mental health provision. Understanding how DMH can supplement the existing treatment and management of mental health is essential. One key area is addressing the opportunities provided by the simulative functions of new technologies and how mobile technologies have enabled these to

become part of the everyday lives of so many people. Finally, the concept of Technology-as-Advocate was constructed to identify the ways that technology can help individuals to help themselves. This study recommends that DMH stakeholders invest and conduct further research that bring together clinical, technical and user paradigms to better understand how changes to devices and resources impact users. It positions DMH within the initial stages of help-seeking and addresses its role as one of many tools in the individual's self-care. It proposes that technology be viewed as supporting self-advocacy and theorises that future technologies, such as personal assistants, be designed to advocate rather than to dictate. It is vital that policymakers recognise the impact of changes for users who find resources that support them in their mental health and apply them within their everyday life.

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## Glossary and Acronyms

*Adherence*: refers to the continuation of use, typically in relation to therapeutic treatments.

*Attrition*: refers to drop-out rates, typically in relation to therapeutic treatments.

*Boolean*: the use of AND/OR in search engines to filter search terms.

*CBT*: acronym for Cognitive Behavioural Therapy.

*cCBT*: acronym for computerised Cognitive Behavioural Therapy.

*Choice Overload*: the potential effect of too much choice on aspects such as decision making.

*Cognitive Dissonance*: the potential that individuals seek and construct consistency in their cognitions.

*Configured User*: the constructed version of an anticipated user, compared to an actual or end user.

*Conventional Services*: traditional and often bricks and mortar services, specifically in mental healthcare within this study.

*DMH*: acronym for Digital Mental Health.

*Forum*: an online group that can interact synchronously or asynchronously, typically about a specific subject.

*GT*: acronym for Grounded Theory.

*GTM*: acronym for Grounded Theory Methodology.

*Hyperlinks*: a highlighted word that can be clicked and will then bring the reader to another section of the document/website.

*I-Methodology*: the development of resources and technologies based on oneself.

*Implicated Role*: the constructed role of another, often where they remain silent.

*Incompatibility*: differences between things that make it difficult for them to co-exist.



*Interdisciplinary*: relating to more than one discipline.

*Interoperability*: things that have the capacity to work together.

*Interpretative Flexibility*: where meaning is changeable and the definition/purpose, usually of an object, is in flux.

*Internet*: global network of connected computers.

*NHS*: acronym for National Health Service.

*Online Disinhibition Effect*: posited by Suler (2004) to account for people's increased disclosure online.

*Ontogenetic*: within this thesis refers to an active role within the development of DMH resources.

*Paradox of Choice*: the apparent paradox where more choice often leads to more dissatisfaction with what is chosen.

*Reverse Salient*: referring to the sub-components of technology that negatively affect its development and use. *Seamfulness*: referring to the 'seams' or problems within a technology that can be exploited by their users.

*Seamlessness*: referring to the absence of 'seams' or problems in the use of a technology.

*Supportive Accountability*: providing human support to encourage adherence.

*Therapeutic Alliance*: refers to the positive and supportive relationship between a therapist and their client.

*Transtheoretical Model of Change*: posited as change in behaviour through 6 stages; precontemplation, contemplation, preparation, action, maintenance, and termination.

*Trigger Warnings*: a warning at the beginning of a story that identifies topics which may potentially have an adverse impact on the reader.

## Digital Mental Health in the Wild

*Website*: collection of pages accessible via the internet.

*Werther Effect*: impact of publicised suicide on suicide rates, which are often increased.

*World Wide Web*: the network of websites on the internet that enable users to search and find information.

## 1 Introduction

### 1.1 Scope of the Study

The exponential and global proliferation of accessible digital technologies – most notably ‘smartphones’, mobile phones with internet capabilities – has transferred the use of many healthcare technologies from their traditional place in the healthcare system towards becoming an increasingly ‘everyday’ part of people’s digital lives. The consumerisation of health – from the reduced cost of purchasing one’s own blood glucose monitor to the capability of most smartphones to track activity levels and, with the aid of an app, heartrate – now means that for the individual there may no longer be a need to enter a physically-located healthcare environment. Information can now be accessed and shared in virtual space, connections made with professionals and peers alike, and health interventions undertaken using technologies downloaded or bought – all without ever seeing a healthcare practitioner.

Sociological research into the use of health technologies has largely focused on their application within conventional healthcare systems – usually with the involvement of healthcare professionals (Bijker, Hughes, & Pinch, 1994; Winkelman, Leonard, & Rossos, 2005). As digital technologies have become more ubiquitous, however, so has research interest increased in how such technologies are used “in the wild” (Minh, Do, Blom, & Gatica-perez, 2011; Rennick-Egglestone et al., 2016).

Within conventional healthcare systems there are often barriers – such as cost, location or availability – to accessing appropriate medical care and diagnoses. Further still, in the case of mental health, Andrade and colleagues (2014) found in the results of the World Health Organisation (WHO) Mental Health survey that the majority of people with diagnosable mental health conditions did not access conventional treatments due to a desire to cope with it

themselves. Research suggests that they may view digital technologies as a suitable alternative (Ellis et al., 2013; Gun, Titov, & Andrews, 2011; Lewis, Pearce, & Bisson, 2012; Wootton, Titov, Dear, Spence, & Kemp, 2011), constructing those who wish to manage their own mental health as a social group of potential users of alternative, digital self-management strategies. Although only a small percentage may yet be sufficiently engaged and receptive enough to digital technologies to actively use them for self-managing their mental health (Musiat, Goldstone, & TARRIER, 2014), they can be viewed as a relevant group for those seeking to apply digital technologies as part of mental healthcare, whether through development and provision or integration into existing services. These users also offer insight into how such resources are being adopted ‘in the wild’, and – alongside the system builders responsible for their creation (i.e. developers, designers, researchers etc.) – may help to configure societal meaning for the technologies and even contribute towards their diffusion (see Pinch, 2005) through their focus on development, implementation or appropriation of such technologies at what is still a relatively premature stage.

By exploring the experiences of these ‘early adopters’ using an adapted Grounded Theory Methodology – a methodology focused on the construction of theory from data (Charmaz, 2014) – the meaning and processes therein can contribute to a construction of the potentialities and meaning of digital mental health. Despite this placing the research at a juncture in technological development where stabilisation of purpose is unlikely to have occurred (and thus introducing a level of complexity to analysis), it can be argued that the development and appropriation of digital technologies is always open to interpretative flexibility (see glossary) and so will remain relatively unstable (Bijker et al., 1994). Therefore, in taking a sociological view of the technology as it is constructed and used by individuals in everyday life, it is necessary to

recognise that the theoretical implications of any findings can contribute to further research only through positioning the present stakeholders as part of a complex, changeable and emerging field.

This field – Digital Mental Health (DMH) – involves the use and development of electronic and digital technologies specifically for mental health purposes. Primary resources are those that have been developed specifically for mental health – e.g. a cognitive-behavioural therapy-based (CBT) smartphone app. Secondary resources refer to existing technologies that have been appropriated for specific mental health use, even though they may not have been originally designed for such. An example of secondary use may include Facebook groups set up for learning CBT techniques. DMH resources are often notable for their use of multiple functions, whether by providing an intervention alongside a social network to enable connections with peers, or through collecting and presenting their users’ information in visual formats. Additional functions are increasingly made possible within DMH with changes in the technological capability of devices. Whilst it is difficult to ascertain exactly what is available at present in DMH, it is clear that this is an area of increasing importance, with research nearly trebling between 2009 and 2014 (Firth, Torous, & Yung, 2016). Within the UK, 78% of internet users search for health information online (Ofcom, 2015), with similar findings in the US (Rainie & Fox, 2000). It is estimated that within the Apple and Android app stores there are now around 165,000 health apps, while mental health is the most common disease-specific category (IMS Institute for Healthcare Informatics, 2015).

Understanding the potentially exponential rise of technology application within mental healthcare, and the increasing ubiquity of its use and development outside the regulated healthcare sphere (‘in the wild’), research must seek to understand the how and why of DMH

from the perspectives of those involved. It is at this juncture, at this shift in the paradigms of healthcare and the move towards a digital world, that research can present insights into the meanings and processes that will lead us into that future. Researchers, in areas such as the social construction of technology, have previously demonstrated that an understanding can be gained from exploring individuals present at the initial stages (Bijker, 1994) and through constructing their application systemically/systematically (Timmermans & Berg, 2003). DMH will be beset by its own challenges as much as it will offer solutions and this dichotomy will not be served well through a narrow focus of research on its efficacy. Instead, understanding the dynamics within and the constructions of it in the 'everyday' and 'in the wild' can best account for its complexity and position as a burgeoning area of study.

### **1.2 Case Study: DMH in the UK**

Technology is already a recognised component in delivering healthcare (e.g. the 3millionlives project: Cruickshank, Harding, Paxman, & Morris, 2013) and has been approved by the National Institute for Health and Care Excellence (NICE) for computerised cognitive behavioural therapy (CCBT) since 2006 (NICE, 2006). Many other services have been commissioned locally with positive results (Davies, Mehta, Murphy, & Lillford-Wildman, 2013). There are calls for mobile technologies to fill the gap that the shortage of trained mental health professionals has left (Lord Darzi, 2015) and recognition of its place within tiered provision (Knowles et al., 2014) yet all therapeutic interventions within the UK remain essentially unregulated at government-level. The role of DMH in service delivery both within the NHS (Cotton, Wilkins, & Young, 2014; NHS England, 2014) and government (Davies et al., 2013) has also been recognised. These policy papers call for a national strategy to be implemented, training and skills development to be delivered and organisations to begin taking

responsibility for regulation and ensuring safety of patients through the establishment of guidelines and research. However, they also recognize the current existence of services that can provide self-support and information sharing, services that have an established user-base. DMH research has been restricted to single therapeutic approaches (Arnberg, Linton, Hultcrantz, Heintz, & Jonsson, 2014; Bendelin et al., 2011), forms of delivery (Beattie, Shaw, Kaur, & Kessler, 2009), attitudes (Ellis et al., 2013), diagnoses (Schrank, Sibitz, Unger, & Amering, 2010) or impact upon established working practice (Ahluwalia, Murray, Stevenson, Kerr, & Burns, 2010). With the implementation of a national strategy there is a need to understand in-depth the experiences of those using and developing DMH, and a need to establish research-based frameworks that can be universally applied. DMH is accessible to individuals via search engines, app stores and through commercial routes, it is not just limited to services that have been clinically approved. Rather it is available to anyone and everyone through their use of apps, websites, activity trackers, online support groups, etc. (Lal & Adair, 2014).

DMH is changeable. Even within the time period of this PhD there have been multiple changes in terms of regulations and its introduction into existing healthcare systems around the world. The NHS Apps Library, often applauded in the interim as an example of providing a directory of good quality health apps for the population, closed in response to two papers - one demonstrating data leakage by the majority of apps (Huckvale, Prieto, Tilney, Benghozi, & Car, 2015) and the other finding little evidence for the depression and anxiety apps listed (Leigh & Flatt, 2015). As of December 2017 there are attempts to initiate a programme of endorsing apps through the National Information Board (National Information Board, 2016) and the NHS Apps Library is once more live. But whilst around the world there have been some successes in curated health app stores, they are often plagued with security issues (e.g. Happtique; Becker et

al., 2014). Notwithstanding the difficulties in regulating based on ‘intended use’ (Medicines & Healthcare Products Regulatory Authority, 2014), essentially how the app is marketed, there are issues around how much or what kind of evidence is needed. This could lead to many taking a ‘soft approach’. If the Food and Drug Administration’s guidelines are indicative of how the rest of the world proceed it is also clear that regulation may not apply to apps for “wellbeing”, suggesting that many mental health apps will continue to be used outside of any kind of evidence base or credibility (Food and Drug Administration, 2015). The NHS Apps Library must already compete with commercial organisations that provide reviewed databases of health apps to clinicians and patients alike. Each year the industry grows and the involvement of clinicians increases (Research2Guidance, 2016). Many non-clinical organisations, including the British Standards Institute (BSI, 2015), have developed criteria for the use and development of health and wellbeing apps which, along with the inevitable commercialisation, suggests that developers and users have an important place in DMH evaluation.

### **1.3 Researcher’s Background**

I am a third generation geek. In my grandfather’s software engineering days, the computers he used filled the basements of buildings. When my father began programming, he did so on the first personal computers – a move to the home office and the affordability to own a computer for oneself. He is now an iOS developer, attracted to the ubiquity of smartphones. I resisted my technological urges and studied Developmental Psychology, being interested in understanding the way the human mind developed but knowing that computers would come for me one day. My first computer was a beautiful orange iBook and I’ve had an Apple ever since. When the first iPhone appeared I was enthralled, but it was a few years before I could afford to discard my ancient flip phone. My first iPhone came with me on a working holiday to India where I used it



to keep in touch with my family, learn about the world I was seeing and keep a blog about my experiences. It was a computer in the palm of my hand. I recognised its importance and it began a process that led to me writing about what I viewed as a potential difficulty in the current medical device regulations that ostensibly covered mental health (and health) apps. Being able to merge two areas I am passionate about – computers and mental health – has been both fascinating and challenging. When I began my PhD, people were confused by the idea of mental health apps; there were only a few hundred available at that point. There are now hundreds of thousands of mental health apps available and practically everyone seems to have a mindfulness or sleep CBT app on their phone (IMS Institute for Healthcare Informatics, 2015). Being part of that process and seeing the meteoric rise in our awareness and use of mental health apps and websites has exemplified, for me, the challenges of research in this area. By developing my understanding of the field through and alongside these changes, I feel this research can offer a way of understanding DMH not just as the application of resources but the weaving of digital technologies and their many potentials into all areas of our everyday lives.

### **1.4 Researcher's Voice**

Within this thesis, I use both the third person and first person. When using the third person, I am exploring an issue or addressing one presented by another researcher that has relevance to others. The use of first person will relate to my own words – to interpretations or suppositions.

### **1.5 Summary**

This chapter aims to introduce the reader to Digital Mental Health, an area that aligns both clinical and technological insights in research. It positions me as a researcher within this area, acknowledging my own background and interest but also mapping the progress that has led me to this focus. I wish this research to be viewed as exploring the practice and application of

digital technologies for mental health within the everyday lives of individuals. It recognises the potential alongside the challenges, constructs what role it may have and explores the ways in which it is applied and produced. Not everyone uses digital technologies in mental health but for those who do it is important to recognise and understand its role.

## **2 Literature Review**

### **2.1 Introduction**

This literature review will explore the research available in the area of digital mental health (DMH), including studies conducted from multidisciplinary perspectives, using a second generation synthesis approach (Pope, Mays, & Popay, 2007). It will demonstrate how the review has been conducted, reflecting on the role of a literature review in Grounded Theory Methodologies (GTM), and the approach that has been taken in reconciling the contrasting views. Following from this it will provide a summary of DMH resources. This particular study has focused on the meaning constructed through the experience of DMH, conceptualizing DMH as a social world in which different social roles interact. This will be considered alongside the theoretical framework that underlies the perspective informing the present study. The purpose of this literature review is to introduce the reader to the complexity of resources in DMH and position the present study within existing research. It will seek to construct an overview of the areas that are of most concern and the areas that have yet to be addressed within the DMH literature.

### **2.2 The Literature Review in Grounded Theory**

Within Grounded Theory (GT) Glaser and Strauss (1967) originally identified the literature review as an element of data collection, rather than the more traditional position of an initial process through which the researcher enables research that advances what is known through analysing “other people’s ideas, those ideas that constitute the body of knowledge on the topic of your research” (Hart, 1998: p.1). Thornberg (2012) challenges the classic GT position that places the literature review post-data collection, held most notably by Glaser (2010), and posits that the literature review allows the researcher to “investigate prior knowledge in the

substantive field to enhance his or her theoretical sensitivity as well as the potential of the study to relate and contribute to this pre-existing knowledge” (p.251). Recognising the rationale of delaying the literature review as a strategy to reduce the influence of preconceived concepts on theoretical development (Charmaz, 2014; Nagel, Burns, Tilley, & Aubin, 2015) I decided to begin with a scoping review that focused on efficacy and technological constructs of DMH, before moving to experiential qualitative research. This enabled me to improve my substantive knowledge, and in turn theoretical sensitivity, and maintain a literature review that was relevant to the concepts that were constructed alongside the data. Whilst there are always external influences to the construction of theory the use of memos helped to reflect on these so they became recognisable within the analysis (Charmaz, 2014). Conducting a literature review in the way outlined in the next section, whilst a challenge, also meant that I was able to reaffirm some concepts and properties when they were found within the qualitative literature after I had constructed them from the research data.

### **2.3 Literature Review Strategy**

The literature review began as an exploration of DMH from a pragmatic context, establishing existing research and resources in the substantive area. The initial scoping review was over 30,000 words and covered broad areas in DMH. During data collection and analysis this outline served the purpose of representing the substantive area of DMH research, as both Thornberg (2012) and Charmaz (2014) have suggested can be useful prior to GT research. A GTM can help identify conceptual categories that may not have been addressed previously in research. The choice to outline the area of DMH enabled the complexity of resources available to be understood in those initial stages, along with an appreciation of the interdisciplinary nature of relevant research. The final literature review was undertaken using a ‘second generation

synthesis’ and aimed to iteratively compare different sources of evidence as a way to reinforce and further explore concepts that arose (Pope et al., 2007). Due to the scarcity of accepted methods to appraise the quality of user experience research in DMH (Feather et al., 2016) the literature was critically viewed through the lens of trustworthiness and relevance (Shenton, 2004). The complete process is outlined in Table 1, and reflects data saturation within a GTM where literature was sought until the concept was comprehensively covered:

Table 1. *Outline of literature review synthesis.*

Stage	Process	Topics	Description
1.	Scoping Review (start date: 11.11.14)	DMH: keywords included ‘smartphone’, ‘mental health’, ‘e-mental health’, ‘digital mental health’. Example search: smartphone OR mobile AND “app” AND depression OR anxiety	Outline of research conducted using research-based search engines, including Google Scholar, PubMed and Science Direct, with relevant search terms including ‘digital mental health’, ‘e-mental health’ and ‘smartphone mental health’. These were then organised into a scoping review of DMH using both resources and specific conditions to illustrate what was available, what research had been conducted, and possible areas that would arise within the interviews to be conducted. The scope attempted to answer the question: What is DMH and what does the literature show?

Stage	Process	Topics	Description
2.	Iterative Literature Search (start date: 21.04.15)	Relevant literature to codes and concepts: keywords included 'self-help', 'people like me', etc	Google, Google Scholar, Zetoc and JMIR alerts were set up for the search terms and researchers with ongoing studies were followed on social media so as to keep abreast of current research as the study progressed. News articles often led to snowballing of more results. Conferences and events, as well as signposting by colleagues, also led to relevant research. These were appraised, although not utilising a formal appraisal tool due to their small number, to assess their relevance and rigour.
3.	Review (finish date: 01.11.16)	The literature was appraised critically, reflecting on the present study and its findings	The current study informed relevant areas of interest, which were brought together into a literature review that was conducted post-data collection and prior to completion of analysis. Although some of the articles are taken from conference proceedings and are therefore not of high quality, they are considered significant when they are relevant to the prominent concepts.

Stage 1 was a scoping review conducted using an adapted version of Arksey and O'Malley's (2005) methodological framework, identifying relevant studies through a Boolean search of electronic databases, reference lists, key journals and existing networks. This review was then iteratively adapted as data collection and analysis progressed (Stage 2) to include new, or newly discovered, research. A final research synthesis was developed using a research matrix akin to a 'narrative review' (Pawson, 2002). This recorded the following information, using Excel, for a total of 118 studies:

1. Author(s), year of publication
2. Condition named

3. Resource/Intervention
4. Methods
5. Target group, number of participants, gender, age range
6. Type of analysis

In addition, a summary of research findings was also coded using themes identified using the constant comparative method (CCM) (Charmaz, 2014) with a total of 65 studies that were deemed to fit the inclusion criteria of qualitative experience of DMH. These themes were seen to represent the researchers' constructed meaning of their participants' experience. An additional Excel matrix visualised the presence of themes within these studies. These themes were then subjected to analysis to identify similarities and differences in an attempt to establish categories. This led to the following categories, constructed for use within the present literature review; accessibility, autonomy, anonymity, pathway or postponement, role of the 'other', role of the individual, and empowerment. These categories link to and represent the majority of themes as can be seen in Figure 1:

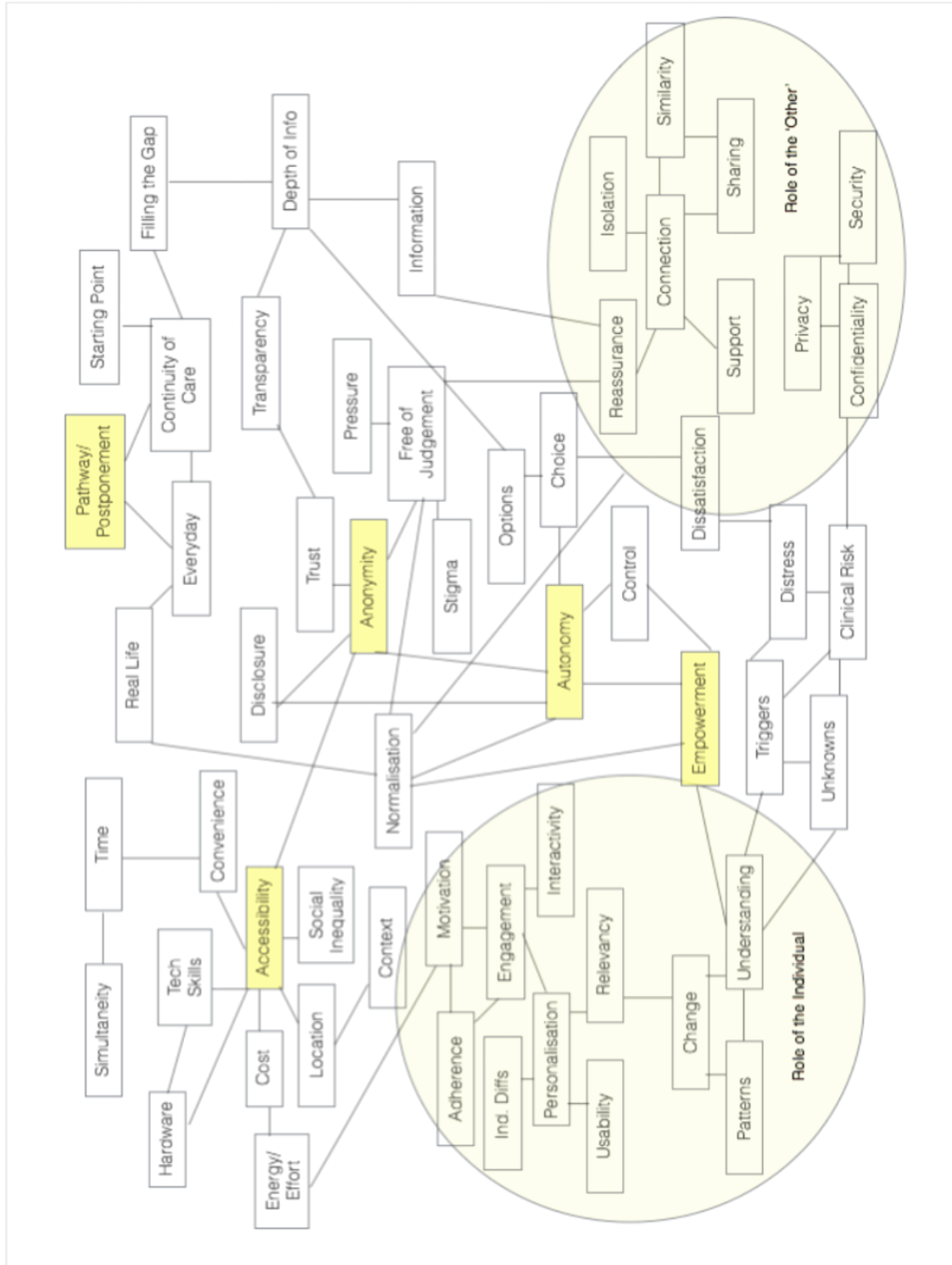


Figure 1. Themes extracted from a literature review of DMH qualitative studies, how they are interconnected, and the resulting categories which are identified in yellow.



Unfortunately, due to the small number of studies that addressed experience other than that of users this approach could not be used in a similar way for research that explored developer or researcher experiences in DMH. Instead, these were individually reviewed with consideration of the themes and categories identified within user experience research. This limited the rigour and relevance of the current literature review but also clearly identified a gap in the research literature – populations other than DMH users.

## **2.4 Theoretical Concepts of DMH**

In exploring a relatively new area such as DMH there are several theoretical approaches that underpin its interest to researchers. In establishing this thesis within the context of present research it must explore not only the networks within which technologies are placed but also the technologies themselves and how they are appropriated by individuals. Taking an holistic approach and viewing ‘technology-in-practice’ (Timmermans & Berg, 2003) through a social constructionist perspective necessitates exploring the social world of DMH and understanding how meaning is found, configured, reconfigured and negotiated (Oudshoorn & Pinch, 2005). The concept of ‘technology-in-practice’ views technologies as components within practice and their application is considered through their use and integration into daily life (Timmermans & Berg, 2003). As DMH is often practiced outside of healthcare institutions and away from traditional mental healthcare contexts, implementation within everyday practice was chosen as a perspective. Considering technology’s construction as a ‘boundary object’, placed at the juncture of numerous social worlds with mutual concerns, the Social Worlds Framework (Clarke & Star, 2007) was appropriated to encompass the multiple actors and actants involved in meaning-making within DMH. The interplay of social worlds within this study is explored further in section 2.6.

## **2.5 Summary of DMH Resources**

Figure 2 shows a summary of the most common DMH resources, their purpose, the types of providers, and the concerns that individuals have when accessing them. It has been adapted from the scoping review and is included to provide the reader with a brief overview of the technologies that are available, the providers of those technologies, and the prominent concerns of users. The next generation of technologies will introduce more active components such as those present within Intelligent Personal Assistants or ‘conversational agents’, e.g. Siri or Alexa (Miner et al., 2016), and deliver multiple functions including information, social support, behaviour change and interventions.

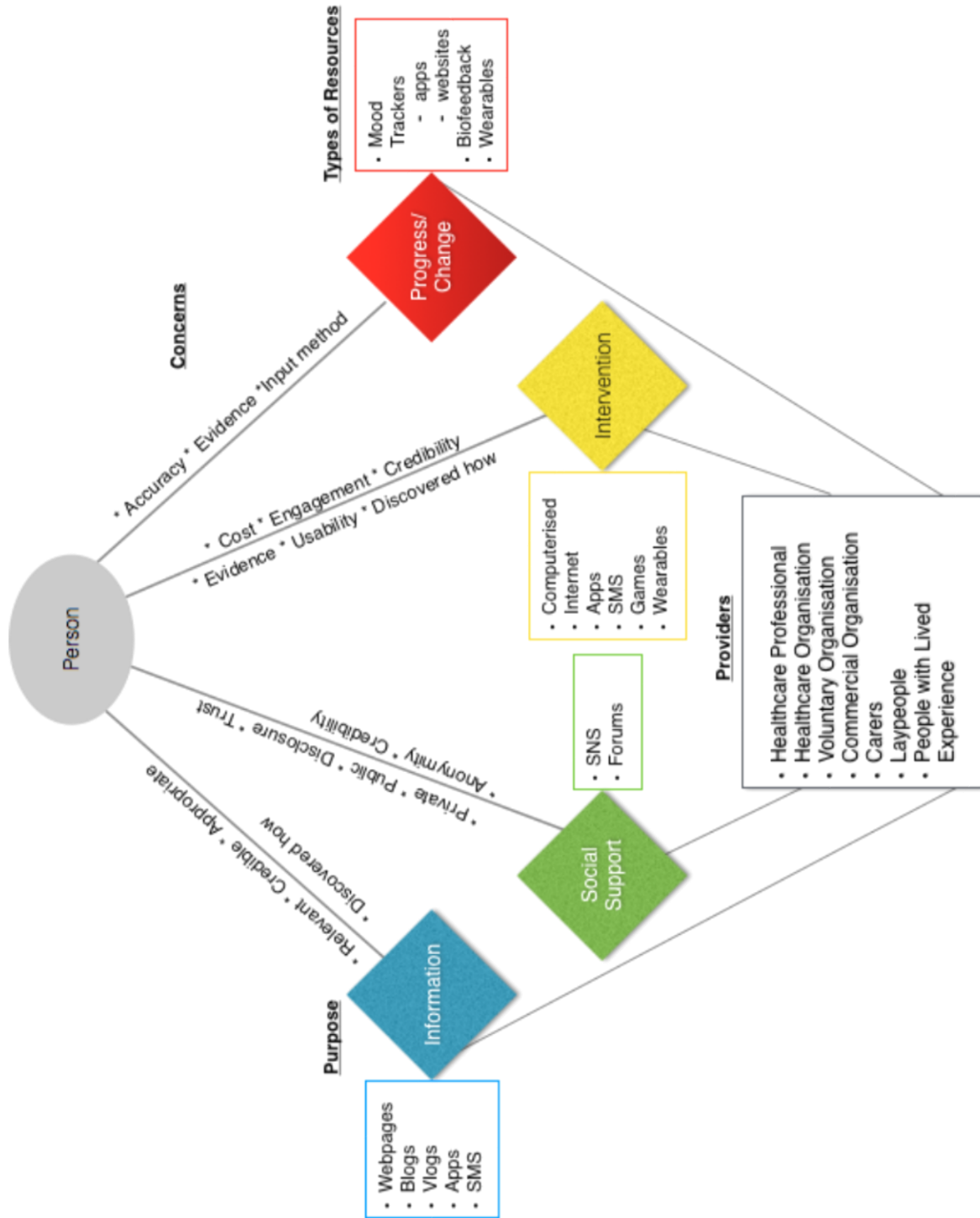


Figure 2. Summary of DMH resources, their purpose, providers and common concerns.

Table 2. *Summary of DMH resources, their purpose, the most common concerns and types provided.*

<b>Purpose:</b>	<b>Information</b>	<b>Social Support</b>	<b>Progress/Change</b>	<b>Intervention</b>
Types of Resources	<ul style="list-style-type: none"> <li>- Webpages</li> <li>- Blogs</li> <li>- Vlogs</li> <li>- Apps</li> <li>- SMS</li> </ul>	<ul style="list-style-type: none"> <li>- SNS</li> <li>- Forums</li> </ul>	<ul style="list-style-type: none"> <li>- Apps</li> <li>- Websites</li> <li>- Wearables</li> </ul>	<ul style="list-style-type: none"> <li>- Computer-based</li> <li>- Internet-based</li> <li>- App</li> <li>- SMS</li> <li>- Wearables</li> </ul>
Types of Provision	<ul style="list-style-type: none"> <li>- Medication</li> <li>- Diagnosis</li> <li>- Lived Experience</li> </ul>	<ul style="list-style-type: none"> <li>- Professional-led</li> <li>- User-led</li> <li>- Research-based</li> </ul>	<ul style="list-style-type: none"> <li>- Mood trackers</li> <li>- Biofeedback</li> </ul>	<ul style="list-style-type: none"> <li>- Cognitive Behavioural Therapy (CBT)</li> <li>- Mindfulness</li> <li>- Games</li> <li>- Psychoeducation</li> </ul>
Concerns	<ul style="list-style-type: none"> <li>- Relevance</li> <li>- Credibility</li> <li>- Appropriateness</li> <li>- Discoverability</li> <li>- Literacy</li> </ul>	<ul style="list-style-type: none"> <li>- Privacy</li> <li>- Public</li> <li>- Disclosures</li> <li>- Credibility</li> <li>- Trust</li> <li>- Anonymity</li> </ul>	<ul style="list-style-type: none"> <li>- Accuracy</li> <li>- Evidence</li> <li>- Passive input</li> </ul>	<ul style="list-style-type: none"> <li>- Cost</li> <li>- Engagement</li> <li>- Credibility</li> <li>- Evidence</li> <li>- Usability</li> <li>- Discoverability</li> </ul>
Providers	<ul style="list-style-type: none"> <li>- Healthcare Professionals</li> <li>- Healthcare Organisations</li> </ul>	<ul style="list-style-type: none"> <li>- Voluntary Organisations</li> <li>- Commercial Organisations</li> </ul>	<ul style="list-style-type: none"> <li>- Carers</li> <li>- Laypeople</li> <li>- People with lived experience</li> </ul>	

## 2.6 The Social World of DMH

In conducting research involving technology it is advisable to identify and describe the relevant social groups, defined as individuals with a shared meaning towards that specific technology (Bijker et al., 1994). Relevant groups are often viewed as users and developers, or alternatively, consumers and producers. However, there are inherent problems within this view. The developer of an app will envisage the potential user during development, often basing it on herself (e.g. I-methodology; Oudshoorn, Rommes, & Stienstra, 2004) and thus may represent

both producer and consumer. The user of an app may provide feedback to the developer, passively or manually, potentially influencing development and again representing producer and consumer. The researcher who wishes to explore that technology will use it for his purpose, potentially altering the technology's meaning and also becoming both producer and consumer.

It may be possible to construct a single relevant social group, defined by their “prosumer”-like qualities. Alvin Toffler was first to elaborate on what this might mean, in discussing the ‘third wave’ or information age wherein production and consumption are realigned (Toffler, 1980), and it has been expanded several times since. The idea that users or consumers are passive receivers of products was argued against by Michel de Certeau (1988) in his book *The Practice of Everyday Life*, positing that consumers develop tactics in their everyday lives that help them assert control over the strategies imposed on them by producers. More recently the discipline of Science and Technology Studies has brought together researchers from multiple arenas to sociologically explore science and technologies in action, particularly with regard to the oft-forgotten practice of everyday life (Bauchspies, Croissant, & Restivo, 2006; Restivo & Croissant, 2008). Recognising the value of these works they together present a complex system of use and delivery wherein the user is contributing through their use and application, both altering and reinforcing purpose. For this reason, it is difficult to assign ‘developers’, ‘researchers’, or ‘users’ to separate and distinct social groups. Rather it could be argued that they inhabit complementary social worlds and co-exist within constructed social worlds that intersect and segment in dynamic fluidity (Bauchspies et al., 2006; Strauss, 1978). Using Strauss’ perspective, through the Social Worlds Framework (Clarke & Star, 2007), the primary activity is that of DMH with subworlds representing use, development, and research. Because the

participants of these subworlds are of interest the context is recognised to be both constructed and perceived, and encapsulated in meaning, which will be addressed in section 2.6.1.

### **2.6.1 Roles in DMH**

If this study is to view DMH from a Social Worlds Framework (Clarke & Star, 2007) it is useful to address the constructed roles that have been assigned by society and research (Clarke, Friese, & Washburn, 2015). These roles reflect the individual perceptions and establish their position in a complex adaptive system, where multiple identities and personas require recognition of the dynamic nature where the role may not be tangible, connected or even identifiable. Users, researchers, and developers are interchangeable but these constructed roles provide structure, which can aid individuals in positioning themselves within a social world. Because roles can be assigned or adopted it is also important to address the process itself, from within the experiences of participants in DMH. Using the existing literature this next section will explore how roles may become constructed in DMH.

#### **2.6.1.1 *Constructing Roles***

In user-centred design potential users are recruited to help shape and evaluate technology during development (Gulliksen et al., 2003). They can be constructed as implicated actors, representatives of their social worlds who may remain voiceless (Clarke & Star, 2007). Inherent to this process is a presumption about who those end users will be. For instance, Topham, Caleb-Solly, Matthews, Farmer, and Mash (2015) recruited only university staff and students during development of their mental health app as it was initially intended for university counselling purposes. Once developed, it became clear that the app would be available to a wider audience although these had not originally been the intended recipients (Bergin, 2015). In the development of a 3D game to be used in adjunct with talking therapies Coyle, Matthews, Sharry, Nisbet, and

Doherty (2005) elicited user experiences via therapists due to the sensitive nature of the interactions. In doing so it became clear during implementation that issues, such as the need for a certain level of literacy, had not been identified during ‘user’ testing. Users may also be constructed as those that apply the technology, or those onto which the technology is applied. This is clear in medical device development wherein end-users may be viewed as clinicians, patients, or both with little recognition of the roles played by others such as managers and relatives of patients who may also be significant in implementation and use (Martin & Barnett, 2012). Therefore, it is not just the constructed role of ‘user’ that inhabits the social world of ‘use’, but rather it is made up of multiple interacting roles that have differing levels of influence and involvement at different times.

System builders (Hughes, 1994) refer to those who are involved in the production and implementation of technologies, and are here identified as both researchers and developers. Constructing researchers as a role within the social worlds of DMH is both reflective and relevant. Reflective, as it leads me – the researcher – to contemplate both my own position and those of the authors from which discourse and knowledge is received. It is relevant as the prominent design processes within health technology development can be identified as based within principles of research, where considerable emphasis is placed on iteratively developing, evaluating, and improving artifacts through analytical processes (Gulliksen et al., 2003). In development it has been recognised that systematically researching and investigating the use, implementation and experience of technology contributes not only to its usability but also to the effectiveness of the health-related purpose for which it has been designed (Yardley, Morrison, Bradbury, & Muller, 2015). Thus the role of researcher is not only relevant in development but also in the construction of meaning in DMH. By identifying this role it acknowledges the

researcher's position within the constructed meanings through receiving and interpreting experience (Clarke et al., 2015). In this way the role of researcher is descriptive of those who act as 'observers' within the social world of DMH, whilst also being an element in the roles of user and developer.

The role of 'developer' is often overlooked in the DMH literature. Users may view them as an unseen other with the potential to access their data (Dennison, Morrison, Conway, & Yardley, 2013), which unfortunately may be well-founded (Huckvale et al., 2015), but their voice is often absent – they are what Clarke and Star (2007) call 'classic implicated actors'. In attempts to regulate or certify health apps developers are seen as responsible through the advantage they gain from certification and their technical know-how to identify when certification has failed (Powell, Landman, & Bates, 2014). Guidance is often aimed at developers in digital health technology development – for example the Privacy Code of Conduct on mobile health apps (European Commission, 2016) – and yet the experiences of mobile mental health system builders is little understood. It appears that the role of developer is often constructed outside the social worlds of 'use' and 'research' and addressed only when they are needed to create a technology, although in some instances the researcher and developer may become aligned. For example, in Topham et al. (2015) the role of developer was constructed as held by researchers, users, and external developers. Involvement came at different times meaning that these roles were fluid, and prior constructed roles were at times challenged. The external developers had to adapt to the researchers' increased involvement, which was atypical of the expected role of a contractor (Bergin, 2015). The points of convergence and divergence between the various roles within the social world of DMH offer insights that can contribute to the existing literature and research.



Researchers and developers are considered in their role as system builders (Hughes, 1994) within this research.

## **2.7 The Experience of DMH**

This section will explore DMH through the experiences of those involved by identifying research and addressing the themes within – particularly the purpose that individuals find. This applies a synthesis approach, with thematic matrices used to explore a diverse range of research into the experience of DMH, and utilises a common GT analytical tool; the CCM (Charmaz, 2014). In the present study meaning constructed around the purpose and use of DMH is illustrative of the intention or motivation, but is not restrained by reality. Thus, it can change and evolve, is not intrinsic, and is a constructed representation of the individuals' perception. In this way it represents the meaning-making within the context of DMH as social world. When a developer creates an app in the UK with an 'intended purpose' that is medical in nature they are regulated by the Medicines and Healthcare Products Regulatory Authority (MHRA). Worldwide there are similar regulations, including those provided by the US Food and Drug Administration (FDA), the European Commission's MEDDEV 2.1/1, and Australia's Therapeutic Goods Administration (TGA). The MHRA guidelines cover "diagnosis, prevention, monitoring, treatment or alleviation of disease" (MHRA, 2014). A discussion that addresses the language and interpretation – including the logistical problems of worldwide access and regulation – is needed, but this review is not the place. Yet it is important to address what the implications are of viewing DMH from the perspective of its intended purpose.

Sherry Turkle (1984) wrote that "a computer program is a reflection of its programmer's mind" (p.19). Often when qualitative techniques are applied to technology, the 'creator' is neglected – the intentions, hopes, dreams and aspirations behind the device or resource that is

then placed into the hands of the user. Users construct meanings around the technology and their use of it but within the social construction of meaning the developer is often omitted. However, they are as much an agent within these constructions as users – through the resource itself and the materials, content, and ‘intended purpose’ with which they present the resource. Livingstone (2007) contrasts the aims of the producers of a youth website with their intended users and demonstrates clearly that technology may be developed for a constructed ‘user’ and produce a resource that contains very different meaning for the actual user. This reflects the ‘configured’ user – the anticipated user for which the technology has been developed (Oudshoorn et al., 2004). When developers were asked to separately produce an automated traffic tickets resource the results differed significantly across the groups, representing the influence of their inherent beliefs and moral codes (Shay, Hartzog, Nelson, & Conti, 2013). Although developed following the same law each developer had interpreted it in their own way, leading to different numbers of tickets given. When danah boyd (2014) explored the ways in which adolescents used technology, she found that there often remained an underlying purpose that drove technological use; for instance the move from MySpace to Facebook remained fundamentally about socialisation/connection. Indeed, to understand the constructed meaning within DMH, we must look not only to its use but also its development and presentation. If there is a purpose to be found it will inevitably involve an interplay of relational dynamics between social and individual meanings co-constructed within the social world of DMH.

This perspective closely follows the social construction of technology approach and sociological study of science and technology, which maintain that the interplay within and between society and technology is involved in the construction of meaning (Bauchspies et al., 2006; Bijker et al., 1994). This stands in contrast to technological determinism where technology

dictates meaning in society (Reinhard, 1976) and social determinism where society dictates meaning in technology (Green, 2002). Rather than imposing meaning of technology onto potential users there is a need to recognise that the meaning of technology is open to ‘interpretative flexibility’ (Bauchspies et al., 2006; Bijker et al., 1994). Purpose or meaning of technology becomes a concept in flux, with new purpose ascribed to old technology and new technologies fitted to old purpose. ‘Reverse salients’ are components of technology that do not develop quickly enough, challenging the meaning, development and success of technological systems (Bijker et al., 1994). Not only do the multiple actors and actants work to co-construct meaning (Clarke & Star, 2007) but technology’s position within the practice of everyday infers a dialectic complexity (Timmermans & Berg, 2003). Even meanings constructed by individuals are not fixed but instead are shaped through social interactions and influenced by temporal and contextual factors, as described in symbolic interactionism (Blumer, 1969).

Similarly, there are individual constructs of mental health and wellbeing stemming from personal experience (Hind et al., 2010) and from accepted language and definition. An entire chapter of the 2013 UK Chief Medical Officer’s report was dedicated to defining the proper use of ‘mental health’, ‘mental illness’, and ‘wellbeing’ (Davies, Mehta, Murphy, & Lillford-Wildman, 2013). Even the definitions of certain conditions continue to be socially constructed, as in the Diagnostic and Statistical Manual of Mental Disorders, which is on its fifth iteration (American Psychiatric Association, 2013). This study takes a salutogenic approach to mental health and wellbeing, considering the factors that support people in maintaining wellbeing in a way that is important to them. In defining mental health the World Health Organisation notes it as “a state of well-being in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a

contribution to her or his community” (World Health Organization, 2004), with the notable absence of the individual’s own concept of health and wellbeing (Nettleton, 2004). Even in mental health there are very individualised views on aspects such as recovery (McEvoy, Schauman, Mansell, & Morris, 2012), suggesting that an important element is understanding its experiential complexity on a personal level.

In understanding meaning within DMH, it is necessary to reflect not only on technology and mental health but also on their interaction. Traditionally in healthcare there has been the understanding that ‘doctors know best’ (Lupton, 2012) but there has been a shift revolving around the encouragement of healthy living, influencing how we live and how we view health. “Lay health beliefs are not simply diluted versions of medical knowledge: rather, they are shaped by people’s wider milieux such as their structural location, cultural context, personal biography and social identity” (Nettleton, 2004, p.37). The social meaning carried by technology is also potentially important in shaping health beliefs. As health becomes a matter of surveillance, for instance when wearables track activity, it has been constructed as a move from the individual being assessed as a ‘danger’ to profiling of populations as being at ‘risk’ (Castel, 1991). This has repercussions, as outlined by Sarah Nettleton in response to Castel’s chapter: the demise of the practitioner-patient relationship; a new role for health professionals as health strategists; an increasing emphasis on profiling of population and the potential marginalisation of groups that cannot consume and therefore cannot participate (Nettleton, 2004). Likewise, the internet has heralded a reduction in the privacy of illness, according to Conrad and Barker (2010), who illustrate that the presence of illness subcultures online is leading to increasingly public experiences, social movements, demands for medicalisation/demedicalisation, the sharing of information and experiences, and the expanding influence of lay knowledge. When concepts

become part of a complex system, their understanding moves from singular to an acceptance of something more chaotic. It may also be that the move towards the self-management of health, through concepts such as informed choice and empowering patients (Coulter, 2002), has contributed to these sociological changes. Digital technologies, such as the internet, may simply act as a tool to support individuals in self-managing their health. For those who manage their health outside of traditional healthcare systems this may lead to ‘digitally engaged patients’ who use new technology only when relevant, engaging, easy and effective (Lupton, 2013). Rather than considering DMH as individual elements, it is useful to see it as nodes within a complex adaptive system (Mitchell, 2011), with none taking causal priority.

### **2.7.1 User Experience within DMH**

The experiences of users in DMH are often isolated by questions aimed at their use of single resources, focusing on CBT-based websites (Bendelin et al., 2011; Pretorius, Rowlands, Ringwood, & Schmidt, 2010), with little addressing the use of new technologies such as smartphone apps (Fulford, McSwiggan, Kroll, & MacGillivray, 2016). As proposed by both the concept of ‘technology-in-practice’ (Timmermans & Berg, 2003) and the Social Worlds Framework (Clarke & Star, 2007), technologies typically exist within complex social systems and can be applied as components within everyday life, suggesting that addressing singular technologies may not offer insight into their actual use. Many explore user experience of commercially available interventions, such as MoodGYM (Lillevoll et al., 2013), and address specific populations, including young people (Bradley, Robinson, & Brannen, 2012) and depression with comorbid physical conditions (Donkin et al., 2013; Hind et al., 2010). Participants typically discuss a range of conceptual experiences, from relational aspects (Bendelin et al., 2011; Purves & Dutton, 2013) to feelings of control (Bradley et al., 2012;

Donkin & Glozier, 2012; Pretorius et al., 2010). In addressing meaning within the user experience of DMH the literature is reviewed thematically and analysed using the CCM (Charmaz, 2014) so as to categorise the main areas of research interest.

### ***2.7.1.1 Accessibility***

The accessibility of mental health information and support through digital technologies, along with resources that can support self-care, is well-documented as a salient reason for individuals to turn DMH. Accessibility is constructed within the research in a variety of ways including immediacy, availability, diversity of options, and convenience. Whilst conventional services are typically accessible only during office hours, DMH can be accessed when it is needed – an important factor reported by young people with mental health conditions (Gowen, 2013). There is an immediacy that appears to be satisfied in gaining access to information and support, whether for individuals with schizophrenia interviewed about their internet use (Schrack et al., 2010) or university students accessing health information ‘on the go’ through their smartphones (Dennison et al., 2013). However, there are various issues that need to be addressed including whether information accessed ‘on the go’ is germane, the privacy concerns of using public Wi-Fi to search for health queries, and the quality and impact of information that individuals locate.

Qualitative research demonstrates that a significant motivator for individuals choosing to use DMH resources is that they can be accessed anywhere and at any time (Bradley et al., 2012; Lillevoll et al., 2013; Pretorius et al., 2010). The convenience of resources accessible in this way is particularly important for those who may be restricted by geographical or temporal barriers. For instance, those living in rural areas may have high travel costs related to accessing support (Lal & Adair, 2014; Pruitt, Luxton, & Shore, 2014) whilst those in urban areas may have to

contend with long waiting lists (Powell et al., 2011). Lal and Adair (2014) also identify the potential to reduce barriers placed by child care needs, transportation, insurance coverage (for countries that have insurance-based healthcare provision), and work absences, as it can be delivered at multiple locations throughout the day. This convenience of access has been noted by multiple groups, including university students in a survey on mental health information and support-seeking (Horgan & Sweeney, 2010), young people with mental health conditions during focus groups (Gowen, 2013) and by individuals with schizophrenia when interviewed about their internet use (Schrank et al., 2010). Participants using DMH resources also identify the flexibility that this allows in accessing and engaging with the materials at their own pace, which may foster a feeling of control over their involvement (Pretorius et al., 2010; Rennick-Egglestone et al., 2016). However, in accessing anytime, anywhere, and anything it is important to note that there are certain presumptions made about device capability, e.g. battery life or bandwidth (Jarvenpaa & Lang, 2005).

Whilst this convenience of access may be a positive factor in people's use of DMH the literature also identifies problems of conventional service availability as potentially contributing to its use. Users identified long waiting lists as a reason for accessing health information through a health website (Powell et al., 2011). Young people and adults with a diagnosis of bulimia nervosa, recruited for a feasibility study of an online CBT based intervention, also spoke about lengthy waiting lists as a driver to engage (McClay, Waters, McHale, Schmidt, & Williams, 2013; Pretorius et al., 2010). In focus groups accessing past users of computerised CBT (cCBT) lengthy waiting lists were given as a factor in their engagement, along with a 'desperate' need to begin on the path of recovery (Rennick-Egglestone et al., 2016). This concept has similarities to the stage of 'preparation' within the Transtheoretical Model of Change (Prochaska & Velicer,

1997) with an inability to move towards action being experienced as disillusioning. Although this may be inherent to the structure of an internet-based trial, where there is an unspoken understanding that it might not work (Advocat & Lindsay, 2010) and individuals may face cognitive dissonance surrounding their use of an unconventional therapy-type, within the UK where these trials were conducted there is evidence that waiting times for mental health support are considerable and distressing (Mind, 2013). Some individuals may also find that they are unable to access the services that they would like to, whether because they are not eligible (Tubaro & Mounier, 2014) or, as in the UK, when they are not offered a choice in the type of therapy they receive (Mind, 2013). Others may have been dissatisfied with prior access (McClay et al., 2013) or have negative expectations (Ellis et al., 2013). In addition, some report that health professionals may not validate their mental healthcare needs (Cheek et al., 2014).

For the individual, access to DMH is often seen as low cost – even free, as identified by participants in an Irish survey (Horgan & Sweeney, 2010). In countries that do not provide free healthcare access, this may be a considerable reason to use DMH. For instance, community focus group participants in Australia held positive attitudes towards mobile use in mental health when there was no cost involved (Proudfoot et al., 2010). It is important to recognise that there is always a cost associated with provision of mental health services, and in DMH this may be absorbed by organisations, individuals, and/or developers. In a UK focus group, participants noted that the large numbers of free health apps bring with them less commitment to use long term (Dennison et al., 2013) whilst in another study the internet was seen as ‘free’ (Todd, Jones, & Lobban, 2013) implying there may be reticence to pay for online services. As healthcare in the UK is provided free by the NHS, individuals may also be disinclined to absorb these costs themselves and may even see provision of digital alternatives in mental healthcare as ‘cost-



cutting' (Rennick-Egglestone et al., 2016). In a study exploring online anxiety interventions all those offering therapist support required payment of a fee (Ashford, Olander, & Ayers, 2016).

Whilst the financial cost of accessing and providing mental health support is clear, along with the need for developers of DMH resources to ensure monetary stability (Yuen, Goetter, Herbert, & Forman, 2012), there is also a human cost in the energy or effort that one must expend in seeking resources. Focus group participants noted their frustration when searching for online mental health information, finding it difficult to assess good quality information (Gowen, 2013; Powell et al., 2011; Schrank et al., 2010) whilst a review of studies found that only half of participants reported succeeding in finding the information they needed (Kauer, Mangan, & Sancu, 2014). When addressing health apps, participants of a focus group perceived the use of health apps as time-consuming and inconvenient, meaning it was unlikely that they would be used for extended periods of time (Dennison et al., 2013). However, it must be noted that accessing conventional services may also be time-consuming and inconvenient, as evidenced by the individuals who reported ease of access to be a facilitator in online mental health information and support seeking (Horgan & Sweeney, 2010; Kauer et al., 2014; Schrank et al., 2010).

#### *2.7.1.1.1 Inequalities in Accessibility*

The inequalities in access to DMH must also be addressed. Whilst there are evidently individuals accessing and utilising digital technologies in their mental healthcare there are those who are not, whether due to negative expectations (Sanders et al., 2012), dissatisfaction with their experience (Rennick-Egglestone et al., 2016), difficulties in accessing the technologies themselves (Schrank et al., 2010), or for further undocumented reasons. The 'digital divide' is often perceived as a reluctance to use technologies but in a survey of 121 individuals using community mental health services non-use of DMH was instead associated with a lack of skills

or confidence, and restricted access (Ennis, Rose, Denis, Pandit, & Wykes, 2012). Sanders et al. (2012) explored the barriers to adoption of technologies within a UK initiative, the Whole System Demonstrator, that aimed to provide telecare to individuals with complex healthcare needs. Although these technologies were viewed as easy to use with little technical competence needed, there were some who expressed feelings of uncertainty and alienation about its use. The study only recruited those who had declined or withdrawn from participation but it provides some insight into personal reasons for the non-use of DMH. Some expressed fears that their current service would be disrupted or reduced, and many perceived the use of telehealth as analogous with dependency. This challenged their identity as independent and in control of their healthcare needs. Whilst some individuals may be given a choice, and may already be provided for by healthcare teams, others must contend with difficulties in access.

There still remains a global digital divide, both a knowledge gap and hardware bias, although mobile internet and widespread free Wi-Fi are aiming to provide cheaper and more comprehensive internet coverage. It may be presumed that as individuals increasingly access digital technologies that their knowledge would increase exponentially around areas such as use, security, and privacy (Shillair et al., 2015) but as evidenced by multiple mass data leaks from within major companies as knowledge of how to protect oneself increases so too does the knowledge of how to overcome those protections. This is further exacerbated by interfaces that obscure the underlying 'technical' programmes to improve usability, further distancing the individual from the way that technologies function and an awareness of how they may be undermined. Developers avoid privacy policies, as they lead to lower user retention, and use third party apps to ensure privacy so as to reduce pressure on time and resources (Balebako, Marsh, Lin, Hong, & Cranor, 2014). For those sharing personal information online the context

rather than the information appears to be more pertinent in their decisions to share, and there are concerns that some individuals may not fully anticipate the potential consequences of sharing online (Brady, Segar, & Sanders, 2016). Individuals reported assessing mental health websites that used cookies as being of poor quality (Schrank et al., 2010) even though it is now best-practice for websites, the majority of which use cookies, to be transparent about their use. In addition, as hardware such as smartphones become more ubiquitous this also brings with it consumerisation. Whilst devices may become more affordable, companies are also prompting consumers to purchase newer versions of both hardware and software by ceasing support for older versions, requiring new competencies. For example, Microsoft ceased supporting Windows XP in the NHS in April 2015 but as of September 2016 42 NHS trusts reported that they were still running an outdated and potentially unsecured system (Cox, 2016).

This same consumerisation also leads to hardware constraints, for instance when cheaper smartphones do not have accelerometers or GPS so cannot run certain apps. However, even with new technologies there is considerable uncertainty as to the accuracy of data collected (Case, Burwick, Volpp, & Patel, 2015). For participants of a qualitative study exploring the use of health apps this led to adaptation of behaviour, including performing the same test twice, to ensure accuracy (Anderson, Burford, & Emmerton, 2016). Jarvenpaa and Lang (2005) found, in several global focus groups exploring mobile use, what they termed “conflict situations” where actions led to consequences that clashed with original intentions, potentially causing frustration. This is also referred to as ‘seamfulness’ within the literature (Barkhuus & Polichar, 2011). Participants in multiple studies identify the need for resources to be easy to use (Proudfoot et al., 2010; Todd et al., 2012) and to have the required technological skill level to make use of DMH, particularly in overcoming technical difficulties that are faced (Gerhards et al., 2011; McClay et

al., 2013). For others there was evidence of a strategy to minimise the time spent interacting with technology (Donkin & Glozier, 2012; Schrank et al., 2010). Use of technologies that are novel or difficult not only potentially causes frustration but may also jeopardise the privacy of individuals who do not have the capacity to ensure they are protected (Brady et al., 2016). The usability of technologies is also of importance when considering engagement, although researchers appear unable to clarify how use is influenced within mental health. For instance, one study found that potential users diagnosed with bipolar disorder disliked the pastel colours of the initial webpages as it reminded them of hospitals, suggesting that individual experiences may contribute to the perceived usability of certain technologies (Barnes et al., 2011). This is discussed further in [Role of the Individual](#) (section 2.7.1.6.).

In reviewing the barriers reported by participants in cCBT the most common cause of non-adherence was cited as personal circumstances rather than technical difficulties (Waller & Gilbody, 2009) – a finding also reflected in a study exploring use of an online bipolar education program (Nicholas et al., 2010). It is important to note that much of the research echoes a perception of DMH interventions as time-consuming, although this may reflect the individual's priorities when integrating DMH into their daily life. Participants reported difficulties 'finding the time' to invest in the interventions (Bendelin et al., 2011; McClay et al., 2013; Wilhelmsen et al., 2013) – perhaps because of other priorities taking precedence (Donkin & Glozier, 2012) or the burden on time of committing to completion of exercises (Boggs et al., 2014; Hind et al., 2010; Wilhelmsen et al., 2013). Whilst the immediacy of access to DMH may be a facilitator this suggests that for structured interventions the need to complete modules in what may be viewed as their 'spare time' may be constructed as a burden. For users of Moodscope, a mood tracker, this meant ensuring privacy by completing it at home was balanced against their perception of

this time as leisure time (Drake, Csipke, & Wykes, 2013). Researchers increasingly recognise the need to explore the individual and their use of technology as an aspect of their daily life – users who are ‘in the wild’ (Owen et al., 2015; Rennick-Egglestone et al., 2016) – as technologies may need to be balanced against other tasks, suggesting that their constructed meaning has broader implications.

### **2.7.1.2      *Autonomy***

In their seminal text, *Principles of Biomedical Ethics*, Beauchamp and Childress (2001) identify four main ethical principles – autonomy, beneficence, non-maleficence, and justice. The use of ‘informed choice’ in healthcare, particularly in treatment delivery, is often used to ensure compliance with the first principle, as a way of respecting the autonomy of patients by providing them with information and options, and the freedom to choose based on their own healthcare goals (Coulter, 2002). In discussing the autonomous patient, Angela Coulter (2002) identifies three models of clinical decision-making; professional choice, shared decision-making, and consumer choice. In accessing DMH outside of conventional services individuals are by necessity using the latter model – consumer choice – although some researchers have anticipated that even within traditional services the presence of clinical information online will re-construct the role of the healthcare professional as a health strategist, responsible for providing structure to decisions rather than being an information provider (Castel, 1991; Nettleton, 2004). The question of interest is whether individuals can make informed choices about their mental healthcare needs without the guidance of a clinician, particularly decisions about which DMH resource to use.

In understanding the concept of personal agency and autonomy in relation to the individual’s experience and their use ‘in the wild’, it is important to also relate this to their desire to take control of their mental health. For many DMH offers a way to do so (Anderson et al.,

2016; McClay et al., 2013; Pretorius et al., 2010), including through enabling privacy-management and choice of whom to disclose to (Bradley et al., 2012). In a World Health Organisation mental health survey 63.8% of individuals with a diagnosable mental health condition identified wanting to deal with it themselves as a reason not to access conventional services, constructing the desire for self-care and self-management as a barrier to help-seeking (Andrade et al., 2014). Of nearly 20,000 individuals using ‘depression’ in a popular search engine only 25% of those anticipated to have a diagnosable condition reported currently being in treatment (Leykin, Muñoz, & Contreras, 2012). In several focus groups exploring young men’s attitudes to mental health and technology, the desire to deal with it themselves was a major theme, and also framed as a barrier, but with the recognition that the internet is often perceived to be a gateway, or a first step, in seeking help (Ellis et al., 2013). The concept of DMH as a first step is discussed further in Pathway or Postponement (section 2.7.1.4.). The capacity of apps to enable participants in self-managing their conditions was seen as an important concept (Anderson et al., 2016). The role of control in the therapeutic process of self-care is present within the experiences of those who have previously engaged in CBT, who consider themselves ‘self-therapists’ and able to apply the skills they have learned in managing their mental health (Glasman, Finlay, & Brock, 2004). Potentially, DMH may be used by some as a way of learning and applying strategies of self-care in the management of mental health.

#### *2.7.1.2.1 Control*

It is clear that the concept of control, or personal agency, is significant in the experience of DMH. For Knowles et al. (2012) this concept reflects the perceptions that individuals have of cCBT whereby ‘enforcing autonomy’ is constructed as treatment without support whilst ‘providing control’ describes welcoming the active nature of cCBT. Users of health apps

expressed concern about the app's activity that they were unaware of, asserting the need to control app settings and permissions (Dennison et al., 2013). This establishing of control over technology is experienced dichotomously, perhaps due to the nature of the delivery or the intervention itself. For instance, two separate studies explored two common cCBT programmes, *Beating The Blues* and *MoodGYM*. Whilst those using *MoodGYM* reported feeling able to exercise control, appreciating the flexibility it offered so they could choose modules relevant to themselves (Wilhelmsen et al., 2013), those using *Beating The Blues* felt unable to diverge and explore what was important to them (Gega, Smith, & Reynolds, 2013). Choice of modules may be constructed by users as exercising choice but may also lead to avoidance of more challenging material, particularly if they do not feel that it is personalised to their needs (Bendelin et al., 2011; Gega et al., 2013). This avoidance may lead to a 'pick and mix' approach to information and treatment (Advocat & Lindsay, 2010) and less motivation for those using publicly accessible DMH interventions where the variety of choice could lead to 'window shopping' as they search for a suitable option (Donkin & Glozier, 2012). Yet the promise of DMH is that the information and support it provides can be personalised and tailored to individual needs (Lal & Adair, 2014). When seeking information and support online individuals refer often to its relevance to their own experiences (Gowen, 2013; Schrank et al., 2010) whilst materials that could exacerbate symptoms or increase distress are avoided (Schrank et al., 2010). Young people not only conceptualised technology as a means to control their mental health (Kenny, Dooley, & Fitzgerald, 2014) but also as enabling them to choose how, when and where they get help, and who they choose to tell (Cheek et al., 2014). This also emphasises the role that autonomy plays in what individuals may be seeking from DMH.

2.7.1.2.2 *Choice*

Choice may be considered not only in terms of a decision between online and offline services but also between the various online resources that are available. In recent years there has been an unprecedented growth in DMH, evident by the large numbers of resources now available. In 2013 the IMS Institute for Healthcare Informatics found 16,275 patient-facing health apps on the US iTunes App Store, with mental health the most common with 558 apps (IMS Institute for Healthcare Informatics, 2013). Only two years later another study by the same organisation estimated the number of patient-facing health apps to be closer to 165,000, with numbers of mental health apps remaining the most common at 29%, or approximately 47,850 (IMS Institute for Healthcare Informatics, 2015). A search for anxiety web-based interventions using popular search engines in the UK in March 2015 found 34 programs, mainly CBT, but with variations in cost, focus and evidence-base (Ashford et al., 2016). With large numbers of heterogeneous mental health resources available through digital media the role of choice is pertinent, particularly when considering the shift to consumer access.

When people are faced with large numbers of options this may lead to what is commonly referred to in the literature as ‘the paradox of choice’ (Schwartz, 2005) and ‘choice overload’ (Scheibehenne, Greifeneder, & Todd, 2010). The former refers to reduced wellbeing as a result of too much choice (Markus & Schwartz, 2010) whilst the latter is similar and posits that increased options lead to adverse consequences (Scheibehenne et al., 2010). Research suggests a rather complicated scenario within decision-making, with specific variables contributing to the experience of these concepts (Scheibehenne et al., 2010), but it is clear that in choosing DMH resources or accessing information online individuals are faced with a more complex and difficult interaction than would be expected in a conventional healthcare context. Questions



surround how individuals are making choices, the impact that these decisions can have, and whether these choices are autonomous or driven by commercial, or other, interests. Considering the limited awareness of available DMH resources in the general population and over-reliance on search engines to find mental health information and support (Neal, Campbell, Williams, Liu, & Nussbaumer, 2011) the influence of technology itself in choice – “technologies of choice” (Graham, 2016), e.g. review sites or recommender systems – may also be important.

Decisions within DMH are further complicated by the potential complexity of technology itself, anticipation of future use of clinical data (Grady, 2015), the changing needs of individuals over time (Batchelor, Bobrowicz, Mackenzie, & Milne, 2012), and complicated End User License Agreements, particularly as privacy policies are often absent from health apps (Sunyaev, Dehling, Taylor, & Mandl, 2014). Data may be accessed by third parties on compromised health websites, potentially revealing sensitive and personal details about the user (Burkell & Fortier, 2013; Libert, 2014). Trust is required not only for the information or resources accessed but also the platform that is being used (Stjernsward, Ostman, & Lowgren, 2012). In assessing good quality DMH information and resources it is not clear if individuals have the necessary evaluative tools, whether heuristic or provisional. Although trust in online information is reported as low (Powell & Clarke, 2006; Schrank et al., 2010) there appears to be different measures of credibility used to evaluate expert, assessed through references, and experiential, assessed through ‘crowd consensus’, information (Lederman, Fan, Smith, & Chang, 2014). Consistent approaches include argument quality and the verification and literacy of contributor. Assessment of information may be influenced by the individual’s preconceived beliefs (Keselman, Browne, & Kaufman, 2008), and their comprehension affected by their digital and health literacy (Barnes et al., 2011; Birru et al., 2004; Gray, Klein, Noyce, Sesselberg, &

Cantrill, 2005). There is currently no research exploring how individuals assess other resources, such as online interventions or smartphone apps, although it is possible that peer groups are acting to signpost and provide some level of credibility to resources, much as websites like MyHealthApps (myhealthapps.net) aim to do.

For individuals signposted to resources by a peer group, trust may be built through interactions and disclosures within the group (Bryce & Fraser, 2014) that aids in evaluation. Blogs and social networks can provide a way of sharing resources with others similar to oneself (Torabi, 2016; Ziebland & Wyke, 2012). Whether this is significant in the decisions of users of DMH remains unknown. Additionally, access to online groups may not be specific to an individual's mental health condition (Torabi, 2016). For these individuals the use of search, including search engines, may offer a more convenient way to access resources. Unfortunately, at present the app stores are limited in the filters that can be applied to searches, meaning that individuals looking for mental health apps must use keywords at which point a list of apps are shown based on unknown algorithms. Search engines are not transparent in the algorithms they use, but may personalise their results based on previous searches (which can be linked to the user or to the computer's IP address if they are not logged in) and the device that is used. Whilst search terms such as 'suicide' will result in many search engines displaying emergency numbers there is uncertainty around how they enable and support those seeking DMH resources and mental health information. Recent forays into healthcare by companies such as Apple and Google may indicate that in future these issues will be addressed. What is clear is that for individuals turning to DMH there are numerous choices available and little support in assessing their independent value and efficacy. Research has not yet fully explored the process of choice in DMH.

### **2.7.1.3      *Anonymity***

For those with a strong desire for anonymity, whether due to the visibility of access (Pruitt et al., 2014) or perceived stigma when accessing conventional services (Lal & Adair, 2014) there is some anecdotal evidence that DMH resources are indeed being used as an alternative. In a review of online mental health service access, it was noted that both reducing and avoiding stigma were reasons for seeking support online (Kauer et al., 2014). Anonymity may help individuals to feel able to access support free of judgement (Bradley et al., 2012; Horgan & Sweeney, 2010; McClay et al., 2013; Pretorius et al., 2010), interact and share personal experiences with others free of personal contact or connection (Schrank et al., 2010), and help them to feel safer when seeking information associated with mental health (Gowen, 2013; Knowles et al., 2014). For health bloggers anonymity was perceived as a choice, enabling them to share information they saw as of value to others whilst maintaining privacy (Brady et al., 2016). For participants in a focus group exploring the use of health apps there was an awareness of anonymity as meaning control over functions, such as notifications, which could reveal aspects of healthcare use that they may wish to keep hidden (Dennison et al., 2013). Possible reasons for anonymity may include perceived stigma and the freedom to address concerns without repercussions.

However, anonymously accessing information and support may contribute to negative behaviours associated with the online disinhibition effect (Suler, 2004) and potentially trigger distress. For instance, individuals with schizophrenia reported that too much information online, or reading of experiences similar to their own, could act as triggers that exacerbated their symptoms (Schrank et al., 2010). Along with participants in another study (Pretorius et al., 2010) there was recognition of a need to balance the benefits of learning from others with the potential

negative repercussions that it might have. The desire for anonymity may also translate into protective behaviours offline – for example users of health apps hiding their use (Dennison et al., 2013) or individuals with schizophrenia avoiding communicating to healthcare professionals that they were seeking information and support online (Schrack et al., 2010). Considering the often disempowering or unsupportive responses that many patients report receiving when approaching GPs with information from the internet (Ahluwalia et al., 2010; Bowes, Stevenson, Ahluwalia, & Murray, 2012), it is possible that anonymity online translates to control of privacy offline also.

#### ***2.7.1.4 Pathway or Postponement***

In a review of research surrounding online mental health services Kauer et al. (2014) found that many who were accessing DMH were considered to be highly distressed. A large survey of individuals searching the keyword ‘depression’ on a popular search engine found that three-quarters had symptoms indicative of depressive episodes, with 44.4% reporting current suicidality (Leykin et al., 2012). A study exploring the characteristics of adults using an online mental health service for depression and anxiety found that the demographic and symptomatic representations were highly similar to users of a real world outpatient clinic (Titov, Andrews, Kemp, & Robinson, 2010). Young people in focus groups discussed their aversion to asking for help for mental health concerns and their preference for online help-seeking (Fleming, Dixon, & Merry, 2012). This research suggests that individuals using DMH are potentially those who are distressed and may not be accessing conventional services. Participants in a series of focus groups also reported, from anecdotal evidence, that some users had been referred to cCBT for suicidal ideation without formal screening or diagnosis (Rennick-Egglestone et al., 2016). It is notable that DMH is accessible regardless of diagnosis. In understanding the role of DMH in self-care Lal and Adair (2014) have identified concerns that it will lead to the postponement or

cessation of help-seeking. Daine et al. (2013) conducted a review of studies exploring the use of the internet for suicidal ideation and self-harm in young people, finding that some studies implicated the role of social networks in discouraging disclosure. The effect that ‘the internet’ can have on behaviour echoes research into new media that explore their impact, for example the Werther Effect (Gould, 2001). It is possible that discouragement comes from the normalisation of unhealthy behaviours by peers rather than as a function of the technology itself. What is important to consider is whether it is an inactive influence, such as presented in the Werther Effect (Gould, 2001), or is instigated by the user, such as confirmation bias (Nickerson, 1998).

For study participants, DMH is often constructed as a pathway towards seeking mental health help and support, a ‘stepping stone’ (Ellis et al., 2013; McClay et al., 2013; Pretorius et al., 2010; Rennick-Egglestone et al., 2016). Lillevoll et al. (2013) identify the theme of ‘taking action’, of doing something about one’s mental health, as integral to the experience of an online intervention. This echoes the need for control but also distinguishes DMH as an important choice in seeking help. For individuals who are unable to access conventional services, whether by choice or not, it may be seen as an acceptable alternative. Participants in a series of workshops spoke about their initial perception of cCBT as a stepping stone towards conventional therapy before realising that it provided them with the help they needed (Rennick-Egglestone et al., 2016). For others it reportedly led to further help-seeking (McClay et al., 2013; Pretorius et al., 2010). Young people who were averse to seeking help viewed computerised therapies as a way of gaining confidence (Fleming et al., 2012) along with online mood tracking which was also perceived as helping to identify mental health needs (Drake et al., 2013). This demonstrates that for some individuals DMH is seen as a first step towards seeking help.

Participants also identify the role of DMH in providing information about services available to them (Schrank et al., 2010), which can be used to prepare for health visits (Gowen, 2013; Pohjanoksa-Mäntylä et al., 2009). In addressing the needs that individuals with bipolar disorder have from an online self-management intervention, Todd et al. (2012) found that they were particularly keen for information that could help them in communicating their condition to those around them. There is some evidence that other people's experiences online can offer individuals a way to better understand what to expect from their condition and the mental health services available (Ellis et al., 2013). DMH offers individuals a way to access tools and resources to support self-care, and a way to connect with others around their condition which may provide validation and reflections relevant to their own experiences. Within social work the concept of universalisation – whereby the understanding that others share feelings and concerns helps to alleviate anxiety about, and feel less alone, in one's experience (Davidson & Clarke, 1990) – may also explain the importance that connecting with similar others has for those using DMH. As suggested by participants of a focus group, when accessing and using DMH this may be more or less appropriate at different stages (Rennick-Egglestone et al., 2016).

#### **2.7.1.5      *Role of the 'Other'***

Often users within DMH research are motivated by the control it provides them over their treatment whilst still seeking human contact and support (Gerhards et al., 2011; McClay et al., 2013; Pretorius et al., 2010; Rennick-Egglestone et al., 2016). Whilst these studies typically refer to the support provided through contact with a professional, participants within other studies express how important the support of family or friends are to their use of DMH interventions (McClay et al., 2013; Wilhelmsen et al., 2013). This reflects the role of perceived behavioural control within the Theory of Planned Behaviour and importance of the subjective norm in

motivating use (Ajzen, 1991). However, there is also a desire to avoid reliance on family or friends (Pretorius et al., 2010), where one may feel like a burden (Drake et al., 2013), and to maintain secrecy about one's condition (McClay et al., 2013), which may mean there is little external support available.

The research surrounding online interventions prominently features, as previously addressed, the apparent dichotomy of the desire for control as well as support (Knowles et al., 2014). Whilst the role of the therapist (Bendelin et al., 2011), the researcher (Advocat & Lindsay, 2010), and family and friends (Wilhelmsen et al., 2013) have been identified as motivating the use of DMH, particularly interventions, the role that online peers can play in promoting engagement and continued use is an area that researchers and developers are increasingly exploring (Balatsoukas, Kennedy, Buchan, Powell, & Ainsworth, 2015). The feeling of community reinforced through recognition of similar others may help in fostering a sense of belonging that can aid in reducing isolation and normalizing their experience of mental health (Pfeiffer, Heisler, Piette, Rogers, & Valenstein, 2011). This normalisation can help encourage more positive views of self (Pretorius et al., 2010) but may also lead to normalisation of unhealthy behaviours through their acceptance or even encouragement (Daine et al., 2013). Reassurance through information and the experiences of others can have both a negative and positive impact. Participants report using avoidance as a strategy to prevent exacerbation of negative symptomatology (Schrank et al., 2010) but, for those actively seeking support or a group identity congruent with existing negative behaviours, online support groups may enable access to individuals who can encourage and sustain these (Daine et al., 2013; Haas, Irr, Jennings, & Wagner, 2011). It is interesting to note that the studies demonstrating negative uses identified above are primarily concerned with eating disorders (Haas et al., 2011; Pretorius et al.,

2010), whilst those discussing strategies to promote positive uses involved participants with other mental health concerns (e.g. schizophrenia; Schrank et al., 2010). This suggests that the search either for reassurance related to negative behaviours or cognitions, or the desire to be part of a related group identity, may be influenced by the type of condition.

#### **2.7.1.6      *Role of the Individual***

One's mental health may play an important role in the use of DMH. An anonymous online discussion between mental health service users and professionals about the use of online resources and their potential within mental health service delivery suggests that the suitability of tools may be based on individual differences, many related to mental health itself (Jones & Ashurst, 2013). For instance, cCBT was seen as helpful for mild to moderate conditions whilst forums were anticipated to be most suitable at certain stages of treatment. The qualitative research indicates that DMH use can be influenced by the user's present state. In exploring the motivational drive of users of cCBT for bulimia nervosa participants reported variations in both their needs and experience of the treatment at different stages (Pretorius et al., 2010). For users of an online mood tracker it was reported that both high and low moods could moderate use (Drake et al., 2013). Motivational difficulties are also noted in adherence research of face-to-face therapies (Barrett et al., 2008) and impact engagement as well as efficacy.

Users of DMH report difficulties in remembering or absorbing information due to the cognitive impairments of their condition (Barnes et al., 2011; Rennick-Egglestone et al., 2016) and, for users with multiple sclerosis, their physical health needs (Hind et al., 2010). Users in the latter study also emphasised that materials must be relevant, noting their frustration that content and structure did not take their pre-existing condition into account. Even when the DMH intervention is relevant or generic participants may construct the material as inappropriate



(Gerhards et al., 2011). Potentially, by ensuring DMH is personalised to the individual's experience – as reported by those accessing information online (Schrank et al., 2010) – use can be supported and improved. In a meta-synthesis of qualitative studies around user experience of cCBT, Knowles et al. (2014) structure this under the concept of 'sensitivity to self' and describe it as the need for resources to recognise the demands of mental health, as well as the individual clinical needs and personal preferences – i.e. "who I am" and "how I feel". An automated system can both offer a way of tailoring interfaces and content to the individual, or of delivering a universal experience that appeals to some but not to others. It is arguable that the appeal of DMH is the former. However, there is no research directly addressing the various mental health concerns and how they impact on human-computer interactions, which limits development of DMH interventions. Individuals also note that personal characteristics including laziness (Nicholas et al., 2010) and not wanting to think about their situation (Nicholas et al., 2010; Stjernsward et al., 2012) can prevent them from engaging with DMH.

Personalisation may encourage users to become more engaged through a similar process to 'therapeutic alliance'. Alternatively, it may be that DMH is seen as a resource that is accessed and used as and when it is needed, rather than continually. Although the role that DMH holds in the everyday lives of users, conceived as 'technology-in-practice' (Timmermans & Berg, 2003) or 'in the wild' (Minh et al., 2011; Owen et al., 2015; Rennick-Egglestone et al., 2016), is not understood well, some research has been placed within this context. Anderson et al. (2016) found that users of health apps often use them to achieve goals, discarding them once they are completed. However, some users found health apps that adapted to their needs and these were used continually. Whilst much of mental healthcare is constrained in its delivery, whether a course of medication or therapy, DMH offers ongoing access to resources even when the

individual is seen as recovered. In a review of online mental health interventions adherence was not significantly different whether they were delivered sequentially (n=65, mean 72.1%, SD 21.3%) or were free to navigate (n=17, mean 70.2%, SD 16.2%, p=0.2) (Brown et al., 2016) suggesting that DMH may not require the same structure as conventional treatments. This is discussed more in the concept of ‘e-attainers’ (Christensen & Mackinnon, 2006; Martinez, 2003) within Empowerment (section 2.7.1.7.) Access to resources at the point of need, resources that are relevant to the experiences of the individual, may support the engagement of users in the self-management of their own mental health.

#### **2.7.1.7 Empowerment**

To understand the role that DMH plays in the lives of its users it can be viewed within the framework of empowerment. A concept such as empowerment is best understood as individually constructed and for this reason the Empowerment Scale may help to identify the important concepts from the perspective of individuals with lived experience of mental health conditions (Rogers, Chamberlin, Ellison, & Crean, 1997). Members of the survivor movement in the USA developed a measure of attributes for empowerment in mental health services that was validated amongst users of self-help groups (Rogers et al., 1997). Whether this was reflective of it being tested by self-help groups, the perception of mental health services at the time, or other moderating variables, it remains a commonly used measure of empowerment in self-help research (Crisp, Griffiths, Mackinnon, Bennett, & Christensen, 2014; Resnick & Rosenheck, 2008; Sklar, Groessl, O’Connell, Davidson, & Aarons, 2013; Stenberg, Haaland-Øverby, Fredriksen, Westermann, & Kvisvik, 2016). It serves as a representation of how users of mental health self-help services perceive the concept of empowerment. The attributes initially developed by the advisory board are as follows:

Attributes of Empowerment (Rogers et al. 1997; p.1043)

- Having decision making power
- Having access to information and resources
- Having a range of options from which to make choices (not just yes-no and either-or)
- Assertiveness
- A feeling that one can make a difference (being helpful)
- Learning to think critically; unlearning the conditioning; seeing things differently
- Learning about and expressing anger
- Not feeling alone; feeling part of a group
- Understanding that a person has rights
- Effecting change in one's life and one's community
- Learning skills that one defines as important
- Changing other's perceptions of one's competency and capacity to act
- Coming out of the closet
- Growth and change that is never-ending and self-initiated
- Increasing one's positive self-image and overcoming stigma

These attributes were subsequently analysed to reveal five factors: self-efficacy and self-esteem, power and powerlessness, community activism and autonomy, optimism and control over the future, and righteous anger. In browsing the attributes, it is significant that much of what has been discussed as concepts within DMH from the perspective of its users are also constructed as aspects of empowerment.

Amichai-Hamburger, McKenna, and Tal (2008) have coined the phrase “e-empowerment” to represent the potential of the internet as a tool for empowerment. When used it can help individuals make changes at a personal, interpersonal, group, and citizen level. Much of what they discuss surrounds self-efficacy, which they associate with empowerment, such as the potential for the internet to enable mastery experiences, connecting with similar others, and reduction of stereotypes. For the individual facing mental health challenges much of what Amichai-Hamburger, McKenna, and Tal (2008) describe as e-empowerment is facilitated by the internet. Individuals may use it to reframe their identity in new environments, use the control that they have for social compensation and learning new skills, and, as it is a hidden social stigma,

they may find it easier to connect with similar others whilst maintaining anonymity. In many ways this echoes the concept of self-advocacy, whereby individuals are encouraged to take control of their own lives (Minoletti, 2003). In exploring people's experience of using smartphones in everyday life they were seen to be constructed individually in their purpose, but also challenged users when their 'seamlessness' was broken, leading to cessation of use for that particular function (Barkhuus & Polichar, 2011). This cessation of use may lead to users continually adopting and discarding technologies rather than feeling empowered by their use. Alternatively, users may adopt and discard technologies as they attain specific goals and cessation of use may indicate achievement rather than disappointment, so called 'e-attainers' (Christensen & Mackinnon, 2006; Martinez, 2003). Thus, DMH use may not be sustained for several reasons.

Much of the literature indicates that user experience of DMH involves some level of positive change. Both adolescents and their parents reported that the increased understanding of depression provided by CATCH-IT, an online depression prevention intervention, contributed to feeling able to actively engage in related situations and improved attitudes towards help-seeking (Iloabachie et al., 2011). For users of an online bipolar education program some users, constructed as 'e-attainers', reported stabilisation of moods as a reason for attrition, and indicated that they would return to the program when they felt it was needed (Nicholas et al., 2010). Individuals using a variety of DMH resources have reported increased awareness of their needs and being able to apply strategies learned to their daily life (Anderson et al., 2016; Gega et al., 2013; Schrank et al., 2010). For some, however, there may be adverse responses to online information (Schrank et al., 2010) and difficulty implementing strategies into daily life (McClay et al., 2013). Whether this dichotomy of experience is a result of the resource or the individual is

unclear and indicates that further research is necessary to understand the experience of DMH in more detail.

### **2.7.2 The Professional Experience of DMH**

This section explores the research surrounding the experiences of system builders within DMH, individuals who contribute to the building of resources. As there are few studies that directly address this area there is much reliance on research into user experience and low quality publications. However, what research there is serves to begin the construction of professional roles and elucidates how these roles are perceived within current literature.

What is particularly important to note throughout The User Experience of DMH (section 2.7.1.) is the role the researcher plays in the experiences of participants. As much of the data is collected alongside or in connection with existing trials of internet or computer-based mental health interventions, the researchers themselves are often a salient part of the user's experience. Donkin and Glozier (2012) incorporated "obligation to researchers" into their model of motivators of adherence to an online psychological intervention. Gerhards et al. (2011) also considered how participation itself could be considered an extrinsic motivator to continue with cCBT. Advocat and Lindsay (2010) explored the experiences of trial participants directly and found similar, that they felt responsible to the researcher. This would suggest that a feeling of responsibility is paramount in user's experiences of DMH and yet it is linked to the role of researcher, which does not exist for users 'in the wild'. However, as discussed in Role of the 'Other' (section 2.7.1.5.), support does appear to play a prominent role within DMH. Whether there is a need for a position to be conceptualised, for motivation or to promote trust, is unclear due to the nature of present research. Within studies exploring the promotion of engagement to online interventions the concept of "supportive accountability" is sometimes used to refer to the

provision of human support to enhance adherence (Danaher et al., 2012). It is possible that researchers provide this function not as an element of their position but as an element of engagement.

Knowles et al. (2014) identified that DMH involves a complex balance between autonomy and support, as discussed in Control (section 2.7.1.2.1.). Advocat and Lindsay (2010) also found that participants saw themselves as autonomous users and free to engage in a “pick and mix” strategy. In Donkin and Glazier’s (2012) study this was termed “window shopping”. These terms echo the ‘consumer’ of healthcare (Eysenbach & Köhler, 2002) and mobile health technologies (Free et al., 2013) and appears to contradict the responsibility users felt to the researcher. It may be that whilst the obligation can lead to motivation to maintain use, that the type of use might remain unaffected as this shifting pattern of usage was considered by participants to be integral to their engagement. This suggests that underlying the purpose that individuals find within DMH there are multiple variables that may differ depending on context, and in turn influence use. Some research has addressed credibility of sources within DMH, particularly authorship of information online (Eysenbach, Powell, Kuss, & Sa, 2002; Reavley et al., 2012). However, earlier findings suggested a discrepancy between consumer’s reported assessment criteria, which closely matches conventional criteria such as verification across sources, and actual use (Eysenbach & Köhler, 2002). Whilst this study is well-cited it has not been replicated. Musiat, Goldstone, and Tarrier (2014) found in a survey asking how people might choose different mental health treatments, including web-based, app, or face-to-face, it was found that credibility was only seen as important for the latter. This suggests that the source, or developer, of DMH resources may not be a salient aspect within use. Indeed, many depression

apps do not clearly state affiliations, evidence, or source of content, thus making assessment of credibility difficult (Shen et al., 2015).

The experiences of developers and researchers in digital health are under-researched, particularly from a qualitative perspective, despite sociological recognition of their role in the construction of meaning around technologies (Oudshoorn & Pinch, 2005). Developers and researchers can be viewed as system builders in that they build some components, but there may be others that contribute to the system (Hughes, 1994). Hughes (1994) identifies them as important for their centrality within the chaos, whilst for Woolgar (1990) it is their configuration of the user, the representation for which they develop, that is of interest. Lindsay (2005) proposed that once a technology is disseminated the users begin to play an ‘ontogenetic’ role through their appropriation, contributions, and lay support, therefore positioning them as developers. Vennik, Adams and Putters (2015) considered how the technology itself can offer insight into the ‘script’, i.e. the projected user ascribed to the technology by the developer. It was hypothesised that a website marketed as encouraging ‘active patients’ could offer insight into how this concept was scripted into the actual design. Through the website and interviews they found not only were there presumptions made about both the users – at times using I-methodology – and the role the website played in promoting ‘active patients’, but the users also modified and disrupted scripts for their own needs, particularly if they did not conform to the developer’s configured expectation of a user (Vennik et al., 2015). The system builder not only views a system from a central perspective, enabling a view of the chaos, but their contributions often represent structure that is rich in meaning, dynamically constructing the anticipated user and potentially positioning themselves in that role.

However, these discourses prioritise the experience of users over developers. Although there is some research exploring provider experience in DMH (Salloum, Crawford, Lewin, & Storch, 2015; Schueller, Washburn, & Price, 2016) there is very little that directly addresses the system-builders of DMH, i.e. developers, researchers, marketers, etc. Instead, this literature review must attempt to capture what little is available from a variety of disciplines. Balebako, Marsh, Lin, Hong, and Cranor (2014) delved into smartphone app developer's understanding of privacy and security in a mixed-methods study that demonstrated restricted awareness and a decision process informed by their limitations rather than best practice, based on 13 interviews and a survey of 228 app developers. Their results suggested a conflict between expectations and beliefs. For instance, although privacy policies are considered important in assessing the 'trustworthiness' of an app (Sunyaev et al., 2014) many saw them as unnecessary, and evidence of legal compliance rather than transparency. However, developers involved in technologies for health or aimed at children appeared to be more aware of privacy needs. Considering these findings, it is surprising that digital health professionals have not been the target of more research. Instead, there have been numerous articles illustrating how developers and researchers can implement features more effectively (Bennett, Bennett, & Griffiths, 2010; Dehling, Gao, Schneider, & Sunyaev, 2015; Filkins et al., 2016) and some that outline the personal experience of the development process.

There are several themes that encompass the majority of articles related to personal experience of the development process. Vermeulen et al. (2014) qualitatively explored the experiences of a multidisciplinary team involving end-users, both clinicians and laypeople, engineers, managers, and researchers in the development of health technologies. Proudfoot et al. (2003) reported on their experience as researchers of developing a computerised therapy



program. Revenäs et al. (2015) addressed the challenges and solutions their multidisciplinary team of users, researchers, an eHealth strategist, physiotherapist, and member of a patient organisation faced during the initial drawing up of specifications for an online self-management platform. Topham et al. (2015) describe the processes, and their experiences, of developing a mental health app in a research environment using students, staff, researchers, and developers. The varied and fluid roles were salient in much of the research, and considered important in addressing the responsibilities expected from individuals, an important element of successful co-design and cooperation (Proudfoot et al., 2003; Revenäs et al., 2015; Vermeulen et al., 2014). Due to the interdisciplinary nature of the various participants establishing a language that could be understood by all was a challenge (Proudfoot et al., 2003; Revenäs et al., 2015; Topham et al., 2015; Vermeulen et al., 2014). For some researchers their position as ‘contractor’ of external developers also proved difficult. For Proudfoot et al. (2003) the first two developers were unable to complete work to a satisfactory standard, necessitating cessation of their contracts. For those involved with the development of a mental health app there was a need to negotiate a new relationship between contractors and developers that required more collaboration than is usual (Bergin, 2015). However, these views are only those of the researchers, the voice of the developers themselves are absent in both development cycles reported.

A literature review exploring the benefits and barriers of involving users in medical device technology development and evaluation found that whilst the benefits included aspects such as improvements and reduced costs, the challenges were considerable (Shah & Robinson, 2007). Developers are dependent on the availability of users who may have low technical literacy and are faced with regulations and ethical approval demands that could be avoided by using non-clinical populations. However, funding is increasingly tied to a requirement that user-

centred design is used within development (Martin & Barnett, 2012). Developers of medical devices constructed users, even patients using devices in their home, as not influential and that their involvement delayed development and incurred unnecessary costs (Money et al., 2011). Developers configured users through involvement of ‘clinical champions’, usually senior staff, who were viewed as those who would market the device and therefore knowledgeable by reason of their decision-making powers. The role of end-users was to verify the value of the fully-developed device, where ‘no news was good news’ (Money et al., 2011). It seems that in development the decisions and uptake depend on satisfying the influencers, i.e. those who buy their product, rather than users (Shluzas, Steinert, & Leifer, 2011). System builders must also weigh up the difficulties of accessing users in ‘sensitive situations’ (Matthews et al., 2008). In these environments ethical approval processes may be lengthy and lead them to construct a development process that avoids disrupting existing practice or avoid user involvement until the ethical application can be situated within a more clinical presentation, such as clinical trials (Money et al., 2011). It is clear from the discourse of qualitative research in DMH that the experience of the user is prioritised as studies addressing other populations mainly focus on their configuration of the user. This study aims to re-centralise them within DMH, consider their own constructed meaning, and explore their experience within DMH as distinct from the user. Thus the subworld of system builders is viewed as complex and offering considerable value in understanding the social world of DMH.

### **2.8 Study Aims and Objectives**

The aim of this research is to explore and co-construct an understanding of DMH through the experiences of those involved outside of the conventional healthcare system. It will consider meaning in the wider context of various social worlds, using an adapted Grounded Theory (GT)

to reflect on the interrelationships between early adopters and system builders in co-constructing a place within the everyday for the implementation of DMH. As clearly shown within this Literature Review there are major gaps in the research surrounding DMH. The experiences and motivations of system builders are underrepresented. This research aims to incorporate their meaning-making within the construction of categories and concepts. User experience research in DMH appears to often contain influential researchers whose presence may motivate users to adhere in their use of resources (Advocat & Lindsay, 2010; Danaher et al., 2012; Donkin & Glozier, 2012). This suggests that more research needs to explore experience “in the wild” (Owen et al., 2015; Rennick-Egglestone et al., 2016) so as to understand how purpose and meaning is constructed when users are outside of clinical and research contexts. Research into the meaning of DMH to users and system builders is often based on surveys or specific resources whilst participation tends to be as part of existing trials. However, the presence of ‘e-attainers’, those who use DMH resources when they are needed (Nicholas et al., 2010), would suggest that use does not conform to conventional perceptions of mental health treatment. Further, there are recognised concepts, such as ‘anonymity’, that are yet to be investigated in the context of DMH use. This study aims to address these gaps in our understanding of DMH and its meaning for users and system builders. It will seek to present rich and in-depth data supporting constructed meanings around the experience of building and applying DMH resources in an everyday context.

### **2.9 Summary**

This literature review has provided a summary of the most common digital mental health resources that are available. It has synthesised research into the experiences of those within DMH and has identified a gap in the literature surrounding the construction of meaning by users,

researchers, and developers of DMH, and recognised the need to explore these in relation to ‘technology-in-practice’ and ‘in the wild’. It identifies a significant gap in the literature with regards the experience of developers and researchers, those who construct the concept of the user and use – the purpose – of the technology itself. In exploring the area of DMH ‘in the wild’ the social worlds involve an interplay of conflicting and at times complementary dynamics, yet it remains largely unexplored. By recognising that individuals with an array of mental health needs are utilising DMH outside of clinical oversight there must also be recognition and involvement of the meanings constructed by those creating and marketing the various resources available, particularly when it is understood that users assimilate and adapt to these meanings. Also of interest to the present study are the processes by which, and through which, individuals take on and act accordingly within the various social worlds in DMH. A greater understanding of these processes can be provided by exploring the construction of meaning theoretically.

### 3 Research Paradigm

#### 3.1 Introduction

*“Because of the essential relationship that human experience bears to its objects, no objects can be adequately described in isolation from the conscious being experiencing it, nor can any experience be adequately described in isolation from its object.” (Crotty, 2015: p.45)*

To understand the methodological choices within this thesis, this chapter will present my ontological, epistemological and methodological perspectives (Denzin & Lincoln, 1998), particularly with regards its relation to the field of digital mental health (DMH). It is asserted that whilst different paradigms might ‘fit’ within DMH it is the researcher’s own position that will most often lead the direction of research. The present study is approached from a social constructionist perspective, representing the many layers of meaningful reality, the differing contexts in which they are communicated, and the position occupied by the researcher who acts to co-construct meaning alongside the experiences of others. Accepting the epistemological approach that the researcher’s engagement helps shape the process of research implies a moderate position in social constructionism (Elder-Vass, 2012). This also accepts the axiological view that I as the researcher influence the research design itself (Yilmaz, 2013). To ensure that this research paradigm is suitable for the present study, including for DMH, this chapter will address my position as researcher, explore several alternatives, and demonstrate how an adapted Grounded Theory Methodology (GTM) was found to be most appropriate.

Traditionally, a discussion of research methodology will begin by addressing qualitative and quantitative methodologies. However, I agree that these terms often relate to the methods used

rather than the methodology, particularly as both can be applied within the same research paradigm (Guba & Lincoln, 1998). A research methodology alone may explicate clearly the ‘how’ of research but it does not establish the ‘why’ – the beliefs that the researcher holds as to how and why this knowledge is sought. It also does not clearly identify the researcher’s role, whether emic or etic. As the chosen methodology is that of Grounded Theory (GT), the multiple interpretations of such lead to what is at times termed a ‘methodological spiral’ that is underpinned by the epistemological beliefs and basis within the research (Mills, Bonner, & Francis, 2006; Mills, Chapman, Bonner, & Francis, 2007). A clear rationalisation of the research paradigm that includes the ontological, epistemological, and methodological positions held by the researcher is advisable (Guba & Lincoln, 1998; Nagel et al., 2015). By so doing, the researcher can be sure that their positions are complementary rather than contradictory. In Guba and Lincoln’s (1998) discussion of four main paradigms; positivistic, postpositivism, critical theory and related ideological positions, and constructivism are named. Through a discussion of these in relation to DMH, the justification for why a constructivist paradigm was chosen will be made. Further, the choice of an adapted GTM will be subjected to a range of challenges and criticisms that will help illustrate how the researcher has reconciled these.

Please note that the term ‘constructivism’ is used to identify the broader perspective that people construct reality whilst ‘constructionism’ typically refers to a social constructionist perspective that frames the theoretical presumption that people construct multiple realities through their actions, e.g. symbolic interactionism (Charmaz, 2014).

### **3.2 Ontological Position**

Ontology refers to beliefs about reality. Whilst there are many levels of belief the main types are realism – the belief that there is a singular and apprehendable reality – and relativism – the

belief that there are multiple and subjective realities (Guba & Lincoln, 1998). This ontological enquiry focuses on whether, as a researcher, the belief and meaning ascribed by individuals is ‘real’ or ‘relative’. Within DMH there are multiple types of resources that utilise different devices and technologies that are developed and designed by individuals and teams for specific purposes. Technology has been of particular interest to researchers who explore the ways in which users reconfigure devices or functions to suit their own needs or traditions (Bauchspies et al., 2006; Bijker et al., 1994; Oudshoorn & Pinch, 2005). For instance, Nettleton, Pleace, Burrows, Muncer, and Loader (2002) found that the World Wide Web can be used to provide and receive support for a range of health issues and social concerns despite it not being designed specifically for this purpose. A relativistic perspective acknowledges that individuals, in their use of technologies, can maintain different beliefs about the reality of that use.

On a more personal and reflective note, I have long held a relativistic ontology. As a teenager I wrote stories in which princes, brought up to commit terrible acts, become kings that terrorise and torture. Their subjects’ anguish reassures them their rule is good; they think this is right. Who might challenge this, who decides what is wrong or right and how do we define what this is: asking these questions resulted in me exploring how we make these decisions, the space between what is right and wrong, and how our realities are formed. Whilst I never questioned the ‘truth’ of certain aspects of reality, such as gravity, it instilled a curiosity as to the myriad ‘truths’ we might hold about more abstract concepts such as power and purpose. A computer might for some be a device on which to play games alone whilst for others it is a conduit to others. Now, as a researcher, I am firmly positioned in my belief that there are multiple and subjective realities for concepts such as these, although I am ambiguous as to whether there is a singular objective reality of, say, a computer.

### 3.3 Epistemological Position

Epistemology relates to the position of the researcher in respect of the object or phenomenon being researched (Yilmaz, 2013). Positivistic and postpositivistic paradigms hold that the researcher is able to remain apart from what is being studied, whilst critical theory and constructivist paradigms recognise the influence of the researcher (Guba & Lincoln, 1998). This is also termed *etic*, an objective perspective, and *emic*, an ‘insider’ perspective. Within qualitative methods researchers will often seek to become closer to the object or phenomenon of interest, welcoming their role as an ‘insider’ (Yilmaz, 2013) whilst for research conducted according to a positivistic tradition, objectivity is ideal. In several DMH studies that have explored the use of resources, a considerable motivator of adherence has been found to be the presence of the researcher (Advocat & Lindsay, 2010; Donkin & Glozier, 2012; Gerhards et al., 2011). This suggests that it may be difficult to truly account for the influence of the researcher, although it may be possible to reduce the impact. It is also potentially of more interest to seek to explore this dynamic rather than try to remove it, by acknowledging and embracing this impact as forming part of an interaction rather than as a confounding variable.

As a researcher I feel that it would be impossible to remove myself completely from the data. Whether it is the choice of questions that are asked or the analytical insights that are made the voice of the researcher, their ‘authorship’ to use Foucault’s term (Foucault, 1979), is ever present and by recognising this its influence becomes an element of the study rather than a bias to be justified. Although it may seem to bypass rather than challenge criticisms of the ‘received view of science’ (Guba & Lincoln, 1998), I believe it is more suitably seen as an acceptance and admittance of these. Rather than attempting to control and thereby deceive or inadvertently obscure the researcher’s role I feel it is important to explicate my part where possible so that



readers might be reminded that it is I who speak and it is I who construct and weave the data together, albeit alongside other individuals who have contributed through their own constructions and voices.

### **3.4 Methodological Position**

The methodological position of a researcher must reflect their ontological and epistemological positions in that it identifies the way in which knowledge is sought based on the beliefs of where it can be found and what can be known (Guba & Lincoln, 1998). For instance, if a hypothesis is formed based on a priori knowledge then the researcher must seek to verify or falsify that hypothesis, necessitating a realist ontology and an objective epistemology such as those within positivist and postpositivist paradigms (Guba & Lincoln, 1998). Likewise, holding a relativist ontology and subjective epistemology, such as critical theory and constructivist paradigms, would challenge the development of hypotheses prior to commencing research. Instead these positions are more suited to a dialogic and dialectical methodology, one that values interactions between the researcher and individuals (Guba & Lincoln, 1998). Although this might be indicative that a quantitative method would be most suited to the former whilst a qualitative more suited to the latter, it can be argued that these methods can both be applied across all paradigms so long as the methodological position is maintained.

It is clear that as a researcher my choice of methodology, and indeed my research paradigm, sit within what Guba and Lincoln (1998) term “critical theory and related ideological positions” and “constructivism”. They themselves are constructivists, which may explain their grouping of postmodern and poststructural approaches into the singular ‘critical theory et al’ paradigm. They describe the critical theory ontology as ‘historical realism’ which, whilst perhaps defensible, also dismisses the much wider discussion that can be had around different nuances

within realism, such as critical realism vs naïve realism (Robson, 2002). In establishing myself firmly within a paradigm it became clear that whilst my ontological position might differ slightly from postmodern and poststructural approaches there was not so significant a difference that I could dismiss them outright. This necessitated a more in-depth analysis of these approaches and reflection as to what knowledge I sought, and how, within my research.

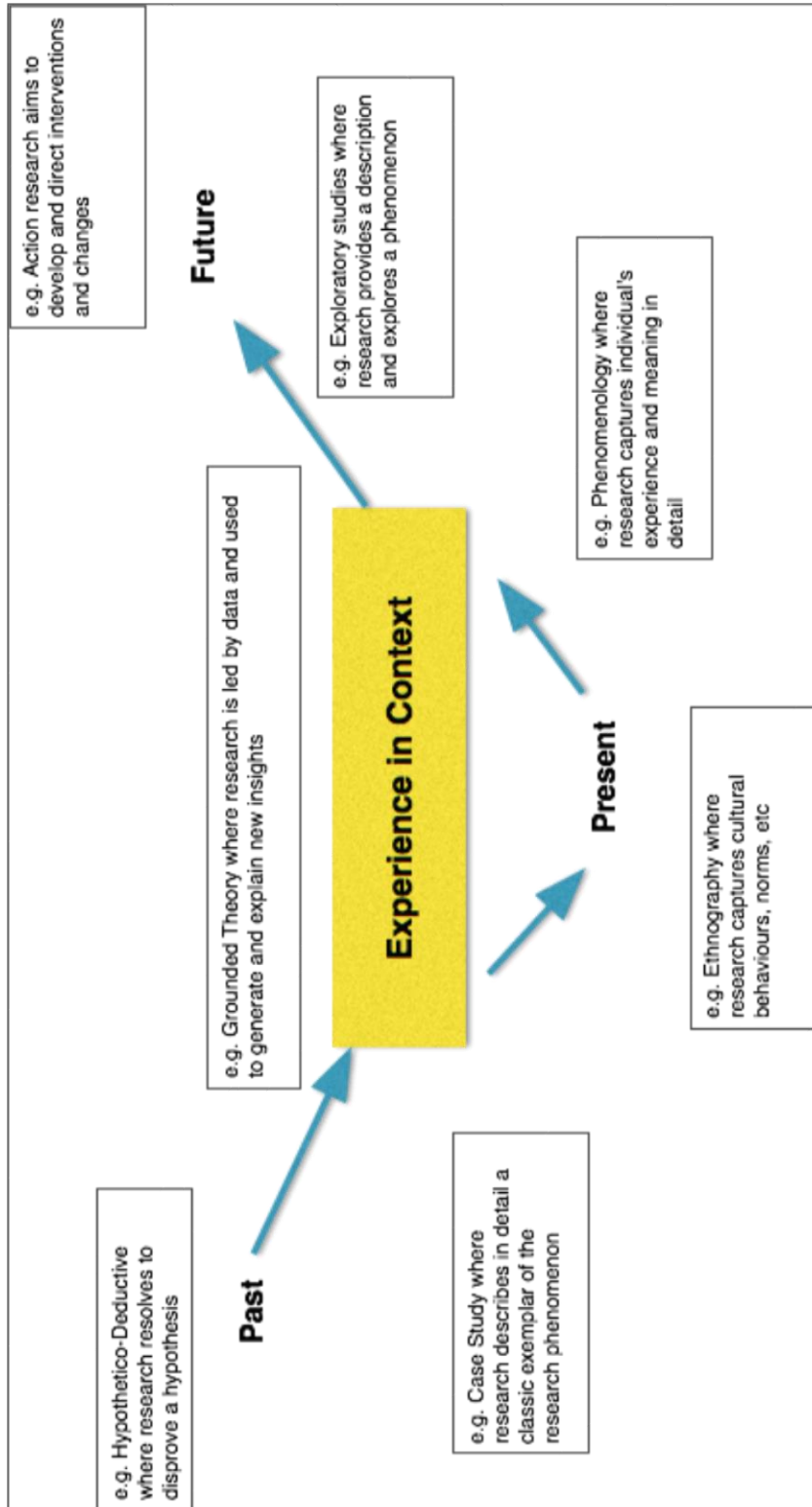


Figure 3. Demonstrates methodologies on a temporal continuum.

The methodological decision was made through the lens of ‘experience-in-context’ (Figure 3.), so as to recognise the reciprocal and extensive interrelation of macro, midi, and micro realities within analysis (Burgoyne & Lorbiecki, 1993). This reflects not only Strauss’ social worlds (Strauss, 1978) as discussed in The Social World of DMH (section 2.6.) but seeks to explore practice in everyday life (de Certeau, 1988), and ‘in the wild’ (Owen et al., 2015; Rennick-Egglestone et al., 2016). ‘Experience-in-context’ describes my research objective to capture the constructed purposes and meaning of DMH within the constructions communicated by participants, recognising that their experience and the context or object are best understood in association. Figure 3 demonstrates my thought process in working through the temporal-spatial positions captured by various methodologies to assess their suitability. The phenomenological approach offers strategies to explore the lived experience of a phenomenon whilst GT seeks a contextual approach that can be used to inform models upon which to build further research or interventions (Starks & Brown Trinidad, 2007). Whilst research seeking to understand the lived experiences of individuals, applying phenomenology, could offer insights for stakeholders in DMH, GT offered a more practical outcome in that it moves beyond description to a constructed theory that recognises the complexity of experience. Results in DMH research are often dichotomous, for instance Daine et al. (2013) found that the internet played a role in both alleviating and exacerbating distress in young people, which suggest the need to embrace complexity. For the reasons outlined here an adapted GTM was deemed to be most suitable.

### **3.4.1 Methods in DMH**

When considering the most appropriate methods in research the various types of approaches must be considered alongside the most applicable data to be collected; whether qualitative, quantitative, or both. One of the key gaps identified in the literature was around

understanding DMH as a component of wellbeing, a perspective that could understand how it is applied in practice by stakeholders ‘in the wild’. Hypotheses extrapolated from the available research would be limited to addressing singular aspects; for instance, of the technology, the treatment, or a condition. In addressing the ‘experience-in-context’ of DMH the paradigm must embrace non-deterministic methodologies that can limit and isolate both technology and its use to viewpoints that do not consider how they interact within social worlds (Latour, 2005), thus limiting their applicability to ‘real life’. Indeed, there have been various calls for a move to study ‘technology-in-practice’ (Timmermans & Berg, 2003) so that these complex issues may be better understood. This is particularly relevant in healthcare considering the interplay of implementation, adherence, power dynamics, and the various social actors that co-exist and co-construct ‘purpose’ within their social worlds (Knowles et al., 2014). Quantitative research is limited in that it can strip away the context and exclude the meanings and purpose attributed by individuals, who are often generalised (Denzin & Lincoln, 1998; Yilmaz, 2013). Mixed-methods, where both quantitative and qualitative data are used in a single study, are gaining in popularity alongside pragmatic approaches (Robson, 2002) but seemed unsuitable for the present study considering the limited literature from which to build hypotheses and theories around the purpose of DMH (Yilmaz, 2013). In personal discussions with developers of DMH resources they communicated that there is often already a deluge of questionnaires within the resources themselves, attempting to demonstrate effectiveness or understand their users better within the limits of calculable data. The speed at which technology changes also leads to the potential for research to easily become obsolete. The depth of a PhD thesis offered me the opportunity to explore these experiences qualitatively and immerse myself in the world of DMH to a level not always possible in research.

### **3.4.2 Analytical Decisions**

To make a choice between the various methods and methodologies available, ranging from quantitative methods such as surveys to qualitative methodologies such as Interpretative Phenomenological Analysis, I felt it was important to consider not only how the research would be conducted but also how it would be analysed. The process of analysis must fit not only the researcher's own intuitive reasoning but also the underlying aim of the research (Guba & Lincoln, 1998; Mills et al., 2006; Suddaby, 2006). As such, I have included a brief outline of the three main branches of reasoning – deductive, inductive, and abductive – along with identification of common methodologies that apply. Each is discussed with reference to the area of study, and the aim of capturing 'experience-in-context' and my own personal considerations.

#### **3.4.2.1 *Deductive Approaches***

To understand the individual's experience within DMH meant that a traditional hypothetico-deductive approach, where an a priori research question is established and tested, presented certain limitations (Denzin & Lincoln, 1998). Deductive reasoning applies more and more narrow premises until a conclusion is reached as the only possible answer. To understand the 'experience-in-context' a broader viewpoint was required, one that could adapt to the concepts revealed through the research itself and that could be informed by the experiences of the people involved. In this instance deductive reasoning contradicted my underlying ontological, epistemological, and methodological beliefs.

#### **3.4.2.2 *Inductive Approaches***

The inductive approaches, including case methods and interpretivist perspectives, offer researchers a way of exploring the experiences of individuals in-depth (Denzin & Lincoln,

1998). Within inductive approaches the aim is to conceive of an explanation, one that appears reasonable and which is built from the premise or premises outlined. In many ways it assumes a reality, or in the least a truth, within the premise or premises viewed that can be induced. When an induction is considered from the interpretivist or constructivist paradigms, for example within ethnography or phenomenology, there is a boundary that is necessarily placed – that of what can be known. For instance, in ethnography we may explore a ‘culture’ but of necessity we restrict our observations to an a priori group we have defined. In phenomenology we must select and observe in great detail a subset of individuals, taking great care in identifying their realities and exploring their meanings. What led me in the first instance to qualitative research was the uncertainty, the complexity and ‘fuzzy’ logics that it seemed possible to acknowledge. I did not feel that inductive approaches were embracing these to their full advantage.

### **3.4.2.3      *Abductive Approaches***

An approach that offered a way to explore an area as under-researched, novel and complex as DMH appeared to be offered via abductive reasoning. Using an abductive approach offered a way to detect phenomena in the area of study and work towards the construction of concepts that might help future researchers, developers, users, and other stakeholders, utilise or work within DMH more effectively (Tavory & Timmermans, 2014). Haig (2005) identifies GTM as capable of exploring both phenomena detection and theory construction abductively. An approach that utilised GT had the potential to enable an exploration of the complexity and uncertainty of DMH, accepting researcher preconceptions but also leading the research to the areas of interest without setting boundaries. A GT approach also offered a way of exploring the purpose and meaning of DMH from an individual perspective to detect phenomena, useful for further research, without necessitating within the limited timespan of a PhD and in such a novel

area that this superficially move to evaluation of theory. It accepts that concepts may be constructed and remain theoretical until further tested, and encourages acceptance of variations (Tavory & Timmermans, 2014).

### **3.5 Grounded Theory in DMH**

Several researchers have utilised a GT approach to explore the experience of DMH (Gerhards et al., 2011; Iloabachie et al., 2011) whilst others have recognised the role it can play in providing stakeholders in the development of DMH resources with significant and practical concepts to improve use and delivery (Leung et al., 2016). A framework, such as that used by Singleton, Abeles, and Smith (2016), has the potential to generate data that enables the researcher to explore subjective perceptions of an experience and construct an actionable theoretical framework, even within a small number of participants. Whilst Gerhards et al. (2011) and Iloabachie et al. (2011) explored experiences specific to a single resource, cCBT, Singleton, Abeles, and Smith (2016) addressed young people's experience of social networking sites in general alongside mental health and wellbeing, demonstrating that theoretical constructs of interest can be constructed around a much broader viewpoint of technology. The young people in their study, whilst accessing mental health services, engaged actively in external technology use that impacted on their mental health and wellbeing. This suggests that exploring technology use outside of services and how they are experienced will not only inform DMH developers and academics, but also providers of mental health services.

### **3.6 An Adapted Grounded Theory Methodology**

*The Discovery of Grounded Theory* by Barney Glaser and Anselm Strauss in 1967 is the seminal work on GT and one of the first to outline a methodology for generating theory from qualitative data. Classic GT, sometimes referred to as Glaserian GT, maintains that the



researcher is an observer and that a theory emerges from the data (Pidgeon & Henwood, 1997). There are alternatives to this positivist approach (Allen, 2010) that offer more structured analysis methods (Corbin & Strauss, 2015) or recognise the position of the researcher as more than an observer (Charmaz, 2014). In choosing GTM it is important to consider the many perspectives on mental health discourse, experiences, treatment, outcomes and research (Brown, 1995) within the meanings held by participants, and also the many perspectives held around technology including uses, purpose, objects, activities, and beliefs (Bijker et al., 1994). As a researcher, but also as someone with previous experience in DMH, I am clearly sensitised to certain concepts. Whilst the aim of this research is to construct meaning from those I interview and observe, it is also essential to reflect on how my own perspective might influence the analysis of meaning. Accordingly, the study used an adaptive social constructionist GT methodological approach, according to Kathy Charmaz (2014), that enables data to be considered from multiple perspectives and sources, to be interpreted in a rich in-depth exploration of the meanings people place on their mental health and the technologies they use, as well as their interactions with the world around them. Memos also contribute to the research process by ensuring consistent reflections and a recognition of the researcher's own meaningful reality alongside the elicited meanings of participants. Table 3 outlines the three main GT approaches, Glaserian (Glaser, 1992, 2002), Straussian (Corbin & Strauss, 2015; Strauss & Corbin, 1990), and Constructivist (Charmaz, 2014) and compares them across a number of dimensions. This is adapted from Jones and Alony (2011) with the addition of the Constructivist column which uses Charmaz's *Constructing Grounded Theory* (2014).

Table 3. *This table demonstrates the differences and similarities between Glaserian, Straussian and Constructivist GT approaches.*

	<b>Glaserian</b>	<b>Straussian</b>	<b>Constructivist</b>
<b>Starting point:</b>	Beginning with general wonderment (an empty mind)	Having a general idea of where to begin	Beginning with sensitising concepts and general disciplinary perspective
<b>Theoretical underpinning:</b>	Emerging theory, with neutral questions	Forcing the theory, with structured questions	Theory is constructed, with neutral questions
<b>Aim:</b>	Development of a conceptual theory	Conceptual description (description of situations)	Construction of an original theory
<b>Process:</b>	Theoretical sensitivity (the ability to perceive variables and relationships) comes from immersion in the data	Theoretical sensitivity comes from methods and tools	Theoretical sensitivity through theorising
<b>Theory source:</b>	The theory is grounded in the data	The theory is interpreted by an observer	The theory is co-constructed by researcher and data
<b>Quality and criteria:</b>	The credibility of the theory, or verifications, is derived from its grounding in the data	The credibility of the theory comes from the rigour of the method	The credibility of the theory comes from the depth and richness of the data along with the strength of analysis
<b>Role of social processes:</b>	A basic social process should be identified	Basic social processes need not be identified	Basic social processes may help construct data
<b>Role of researcher:</b>	The researcher is passive, exhibiting disciplined restraint	The researcher is active	The researcher is active
<b>Role of data:</b>	Data reveals the theory	Data is structured to reveal the theory	A theory is constructed by the researcher from the data

	<b>Glaserian</b>	<b>Straussian</b>	<b>Constructivist</b>
<b>Coding:</b>	Coding is less rigorous, a constant comparison of incident-to-incident, with neutral questions and categories and properties evolving. Care must be taken not to ‘over-conceptualise’ but to identify key points	Coding is more rigorous and defined by technique. The nature of making comparisons varies with the coding technique. Labels are carefully crafted at the time. Codes are derived from ‘micro-analysis which consists of analysis of data word-by-word’	Coding is less rigorous, involving constant comparison, neutral questions and the construction of categories from the data.
<b>Analysis:</b>	Two coding phases or types: simple (fracture the data then conceptually group it) and substantive (open or selective, to produce categories and properties)	Three types of coding, open (identifying, naming, categorising and describing phenomena), axial (the process of relating codes to each other) and selective (choosing a core category and relating other categories to that)	Coding begins with initial codes, where data is coded line-by-line or incident-with-incident. This then moves to focused coding where relationships between initial codes are refined into categories. Lastly, theoretical coding brings categories together.
	Regarded by some as the only ‘true’ GTM	Regarded by some as a form of qualitative data analysis	Regarded by some as a ‘modern’ GTM

*Note. This table is taken in part from Jones and Alony (pp.99-100; 2011) but with the addition of the constructivist approach, most recognisable as that held by Charmaz (2014).*

Table 3 shows numerous divergences from the ‘classic’ Glaserian approach through to the updated Straussian and Constructivist approaches, although there are also similarities that may be seen as the underlying processes within the GTM. These include theoretical sampling, constant comparison, coding, and memo-writing (Nagel et al., 2015). Although different

paradigms and methods are prioritised and applied, these serve to structure this research methodology and identify it within a GTM.

### **3.6.1 Critique of GTM**

As with any methodology, and particularly inherent to qualitative research (Yilmaz, 2013), there are numerous criticisms that have been aimed at GT approaches over the years. For Glaser and Strauss, in the original GTM, it was *only* (emphasis in original) sociologists that could generate theory, which was discovered within the data collected by the sociological researcher (Glaser & Strauss, 1967). Strauss and Corbin later considered theory to be built and emphasised the importance of its resonance with the everyday reality of the individuals who had been studied (Strauss & Corbin, 1990). However, they also identified theoretical sampling as stemming from the researcher, which challenged the classical view that data indicated the direction of sampling and introduced the concept of a more active researcher. Critics saw this as creating a preconceived bias that meant the research was led by the researcher (Evans & John, 2013) but others such as Charmaz (2014) acknowledged the role of researcher through a constructivist approach, recognising these ‘preconceptions’ within the methodology itself. This approach also accepted Glaser and Strauss’ initial basis for GT as theory grounded in data (Glaser & Strauss, 1967), Corbin and Strauss’ recognition of both researcher and participant (Corbin & Strauss, 2015), and applies a research paradigm that attempts clarity and trustworthiness by identifying the researcher’s part in constructing theory.

GTM aims to develop, build or construct – depending on the chosen paradigm – a theory. It is important to define what is meant by this term as one of the prominent criticisms of GTM is the multiple definitions of theory given by researchers (Charmaz, 2014). The term theory comes from the Greek word “theoria” meaning “contemplation, speculation; a looking at, viewing”

(Harper, n.d.). For Glaser and Strauss (1967) theory could be either substantive, based on the narrow context in which the research was conducted, or formal wherein the analysis could be abstracted to formulate theories applicable to wider contexts. Formal theory was desirable. Strauss and Corbin (1990), however, identify formal theory as emerging from a study that explores a particular phenomenon in a variety of different situations. This establishes theory as an element of either broad or narrow contextual data collection. Charmaz (2014) once again sees the move to formal theory as dependent on the level of abstraction within analysis, although emphasises that it must then be applied to different substantive areas for refinement. This approach also appears to favour substantive theory, suggesting that the type of theory sought is linked to the paradigm used. For instance, the purpose of positivist and postpositivist paradigms is to explain phenomena, whilst constructivism aims to understand constructions, and critical theory a critique of structures (Guba & Lincoln, 1998). Whilst critics may view these definitions as indicative of multiple definitions of theory (Suddaby, 2006) it can be argued that this is in fact an element of the research paradigm within which the methodology sits (Mills et al., 2006). GTM has multi-paradigmatic applicability and there are numerous interpretations by researchers as to how the methodology must be conducted (Allen, 2010), so its limitations may be more associated with how well the methods fit within the paradigm (Jones & Alony, 2011; Mills et al., 2006).

Finally, a challenge for any researcher choosing the GTM is recognising and responding to the multiple methods used, paradigms applied, and, indeed, the many studies that claim GT without clarity of methodology (Nagel et al., 2015; Suddaby, 2006). Many have raised concerns surrounding the quality of, and criteria for, research that applies the GTM (Draucker, Martsof, Ross, & Rusk, 2007; Elliott & Lazenbatt, 2005; Nagel et al., 2015). The concept of a

‘methodological spiral’ has been applied to identify the use of a research paradigm as paramount to establishing which ‘type’ of GTM is most appropriate for the researcher (Mills et al., 2006, 2007). This chapter clearly identifies my own ontological, epistemological, and methodological beliefs and position them within the present research. However, this is clearly also reliant on the ‘trust’ that the reader must have that the position I have identified myself within is indeed the one that I hold (Guba & Lincoln, 1998). As a relativist it is entirely possible that the reality of which I speak will not be constructed by the reader in the same way but I must believe that through a clear explanation it will at least have similarities. In answer to the issues of quality and criteria it is apparent that throughout the various GT methodologies – including Glaserian, Straussian, and Constructivist – there are underlying concepts that must be applied. These include theoretical sampling, analytical abstraction – through, for instance, constant comparison, category generation – and transparency of process, coding, and memo-writing (Allen, 2010; Birks & Mills, 2011; Charmaz, 2014; Corbin & Strauss, 2015; Elliott & Lazenbatt, 2005; Glaser & Strauss, 1967; Nagel et al., 2015; Suddaby, 2006). Although there may be different interpretations of how these might be applied there is a singular and important aim in conducting a GT study that lies within its name – that of grounding theory within the data. I have outlined the research methodology and analysis for the present study as transparently as possible within the following chapters and hope that for the reader the application and quality of GTM will be clearly demonstrated.

### **3.7 Rigour**

The concepts of validity and reliability, terms used to describe the consistency and accuracy of results respectively, are often used to assess the rigour of quantitative research (Guba & Lincoln, 1998). However, qualitative researchers challenge their applicability and prefer

instead to rely on the trustworthiness of findings, defined by Shenton (2004) as the credibility, transferability, dependability and confirmability of research. As identified within this Chapter the ontological, epistemological and methodological position of the research challenges the objectivity often found within quantitative research. Instead, the reliability of the research is considered through its confirmability, which addresses the influence of the researcher within the findings, and dependability, which addresses the replicability of the research (Shenton, 2004). Likewise, the validity is instead considered through its credibility, the researcher and reader's confidence in the findings (Charmaz, 2014), and transferability, the applicability of findings to other populations and contexts (Shenton, 2004). Rigour and trustworthiness within this study has been addressed through the following:

#### Credibility

- Appropriate adoption of methodology (section 3.4.)
- Triangulation through use of different methods (section 5.10) and types of participants (section 5.9)
- Iterative questioning throughout data collection (section 5.4.)
- Description of researcher's experience and background (Chapter 1 and 3)
- Examination of previous research to frame findings (Chapter 2)

#### Transferability

- Detailed description of contexts and phenomenon (Chapter 5-8)

#### Dependability

- In-depth methodological description (Chapter 4 & 5)
- Use of overlapping methods (Chapter 4 & 5)

### Confirmability

- Triangulation to reduce/identify influence of researcher (section 5.9)
- Description of researcher's ontological, epistemological and methodological position to identify influence of researcher (Chapter 3)
- In-depth description of methodology and analysis (Chapters 4-8)

The use of the constant comparative method (section 5.9.) is particularly important in ensuring qualitative research is trustworthy and relevant (Dye, Schatz, Sout, Rosenberg, & Coleman, 2000) and has been applied rigorously. The success of these strategies is discussed within Limitations (section 9.8).

### **3.8 Summary**

This chapter serves to position the researcher and the present study within a research paradigm by reflecting on both the beliefs of the researcher and the area of interest. It is clear that I hold a relativist and subjective perspective which is also applicable within DMH, particularly when considering existing research that demonstrates the ways in which users can often reconfigure the purpose of technologies (Bauchspies et al., 2006; Oudshoorn & Pinch, 2005) and that the presence of researchers can impact use (Advocat & Lindsay, 2010; Donkin & Glozier, 2012). Whilst many constructivist approaches to methodologies may be suitable, the interest in exploring 'experience-in-context' and the everyday meaning of DMH was considered to be suited to the use of a Grounded Theory Methodology. Although there are many challenges to the use of this methodology, which were discussed, it was considered to be appropriate for the present study as it recognises the plurality of meaning in DMH and fits within the researcher's beliefs. The following chapter will outline the research methodology used.



## 4 Research Methodology and Design

### 4.1 Introduction

This chapter will introduce and describe the research methodology and design used in this study. It will provide a description of the methodological steps taken from data collection to analysis, and conclude with an exploration of credibility based on Charmaz's (2014) criteria for a Grounded Theory (GT) study.

#### Aims of the Research Methodology

1. To explore and co-construct through interviews and extant documents the experiences of those using, developing and researching digital mental health (DMH).
2. To place the co-constructed meanings in the wider context of the various social worlds.
3. To use a GT approach to explore the context and the process of using DMH, reflecting the co-constructed meanings of developers and researchers (system builders).

Purpose: The objective of the current study is to explore the meaning of DMH through the experiential accounts of those involved, and the written documents produced, so as to contextualise and conceptualise the meanings constructed.

The research question is both ontological and epistemological in that the research aims to address the experiences of those using, developing, researching, and contributing to DMH with the aim of exploring the meaning behind that experience.

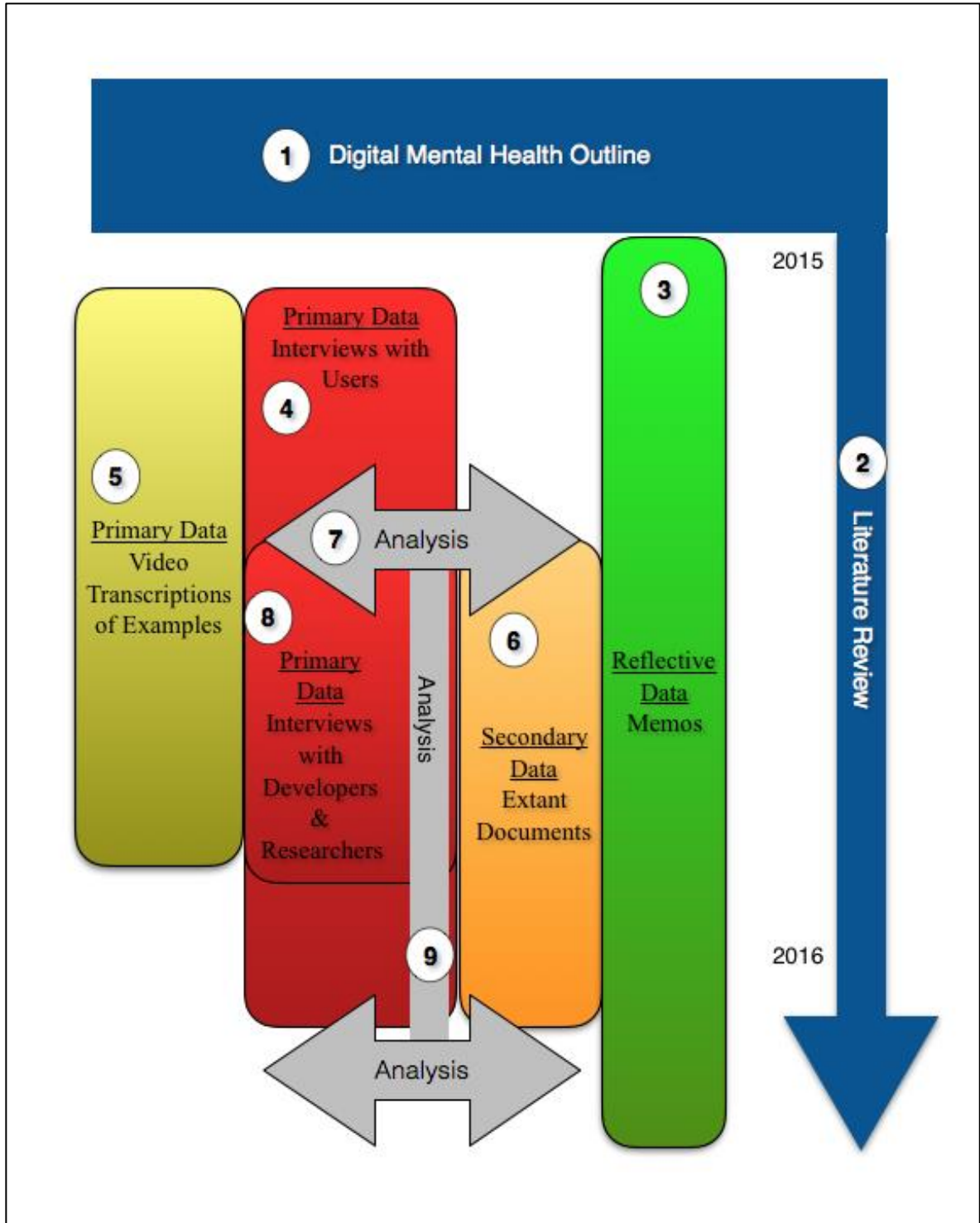


Figure 4. Illustrates process of data collection and analysis within the overall research design.

Research design in GT occurs through an iterative process (Charmaz, 2014). Figure 4 illustrates the research design that the present study has adopted.

1. The underlying principle of beginning research from an informed position as espoused by both Charmaz (2014) and Thornberg (2012) was applied at the initial stage, taking the form of an outline of DMH (this can be seen in Figure 4 above). This involved both a review of the literature and of existing guidelines and resources available.
2. This became a more traditional literature review, incorporating research that reflected the categories and concepts arising through analysis.
3. Reflective memos helped the researcher identify sensitising concepts at the beginning of data collection, and in exploring the categories and concepts that arose throughout the research process.
4. Primary data collection included interviews with users (4.), interviews with system builders (7.), and transcribed videos of demonstrations of resource use by participants (5.).
5. Videos were recorded of participants demonstrating an example(s) of DMH resources that they had experience with. These were chosen by participants and were optional. Videos were deleted after transcribing.
6. Secondary data was collected in the form of extant documents from a variety of sources.
7. Analysis was initiated early on, during data collection. This is an intrinsic part of Grounded Theory Methodology (GTM) (Charmaz, 2014). Analysis informs theoretical sampling, indicating where data collection should progress.

8. Interviews were conducted with system builders.
9. Analysis constitutes a continual process throughout data collection and for a period of time after, with the aim of constructing a theory.

## **4.2 Primary Data Collection**

As discussed in [An Adapted Grounded Theory Methodology](#) (section 3.6.), within a constructivist study data is often qualitative in nature, although quantitative data can be used when appropriate to the paradigm. Within constructivist GTM, which may be considered inherently qualitative due to its focus on interactions and construction of meaning (Charmaz, 2014; Mills et al., 2006; Sbaraini, Carter, Evans, & Blinkhorn, 2011), it is acknowledged that it is through interactions with people that theories are constructed (Allen, 2010; Charmaz, 2014). Data itself is considered to be a construct, however, which leads Charmaz (2014) to expand focus from interactions with people alone to a recognition of the purpose that extant documents and the researcher's own emic experience might hold as representations of meaning. When considering the everyday practice of DMH, interactions with people – whether users or system builders – are essential in understanding meaning and constructing theory. Representations of meaning within extant documents and observations made in the field can aid the researcher in becoming increasingly theoretically sensitised and with category generation. For this reason, data collection was divided into primary data collection and secondary data collection. This section will outline the considerations and procedures involved in conducting in-depth interviews with users and system builders within DMH.

### **4.2.1 Intensive Interviews**

The intensive interview is an important method of data collection in qualitative research and a term used by Charmaz (2014) to describe an in-depth interview that aims to explore

experience within a directed conversation, eliciting participants' descriptions and reflections so that the interviewer might better understand their experience. It places the participant as the knowledgeable other (Vygotsky, 1987) within the interaction and the interviewer's role is to listen and encourage. Because of this dynamic, researchers will often develop broad, open-ended interview questions and take an iterative approach to questions wherein the participant may influence the direction that the interview takes. By respecting this, and using theoretical sampling to further explore topics that arise, a trusting, negotiated interaction on which to construct insights and further questions can be stimulated (Sbaraini et al., 2011). These in-depth interviews provide rich contextual dialogic and potentially dialectical data in the form of negotiated conversations, wherein participants construct or reconstruct a reality (Charmaz, 2014).

In any interview it is important to build rapport, constructing a safe and trusting environment in which participants can share their experiences. Diccico-Bloom & Crabtree (2006) map the interview as a series of stages, from apprehension to exploration and then to co-operation and participation. Apprehension is surmounted by being open, prompting the participant with repeated words and encouragement. The position of a researcher is as a 'gardener' who must plant the seeds (questions) and cultivate them with follow up questions (Salmons, 2015). This can move the participant to the stage of exploration in which rapport can be built through learning, listening, testing and sharing (Dicicco-Bloom & Crabtree, 2006). Once past this, the stage of co-operation is reached where constructions are elicited from a cooperative other and rapport built in a safe and trusting environment. This necessitates that the researcher considers not only the conventional requirements of interviews, such as ethics and sampling, but also the most appropriate location in which to conduct them.

Although qualitative interviews are often used to address experiences within technological areas, including software development (Adolph, Hall, & Kruchten, 2011), electronic medical records (Winkelman et al., 2005), experience of online mental health treatments (Bendelin et al., 2011; Iloabachie et al., 2011), and much more, there appear to be discrepancies in their use that may be attributable to disciplinary differences. Myers and Newman (2007) have identified the need for information systems research to better address the use of qualitative interviews, including the model and interview process used. Within a recent review of methods used to evaluate the experience of users of DMH, Feather et al. (2016) identify the need for methods that bridge the gap between the evaluation of digital technologies (e.g. user experience or usability studies) and those with a psychological basis.

#### **4.2.2 Ethical Considerations**

All participants were provided with a [participant information sheet](#) (Appendix 11.1), directed to a website with further information, and signed or verbally expressed their consent. Ethical approval was granted by the University of Chester Health and Social Care Ethics Committee (RESC1214-584). Ethical guidelines from the Association of Internet Research (Markham & Buchanan, 2012), the British Psychological Society (British Psychological Society, 2014; Hewson et al., 2013), PatientsLikeMe (Browne-James et al., 2014), and the University of Chester were followed. A poster was published at the University College London 2<sup>nd</sup> Behaviour Change Conference by myself and Claire Harding, the Head of Research for Big White Wall, that brought together both our experiences to attempt to elicit further conversations surrounding how best to ensure ethical research in DMH specifically (Bergin & Harding, 2016). The four main ethical considerations will be reiterated here with respect to this particular study and the ways in which I have attempted to address them.

#### **4.2.2.1      *Respect for Autonomy and Dignity***

Respect for the autonomy and dignity of participants is an inherent ethical requirement for research that often involves a process of informed consent, the right to withdraw, and maintaining confidentiality. Autonomy was ensured by providing a website with information about the study to which individuals were signposted when recruited. If they were then interested in participating they could indicate this via a secure online form or directly via email. Following this an email was sent containing the [participant information sheet](#) (Appendix 11.1), [consent form](#) (Appendix 11.3), a list of mental health services available and [a list of types of DMH resources](#) (Appendix 11.4). A list of mental health services was sent according to the suggested procedures when researching potentially vulnerable groups so that there is a continuum of support (Liamputtong, 2007) but was also to make participants aware of options that are available. Every attempt was made to ensure that they were informed as to the research subject area and it was made clear that they could withdraw participation at any stage. Individuals were self-selecting for participation and were fully informed prior to research as to its purpose and their right to withdraw via both the website and the participant information sheet. Once contact was initiated via phone or Skype, an introductory meeting was held to ensure understanding and answer questions. Consent was granted through signing the consent form and, in one instance, through verbal consent at the beginning and end of the interview.

Confidentiality is a pertinent issue in DMH as many users may wish to remain anonymous whilst ownership of online data is an area that requires considerable updating (Bergin & Harding, 2016; Perez Vallejos et al., 2017). It is reported that anonymity and confidentiality have become more difficult with the increasing use of digital services (Bennett et al., 2010; Filkins et al., 2016). For this reason, I made explicit the issues that surround any use of

technology to collect and store data, and provided a [summary of Skype's privacy policy](#) (Appendix 11.2). This transparency meant that at the failure of the Safe Harbor Agreement, which led to concerns about the use of data outside the European Union (Court of Justice of the European Union, 2015), a risk assessment could be made as to the security of the participants' data. As they had provided informed consent and acknowledged the potential risk, it was felt that confidentiality had been ensured to the best possible extent. Participants retained their right to withdraw from the study throughout.

#### **4.2.2.2      *Scientific Value***

An issue voiced by Claire Harding as typical of DMH research was that researchers at times study a heterogeneous group of services under the umbrella term of “internet interventions” (Bergin & Harding, 2016). Her concern, as Head of Research for such a service, was that in grouping data the value of findings may be undermined. However, as this research was exploring the construction of DMH as an aspect of everyday life it was felt that these concerns were not applicable to the present study. The scientific value of the present study and the applicability of methodology used is addressed within [Chapter 2](#) and [Chapter 3](#).

#### **4.2.2.3      *Social Responsibility***

Researchers have a responsibility both towards their participants and the social worlds in which they interact. There is a concern that trust held towards a specific DMH resource can be undermined (Sharkey et al., 2011) along with the danger of ‘consultation fatigue’ whereby individuals are bombarded with use/outcome measures when interacting with a DMH resource (Bergin & Harding, 2016). It is also important that those who might benefit from research, such as users or developers, are able to access it in a comprehensible format when findings are released. In the present study I attempted to ensure that users were not subjected to



‘bombardment’ by utilising more passive methods of recruitment and collection of data, i.e. gatekeepers and the use of video conferencing. I also felt it was important that trust was maintained towards the resources. This led to discussions with The International Society for Research on Internet Interventions, users and system builders around the naming of DMH resources in qualitative research. It was decided that as the research focused on individual experiences and seeks to construct abstracted meaning rather than identify resources as ‘effective’ or ‘harmful’, there is little risk of influencing individual perceptions of resources.

#### **4.2.2.4      *Maximising Benefit and Minimising Harm***

Constructivist qualitative research places ethical considerations as intrinsic to research and respects the individual’s perceptions and values, meaning issues of confidentiality and anonymity are more likely (Guba & Lincoln, 1998). An emerging area such as DMH is subject to evolving ethical guidelines that are developed iteratively as a product of research. One example of such is the manipulation of Facebook feeds to investigate emotional contagion (Kramer, Guillory, & Hancock, 2014) and the resulting change in ethical guidelines in response to challenges surrounding the absence of direct informed consent (Guillory et al., 2014). Individuals ascribe complex concepts of privacy to the data they contribute in an online environment, dependent on context and content as well as personal attributes (Brady et al., 2016). It is also unclear whether online provision of mental health interventions will lead to recruitment of vulnerable groups who may not be able to provide consent, such as children, as research indicates that it is likely that vulnerable groups are accessing DMH services and resources (Sharkey et al., 2011; Titov et al., 2010). For this reason, participants were required to demonstrate that they were adults and capable of consent. Capacity for consent was assessed using an adapted British Medical Association toolkit (Appendix 11.5) to ensure that participants

understood what they were consenting to (British Medical Association, 2007). Visual confirmation and other forms of proof were used to confirm that participants were not below the required age of consent.

**4.2.2.5 Ethics-as-Process**

In response to the expected difficulties with accessing an unframed target population I chose to use ethics-as-process (Ramcharan & Cutcliffe, 2001) as advised by the Association of Internet Researchers (Markham & Buchanan, 2012). Ethics-as-process reflects the ecological approach to ethics in which the researcher remains attentive to the environment in which research is conducted, respecting the broader potential impact (Flinders, 1992). It involves an iterative process of reflection and ethical amendments based on experience throughout research. This enables the researcher to respond and adapt to unanticipated issues but also fits well within a GTM where theoretical sampling may lead to changes. Below is an outline of the process of ethical approval and amendments:

Table 4. *Showing amendments made throughout current study using ‘ethics-as-process’.*

	<b>Submitted</b>	<b>Approved</b>	<b>Changes</b>
<b>Original Application</b>	18.12.14	04.03.15	
<b>Minor Amendment 1</b>	17.04.15	21.04.15	Inclusion of email reminders
<b>Minor Amendment 2</b>	17.07.15	23.07.15	Inclusion of observations, extension of recruitment to system builders and via social media, alteration of interview guide
<b>Research and Knowledge Transfer Approval</b>	22.10.15	19.11.15	Extension of recruitment to international participants

Although the use of ‘ethics-as-process’ led to delays in data collection I felt that it was justified and useful both for research using a GTM and studies that take place within an under-researched topic or area. As can be seen in Table 4, minor amendments included the extension of recruitment to system builders – a population that were indicated through theoretical sampling rather than a priori. Approval was also sought to conduct online interviews with international participants. The global nature of digital technologies mean that international boundaries are less relevant online and it would be advisable that further research accounts for this. Rather than excluding individuals because of their physical residence, acknowledgement of their presence in a ‘global village’ (Rheingold, 1993) recognises that interactions are occurring in virtual spaces outside of spatial, and temporal, restrictions. There are further ethical quandaries to address in further research, such as the need to recognise fluctuations in the individual’s capacity to consent (Batchelor et al., 2012), but the use of ‘ethics-as-process’ ensured that the present study could respond to new challenges effectively.

#### **4.2.3 Location of Interviews**

Traditionally, interviews have been conducted face-to-face and in a setting where the participant feels comfortable and the interviewer remains secure. However, recent research has begun to subvert the temporal and spatial limitations of conventional contexts with the use of digital technologies. These include the use of online focus groups that can bring together diverse individuals confidentially to discuss sensitive topics (Jones & Ashurst, 2013), the use of online forums and websites that elicit responses at times convenient to users (Horgan, McCarthy, & Sweeney, 2013), asynchronous interviews via email (Corbin & Strauss, 2015), and synchronous interviews via video-conferencing software (Cater, 2011; Deakin & Wakefield, 2013; Scott, 2011; Sedgwick & Spiers, 2009). Online interviewing and sampling is frequently identified as an

‘easy’ option although researchers advise that it can be challenging (Hamilton & Bowers, 2006). Considerations must be made for the research aims and the appropriateness of the format with regards the topic, the participants, and potentially the credibility of participants’ experiences and their ‘truth-value’ within the chosen research paradigm (Salmons, 2015).

**4.2.3.1 Appropriateness**

Janet Salmon (2015) provides a framework for ensuring that the use of online interviewing is appropriate and justifiable for a particular study. Table 5 demonstrates how the styles and structures were adopted according to their appropriateness to the participants and paradigm of this study.

Table 5. *Process of choosing appropriate e-interview style.*

<b>Research Stage</b>	<b>ICT</b>	<b>Rationale</b>	<b>Access/Level of Expertise</b>	<b>Questions, Concerns or Issues to Address</b>
Recruit	DMH Resources	Members and visitors are those engaged in DMH	Expert Gain access through moderators and website	Will need permission from the digital resource admin. Will need to design post to comply with their needs.
Recruit	Gatekeepers	People involved in DMH and able to direct interested participants	Expert	Will need their permission.
Negotiate consent	Website	The study rationale will be explained with no requirement to participate.		
Arrange interview	Email	Contact can be first established using a medium that most people have experienced.	Expert	No response – a reminder email may be sent.

Research Stage	ICT	Rationale	Access/Level of Expertise	Questions, Concerns or Issues to Address
Conduct interview	Skype	I want to see the person's non-verbal messages and attain synchronicity with full focus of participant	Expert Population use skype (i.e. 42% of internet users (Ofcom, 2014)	I have experience conducting interviews over Skype. Important to plan, ensure recording software works effectively, environment is secure and quiet
Follow-up	Email	Attach transcript	Expert	Will need their permission.

Note. This table is adapted from Salmon (2015).

In a study that analysed discussions between mental health service users and professionals about Skype's potential in mental healthcare, professionals were concerned that the technology was unreliable, that prior contact would be needed and that it offered little over the use of a telephone (Jones & Ashurst, 2013). However, service users were more positive and felt that it was a suitable alternative to face-to-face contact and offered more accessibility and cost-efficiency. As one service user expressed *"I think skype is really good, I use it a lot. I agree that you would need to have 'ground rules' or something similar..."* (p.288, Jones & Ashurst, 2013). In qualitative research, Bertrand and Bourdeau (2010) conducted workshops exploring the role of Skype. Many of the limitations are avoided in this study including ensuring confidentiality through the use of audio recording except when screen sharing where the video was recorded, transcribed and deleted to ensure anonymity. Participants were also fully informed about what would happen with their data and their capacity to quit at any time was constructed as respect for their autonomy. Janghorban, Latifnejad Roudsari, and Taghipour (2014) maintain that similar ethical issues exist as in face-to-face interviewing but that Skype interviewing allows a more convenient interview design for participants and more ease of withdrawal. However, choice may

be considered an ethical necessity as not all individuals are capable of utilising video conferencing software so alternatives should be provided.

#### **4.2.4 Development of Interview Questions**

Within GT it is important to be theoretically sensitive in sampling and in the data you collect. Open-ended questions were adapted to reflect concepts and categories that were constructed from the data. To provide context to the experiences and meanings the questions were developed to reflect a temporal process using Seidman's (2006) interview structure of asking initial questions around the context of past experience, then bringing their experiences into the present before moving to a more reflective meaning-making. 'Grand tour' questions encourage participants to share experiences more openly (Scott, 2011) and are followed by prompts, such as asking for clarification as to their meaning or how something they shared affected them (Charmaz, 2014). Viewing the interview as a series of stages, progress is made from one stage to another through generating trust and building rapport (Dicicco-Bloom & Crabtree, 2006). Rather than making assumptions based on preconceived notions, as a researcher it is inherent in GT that you learn the participant's words and meanings (Charmaz, 2014). In-depth discussion occurs once the uncertainty of the strange situation has been overcome. Once the participant is comfortable, the interview reaches the stage of co-operation at which point the researcher can ask more sensitive questions (Dicicco-Bloom & Crabtree, 2006). Ideally the interview reaches the stage of participation in which the participant begins to guide and teach the researcher.

##### **4.2.4.1 Interview Question Amendments**

Once data had begun being analysed and coded it indicated certain aspects of experience that were relevant to the present study. Charmaz (2014) identifies these interviews as a useful

way to identify properties and clarify conditions of theoretical categories appropriate for focused analysis. Accordingly, the initial interview guide was left sparse, although areas of interest were included to serve as a guide. Amendments to the interview questions (Appendix 11.6) were made in response to analysis of data collected from the initial interviews along with inclusion of conceptual topics constructed from previously collected data.

#### **4.2.5 Recruitment**

##### **4.2.5.1 *Sampling***

In any qualitative research it is important that participants are not only appropriate but that suitable sample frames are used. Unfortunately, this can be difficult within internet research as online populations are not as well-researched and so not as easy to identify as those within traditional sample frames, e.g. organisations (Hamilton & Bowers, 2006; Salmons, 2015). However, in GT – rather than searching for probability or variability – the priority is to collect rich in-depth data around phenomena and concepts that are identified within initial codes (Charmaz, 2014). Opportunistic sampling – appropriate when little is known about a research area and a priori sampling decisions are difficult – enables populations to be recruited who meet a predetermined yet broad set of criteria so that central themes can be explored (Patton, 1990). Similarly, intensity sampling offers a way of capturing a richness of meaning by focusing on recruiting participants with in-depth experiences of DMH (Patton, 1990). Theoretical sampling (Charmaz, 2014) is used in response to concepts and gaps within the data, directing research to include, for instance, system builders.

##### **4.2.5.1.1 *Criteria***

Inclusion criteria were as follows:

1. They identify autonomous experience with multiple DMH resources/activities (see [Appendix 11.4](#)).
2. An adequate grasp of English as it is essential for participants to be able to communicate the complexity of their experiences and understand the information related to the study.
3. Over the age of 16.
4. Able to provide informed consent (see [Appendix 11.5](#))

#### *4.2.5.1.2 Sample Size*

The issue of sample size in qualitative research is one that cannot be answered away from the context of the study and this is no different for those using a GT approach. It has been suggested that 25 participants for a small study, if claims are not considerable, would be sufficient but this did not factor in alternative data sources (Charmaz, 2006). Indeed, the very same author retracted this number in a more recent edition of the book, stating that sample size is a product of individual studies rather than a singular ‘gold standard’ (Charmaz, 2014). This position is held by other researchers (Baker & Edwards, 2012) and so it places the optimal number of participants not on a superfluous number but rather based on the justification for each individual study, although extraneous factors may influence sample size. In a paper exploring PhD studies specifically it was found that those using a GT approach used between 4 and 87 interviews (Mason, 2010). Morse (2000, 2001) identifies five components of sample size in qualitative research - the scope of the study, the nature of the topic, the quality of the data, the study design, and the use of shadowed data (when participants speak of others’ experience as well as their own). For many of my participants their experiences reflected not only their own but also those using the resources they were involved with, i.e. shadowed data (Morse, 2000; Morse, 2001). Sixteen participants were recruited, a sample size not dissimilar to other theses



using GTM (Baker & Edwards, 2012; Soklaridis, 2009). They provided rich, in-depth constructions of meaning that were based on personal and perceived experiences with DMH.

#### **4.2.5.2      *Recruitment Process***

Not only is internet recruitment wrought with its own associated challenges but recruitment within mental health research is also notoriously difficult due to a range of issues, including stigma, accessibility and the use of stigmatising language (Woodall, Morgan, Sloan, & Howard, 2010). Use of Skype to conduct interviews reduced the burden of travel costs and time, and I sought others to review the website and other materials prior to their use. I am not the first to have seen the potential that the internet and websites can offer in mental health research recruitment (Markham, 2016). Recruitment was conducted through three pathways to help ensure that participants were appropriate (Salmons, 2015) and to reduce the potential stigma associated with identification of mental health issues.

The recruitment pathways were as follows:

##### **4.2.5.2.1    *Gatekeepers***

For the purposes of maintaining sensitivity participants were initially signposted to the research via ‘gatekeepers’, who have been identified by Salmons (2015) as a way to make contact with online groups. These ‘gatekeepers’ enabled initial sampling through ‘word-of-mouth’ and ‘snowballing’. It was important to allow prospective participants to freely opt-in to the study. A website was set up to provide information about what the research entailed, accessible prior to any expression of interest in the study. The participants recruited through ‘gatekeepers’ lead the initial data collection.

#### 4.2.5.2.2 *Digital Resources*

Recruitment via the internet is becoming more common (Fenner et al., 2012) including within GT studies. Corbin and Strauss (2015) report on a study they designed that recruited veterans to discuss their experiences during the Vietnam War through a veterans' website. Hamilton and Bowers (2006) illustrate the advantages that internet recruitment has, including the potential to reach small distinct populations, the ability to be more specific when recruiting and the opportunity to establish an 'opt-in' format. These advantages indicate that accessing participants through digital resources would be most suited to recruiting an appropriate sample of individuals who use DMH resources, especially considering they can be accessed through the point of interest itself. Social media proved successful for recruitment.

#### 4.2.5.2.3 *Organisations*

Organisations offer a useful recruitment tool by providing a population that is directly accessible, unlike when relying on gatekeepers or digital resources. Several organisations shared details of the research.

### **4.2.6 Participants**

The target population for this study, as outlined in the criteria, were participants with autonomous experience of DMH. A total of 16 participants were recruited for this study, with eight identifying as male and eight as female, ranging in age from their 20s to 60s. They represented a heterogeneous selection of positions within DMH, from users to developers. These roles are discussed in [Analysis and Findings](#) (Chapter 5) in more detail.

## **4.2.7 Procedure**

### **4.2.7.1 *Introductory Meeting***

An initial meeting, conducted via Skype or telephone, allowed the participant to become accustomed to the set-up and for introductions. The entire procedure was discussed and I ensured that they were comfortable, confident, and capable with the selected interview technology (e.g. Skype). Their compliance with the criteria was assessed using the Assessment of Compliance (see Appendix 11.5).

### **4.2.7.2 *Preparation***

Within the current study it was considered essential for participants to be fully informed not only about the procedure and content but also about the use of Skype. They were provided with both a Participant Information Sheet (Appendix 11.1) and a Skype information sheet (Appendix 11.2) which outlined what to do in the event that the technology failed to work. Participants were provided with enough information to familiarise them with the subject area through both a website and the information sheets.

They were also provided with a list of digital resources (Appendix 11.4) and asked to indicate which they had used or were using to maintain positive mental health and/or wellbeing. This provided me with additional data around the popularity of resources, although this was only returned by eight participants. This is discussed in more detail in the Analysis and Findings Chapters (Chapters 5, 6, 7 and 8) as it became an important aspect within the analysis and findings.

### **4.2.7.3 *Interviews***

The Skype interviews were arranged during the Introductory Meeting or via email. Interviews were conducted between March 2015 and March 2016. Participants were given the

option to screen share whilst they engaged with a DMH resource or activity, thinking-aloud as they did so. The use of visual elicitation and sharing with the researcher enabled more salient meaning-making within the interview. I was able to view and navigate alongside the participant, both over a camera and at times in an immersive visual environment. The participant was free to choose what resource they accessed, ensuring that they felt comfortable with what they showed. Gillian Fergie (2015) used a similar design within her thesis exploring the production and consumption of content on social media by young adults with a diagnosis of diabetes or common mental health disorders. Although example webpages were used as stimulus material, Fergie (2015) discusses how participants often demonstrated examples of sites that they themselves visited. As I wished to explore the experience of participants I felt that allowing them to choose the examples provided a more relevant point from which to discuss this.

#### **4.2.7.4      *Software***

The interviews were recorded using QuickTime Player on an Apple MacBook Pro and the Voice Memos app, as a backup, on an iPhone 6 and 6S. This allowed for audio and screen recording as appropriate and all devices were password protected. The interviews were mostly conducted using Skype but a virtual environment was used when a participant wanted to demonstrate their experience using a virtual platform. In that case an avatar was created, much like a Skype name, specifically for the study. Transcribed data is stored on an encrypted external hard drive which will remain in a locked filing cabinet for 10 years.

### **4.3    *Secondary Data Collection***

This section outlines the use of extant documents and observations, along with the requirements of data collection through these mediums, within this study.

### **4.3.1 Extant Documents**

Charmaz (2014) lists various questions that one must ask before including an extant document in the analysis as a document can provide insight into the meanings and realities that people are attempting to communicate to a much larger audience. These can also provide collaborative and collective meanings. Rather than narrow the data collection to a worldview purely constructed by the individual, it was considered important to introduce the societal, cultural and historical context in the form of documents produced by various organisations and individuals. These documents offered insight into a world inhabited by the technology itself – for instance, as a smartphone has no way to communicate its experiences, documents can provide insights into where they are placed in situations. I view technology not as an anthropomorphised object but rather as an evocative object (Turkle, 1984) and in many ways as an actor that helps construct meaning around the experience of DMH. This role of technology as actor is not unique (Latour, 2005) but there is little research exploring its role within the construction of meaning. Adele Clarke's (2005) situational maps are aimed at providing analytical tools for grounded theorists that aim to encapsulate the meaning held by technology and are discussed further within Situational Analysis (section 5.10). Documents were selected through theoretical sampling, with the following criteria providing a guideline for relevance:

#### **4.3.1.1 Criteria**

1. They must be relevant to the issues present in DMH and technology, and its users.
2. They must indicate the authors and purpose of the document clearly.

In addition, the questions suggested by Charmaz (2014) and contextual positioning proposed by Ralph, Birks, and Chapman (2014) were both adapted for the present study so as to position the extant documents within DMH (see Appendix 11.7).

#### **4.3.1.2      *Types of Documents***

Reports were identified as documents authored by organisations and aimed at assimilating information for dissemination on specific topics in DMH. These provided data related to commercial interests. Blogs were those authored by individuals with no affiliations, and aimed at exploring personal experiences of DMH. These provided unsolicited narratives around DMH. Publications were identified as documents authored during events by individuals with different affiliations and aimed at exploring specific topics in DMH from multiple perspectives. These provided a range of interests including commercial, academic and personal.

#### **4.3.1.3      *Sampling***

Throughout data collection the researcher identified relevant documents through searches related to the qualitative interviews, was signposted by participants, and signposted by organisations or individuals involved in DMH. See Appendix 11.7 for extant documents.

#### **4.3.1.4      *Ethical Considerations***

The use of blogs in particular demonstrates that the use of extant documents cannot always be distanced from those who produce them and their authorship should be respected in an ethical manner. When blogs were used in data collection the permission of the author was sought. This ensured that:

- a) the blog was considered, by them, as public data.
- b) they could choose to remain anonymous or have their ownership made explicit.

This ensured that my own values around ownership and authorship were upheld, as well as recognising the rights of bloggers. Not only are there issues of copyright that remain unresolved (Erickson, Heald, Homberg, Kretschmer, & Mendis, 2015) but the personal perception of public and private expectations online differ by individual and should also be respected (Perez Vallejos

et al., 2017). However, when bloggers could not be contacted some relevant blogs were excluded. However, considering the value of the primary data that was collected and the secondary data that remained inaccessible, it was felt that the ethical considerations, whilst restrictive, should be maintained.

### **4.3.2 Observations**

GT is different from ethnography in that it does not describe but rather finds the meaning in the phenomenon or process being studied (Charmaz, 2014). Observations can still provide much needed context to GT research, allowing the researcher to place meaning into a wider significance and enabling theoretical sampling of the present. Observations can provide an important contextual layer of meaning to the grounding of theory within data itself. As the environment of DMH is fast moving, with technological innovations, regulatory issues, government investment and consumer awareness changing quickly, I recognised the significance of my own observations. At events where the discourse was around DMH, data was collected around the actions and anecdotes, the language and context as well as the areas that were considered most interesting or problematic (Charmaz, 2014). These were published, where possible, as conference reports. See Appendix 11.8 for list of events.

#### **4.3.2.1 *Ethical Considerations***

Informed consent was obtained to take notes throughout observations except in instances where existing publications or reports were made public in response to discussions as prior approval for general research purposes had been sought by organisers. For observations made during public events no informed consent was needed as attendees did not have an expectation of privacy and notes were not made based on private conversations. Few of the observations required consent forms to be completed.

#### **4.3.2.2 Credibility**

Whilst Glaser and Strauss (1967) view the resulting theory of the GTM to have a “truth-value”, I view a theory as more of a metaphorical explanation – a way to represent ‘what is’ rather than a description of ‘what is’ (Abend, 2008). Thus Charmaz (2014), in using credibility to substantiate the claims within a GT approach, presents a more appropriate way of validating findings. She suggests doing this through rich data and an immersion in the world of your participants. The concepts and categories themselves may have some ‘truth-value’ in that they can be recognised as important and as valid to the experience of DMH. I was fortunate to be able to present some of my findings, including core concepts and categories, to a group of experts in DMH – users, researchers, and developers. Consent forms were collected from attendees and their views noted. Their response was positive and, indeed, they shared the opinion that the concepts and categories were credible.

#### **4.4 Summary**

The research methodology has been outlined, including both primary and secondary data collection. Key components of a constructivist Grounded Theory Methodology, including theoretical sampling and recognition of the role of the researcher, have been shown to be represented. This chapter also served to address concerns surrounding the use of digital technologies within research, including for interviews, and ethical considerations in DMH. ‘Ethics-as-process’ was considered appropriate and effective (Ramcharan & Cutcliffe, 2001). The analysis will be addressed in the next chapter.



## **5 Analysis and Findings**

### **5.1 Introduction**

Within the context of the present research the aim of analysis was to construct concepts from the data and move towards categorisation to begin forming a substantive theory, according to the framework outlined by Charmaz (2014). The data was qualitative and meaning was constructed by both the researcher and the participants, representative of participants' experience of technology and mental health. As the data became theoretically saturated participants were encouraged to elaborate on specific experiences and thus became an element of the data itself. As the data was coded; concepts (an understanding), properties (an attribute of a category) and categories (saturated representations of concepts) began to be constructed. This chapter outlines and explains the initial analysis – from line-by-line coding through to memo-writing – along with the participant roles that were co-constructed through the existing literature, interviews and analysis. It also outlines the development of categories.

### **5.2 Presenting Findings and Analysis**

There is little consensus on how to present the findings of a PhD thesis within a constructivist Grounded Theory (GT) study (Nagel et al., 2015). For Charmaz (2014) the flexibility of the methodology and its use indicates its results are symbiotic with the research itself; she does not explicitly outline possible structures whilst Corbin and Strauss (2015) suggest the use of categories to explicate the theory. Both of these important texts consider the act of writing paramount over presentation concerns. Many of the issues identified within Chapter 3 surrounding the use of GT as a methodology and its adaptation to multiple research paradigms are illustrative of the difficulties faced when establishing exemplars. I have taken two publications that illustrate different ways of presenting findings and have identified the structure

that appears to reflect both transparency of process and clarity of findings. Peggy Gregory explored patient experience of using a diabetes e-health platform (Gregory, 2012). Her research methodology led to the presentation of findings, listing and discussing three categories and their subcategories. This is followed by the conceptual framework, aiming to present the relationship that ties these categories together. The discussion is designated to its own chapter. Andrea Gorra, in her thesis exploring the experience of mobile privacy, focuses on presenting her findings first, outlining the process of analysis from initial coding to the development of categories, followed by a chapter in which she discusses the analysis of findings *and* discussion (Gorra, 2007). Gregory's (2012) publication is structured in a more traditional way, presenting her results before moving to a discussion and emphasising the clarity of her findings, yet I feel it does not provide the reader with clarity as to the analytical journey. Gorra's (2007) thesis is innovative in that it clearly demonstrates the analytical methods she used, emphasising its replicability, though I feel the structure is difficult to follow within a linear text. I decided to adapt the structures used by both, using a clear analytical journey to ensure that the reader can identify the process whilst maintaining a more traditional linear narrative. Thus analytical tools and examples will be placed alongside findings, linking the process and outcome. This will be done linearly with recognition that GT is an iterative methodology.

## **5.3 Preparation**

### **5.3.1 Sensitising Concepts**

GT is associated with sensitising concepts, areas that act as the starting point for coding without influencing the direction of analysis (Bowen, 2006; Charmaz, 2014; Clarke & Star, 2007). Charmaz (2014) associates them with various theoretical frameworks, although I find it interesting that she views the framework as coming towards the end of analysis and these

sensitising concepts as arising during the initial stages. Clarke and Star (2007) also identify several sensitising concepts that sit within the Social Worlds Framework. I used concepts to sensitise myself to the data initially and found it challenging to assess their worth later in analysis without doubting their inclusion as merely an element of preconception. However, sensitising concepts may help to contextualise the research further. By naming them they become concepts to explore and challenge, for myself and the reader.

1. Action – this is implicit when using gerunds, words of action.
2. Self – numerous studies focus on the representation of self via technologies that allow anonymity (Anstadt, Bradley, Burnette, & Medley, 2015; McDermott & Roen, 2012; Suler, 2004) or an alteration in self-representation (Dwyer, Hiltz, & Passerini, 2007; Gil-Or, Levi-Belz, & Turel, 2015).
3. Agency – how presence is felt online may be complex.
4. Meaning
5. Actors and Actants
6. Situation
7. Boundary Objects
8. Interaction – are interactions similar to how they are face-to-face? Are they similar across different technologies?
9. Time – the experience of time online can be both synchronous and asynchronous.
10. Privacy – including anonymity and the experience of stigma.

### **5.3.2 Software**

To transcribe the interviews, I used ExpressScribe Pro – software that enables encrypted files to be uploaded, played, and controlled. As I conducted the transcriptions myself the way

that participants spoke was represented within the writing and my understanding. I used pen and paper methods for initial coding followed by an assessment of various software including NVivo, Quirkos and Atlas.ti, all computer assisted qualitative data analysis systems (CAQDAS). These are useful in very different ways. NVivo and Atlas.ti provide more functions, including ways of conceptualizing and comparing codes, but I felt they were limited by minimal visualisation of data and linking of concepts to multiple nodes. Quirkos offers more visualisation but only captures a small number of concepts, and so may be more useful for focused coding and development of categories. However, it was necessary to select a single CAQDAS application due to monetary limitations. NVivo was assessed as the most useful. As analysis became more complex I found my use of this software to be challenged considerably. It became clear that its use was restricted on the Apple Mac Operating System. Several times I lost work, even after saving, due to the software unexpectedly quitting. As a result, I decided to return to Microsoft Excel and Word where it was possible to insert codes and search through documents. These appeared to offer a more reliable means of analysing my findings but required considerably more energy than expected as codes were re-inserted and novel ways were sought to bring the data together whilst remaining true to a GT analysis.

#### **5.4 The Iterative Process**

Research conducted using a Grounded Theory Methodology (GTM) is by necessity an iterative process, particularly when used within a constructivist paradigm (Nagel et al., 2015). Not only does it require the researcher to be reflective but also responsive, particularly to challenges that may arise. Throughout data collection I maintained a personal journal of my experiences and potential challenges. This enabled me to address situations that arose and respond in a way that could account for my beliefs as a researcher and maintain respect for the

participants. One challenge that arose was changes in data protection laws, namely the breakdown of the Safe Harbor Agreement which enabled transatlantic data transfers (Court of Justice of the European Union, 2015). I had informed participants throughout, using the [Skype information sheet](#) (Appendix 11.2), that use of Skype necessitated agreement with their privacy policies. This indicates that researchers may need to monitor and account for potential changes in information and communication technology (ICT) frameworks, guidelines, policies, and agreements.

It is also advisable to allow participants to choose how e-interviews are conducted. Although Skype was identified as the main method for conducting interviews it was also made clear to participants that they could request other applications if needed. It would be ethically dubious to exclude the use of different applications or face-to-face entirely if it is possible, particularly considering inequalities remain in access to utilities such as broadband (Ofcom, 2015). It's appropriateness to the [research paradigm](#) (see Chapter 3 and section 4.2.3.1. for [discussion of appropriateness of e-interviews](#)) must be paramount. In three instances the location of the interview was changed within the present research, which are addressed in the following sections.

#### **5.4.1 Visiting Developer's Offices**

David (all names are pseudonyms so as to maintain confidentiality of participants), a Developer, invited me to conduct the interview at his offices. I felt that this visit provided me with an opportunity to observe a development team and experience the environment in which they worked. Whilst the interview did not differ substantially from those conducted over Skype there were two differences that are noteworthy. When conducting an interview over Skype the screen shows the face and much of the upper torso. Because it is viewed through a computer

screen it can be enlarged, allowing more focus on facial expressions and less distance between the interviewer and interviewee. Within a face-to-face meeting there may be objects placed between them although potentially more body language can be viewed, particularly expression using limbs. We also did not have access to a computer during the interview so David was unable to demonstrate the resources he was involved with and, when mentioning numerous web addresses, was not able to direct me to them during the interview.

#### **5.4.2 Using Emails for an Interview**

Norman, a User, requested that we conduct the interview over email due to personal reasons. He was aware that this posed more risk to confidentiality, as emails are difficult to encrypt, but wished to continue. I found this method demanding, particularly as it extended the interview over a week. Although this could provide ample time to code and consider the next question carefully I felt there was an expectation that I would respond quickly to emails. The asynchronous nature did provide a relatively in-depth interview but I found that at times it was difficult to clarify certain aspects, which meant negotiating the space and establishing guidelines at the beginning. Our emails ended when unrelated personal reasons prevented Norman from continuing the interview.

#### **5.4.3 Interviewing in a Virtual World**

Rita, a User/Provider, invited me to join her in a virtual world, Second Life, so that she could demonstrate a number of virtual ‘tours’ that had provided her with information surrounding mental health. This was the second interview that we engaged in, the first was using Skype. This allowed me to experience the use of digital resources for mental health as a representation of my ‘self’, an avatar. There were some key differences that are important to note. Instead of body language I had to rely on the voice and interaction of a controlled avatar.

The virtual world had its own sounds and visual displays, different to a typical interview in which participant and interviewer are in a contained dyad. It also demonstrated a shift in the power dynamic as I became the novice in a world where Rita was very much at home.

### **5.5 The Visible Researcher**

Charmaz (2014) reminds researchers that whilst they may be viewing the participant, the participant too is viewing them. When interacting with participants' adept at using digital resources this is not limited to how researchers present themselves in an interview but extends to their online identity. Consideration was needed for how I was presented online as well as offline. Some participants noted how they had used my email to search and find online profiles so as to assess my credibility. Within the virtual world I used a generic avatar whose generic clothes were identified as "ugly" (RVW94) by Rita. It would be advisable for future researchers to take note that their online 'selves' will become part of their participant's constructed perception of who they are and may contribute to the trust they garner.

### **5.6 Coding**

Coding allows the researcher to analyse the data in-depth by constructing, categorising and moving to a more abstract understanding of the meanings being communicated (Charmaz, 2014). Charmaz (2014) suggests using gerunds in codes so as to underpin the analysis with an exploration processes and action. The act of coding is an act of naming and within social constructionist approaches there is recognition that as the author we are linked to that act of naming, recognisable within it and responsible. This claim of authorship was intriguing to consider as a researcher, particularly as I tried to capture the speaker's voice, meaning and purpose succinctly. It intrigued me that this abstraction removed authorship from the participant but that it can then be returned when reporting the results. There is pride in naming, in

authorship, and as a researcher there is a level of ethical responsibility and moral ambiguity about taking participants' words and assigning meaning to them (Foucault, 1979). I felt this particularly around in-vivo codes, codes that reflected the words of the participants directly, and tried to ensure that throughout the findings and analysis chapters that I reflected on participant 'ownership' of their experience alongside my constructed analysis.

As an iterative methodology, GT utilises data analysis to indicate areas of theoretical interest, thus driving data collection and coding to become ever more theoretically focused (Glaser & Strauss, 1967). Coding is not always structured and involves moving between different types, even within a single data point or at a single point in time (Strauss & Corbin, 1990). Figure 5 shows my process of analysis. The process was an iterative feedback loop of codes, memos, and concepts that all informed each other:



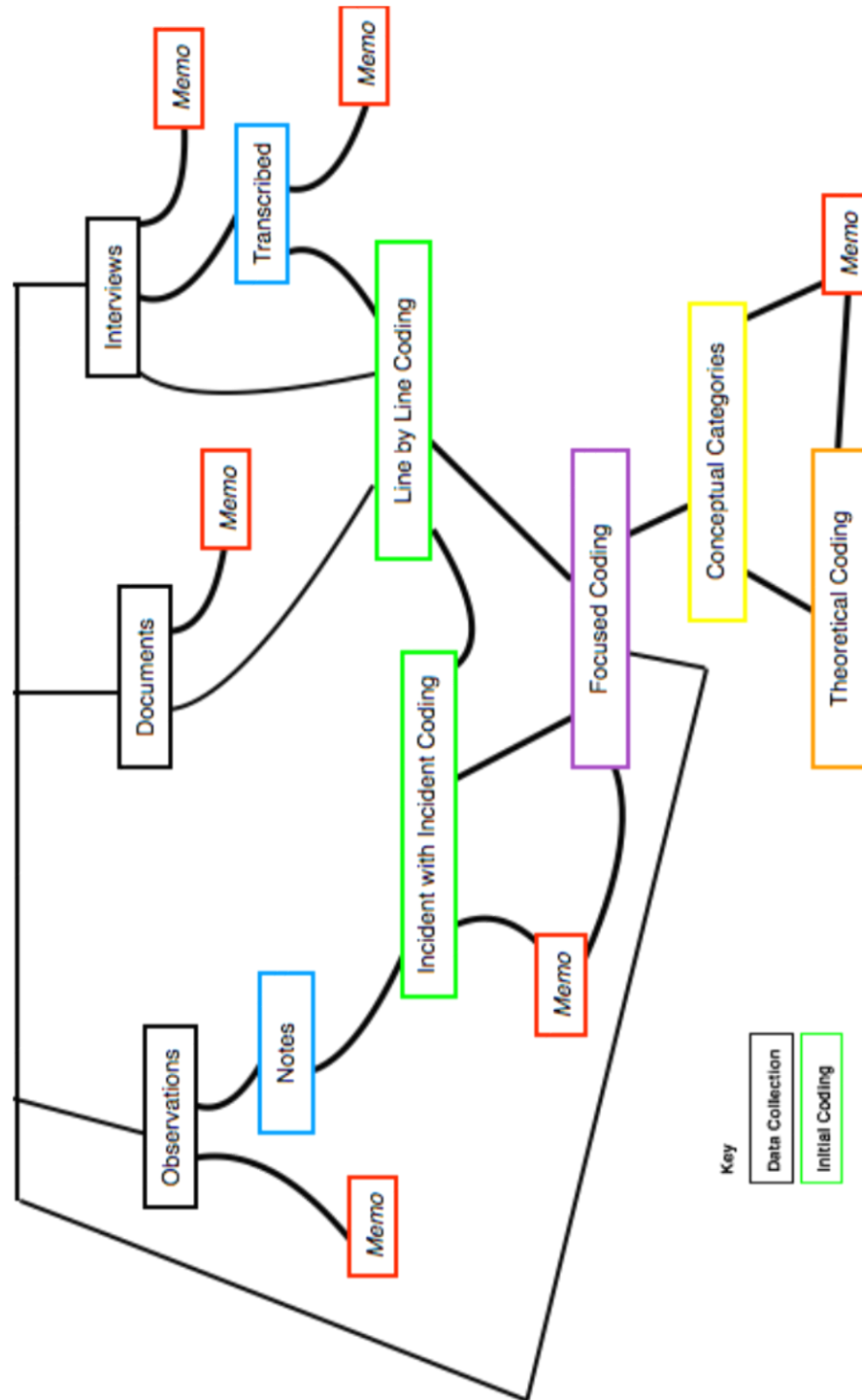


Figure 5. *Process of analysis using GTM.*

### 5.6.1 Initial Coding

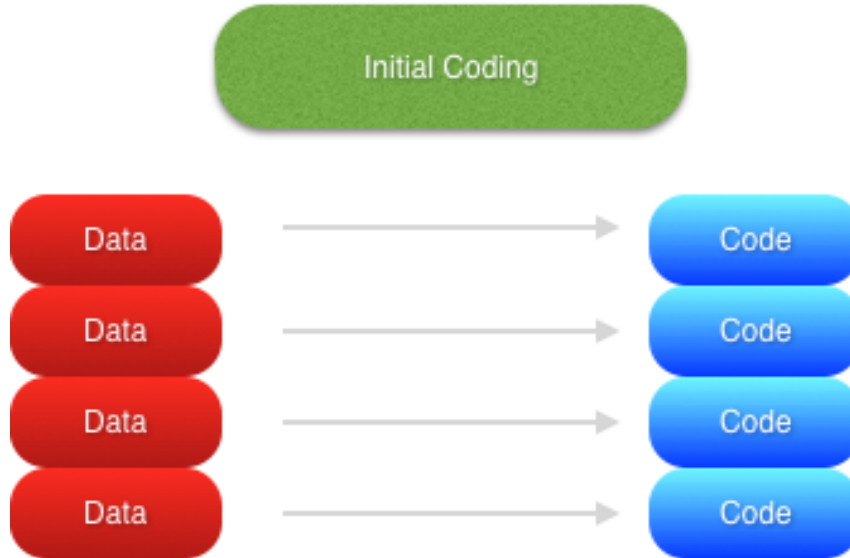


Figure 6. *Initial coding process.*

Transcribing brought me closer to the data and enabled a depth of dialogical exploration that was difficult during the interview. I listened to the audio recordings numerous times so that I remained salient of the participant’s voice as well as the content. Words, lines and even segments were coded following transcription. The present study initially coded the interviews line-by-line, which breaks up the data into components and attempts to help the researcher move away from imposing their own perspective (Charmaz, 2014). Figure 6 shows the direct relationship between the data and codes. Comparing data not only helps in the construction of new concepts and categories but can also be a way of understanding what is important to the participant.

Interviews were copied line-by-line to Excel and coded with the initial codes. These included quite wordy codes such as “feeling unable to speak to others offline causing difficulties finding people to speak to online” and “difficulty connecting and finding things initially because of reticence to talk to others”. Reflecting on these I recognised that rather than taking the data apart and analysing the meaning within fragments as advised by Charmaz (2014) I was

attempting to simply summarise. Recognising that I was losing the concise analytical purpose of coding I decided to print a paper copy of the anonymised interviews. I provided only a small area in which to write my codes. This forced me to delve into the meaning and actions that were being communicated so as to incisively interpret each component of data and worked effectively for initial codes. The two lengthy codes above became “searching for online connection” and “connecting without speaking” respectively.

### 5.6.2 Focused Coding

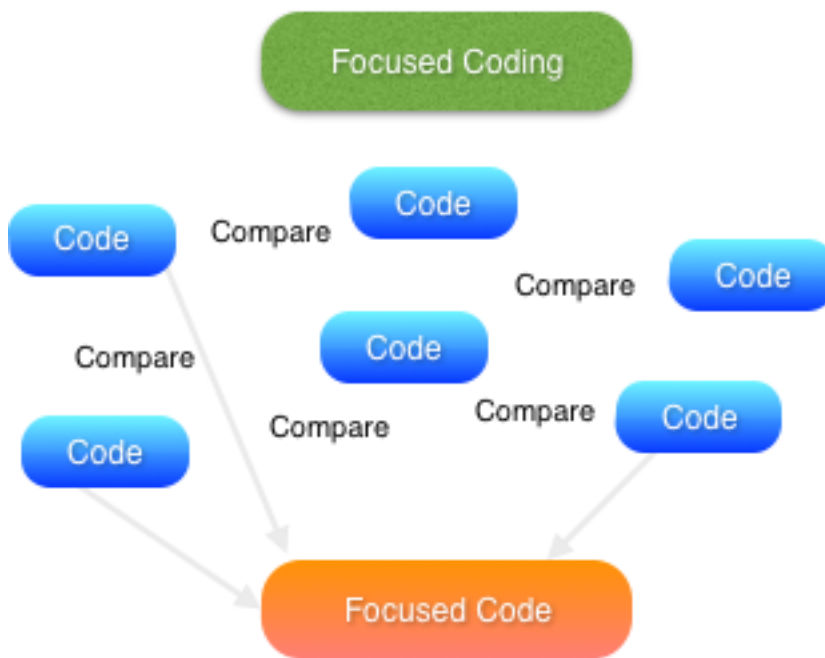


Figure 7. *Focused coding process.*

The move to focused coding utilised both Microsoft Word and Excel applications. Through comparing the codes and data, and finding similarities between or even within the different sources, new lines of inquiry arise and the researcher’s perspective becomes simply one view among many (Charmaz, 2014). Theoretical sampling enabled me to focus on areas where there were gaps or questions, but focused coding gave me the tools to explore the large amounts of data and begin to consider meanings. I found that examining codes using a symbolic

interactionist perspective (Blumer, 1969), particularly as extended by Charmaz (2014), aided in recognising meanings within situational changes. Using this bricoleur approach (Denzin & Lincoln, 1998; Kelle, 2007), and exploring the data from pragmatic, heuristic, symbolic interactionist, dramaturgical, and psychological viewpoints gave me a variety of conceptual ideas that could be built upon. Focused codes enable the researcher to conceptualise aspects of the initial codes by comparing them with the data and identifying those with greater analytic power (Charmaz, 2014). Rather than immersing yourself in data as you do with initial codes this process is about gaining a greater theoretical sensitivity to the data and questions that arise. This is done through an iterative process of comparing codes using the constant comparative method (CCM) (see section 5.9) and focused coding (Figure 7).

Microsoft Excel offered a way to input both initial and focused codes alongside each other, and I could also search through to find similar clusters using keywords. Focused codes were gathered together in clusters using text boxes (Figure 8) enabling structure and the visualisation of the complex interrelationships between initial and focused codes. This was laborious but proved an effective analytical tool. Clustering also proved an effective tool in the development of categories (section 5.12) with the process of focused coding also leading to the construction of potential categories, as Figure 8 shows with the code “People Like Me” which later became a category (section 7.4).

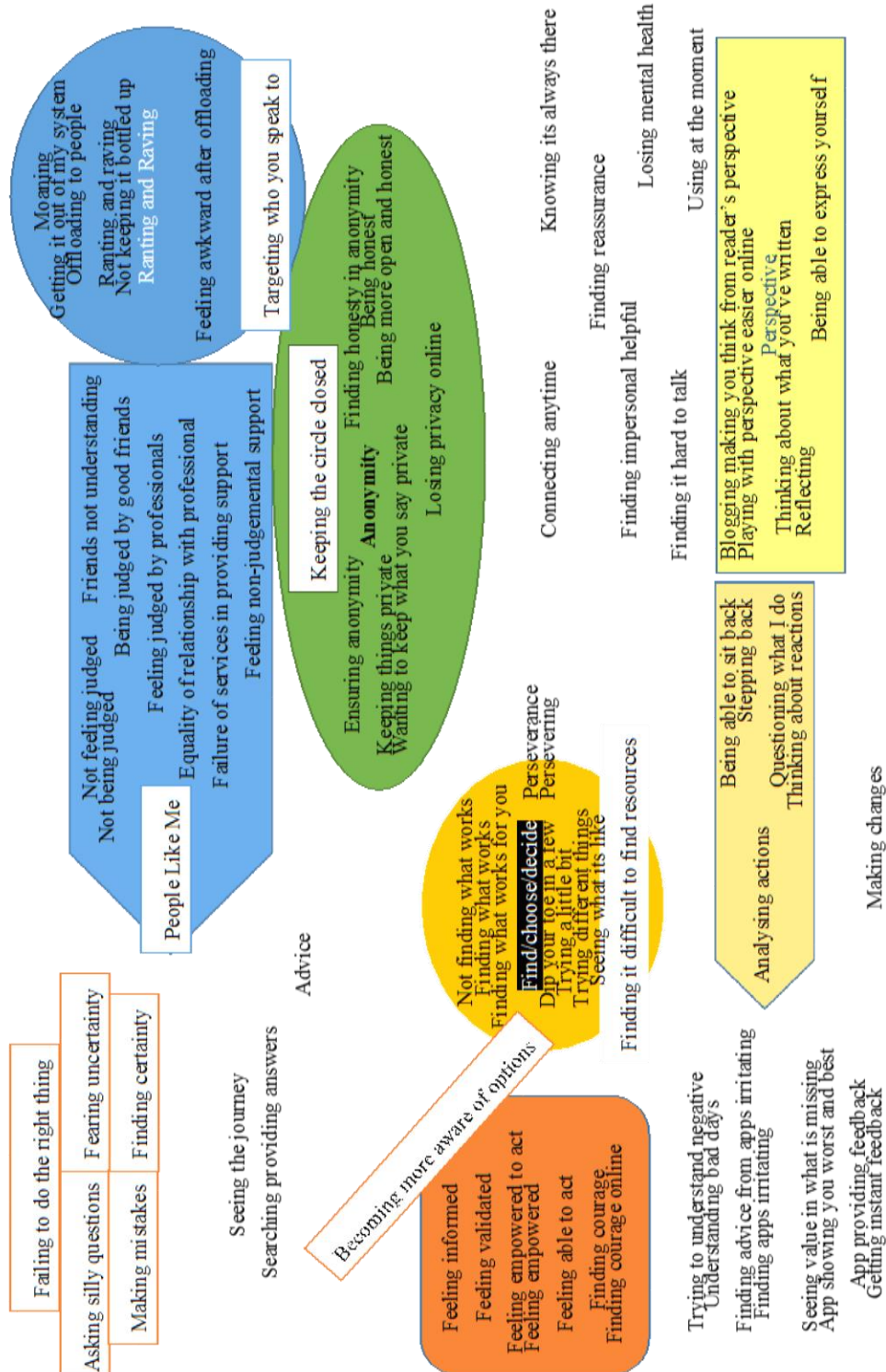


Figure 8. Example of clustering using initial and focused codes.

Different Excel columns were used for line-by-line coding (initial codes), incident-with-incident coding (situations) and focused codes. Categories were then inputted at a later stage. Table 6, an excerpt from my interview with Sandra, shows the different types of codes used. Whilst codes were inputted sequentially, categories were placed at a later stage at the beginning of the row. Excel offered a way not only of moving columns around so as to reflect their prominence at different stages but also allowed me to search within and between interviews for clusters of meaning. One criticism would be that by dividing interviews line-by-line the analysis could be influenced by the separation of sentences once it has progressed to focused coding and categories. As can be seen by “connecting for empathy” and the category “finding what works”, focused codes can cover a broad section of data alongside the line-by-line codes. The category “People Like Me” (section 7.4.) demonstrates that at times a category may be linked to another but in specific ways that can help in comprehending the interrelationships. This is discussed in the development of categories (section 5.12.).

Table 6. *Demonstrating different types of coding used.*

Interview Data	Category	Category	Initial Codes	Focused Codes	Situations
39. Ok. Um. This was one of the main websites that I was using because my partner has problems with alcoholism.	finding what works		using website for partner's problem	connecting for empathy	finding something useful although not directly related
40. So I found this group on Yahoo, which is a forum for other people who live with somebody with alcoholism,	finding what works	people like me	finding suitable based on partner's problem	connecting for empathy	
41. um, but I find a lot of posts and things that they make are again around general mental health and things like that	finding what works		finding posts about mental health	connecting for empathy	
42. and of course a lot of the things became quite specific to my situation	finding what works	people like me	encountering relevant experiences to her situation	connecting for empathy	finding support via empathy

Towards the end of data collection and analysis participants' interviews became more sparsely but intentionally coded as areas of theoretical import became clearer and the saturation of categories was sought. At times this required going back to previous interviews or closely coding the more recent when areas of surprise or contradiction were found (Charmaz, 2014).

This is known as the CCM (see section 5.9.).

## 5.7 Participants

Table 7. Pseudonymised participant names, demographics, recruitment pathway, their identified role, length of interview, and length of video (if included).

	Name	Info	Recruitment	Role	Length of Interview	Video
1.	Sandra	Female, 20s	Gatekeeper	User	27.30	✓ 0.3.22
2.	Phillip	Male, 30s	Gatekeeper	User/Provider	1.02.05	✓ 0.9.00
3.	Carol	Female, 40s	Snowballing	User/Provider	43.38	
4.	David	Male, 30s	Gatekeeper	Developer	51.06	[F2F]
5.	Rita	Female, 20s	Digital Resource	User/Provider	2.20.57	✓ 3.21.00 [VW]
6.	Harold	Male, 50s	Digital Resource	User/Provider	1.36.36	
7.	Anne	Female, 20s	Organisation	User	1.06.51	
8.	Jessie	Female, 20s	Gatekeeper	User	1.09.01	✓ 0.11.28
9.	Tom	Male, 40s	Digital Resource	Developer	46.07	
10.	Sarah	Female, 20s	Gatekeeper	User/Developer	1.51.31	✓ 0.4.24
11.	Patricia	Female, 30s	Digital Resource	Academic/Contractor	43.25	
12.	Sean	Male, 30s	Snowballing	User/Developer	2.08.09	
13.	George	Male, 40s	Organisation	User	41.21	
14.	Norman	Male, 60s	Digital Resource	User	N/A	[Email]
15.	Sam	Male, 20s	Digital Resource	User/Developer	59.06	
16.	Sharon	Female, 30s	Organisation	Academic/Contractor	50.37	✓ 0.11.25

Note. F2F refers to face-to-face interview whilst VW refers to a virtual world.



The target population for the study (see [criteria](#), section 4.2.5.1.1.) were participants with autonomous experience of digital mental health (DMH). Table 7 shows participant characteristics including a pseudonymised name, identified gender, age range, length of interviews and pathway of recruitment. Ages ranged from their 20s to their 60s, and there were eight male participants and eight female participants. The length of audio interviews ranged from 27 to 140 minutes (total 1,033 minutes) whilst video recordings ranged from 3 to 201 minutes (total 240 minutes). It is important to note that video recordings were only provided by 6 participants. Participants who declined did so as they were using their device for the interview, wished to show me at a later date when they had more time, and in the case of the face-to-face interview there was no computer within the interview room. A total of 21 hours of primary data was transcribed. In addition, one of the interviews was conducted via email and so is not represented by these figures. The interview conducted during a visit to a virtual world was transcribed and coded separately from the original interview and titled “Rita Virtual World”. It was viewed as a second interview as it occurred in a new location at a different time and involved immersion in a virtual world.

### **5.7.1 DMH Resources**

When participants completed the [consent form](#) (Appendix 11.3) they were also asked to indicate how many technologies they had used to maintain positive mental health and/or wellbeing from a list provided by the researcher (see Appendix 11.4). Although only half of the participants (8/16) returned this list their responses presented some interesting insight into what the more common technologies are amongst the participants that answered. SMS, email and websites are the most common, followed by social networks, forums and search engines (Table 8).

Table 8. Responses to the question "Do you use or have you used any of the following to maintain positive mental health and/or wellbeing".

	Rita	Phillip	George	Carol	Sandra	Norman	Harold	Anne
SMS	X	X	X	X	X	X	X	X
Email	X	X	X	X	X	X	X	X
Websites	X	X	X	X	X	X	X	X
Social Networks	X	X	X	X	X	X	X	
Forums	X	X	X	X	X	X		X
Search Engines	X	X	X	X	X		X	X
Smartphone Apps	X	X	X	X			X	?
Software	X	X	X				X	X
Video	X	X			?	X	X	
Audio	X	X	X			X	X	
Blogs	X	X		X				
IM	X				X	X	X	
VR	X						X	
Games		X			X			
Web Apps			X					X
Podcasts	X							
AR								
Wearables								
Sensors								
Telecare								

Please note that question marks represent contradictions between the interviews and their response. For instance, Anne discussed her considerable use of apps and yet failed to indicate that this was a resource with which she had experience. Whilst this calls into question the veracity of this survey it is not being used to maintain that these resources are most widely used in populations accessing DMH but rather to provide the researcher with a further analytical tool surrounding the resources most salient in the participants' experience. The fact that Sandra failed to include video and yet discussed her use of mental health-related YouTube videos, and Anne

likewise with smartphone apps, suggests that perhaps these terms do not represent clearly enough their constructed meaning surrounding use to maintain positive mental health and/or wellbeing. Table 8 also demonstrates that whilst most were used by participants there were four that were not a part of their everyday experience: wearables, sensors, augmented reality, and telecare.

## **5.8 Participant Role**

The role of each participant was constructed from the content of the interviews as some participants identified themselves within one role but had considerable experience in others also, demonstrating overlap. Although these roles are subjectively constructed they proved essential in identifying the social worlds in which participants existed during analysis (Clarke, 2003). These roles, constructed from the data, are used as analytical tools in understanding the participants situatedness within the social world of DMH (Figure 9).

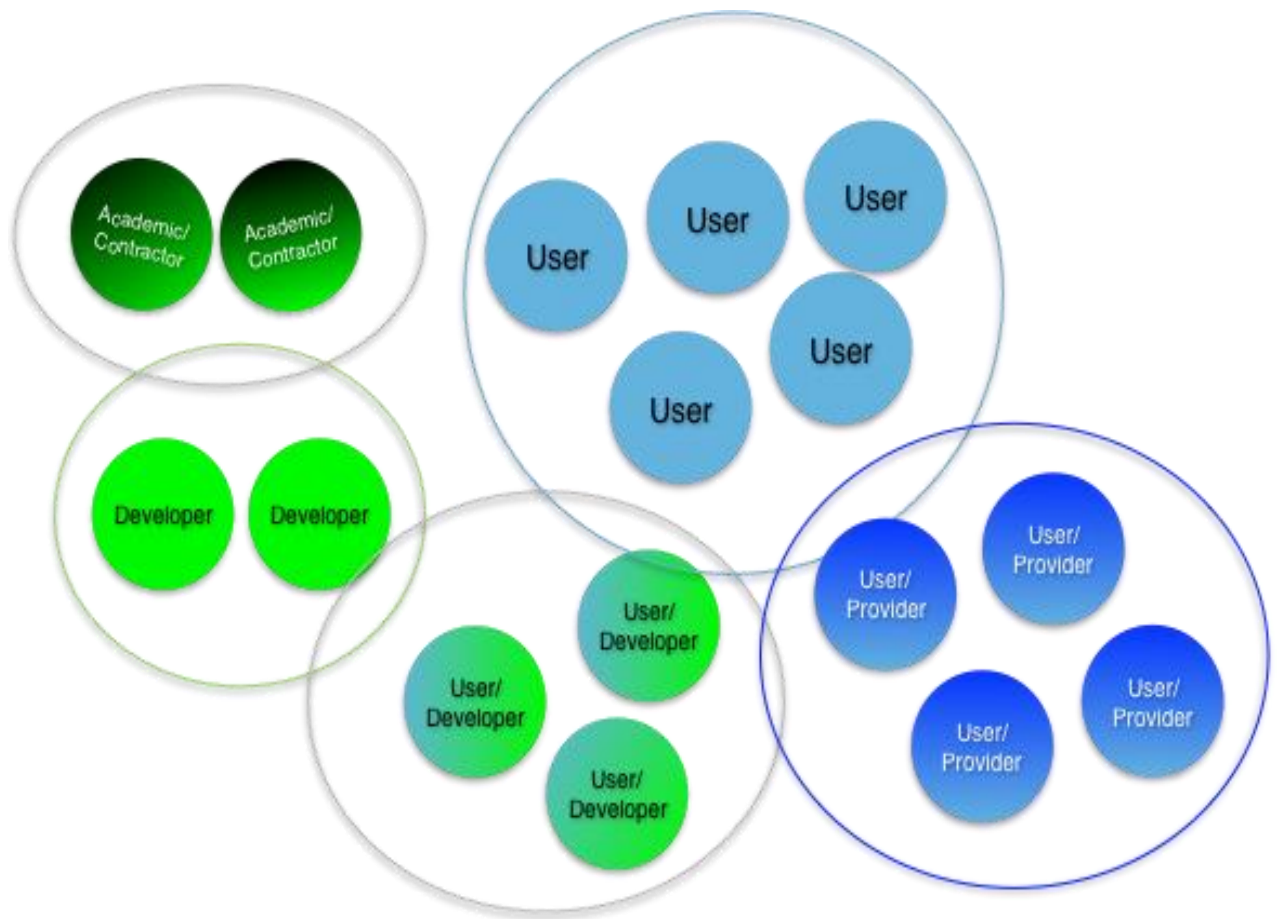


Figure 9. *Demonstrating participant roles and how social worlds are connected.*

Although the majority of these roles are constructed within the data and through the interviews with participants, it cannot be denied that there are defined roles in research. The role of external literature within a GTM is discussed in more detail in section 5.9., as an element of the CCM. Therefore, these roles are constructed through comparison not only between and within interviews, but also between and within data. The interview and coding data has been included in this section to demonstrate the use of all aspects of data in constructing roles.

### 5.8.1 Users

Users are identified as those who interact with DMH resources but who are perceived to hold a more passive role than system builders (section 5.8.2.). Whilst they may actively adapt the resources they use, for instance by running online support groups through an existing system, they are not involved in technical development and their most salient experience of DMH is as a user.

#### 5.8.1.1 User

In my research it has become clear that, whilst there are external social expectations that users are aware of, avoidance of the associated pressures can be a salient aspect of their role as user. In Table 9 Sandra is responding to a question about her use of coping mechanisms that are shared via YouTube. The choice and 'Freedom to Fail' (see section 7.2.) of these online videos are compared with her perception of interactions within a conventional healthcare setting:

Table 9. *Interview excerpt from Sandra (User)*

<b>Interview Data</b>	<b>Categories</b>	<b>Categories</b>	<b>Initial Codes</b>	<b>Focused Codes</b>	<b>Situations</b>
<i>131. And do you use the coping mechanisms that you find online?</i>					

132. Some of them yeah. I've tried them all. Things I wouldn't necessarily have thought to have tried and some work and some don't. It's quite nice.	finding what works		finding comfort in trying lots of options, finding new options	finding what works for you	trying different things
<b>Interview Data</b>	<b>Categories</b>	<b>Categories</b>	<b>Initial Codes</b>	<b>Focused Codes</b>	<b>Situations</b>
133. Quite a lot of the time, especially going to the doctors and things, it is quite a prescribed, you kinda feel like you're in a course, like this is what you do,	finding what works	freedom to fail	feeling controlled by professionals	finding what works for you	
134. this is what you do and you will feel better in 6 weeks, there you go, bye!		freedom to fail	being told how she will feel	finding what works for you	
135. And you're doing worksheets, do this, do that and that	finding what works		doing what they tell her	finding what works for you	
136. and I got that feeling, whether it was right or wrong,	finding what works		questioning herself	finding what works for you	

137. that if I went back again and the worksheets hadn't worked then it would be like "now what do you expect"	finding what works	freedom to fail	feeling like there are no options if this fails	finding what works for you	
138. whereas something like that there is so many, there is such a wide range of what people would do and say and things	finding what works	freedom to fail	appreciating the expanse, the options	finding what works for you	
139. so it's quite nice, things that you wouldn't necessarily think of, is quite nice.	finding what works		finding comfort in new things	finding what works for you	

By establishing DMH as external to conventional healthcare provision the user constructs themselves, and is constructed, as more than just a user of healthcare or a patient. Users may play a part in the design or development of resources as collaborators. In the excerpt below David, a developer, is discussing how feedback from users about a change to the platform led to a reversal of those changes:

*"But there's other lovely things like we pushed live the wrong set of code and the typography went really small and actually just a bit smaller and a grey colour, and someone just started a forum post saying like "this is really hard to read, can you change it back" and within twenty-four hours we had changed it back and improved it from what it was". (D204)*

Developers do not always view the 'user' as an inactive role at the end of an interaction but may construct them as active components within the resource itself.

However, users are not always viewed as active components. Sandra's experience demonstrates that users cannot be simply constructed as 'patients' whilst Table 10 shows an

example of users asserting novel and more personal strategies of use. Jessie is talking about her use of Big White Wall, a resource that provides levels of access from peer forums to online counselling. Although the peer support forums are moderated by trained counsellors, Jessie discusses her desire to speak with them directly and relates how they respond to her subversive use of private messaging on the platform by reasserting its purpose and signposting her to the forums to which she has access:



Table 10. *Interview excerpt from Jessie (User)*

Interview Data	Category	Category	Category	Focused Code	Initial Code
231. I don't know, so I've, sometimes when I've felt really bad I've messaged the moderators directly just because I know that they are actually professionals but then they, that can be really frustrating as well because it's like they very much tell you to then post something on the forum or post somewhere else or something and encourage that peer support.	finding what works	compromising	freedom to fail	feeling validated	Using a feature that is available but that signposts her elsewhere rather than providing support is frustrating
232. I know that's what it's there for but it's hard.	finding what works	compromising	freedom to fail	recognising purpose	accepting without wanting to

Here, the role of user is constructed as an inactive component by the moderators of the forum, relegated to specific allowed use. As an active user Jessie is frustrated by this.

Thus, the role of user is constructed within this research as autonomous, able to form their own concepts and use through their interaction with resources as well as their position within the social world. The role of 'user' may be constructed as either active, whether through innovation or collaboration, or inactive whereby they may be represented by their expected use rather than actual use.

### 5.8.1.2 *User/Provider*

This role was first constructed under the heading ‘User/Carer’ as it represented those users who utilised resources for others’ needs as well as their own. However, it became clear that their role as ‘carer’ could be more widely applied to their role as ‘provider’. Provider refers to their contributions not only to significant others but also to a much wider audience. In Table 11 Carol is sharing how important blogging is for her, not just as a way of exploring her own thoughts but also as a way of sharing her experiences in the hope that it might help others:

Table 11. *Interview excerpt from Carol (User/Provider)*

<b>Interview Data</b>	<b>Category</b>	<b>Category</b>	<b>Focused Codes</b>	<b>Initial Codes</b>
89. I've blogged on [name], for them, anonymously, about the problems of dealing with somebody with anorexia	finding what works	freedom to fail	blogging anonymously	blogging anonymously about own experiences
90. and I found that that's quite therapeutic because I can actually talk about my experiences.	finding what works	freedom to fail	finding blogging therapeutic	talking about experiences in a blog being therapeutic
91. I sort of change things very slightly so that if my daughter ever found it she may not realise it's her.	finding what works	freedom to fail	maintaining privacy	changing things so no one can recognise themselves
92. But I found that that's actually been really helpful	finding what works	freedom to fail	finding blogging therapeutic	finding it helpful
93. and then people comment "oh yes I felt like that" you feel like... if it helps, if somebody else can empathise then it might help them too.	people like me	seeing the journey	empathising as helping	shared experiences leading to being helped
94. So I feel like I'm doing something. Yeah?	people like me	seeing the journey	feeling empowered through action	feeling like she's doing something

Blogging, where the audience is potentially unknown, is not the only way that participants report helping others. Rita set up an online support group within a virtual world where she provided mental health peer support, which involved more direct contributions. These participants share a need to learn not only about themselves but also about others and a drive to provide support or information, often based on their own experience, to a wider audience. In this way there are parallels to the role of User/Developer (section 5.8.2.3.). However, they differ in that their role is often not constructed as overly technical, instead emphasising their personal experiences of supporting others using pre-existing resources.

### **5.8.2 System Builders**

The group of system builders are constructed through their role in the development and implementation of DMH resources. They are considered influential in the products that are created and do not just adapt existing services as the User/Providers do, rather they play a role in the development process itself, particularly the technical aspects. My experience participating in the ‘People Driven Digital Health and Wellbeing’ event (Betton, Brown, Cooper, & Howe, 2015) demonstrated that there are a considerable number of developers who play active roles in both development *and* implementation, reinforced by the CCM within the data collected from participants (see section 5.9.). I have separated the constructed role of developer into two roles, Developer and User/Developer (section 5.8.2.3.), not because I feel there is a clear distinction but because the latter participants emphasise their own use whilst the two participants within the role of Developer prioritise technological implementation. They are also separated from the role of Academic/Contractor (section 5.8.2.1.) as, although they may also be contractors, they position themselves outside of an academic and clinical role. Constructing roles is clearly difficult and involves much overlap when participants are sharing a social world.

**5.8.2.1 Academic/Contractor**

This role was first constructed as ‘Academic/Developer’ in recognition of the role participants play within the development of DMH resources for research purposes. However, through analysis it became clear that they did not share the technological drive of Developers (section 5.8.2.2.). By using the term ‘contractor’ the commercial aspect is emphasised, that developers are external and employed rather than necessarily collaborated with. Although there are potentially ‘Academic/Developers’ the participants identified themselves more strongly with a role of Academic/Contractor. This distinction demonstrated a close yet not entirely symbiotic relationship between academia and developers, one with more financial links than shared interests. For instance, in Table 12 Sharon discusses her realisation that involving the developer in the business would have been useful from the beginning but that once development had begun she felt that it would not be financially viable:

Table 12. *Interview excerpt from Sharon (Academic/Contractor)*

Interview Data	Category	Focused Code
218. I did have the conversation with my programmer who I really respect, I really respect my programmer, and I did have a conversation with him at one point about ‘look shall we do this together’ but I think it kind of got to the stage where I had already spent so much money on the programming that I couldn’t, it kind of got beyond the added value to be honest.	DMH as product	needing technological expertise
219. And I think because, I think if I did it again I would do that from the beginning I think. Got a programmer and somebody marketing. I think you need those two things.	compromising	needing developer and marketing expertise from beginning

Interview Data	Category	Focused Code
220. You need the clinical knowledge for the interventions, you need a programmer and I think you need somebody who is really hot on marketing and knows about testing the market beforehand and really testing the market.	compromising	needing clinical, developer and marketer

The Academic/Contractor needs a developer to translate the knowledge they hold into a technological resource but this is not always an easy relationship. Patricia describes in Table 13 the challenges of contracting individuals who hold such a different role, meaning that at times there are presumptions and misunderstandings based on a contractual rather than collaborative relationship:

Table 13. *Interview excerpt from Patricia (Academic/Contractor)*

Interview Data	Category	Category	Focused Code
101. I did find that people who work in a technological field make an awful lot of assumptions about the rest of us that are less technical savvy, and assume things are intuitive and assume it's straightforward that this is how it works, this is why you'd do that.	seeing the journey	compromising	presuming expertise in technology
102. And actually I don't consider myself particularly, I'm probably above average technologically compared to the general population but only just. I don't have a natural interest in technology for technology's sake or, I only use it if it enhances the things I do in my work so I wouldn't necessarily understand many of the issues that they might be discussing, talking about.	seeing the journey	people like me	presuming expertise in technology
103. The problem is they made assumptions that were incorrect along the way.	seeing the journey	freedom to fail	presuming expertise in technology

These participants are engaged in research as academics and may be more attuned to the clinical component of DMH. Both Patricia and Sharon held the intended use of their resources to

be an important part of use. Within research there is often an emphasis on controlling variables, in this case the unintended use of resources. Their role is interesting as they construct meaning in DMH through a paradigm that I as a researcher can recognise, one that at times led me to challenge my own preconceptions and expectations. As Phillip, a User/Provider, stated, change will “*come from the academics*” (Phillip202) suggesting that recognition of its promise, as well as its limitations, can aid in constructing meaning in the development and use of DMH.

The role of Academic/Contractor appears to require a relationship with other system builders which may be a very salient aspect within the construction of meaning in DMH. Whilst these participants identified themselves as researchers and were using the tools that they had designed for research purposes, the experience of research was only one aspect of their role. The other prominent concept that aided in the construction of this role was the reliance on developers, and the financial need and technological involvement that this necessitated.

#### **5.8.2.2 Developer**

The constructed role of Developer in DMH is necessarily involved in future-thinking, in financially supporting a business and considering how technology might evolve. They wish to provide the best service or product for their users but may need to compromise so as to ensure that it is sustainable (see [Compromising](#), section 8.2.). This is interesting to position alongside the [Academic/Contractor](#) (section 5.8.2.1.) as it too is a role that represents a balance between the duty of care to users and a need to ensure stability. In Table 14 Tom discusses the needs of a DMH product development process, a triumvirate of user focus, social value, and financial stability:

Table 14. *Interview excerpt from Tom (Developer)*

Interview Data	Category	Category	Focused Code	Focused Code	Initial Code
77. You got to have user values, so it's usable and fits into the user's lifestyle in a way which is makes them want to use it,	finding what works	dmh as product	being usable	integrating into daily life	finding what fits
78. it's got to deliver some kind of social value so it's got to change people's lives,	compromising	dmh as product	changing lives	integrating into daily life	ensuring social value
79. and it's got to deliver some kind of financial value in the sense that it's worth someone funding you to make it, or users paying for it, or someone else funding paying for the data or you go down the advertising route.	finding what works	dmh as product	needing a business model	difficulty of sustainability	ensuring sustainability

Developers emphasise values that are different to those of Academic/Contractor (section 5.8.2.1.). Whilst they consider the usability, social impact and financial stability as important, they also value the contributions of users with specific skillsets - clinical or technical experts - as well as volunteers helping to support the business. They recognise the Freedom to Fail (section 7.2.) that individuals have in accessing and adapting technologies for their needs, rather than encouraging intended use like Academic/Contractors (section 5.8.2.1.). In Table 15 David is discussing anonymity and how he feels it is up to the individual to decide whether to remain anonymous:

Table 15. *Interview excerpt from David (Developer)*

Interview Data	Category	Focused Code	Initial Code
85. I forget to say these things because they seem so obvious to us but people always ask these questions “how do you make sure that someone doesn’t write their name”.	freedom to fail	allowing anonymity	people asking questions with seemingly obvious answers
86. I’m like “you don’t”, you just give them the choice to choose any name they want and if they choose to write their name. (shrug)	freedom to fail	allowing anonymity	giving people choice to stay anonymous

Developers may or may not be clear about who their users are but are likely to respect their autonomy of use. The technology itself is important and they prioritise the sustainability of their product through business models and future-thinking.

### 5.8.2.3 *User/Developer*

User/Developer is a term that attempts to encompass more than just programmers and designers of technological resources. Rather than restricting this construct to those that have the technical expertise to implement, it is expanded to those who are involved in understanding the how and why of implementation. For instance, Sean considers himself not to be “*a technical person*” (Sean79) or a developer, yet his role is to aid in the development process by understanding and reconstructing problems in a way that can be addressed technologically (Table 16):



Table 16. *Interview excerpt from Sean (User/Developer)*

Interview Data	Category	Focused Code	Initial Code
79. I'm not a technical person,	seeing the journey	constructing role	identifying himself
80. I'm not a developer,	seeing the journey	constructing role	identifying himself
81. but what I am capable of doing is helping the formulation of problems that technology can solve.	seeing the journey	constructing role	helping formulate problems that technology can solve
82. If you set the problems out right people will tell you what's possible to solve them.	simulating mh	speaking the language	finding solutions

The construct of User/Developer expands the role of Developer (section 5.8.2.2.) and User (section 5.8.1.1.), wherein both mental health and technology discourses co-exist. During my research I participated in an event titled ‘People Driven Digital Health and Wellbeing’ – a viewpoint that recognised “everyday people sorting out everyday problems” (p.2; Betton, Brown, Cooper, & Howe, 2015). People are driving digital health and wellbeing, with speakers sharing their personal stories of innovation grounded within their own experiences in health and wellbeing. The User/Developer, as constructed within this thesis, focuses on the involvement of individuals within the development process and includes those who are not in a technical position. These individuals are capable of straddling two discourses, that of mental health and technology, although they may be more or less oriented to either one. As with the role of developer it reflects involvement in both development and implementation, and further emphasises the important contribution that experience plays. In this way there are links to the role of User/Provider (section 5.8.1.2.), although the participants not only have experience with the use and provision of resources but also with the development process. This includes a salient

awareness of the challenges of implementing DMH into existing systems, whether these come from conventional healthcare or prospective users.

Whilst this thesis emphasises the interrelationship between technical interest and user experience as co-creating the duality of User/Developer there is potential for other roles to act in a similar way. Whilst an academic knowledge of mental health experiences or technology use is important it could be argued that within DMH there is a mutual discourse that is difficult to find within academic literature of one or the other. Sam (Table 17) echoes this when he discusses well-known technological design concepts such as persuasive technologies or gamification, which aim to influence behaviour, and the sparsity of research exploring how this might impact mental health:

Table 17. *Interview from Sam (User/Developer)*

<b>Interview Data</b>	<b>Category</b>	<b>Category</b>	<b>Initial Code</b>	<b>Focused Code</b>
203. I think we need to be careful because we know that these things work in a very simplistic way			stepping carefully	
204. but I think if we are to implement these things in mental health... that scares me.			concern re implementing	
205. Because we know we can persuade people to do behaviours by doing certain things	freedom to fail	DMH as product	controlling reception	technology as advocate
206. or we know that everyone loves the idea of gamification				

<b>Interview Data</b>	<b>Category</b>	<b>Category</b>	<b>Initial Code</b>	<b>Focused Code</b>
207. but it isn't ever going to be a sustainable thing but we don't know how safe gamifying a kind of calorie counter is for an anorexic.	freedom to fail	changing purpose	controlling reception	technology as advocate
208. The way they understand the world, the way they understand the world, their mental health.	freedom to fail	changing purpose	controlling reception	technology as advocate

This is further illustrated within the mental health literature when Sean challenges researchers who focus exclusively on the clinical aspects of their products (Table 18):

Table 18. *Interview excerpt from Sean (User/Developer)*

<b>Interview Data</b>	<b>Category</b>	<b>Category</b>	<b>Initial Code</b>	<b>Focused Code</b>
264. It's like we have to test whether it works within these constraints so here it is in systems font with check boxes and its red text on a green background.	finding what works	changing purpose	needing user experience	isolating variables
265. Forgetting that the user experience is actually probably fundamental to peoples response to it.	finding what works	changing purpose	experience as important	isolating variables

The role of User/Developer is constructed to represent the participants that are aware of both technological needs in mental health and mental health needs in technology. They represent individuals who are consolidating two seemingly separate areas of interest – mental health and technology – and constructing a discourse around what they perceive to be mutual requirements. Although both Users and Developers also share some elements of this discourse it is less prominent within their interviews.

### 5.9 Constant Comparative Method

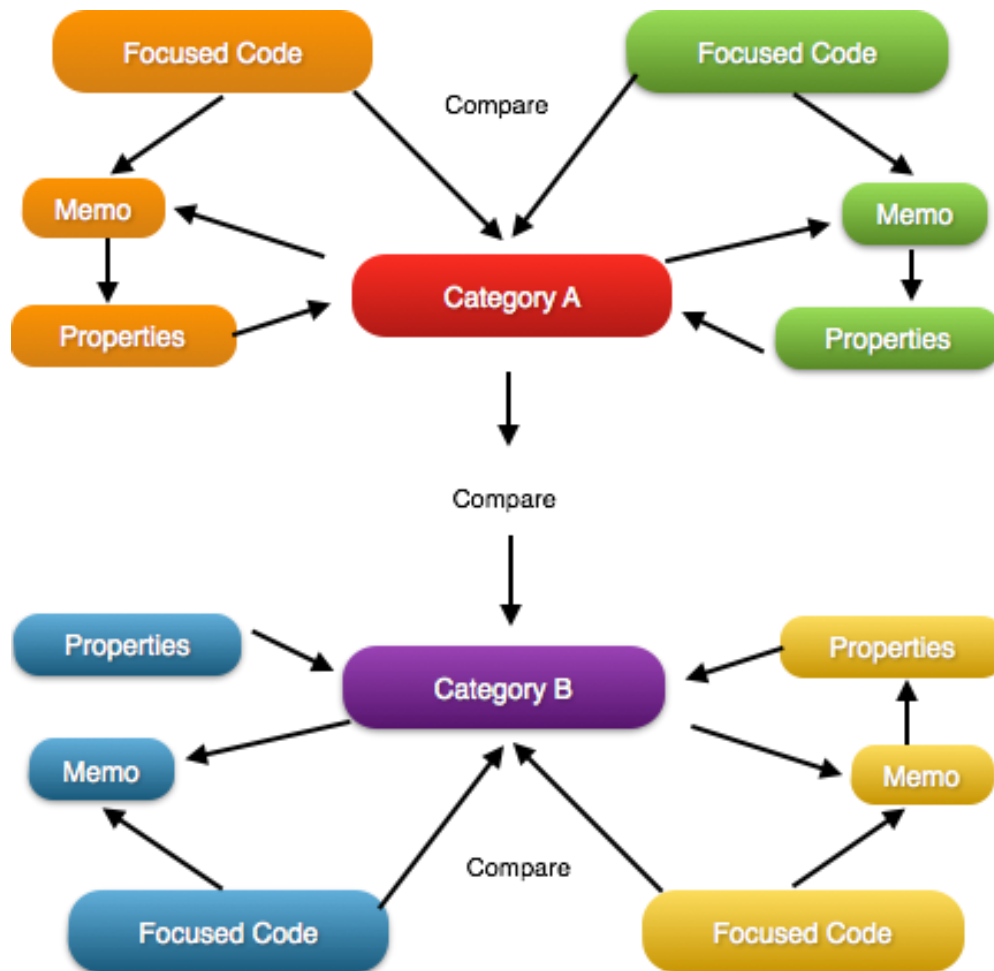


Figure 10. *The constant comparative method.*

The constant comparative method (CCM) is illustrated in Figure 10, demonstrating how focused codes, memos and properties interact. CCM is a process of analysis whereby data and codes are compared, where concepts are included and discarded, and explored for their similarities and their differences with the intention of generating abstraction (Charmaz, 2014). This process is integral at every level of analysis and helps the researcher in gaining a deeper understanding of the data and codes, thus contributing to memo-writing. The CCM often involves a return to previous interviews with codes or concepts constructed from later interviews.

This emphasises the iterative nature of GT analysis, as addressed within The Iterative Process (section 5.4).

The inclusion of existing theories that have low empirical content to supplement the development of categories from codes can provide heuristic devices within the analysis of data in a GTM (Kelle, 2007). When used alongside the CCM they can help to reduce terminology and aid in generalisation (Glaser & Strauss, 1967). As the CCM progresses, concepts are constructed that require a further level of theoretical coding to identify relationships between them. Glaser (2013) views theoretical coding as an emergence of abstract models through the use of the CCM whilst Charmaz (2014) challenges this objectivity by establishing them as frameworks from which to work, although they remain implicit within the codes. Within this research I have used several theoretical frameworks to both challenge and construct relationships. The most prominent is that of social worlds (Clarke & Star, 2007; Strauss, 1978), which enabled me to represent the relationships between and within participant roles more clearly. A difficulty at times in writing up GT research is its iterative nature. The presence of a discussion of social worlds within the literature review (section 2.6.) would suggest that it was a guiding theoretical framework and yet it was only through analysis that it became clear that it would aid in my construction of the complementary and contrasting roles that participants represented themselves within.

The CCM is an essential analytical process in GT (Charmaz, 2014). During the initial stages this was done within single interviews and between codes, exploring the data for contradictions and consistency. As data collection progressed it became possible to compare between interviews. Boeije (2002) also conducted a study that involved several different groups and the coding paradigm was adapted for the current study to provide a structured approach to

clustering when exploring individuals across different roles. Thus comparisons were made between participants with similar roles, and participants with different roles. The stages and relevant aims are outlined in Table 19:

Table 19. *Outline of a constant comparative framework for multiple groups.*

<b>Type of Comparison</b>	<b>Type of Analysis</b>	<b>Aim</b>	<b>Analyse</b>	<b>Results</b>
Comparison within a single interview	<ul style="list-style-type: none"> <li>• Line by Line Coding</li> <li>• Incident with Incident Coding</li> </ul>	<ul style="list-style-type: none"> <li>• Develop categories and focused codes</li> <li>• Summary of interview</li> </ul>	<ul style="list-style-type: none"> <li>• Core message of interview</li> <li>• Consistency and contradictions of codes</li> </ul>	<ul style="list-style-type: none"> <li>• Summary of interview</li> <li>• List of provisional codes</li> <li>• Inventory of provisional codes or conceptual profile</li> <li>• Memos describing analysis process</li> </ul>
Comparison between interviews within same group	<ul style="list-style-type: none"> <li>• Incident with Incident Coding</li> <li>• Focused Coding</li> </ul>	<ul style="list-style-type: none"> <li>• Exploring concepts</li> <li>• Clustering</li> </ul>	<ul style="list-style-type: none"> <li>• Similarities and differences</li> <li>• Relationships between codes and categories</li> </ul>	<ul style="list-style-type: none"> <li>• Covering all themes</li> <li>• Describing concepts</li> <li>• Clusters/typologies</li> </ul>

<p>Comparison between interviews from different groups</p>	<ul style="list-style-type: none"> <li>• Triangulating data</li> </ul>	<ul style="list-style-type: none"> <li>• Exploring concepts and relationships</li> <li>• Clustering</li> </ul>	<ul style="list-style-type: none"> <li>• Similarities and differences</li> <li>• Relationships between codes and categories</li> <li>• Contradictions</li> </ul>	<ul style="list-style-type: none"> <li>• Verification of relationships</li> <li>• Memos</li> <li>• Theoretical codes</li> <li>• Insight</li> </ul>
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*Note. This framework is adapted from Boeije (2002).*

Figure 11 shows that comparisons were made between and within various participant interviews that aided in reinforcing their positions within their constructed roles. One important purpose that this process served was to triangulate the data by comparing the relationships, consistent and contradictory, between the various roles and stakeholders. Triangulation is typically adopted by realist paradigms that seek to uncover ‘reality’ through consensus and consistency of meaning but it may aid in relativistic paradigms by offering a tool for internal coherence, a way to explore challenges and understanding more deeply (Madill, Jordan, & Shirley, 2000). Although it is not possible to conclude that the data is triangulated as this is a small qualitative study – indeed this is not its purpose – the heterogeneity of the participant sample provides a modest cross-verification that can aid in exploring concepts as constructed by certain participants within the overarching social world.

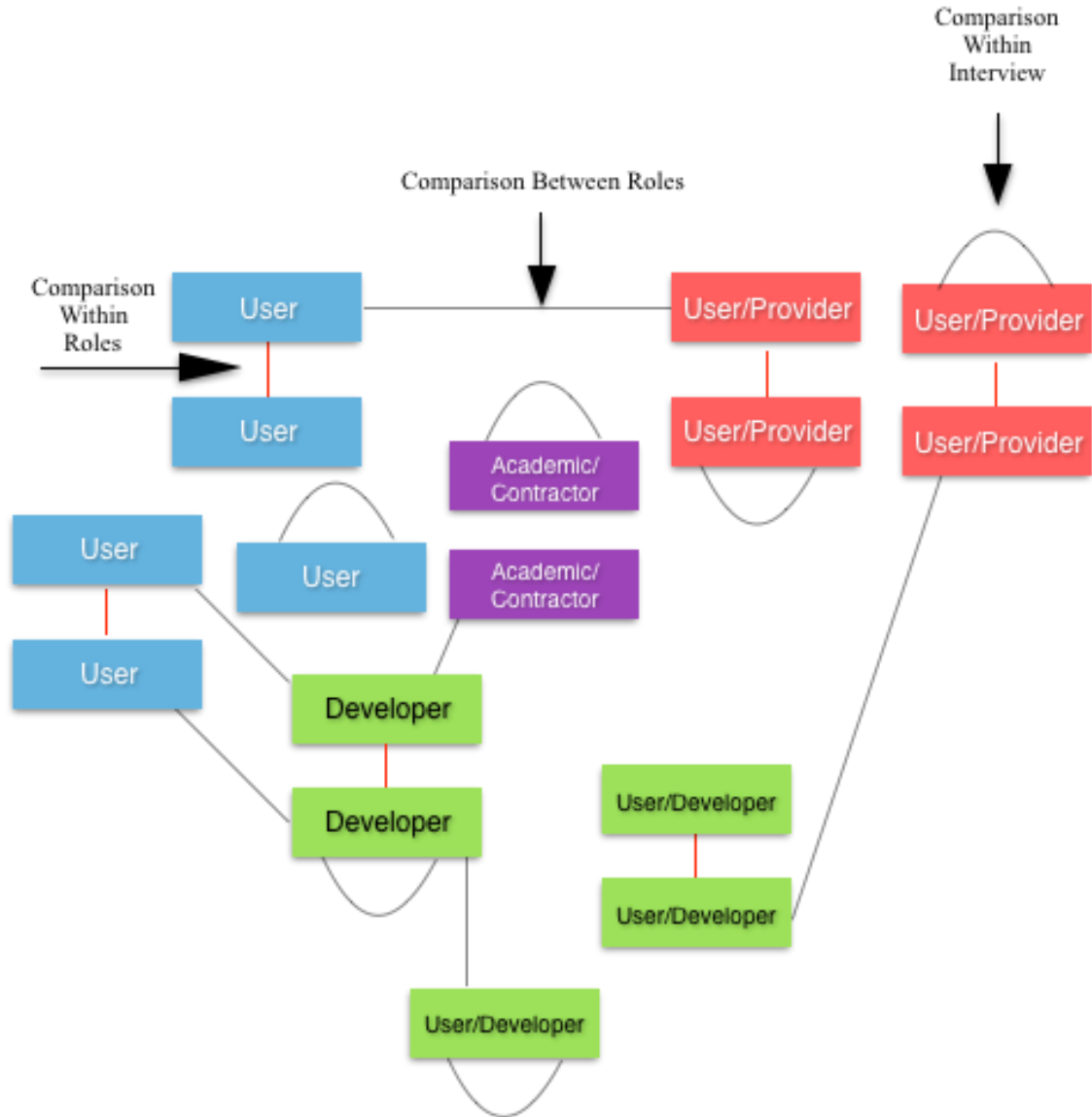


Figure 11. *Demonstrating the comparisons made to explore concepts, triangulate participant roles, and develop categories.*

### 5.10 Situational Analysis

Although I felt I had managed to maintain an element of the participants’ voice throughout analysis, particularly with the use of adjoining columns within Microsoft Excel, it became clear towards the end of data collection that I had left the technology behind. The iterative analysis outlined by Charmaz (2014) did not seem able to account for all the



complexities of interactions involving both social and technological agents, although this may have stemmed from being a newcomer to her methodology. Nonetheless there appeared a gap between the interviews and the secondary data, including the collected visual observations of DMH examples. This gap was not from an absence of data but from difficulty clarifying the relationships between the social worlds of participants, the wider context and the exigency involved in encompassing the roles of technology. This led to adopting Adele Clarke's situational maps (Clarke et al., 2015), providing a supplementary component of analysis. The aim was to utilise this practical analytical tool alongside the constructionist GT so as to embrace the complexities within the data.

Clarke's (2005) embracing of complexity, and indeed technology, is clear from the beginning of her seminal work on situational analysis when she describes what she is attempting to capture with her analytical tools; "partialities, positionalities, complications, tenuousness, instabilities, irregularities, contradictions, heterogeneities, situatedness, and fragmentation – complexities" (p.xxiv). To do this she describes three types of maps that can be used to lay out and analyse the various conditions within the situation. These are outlined in Table 20:

Table 20. *Outline of analytical maps.*

	<b>Description</b>	<b>Purpose</b>	<b>Components</b>
Situational Maps	Lay out elements of the research situation.	Analyse relations between elements.	Human and nonhuman.
Social Worlds/Arena Maps	Lay out the size, locations, and intersections of the social worlds within the arena.	Analyse how and why social worlds come together within an arena.	Social worlds and arena.
Positional Maps	Lay out the different points of view within the situation.	Analyse the views and positions.	Views and positions.

Note. Table taken from Clarke (2005).

Clarke (2005) specifically relates her use of analytical maps to the necessity of including the nonhuman in interactions and refers to Latour's (2005) Actor Network Theory, a well-known theoretical perspective in technological discourse that accepts the role of objects as agents. I return here to my earlier view of technology as evocative, reflecting and provoking through their representation within an interaction rather than necessarily in themselves having any particular agency. They are objects that can represent experience-in-context, even in-action, and therefore deserve a more salient role than was clear using Charmaz's (2014) analytical methodology alone.

The use of situational analysis has been challenged within a constructionist perspective and reconciled using symbolic interactionism (Mills et al., 2007). Mills and colleagues (2007) discuss in detail how situational analysis can not only enable the researcher to conceptualise the ways that codes may fit together within social worlds, but also how it can help bridge the analytical gap between document and interview data. Although Clarke suggests that their purpose is more explicit in theoretical sampling (Clarke, 2003), I found them useful even when data collection was completed. For some studies the need to account for such complexities may

not become apparent until it has been ongoing for some time and I did not face any significant problems with incorporating them at a later stage.

Using situational maps was a useful analytical tool to also acknowledge the roles of User, User/Provider, Developer, User/Developer, and Academic/Contractor. Charmaz (2014) suggests using Clarke's (2003) situational maps as a way of identifying structure and the positioning of actors and elements in constructions of social worlds that are studied. This was particularly of relevance at this stage as it places technology actively in the construction of meaning (Clarke et al., 2015). In doing so the social world in which the study is positioned includes not only the visible social processes but those that are invisible, such as the type of resource through which use occurs. This enables a clearer perspective on the dynamics between participant roles. For instance, David spoke about developing a platform to enable people "*to ask the naughty questions or silly questions*" (D32) whilst Sandra feels that anonymity online can encourage communication about mental health because "*a lot of the time a lot of the questions that people would have about mental health and how they're feeling and things like that they worry that they're silly questions*" (Sandra90). By recognising the social world in which they interact the subjective inherent purpose implemented by the Developer, David, is positioned alongside the constructed meaning of 'anonymity' through a shared goal with a User, Sandra. An example of a situational map within this research, adapted from Clarke (2003) can be found in the Appendix 11.9. Please note that it evolved throughout analysis and was replaced or adapted, with concepts and actors included and excluded as categories became more saturated.

### **5.11 Memo-Writing**

Memos are very important in GT because they provide a way for the researcher to contemplate, reflect and construct concepts based on their codes. They also aid in theoretical

sampling by demonstrating gaps in the data collection (Charmaz, 2014). By exploring deeply and continually questioning your codes and your categories it can enable researchers to build towards their theoretical integration.

As can be seen in [Figure 5](#) (section 5.6.) memo-writing has a significant role at every level of analysis. Charmaz (2014) emphasises the role it plays in helping to capture not only the participant's voice but also the researcher's. An example of a memo is included (Appendix 11.10). As data collection and analysis ran side by side for the initial stages the memos were often restricted to short, freehand speculative comments on particular participants' experiences, incidents, or codes. As analysis progressed the memos began to accumulate and become in themselves a source of comparative strength within the analysis.

## **5.12 Developing Categories**

The purpose of a GT study is to move beyond description to abstraction (Charmaz, 2014). One way to do so is through clustering (Miles & Huberman, 1994). Clustering, alongside situational analytical tools and memos, can bring codes together so as to explore their interrelationships and can help identify closely related concepts. Diagramming plays an important role throughout analysis not only in contextualising concepts within the social worlds and arenas but also as a way of visually representing processes, relative power, and scope (Charmaz, 2014). Both analytical techniques can help the researcher to move beyond description to more abstract constructions of the prominent concepts and aid in theoretically saturating categories.

### **5.12.1 Clustering**

When David, a Developer, first spoke of 'asking silly questions' as an integral purpose of building a DMH resource the understanding that the resource itself was a type of social network,

aimed at connecting people together, enabled a positioning of the code “asking silly questions” alongside “People Like Me” (section 7.4). For Sarah, a User/Developer, this became aligned to the concept of anonymity, of being able to open up without being identified and find answers to questions that may not otherwise have been asked:

*“so you don’t have to see someone about a taboo subject or look them in the eye when you’re telling them something embarrassing. You get the information you need discretely and you don’t even have to leave the house. No one has to know.”* (Sarah 434-437)

This concept, “asking silly questions”, is once again discussed by Sandra, a User, in relation to a type of anonymity – that of being able to pull on and discard pseudonyms, and the empowering aspect it can have: *“it sort of allows you to be a bit bolder and you can ask the question and get a silly response... you can sort of go ‘well it’s ok, nobody knew that was me’”* (Sandra 87-89).

Taking note of the technology they are referring to – David (a Developer) and Sandra (a User) both refer to forums whilst Sarah (a User/Developer) is referring to a text-based information service – can aid in aligning the relationships between categories (blue) and their properties (yellow), as shown in Figure 12:

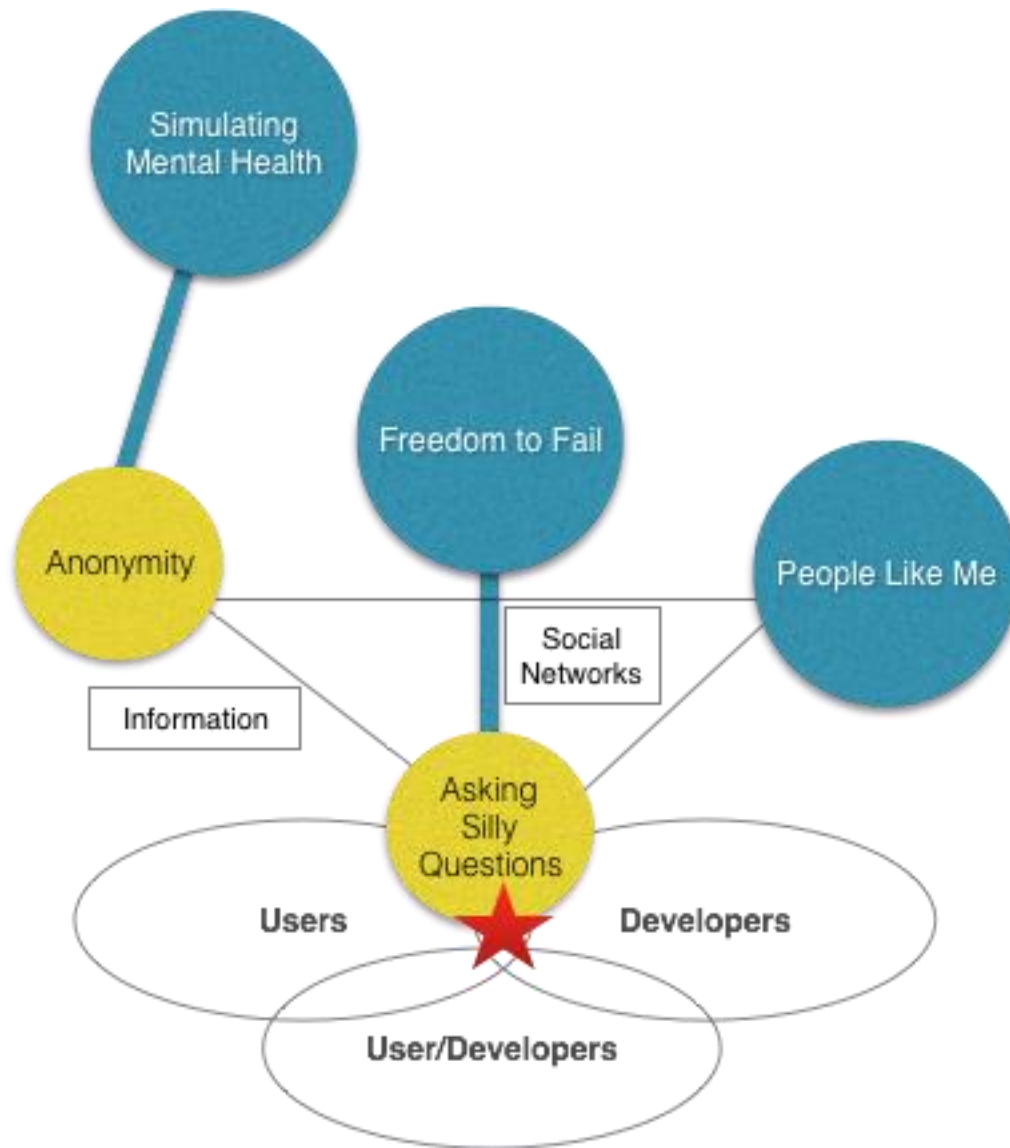


Figure 12. *Illustration of clustering using codes, properties, categories and participant roles.*

### 5.12.2 Diagramming

Diagramming was used to explore properties within categories. Additional concepts within the broader context, taken from the situational maps outlined in [Situational Analysis](#) (section 5.10.), were used alongside theoretical concepts that could aid in providing a deeper understanding of processes that may be constructed around meaning. The category of [Freedom to Fail](#) (section 7.2.) was constructed early on and diagramming helped to challenge and

theoretically saturate it throughout analysis. In Figures 13 and 14 the initial diagrams are closer to unstructured concepts littered on a page than diagrams that can serve to visually represent a category.

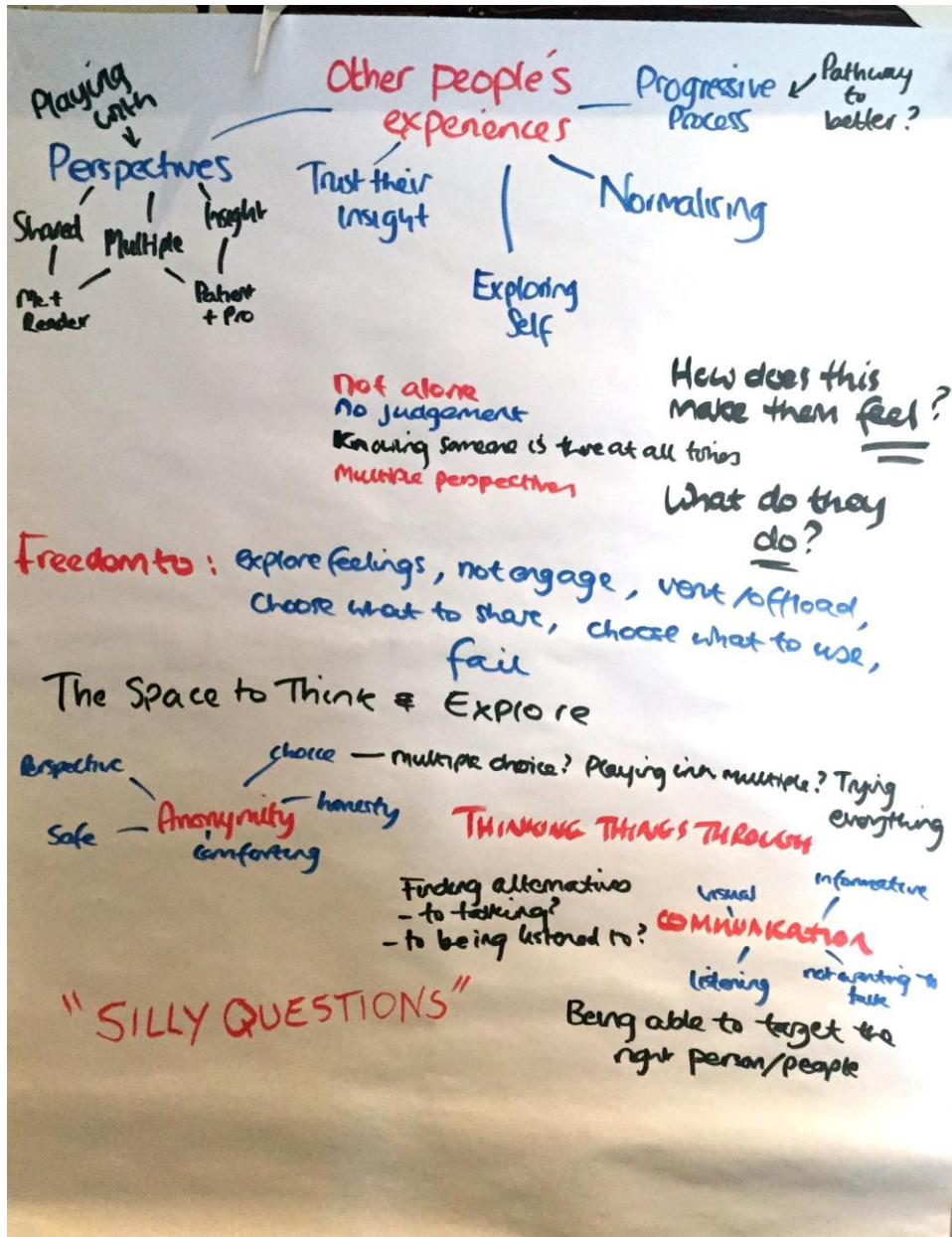


Figure 13. Example of initial diagrams for the category 'Freedom to Fail'.



Figure 14. Example of initial diagrams for the category 'Freedom to Fail'.

However, these 'messy' diagrams were useful as a blueprint for more abstracted and structured computer-generated diagrams. Figure 15 shows an example of one of the diagrams that developed from those shown in Figures 13 and 14.



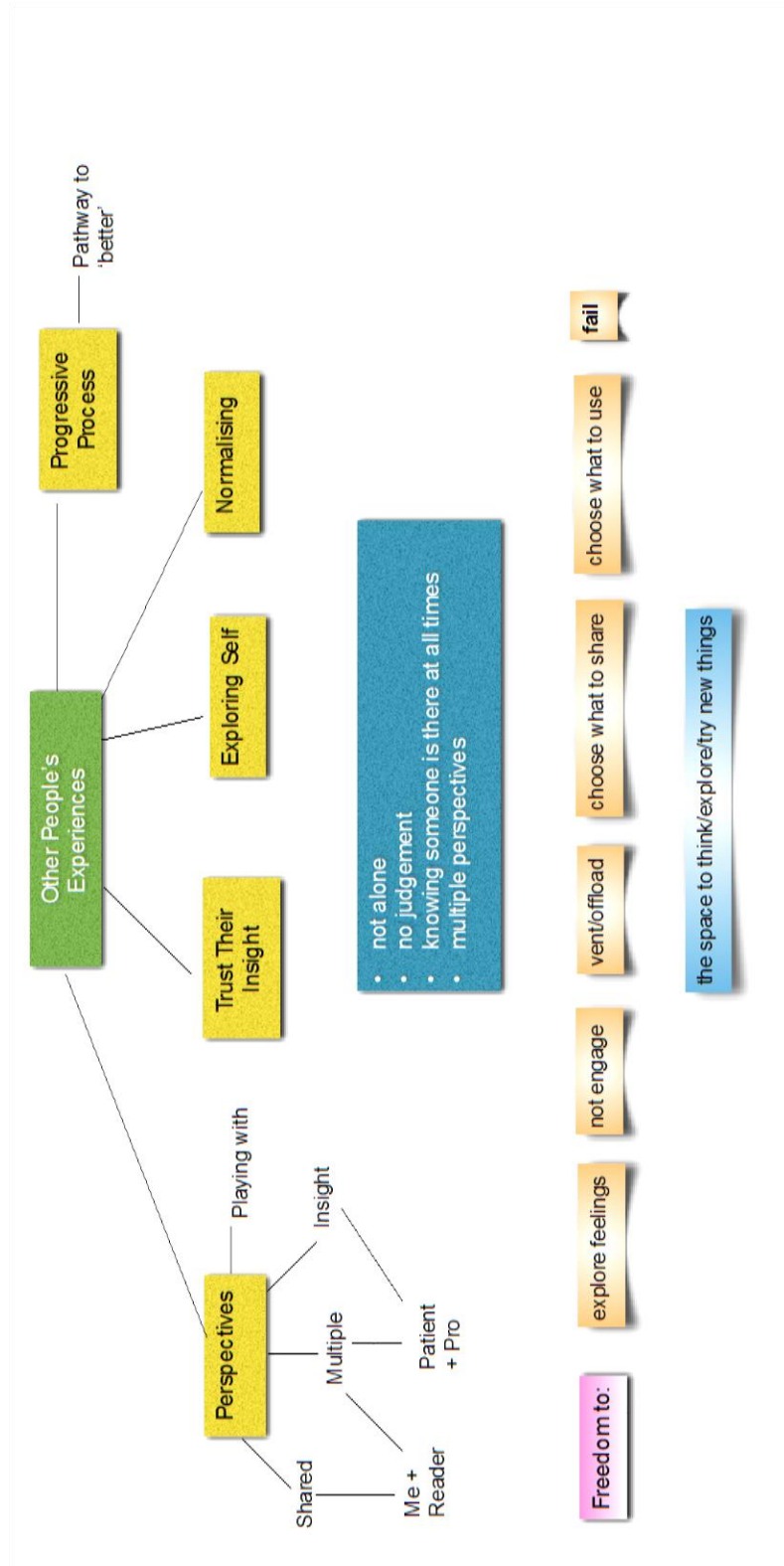


Figure 15. Example of computer-generated diagramming.

### **5.12.3 Navigable Tabular Sorting**

Word documents offer assorted functions that can be utilised as alternatives, or in addition, to the conventional analytical methods used in qualitative research. Hyperlinks can provide a navigable experience through a document, linking sections and words together at the click of a button. Memos can be included as comments attached to specific sections of text. The ‘find’ function enables not only specific words or phrases to be navigated to instantly but it can also show all examples within a document or section of text. I placed tables of interview data, codes and categories within documents for each category, arranged by participant. Hyperlinks were made between and within the data to provide an interconnected document exploring categories and their properties.

### **5.13 Summary**

This chapter has addressed the initial critical analysis of data within an adapted GT framework using examples to demonstrate the methods used. It has also explicated the constructed participant roles and situational analysis that acted as analytical tools within the constant comparative method, and described the development of categories. Moving from initial coding through to the development of categories, the use of interview data, codes, and categories and their properties ensures that the analytical process is made clear.

## **6 Analysis and Findings: The Milieu of Digital Mental Health**

### **6.1 Introduction**

Within this chapter several categories are displayed and discussed. Please note that Participant Roles are identified through the use of abbreviations to denote the different roles – Developer (D), Academic/Contractor (A/C), User/Developer (U/D), User (U), User/Provider (U/P). This chapter explores the categories associated with the milieu of digital mental health (DMH). This includes the social environments in which they are developed and used, how the various subworlds overlap and interact, and the ways in which they converge and diverge.

### **6.2 DMH as Product**

Recognising DMH as a product brings together the concepts and properties of Human Interoperability, The Interminable Product and Ratings Over Research. This category positions the commercial contexts and complexities within DMH alongside the convergences and divergences of users and system builders.

#### **6.2.1 Human Interoperability**

The concept of interoperability is well-known within digital technologies and describes the ways that systems can work together (PWC, 2013). However, interoperability is also required between actors within a system. This is constructed as involvement of and respect for all stakeholders within development.

### 6.2.1.1 *Conflicting Paradigms*

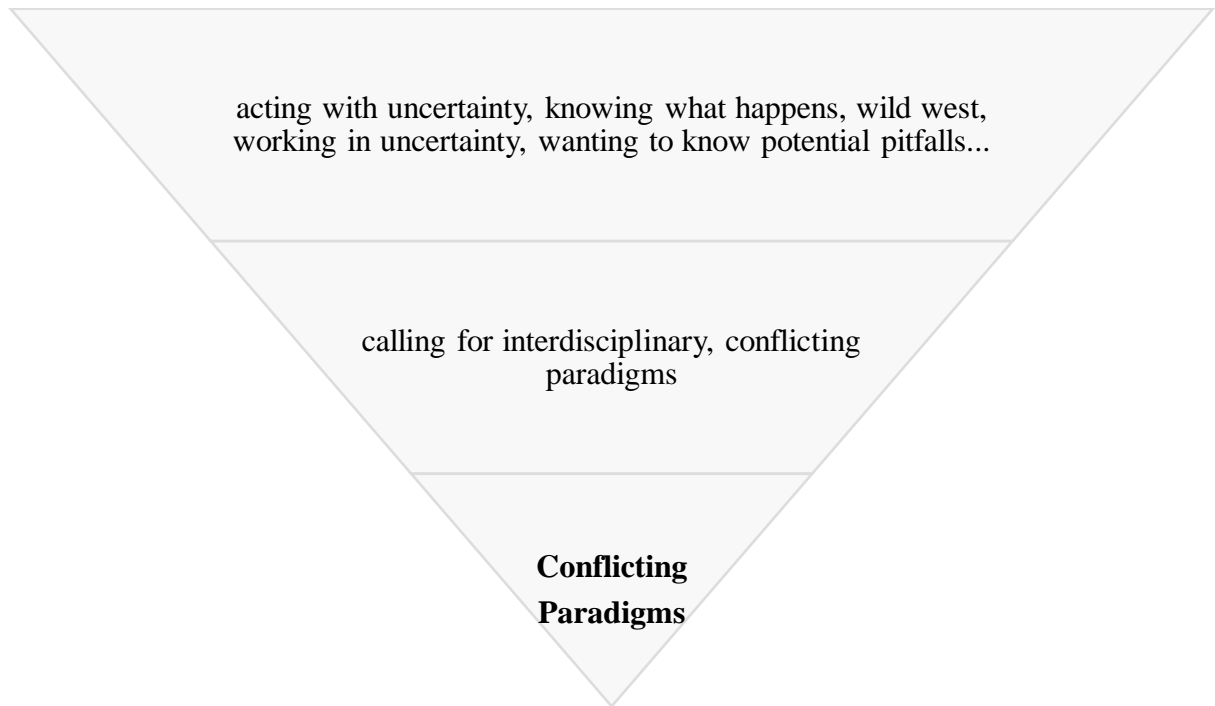


Figure 16. *Showing analytical process of codes resulting in the concept of Conflicting Paradigms.*

Figure 16 demonstrates the analytical process through which subtitles were conceptualised. Each level represents codes assigned to lines of the interviews, becoming more relevant as it is abstracted downwards until a concept could be constructed to account for the meaning within these codes.

Sam (U/D) sees little cohesion between the technical and clinical side of DMH. Clinicians “*think they know best because they know the science... but they don’t know the other parts*” (Sam221). Developers also make presumptions; “*for them it’s any old project*” (Sam220). Sam constructs this as the use of existing design techniques by developers with little consideration of the potential impact they may have on mental health - “*we know least about how people interact with technology than we do anything else*” (Sam260-264) - and a blasé drive

which he views as “*let’s disregard the rules and see what the hell happens*” (Sam227). Sean (U/D) perceives this as a disconnect between two paradigms, the clinical in which “*you need to know before you do*” (Sean163) and the digital paradigm of you “*won’t know until you do*” (Sean164). Sharon (A/C) recognises her interest is in the content rather than the technical aspects – “*what I have is an understanding of the evidence base*” (Sharon190) – as does Patricia (A/C) – “*my priority has always been the content because that’s where I was comfortable*” (Patricia94). David (D) is interested in the design and delivery – “*I’m not that interested in [condition]... I’m interested in the innovation behind the service design and interactions*” (D93). This divide is seen as one occurring through their different interests and chosen methodologies; as well as financial pressures, available knowledge, and stakeholder involvement. The Academic/Contractors, Sharon (A/C) and Patricia (A/C), by necessity relied on developers (who financially gained from their involvement) to know what was technologically possible when developing their resources. This meant that Patricia (A/C) was unable to anticipate “*the potential pitfalls... there was nowhere really to learn about them*” (Patricia99) and Sharon (A/C) was faced with added costs due to her limited knowledge in the area, as developers did not identify a “*more effective way we could do this, because they’re not incentivised*” (Sharon196-197). These demonstrate the difficulties that arise when human interoperability is challenged by apparent conflicts within the underlying viewpoints, or paradigms, of those who are required to work together.

### 6.2.1.2 Involving Stakeholders

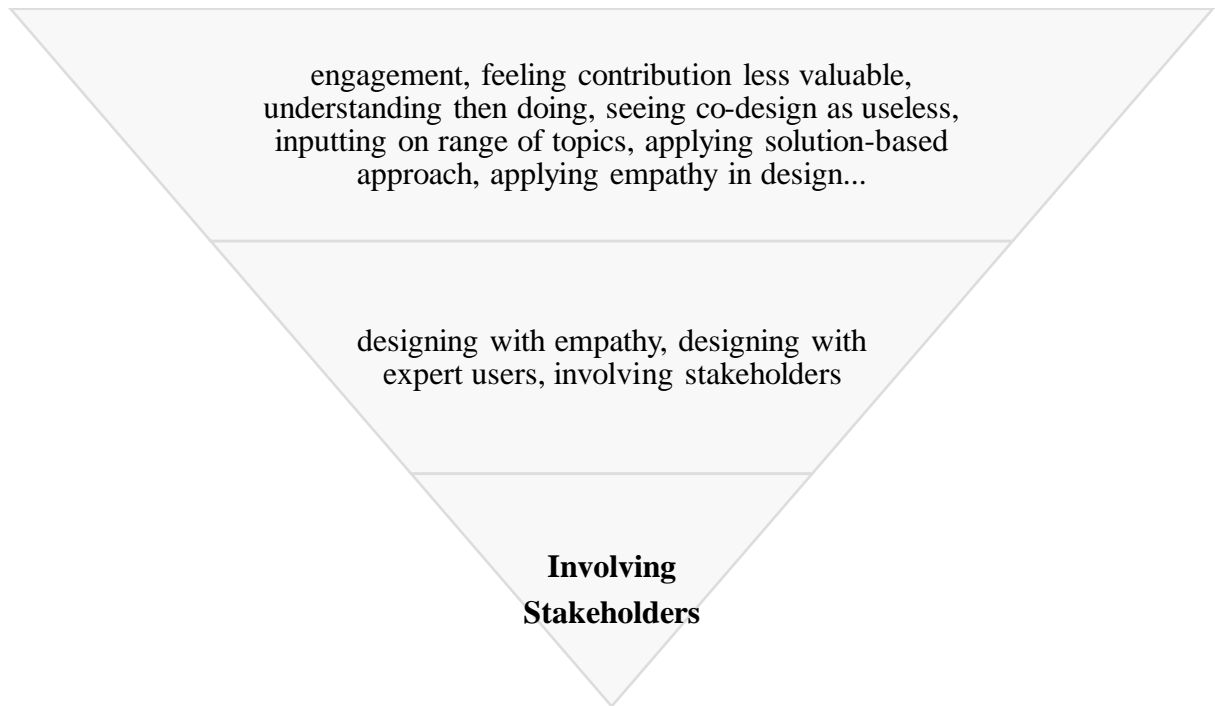


Figure 17. Showing analytical process of codes resulting in the concept of *Involving Stakeholders*.

Interoperability also relates to the involvement of stakeholders within the development cycle. However, within mental health there are challenges that must be overcome. DMH brings together various challenges and limitations that can impact involvement. Patricia (A/C) notes that whilst she “*would have liked somebody who was a carer to be part of the project team... [she] couldn’t manage that in the time constraints*” (Patricia50). Others “*felt their contributions wouldn’t have been as valued and actually it would have been more valuable*” (Patricia56). David (D) also emphasises that within health there is an unpredictable nature that must be accounted for when involving users with various healthcare needs – “*people have to stop... because life’s quite shit or, conversely, because life’s got really good*” (D257). Involving stakeholders may be challenged by the constructed meaning of their involvement. David (D)

considers the meaning of co-production, constructing it as *“kind of box ticking. You get people around the room, they tell their story and you go away and design what you were going to design anyway”* (D115-116). Users may request resources that are not possible or difficult to implement given the limitations, whilst those with more technical expertise will understand and *“know how many developers Facebook have”* (D118). In other words, they can grasp the difficulties of developing more complex resources. Tom (D) constructs what is needed as an empathic development process that seeks to understand the user’s experience, that *“involves... trying to understand that user’s experience, their life and what goes on, and building as much empathy as possible so you can then apply your design thinking... to a solution that actually fits..., the user might not have even thought of what they need”* (T123-127). This divide in knowledge demonstrates that, whilst developers may have solid technical skills, other stakeholders can provide the experiential and practical knowledge-base from which useful DMH resources can be built. It appears that it is through human interoperability that innovation is made possible, as it enables both clinical and technical aspects alongside appropriate user involvement. However, it is also necessary to consider stakeholder needs when involving them.

### **6.2.2 The Interminable Product**

The word ‘interminable’ describes something that is seemingly endless, often used hyperbolically. It is a concept that emphasises the necessity of continuity in DMH products.

### 6.2.2.1 Sustainability

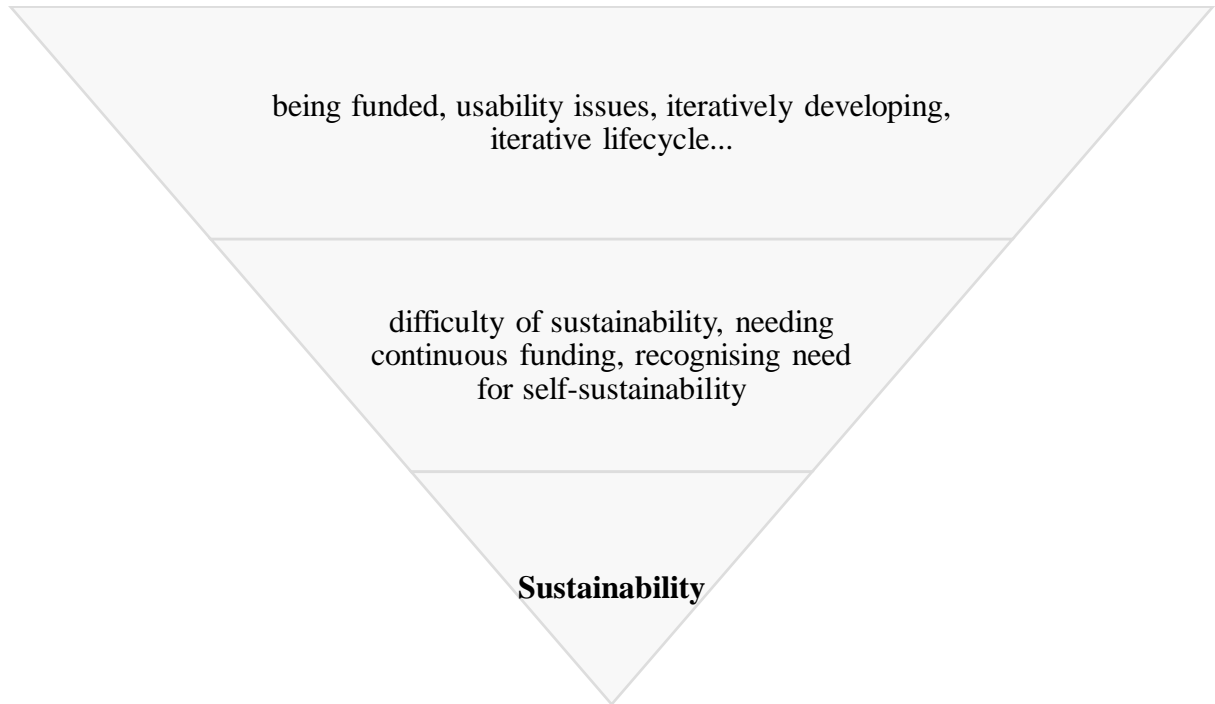


Figure 18. Showing analytical process of codes resulting in the concept of Sustainability.

Innovation Labs, a DMH organisation that developed and brought several mental health apps for young people to market, identify ‘sustainability’ as an important concept within DMH as a product (Roberson, 2013). Tom (D) addresses this when he states that *“an app cannot just stay still. If you stay still it won’t continue to work. It’ll fall by, it’ll get bugs”* (T69). This requires ensuring a sustainable business model that factors in ongoing costs – *“some kind of model that’s gonna help you to continue to finance the maintenance of a product and develop it”* (T70). Tom (D) clearly identifies the interminable nature of DMH as product when he states *“no product is ever finished; you get to certain points in it but there’s always more you can do”* (T71). The use of ‘can’ reinforces the role of system builders within the construction of its meaning as interminable. For Patricia (A/C) problems arise through the finite funding available for research – *“I still have some money to be able to address anything that comes up but there*



*will be a point when I haven't and if anything comes up it will just sit there, left like that"*

(Patricia82). This emphasises not only how cost may lead to the resolution of development but also the need to consider the business aspects of producing a DMH resource when considering the needs of its users. Anne (U) relates how she is often faced with usability issues, even after having used a resource for a length of time, *"I've kind of tended to use things for a while and then found... they're full of bugs and they often don't kind of quite work as well as they should"* (A11). This may mean the loss of mental health data that has been inputted over this period – potentially distressing – and for providers it could mean losing users. This demonstrates the importance of recognising the interminable nature.

### 6.2.2.2 *Impact on Users*

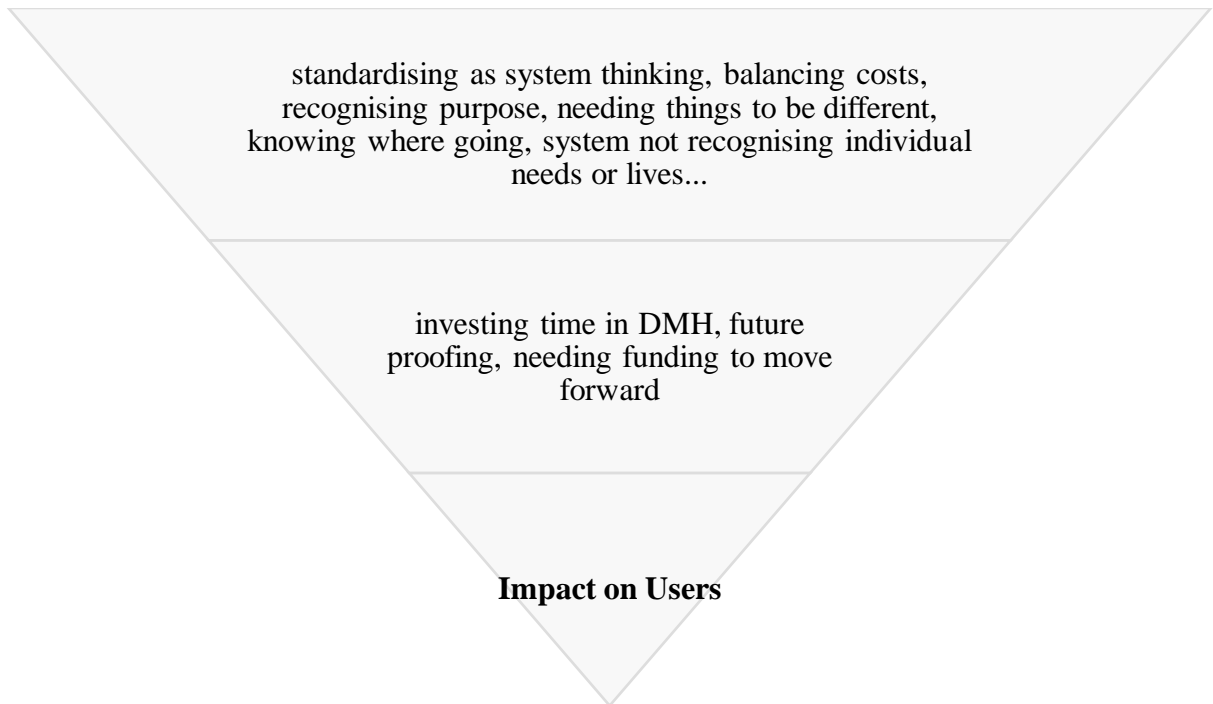


Figure 19. Showing analytical process of codes resulting in the concept of *Impact on Users*.

Sharon (A/C) is the only system builder to identify the need to work towards *"a vision of where you want to be"* (Sharon248). Although the product may remain 'interminable', Sharon

(A/C) acknowledges that it is still essential to work towards that vision. Whilst the hyperbole of ‘interminable’ may not be prominent in the discussions with participants its futility is clear. Both Sam (U/D) and Jessie (U) identify the lack of funding within DMH as a challenge to its usefulness. Sam (U/D) feels “*if I’m going to invest time in trying to use digital to maintain my mental wellbeing I think things are going to have to be different... we are behind because of the funding*” (Sam334-335) whilst Jessie (U) feels “*if more funding goes into it then potentially one day it could be but at the moment I don’t think you can use it as a sole source of support*” (J265). Anne (U) relates how she had to find a new app after using a mood tracker that she “*quite liked but then I don’t know whether they just stopped updating it or whatever because it just seemed to slip out of use*” (A130) and feels an important question when deciding to use is whether “*they are going to carry on in use*” (A132). The need for a product to be continually maintained appears to be constructed by users as a challenge to the full integration of DMH within mental healthcare self-management.

### **6.2.3 Ratings Over Research**

There appears to be a drive towards acceptability over effectiveness within DMH. However, this seems to be inherent to its commercial and consumer nature rather than due to a disinterest in research.

### 6.2.3.1 Ensuring Engagement

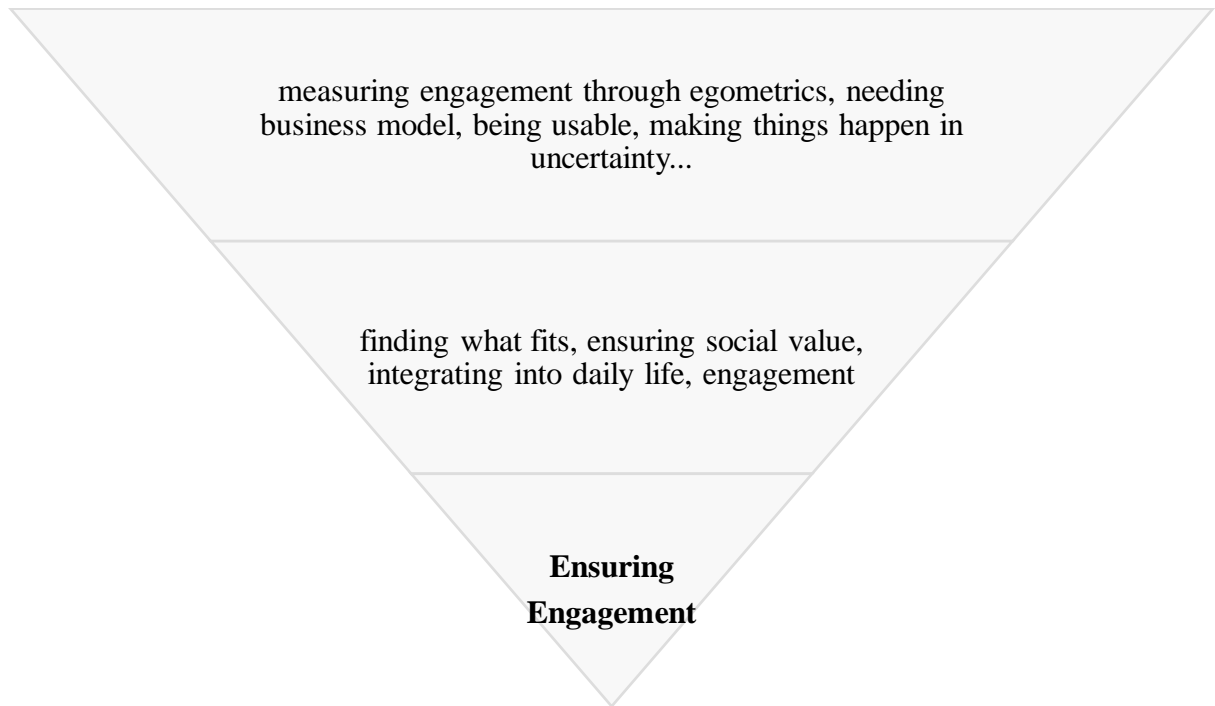


Figure 20. Showing analytical process of codes resulting in the concept of Ensuring Engagement.

Sharon (A/C) refers to ‘ego-metrics’ when discussing the value of a DMH resource from the perspective of the developer – “so if you’re looking at how many people log onto your website you’re talking about kind of ego-metrics... if only two of those people purchase then actually that’s the metric you should be keeping an eye on” (Sharon263). The concept of engagement is important within DMH, yet it appears to be a difficult concept to account for. Understanding consumers ensures that DMH resources are more attractive to them and yet at times those consumers are constructed not as end users but as middle-man providers. For Sharon (A/C) the divide means there is a “presumption that [providers] ... are going to buy... and [users] are going to do it but [users] aren’t” (Sharon239) whilst for David (D) the need to find alternative funding streams stems from the fact that “it costs money to run, that we started as a

*charity and not wanting to charge people to be there*” (D213). Tom (D) addresses the balance needed, *“the right mix”* which involves:

*“user values, so it’s usable and fits into the user’s lifestyle in a way which... makes them want to use it, it’s got to deliver some kind of social value so it’s got to change people’s lives and it’s got to deliver some kind of financial value in the sense that it’s worth someone funding you to make it, or users paying for it, or someone else... paying for the data or you go down the advertising route”* (T77-79).

The concern is, as identified by Sean (U/D), that resources will be purchased and merely endured by end users – *“a product [that] in some way meets that need or is at least tolerated”* (Sean194). He also constructs the paradigms, as in Human Interoperability (section 6.2.1.), of development as involving Finding What Works (section 8.4.) – or *“we won’t know until you do”* (Sean164) – whilst mental health relies on working with what *is* known – that *“you need to know before you do”* (Sean163). This emphasises the different perspectives of the duty of care between technical and clinical professionals. Regulations and gold standards necessitate knowing what works and establishing this, whereas DMH appears to focus more on the innovation and improvement of existing processes. Thus, engagement becomes less defined and more fluid in response to market forces.

### 6.2.3.2 *Impact on Users*

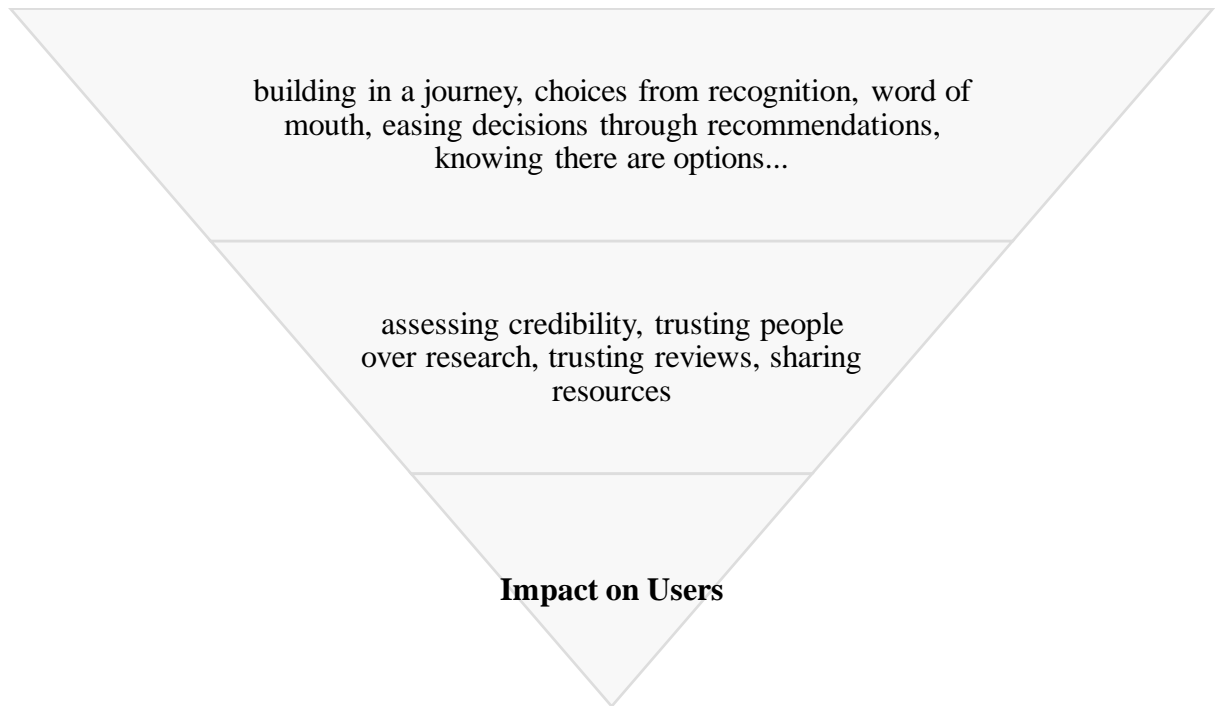


Figure 21. *Showing analytical process of codes resulting in the concept of Impact on Users.*

A significant factor within the prioritisation of Ratings over Research is the focus on how resources are perceived to be found, a concept discussed further in Finding What Works (section 8.4.). Sarah (U/D) felt that good reviews from others would incite more trust than professional appraisals – *“I would trust something far more if five people had given it five stars and said this is great and this is why, rather than something that was top of the list and had the five-star evidence base”* (Sarah257). Participants also felt that resources that were less engaging were less likely to motivate use. Norman (U) reflects that *“having tried to used technology as therapy I feel it is extremely difficult”* (N62). This suggests that for providers of DMH resources the appeal of their apps or websites is not only an element of its design and engagement but also of the perception and marketing that surround it. The impact of Ensuring Engagement (section 6.2.3.1.) and the prioritisation of Ratings Over Research is discussed further as an element of

Finding What Works (section 8.4.) whilst the category of Changing Purpose (section 6.3.) explores the impact of aspects such as Marketing (section 6.3.3.1.).

#### **6.2.4 Summary**

Constructing DMH resources as products provided a way to account for the complexity of concepts that arose within and between the different groups of participants. By understanding the dynamics within a commercial environment the various processes involved in developing, marketing, implementing and using became constructed within the meaning. Understanding first that there are multiple groups involved and that success relies on interoperability not just between technologies but also between actors demonstrated the complexity of clinical, technical and user cooperation. Establishing the constructed lifecycle of a product as interminable further emphasised the need to maintain these relationships over an extended period of time, as well as recognising the potential impact on users of unsustainable business practices. Finally, the importance of considering the strength of meaning constructed around the appeal of resources – rather than their clinical evidence – identifies a concept that may be unique to DMH. This emphasises the role that the individual plays in autonomously entering and interacting within the social world of DMH. This is addressed in more detail in The Experience of Digital Mental Health (Chapter 7).

#### **6.3 Changing Purpose**

This category reflects the constructed meaning of DMH as a changeable product within an evolving area of need, namely mental health. Change is an active process that may be driven by users, system builders or even the technology itself.

### 6.3.1 The User and Changing Purpose

As identified within the role of User (section 5.8.1.1.) there are active and inactive components that must be addressed. This concept explores the constructed active role of users as they engage with and apply DMH resources.

#### 6.3.1.1 Adaptation

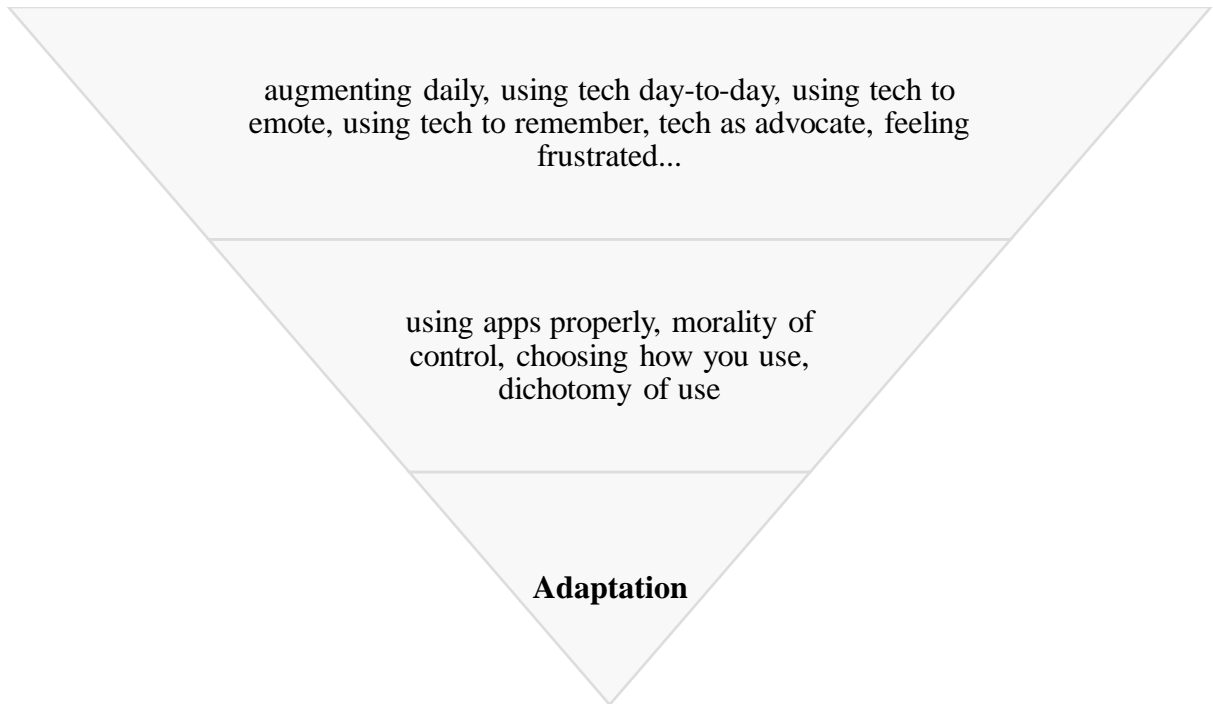


Figure 22. Showing analytical process of codes resulting in the concept of Adaptation.

Participants appear to adapt resources to novel purposes. Jessie (U) overcomes the reluctance of moderators to provide advice on Big White Wall by messaging them directly, “sometimes when I’ve felt really bad I’ve messaged the moderators directly just because I know that they are actually professionals” (J231). Thus the platform becomes used as a means to access professional support, not just peer support, although this is not its intended purpose. Her experience is challenged by the moderators who signpost her to the appropriate use – “they very much tell you to then post something on the forum” (J231). For system builders, user adaptation

may be difficult to reconcile once their user's ability to reconfigure purpose through use is recognised. Patricia (A/C) identifies "*one of the things that concerns me slightly, with any app, is that people don't use it in the sequence you think they're going to use it*" (Patricia179). Patricia (A/C) is recognising the potential for use to be adapted, particularly in ways that are inaccessible to her. Sharon (A/C) also discusses her inability to view the actual usage of her platform – "*I can't see... what they do on there*" (Sharon55). This suggests that for many system builders actual use may be difficult to ascertain once implemented.

Whilst adaptation may be used when expectations about resources are challenged, some users may also actively seek out novel uses for non-DMH resources. Sean (U/D) describes using existing apps, such as calendars, for mental health purposes – "*the apps I sort of use on a day-to-day basis to offset the cognitive impairments involved in my condition... basically a suite of Google apps*" (Sean59-62). His use is specific, as he relates "*I use this app and it makes it possible for me to emote when I'm not feeling very well. I use this app and it mitigates the effects of poor recall and poor encoding of information*" (Sean60-61). Both Sam (U/D) and Sarah (U/D) discuss the potential use of fitness trackers by those with eating disorders. Sam (U/D) is concerned that there is little anticipation of the consequences of technological functions in mental health – "*we don't know how safe gamifying a kind of calorie counter is for an anorexic*" (Sam208) – whilst Sarah (U/D) identifies that fitness apps may be "*misused by people who don't need to lose weight but want to*" (Sarah235). Adaptation may occur in response to the perceived limitations of a resource, the challenges of usability or functionality experienced by the user, or through the application of non-DMH resources to mental health purposes. The difficulties for system builders are in anticipating unintended consequences of the adaptations initiated by users.



### 6.3.1.2 *Changing Resources and Needs*

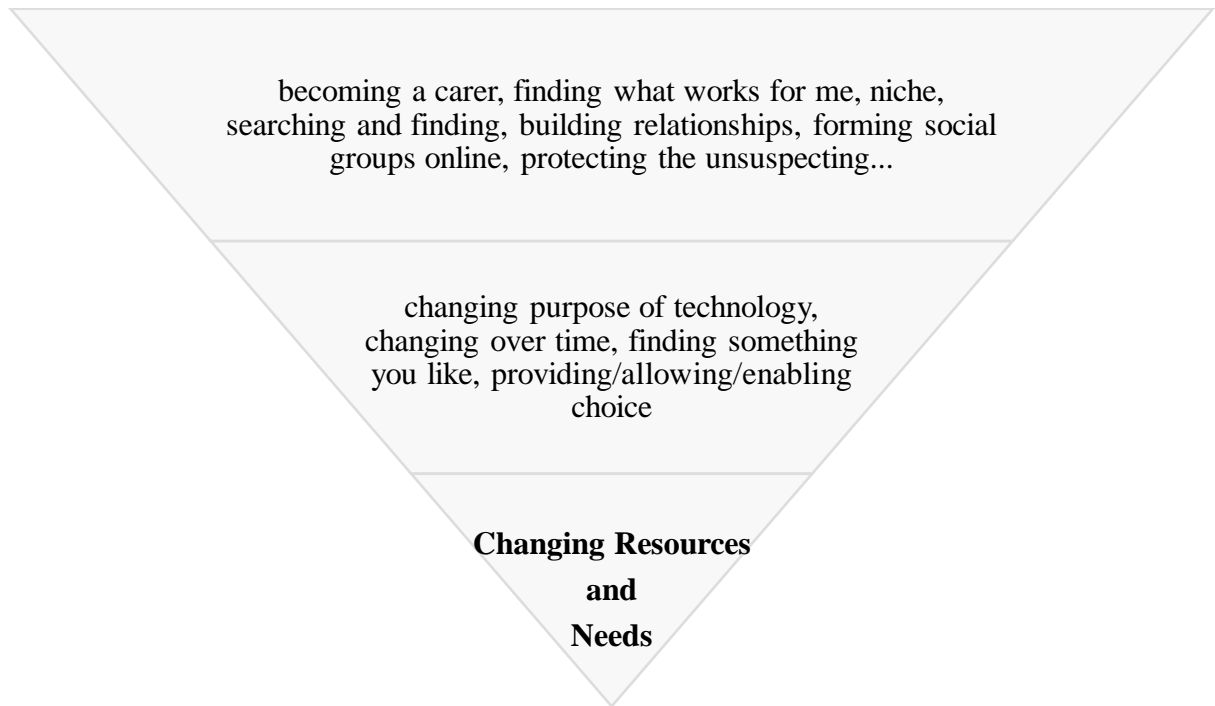


Figure 23. *Showing analytical process of codes resulting in the concept of Changing Resources and Needs.*

Jessie (U) relates how the complexity of interactions online – where “*people gang up against each other, even on mental health forums*” (J179) – led her to use apps where interactions are moderated. The constructed purpose appears to have changed through her use from a place in which to talk about her mental health to one that may negatively affect her wellbeing. Rita (U/P) was introduced to a virtual world and through use began to identify ways that it could be used for her mental health, she “*didn’t see it at first as a virtual help*” (R20), whilst Sarah (U/D) did so through “*looking around on search engines and... finding mental health forums and just dipping my toe in the water*” (Sarah30). Phillip (U/P) discusses how his use evolved as his needs changed – “*as I became a carer I noticed I was connecting and adding friends from a carer background*” (Phillip27-28). This suggests that the use of DMH can develop

through and alongside the changes within the individual's own experiences. Also of consideration are the changes in the perception of technology itself, as identified by several participants. Carol (U/P) described the expansion of the types of forums that are available, offering more choice and less specificity – *“it's not just an online forum now, there are plenty of other things. If you don't like online forums you can find something else”* (C368-369). Sarah's (U/D) perception of the internet has evolved over time too, from *“quite a niche thing to do”* (Sarah20) to more mainstream. She also notes, along with Carol (U/P), that the resources themselves have changed. Sarah (U/D) feels that for pro-anorexia websites, *“back in the day there did used to be, like, no disclaimer”* (Sarah141) but that *“most of them are moving towards the recovery stance or a pro-choice”* (Sarah142) position. Whilst this move may have come as a result of attempts to shut down forums, or even as a result of a change in Sarah's (U/D) use, it demonstrates that her perception has changed over time. The constructed purpose may be changed as an element of the individual's altered perception.

DMH resources are potentially affected not only by users, who may alter the meaning and purpose of resources through Adaptation (section 6.3.1.1.), but also through the context and environment in which the user interacts with the resource. As Sam (U/D) states, *“just because we can do an online therapy session on the bus that might not be appropriate. Because you aren't going to think in the same way, you aren't going to feel in the same way, because the environment is very different”* (Sam247-248). For the user this at times may represent the purpose of the resource, as Jessie (U) identifies there are times when a resource may offer support at the moment of need – *“you can start feeling really bad when you're out somewhere and maybe you don't have your laptop with you or you can't sit down and that's when, like, it's*

*useful to have an app*” (J58). The user may adapt the resource to suit their current need, even when the environment is typically viewed as unsuitable for its use.

### 6.3.2 The System Builders and Changing Purpose

#### 6.3.2.1 System Builders and Constructing Change

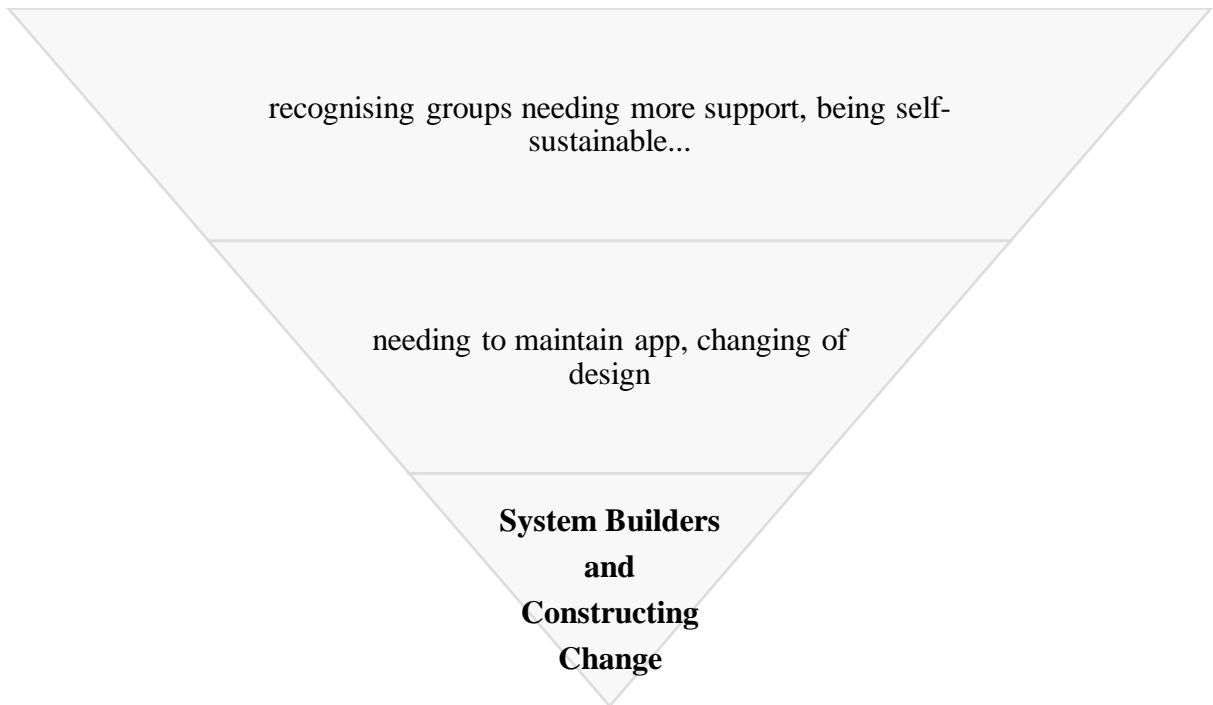


Figure 24. Showing analytical process of codes resulting in the concept of System Builders and Constructing Change.

The system builders too have a role in changing the purpose of their resources. Tom (D) identifies the difficulties of regulation “*when products change, by people who are not using those products*” (T98) and feels that whilst “*data can help products to develop*” (T93) that “*self-certifying around good practice in development*” (T91) would be more suitable. This is discussed further in Ratings Over Research (section 6.2.3.). Another aspect of The Interminable Product (section 6.2.2.) recognises that the resource can be improved over time. David (D) is involved in ‘future-proofing’ his product, necessitating a “*rebuild... from the ground up*” (D49). System

builders construct change not only around their own needs but also around their expectations of social and user-based needs. Sharon (A/C) is faced with understanding that her resources must remain stagnant – although she can “*see what needs to change*” (Sharon259) – not only for proving its efficacy through research but also for financial reasons – “*you can't keep subsidising and investing money in it*” (Sharon262). System builders can be influenced by their perception of socially approved design in research, which may change over time – “*I think the look changes*” (Sharon203). Through coming into contact with different user groups, their perception of what their needs are may change. For instance, David (D) has identified that some users of his resource are those “*who are not seriously ill enough to be escalated to actually getting face to face treatment*” (D52) whilst Sharon’s (A/C) resource evolved through interactions with potential user groups so it was not then “*aimed at that [original] market*” (Sharon29). Still further are aspects of changes made in response to the technology itself, for instance Patricia’s (A/C) recognition of the need to resolve bugs within her app – “*it's going to need care and attention over the years*” (Patricia90) – and the addition of intervention components more suited to particular mental health conditions or user groups, such as “*specific stress issues*” (Sharon85). This suggests complexity in adaptations, made by system builders, to both individual and technological needs.

### 6.3.2.2 *Impact on Users*

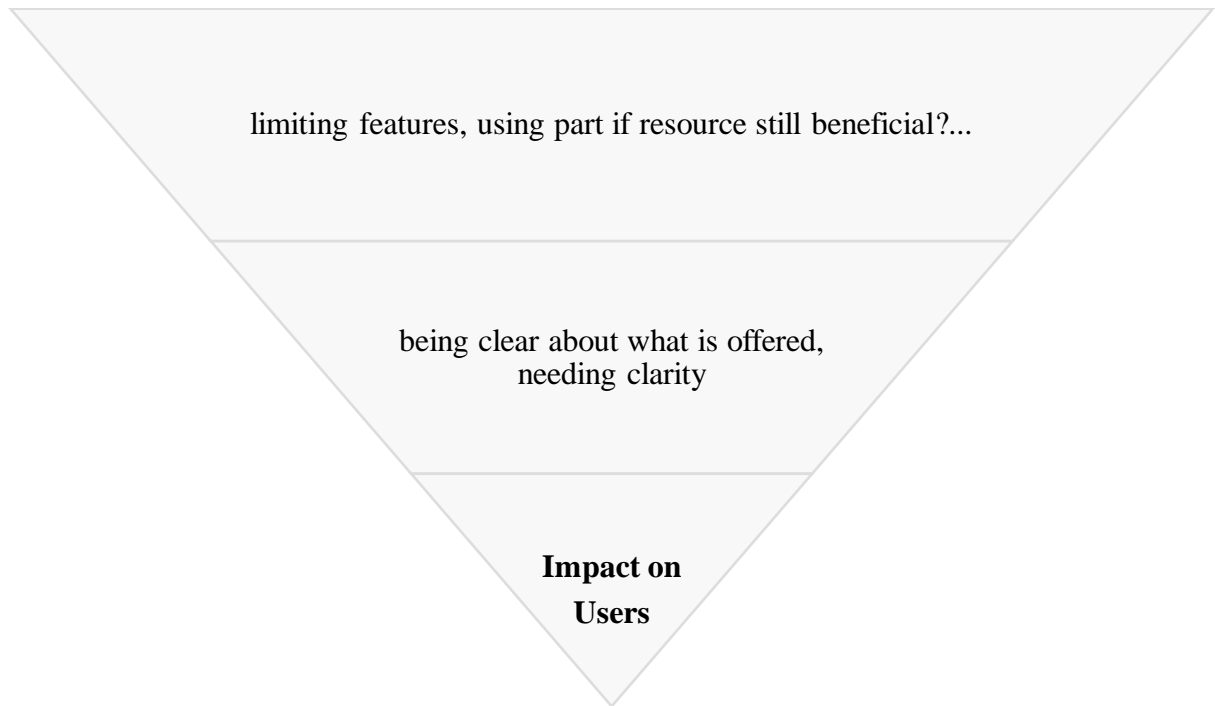


Figure 25. Showing analytical process of codes resulting in the concept of *Impact on Users*.

Users themselves are aware of the potential for changes implemented by system builders to impact on the product’s usability. Anne (U) discusses an app that she used which failed to be maintained and the challenges she then faced – the “*mood tracking one that I quite liked... I don’t know whether they just stopped updating it... it just seemed to slip out of use and then I thought... well I’ll have to find something new... that’s another element to using some of these apps. It’s like, are they going to carry on in use?*” (A130-132). Jessie (U) relates how her use of DMH platforms through a browser provides significantly more functionality than through the apps they provide and asks “*how beneficial is it if you can’t access the full thing, like, through the app?*” (J59). This also applies to access being restricted via paywalls or other means. System builders must be conscious of their existing users’ response to changes that are implemented and consider the impact of limiting access. Jessie (U) is concerned that, as DMH resources are often

accessed by people in distress, this may exacerbate their mental health concerns – *“it’s important that right from the beginning people know what that service is about because... if you go into it thinking that it’s one thing and you’re really struggling and then you find out that it’s not then that’s going to make things even worse”* (J283). Her solution is for apps to be transparent about what they can and cannot offer, a challenge for system builders when considering its position within DMH as Product (section 6.2.). Phillip (U/P), when demonstrating a CBT app, was notified via a pop-up window of changes, which he summarily dismissed (*“Basically it’s just saying they’ve made some changes”* Phillip306) suggesting that, even when system builders attempt transparency, some methods are likely to be more effective than others. This challenges The Interminable Product (section 6.2.2.) by potentially leading system builders to limit the changes made to implemented products even as they attempt to accommodate users and technologies.

The Adaptation (section 6.3.1.1.) instigated by users leads Patricia (A/C) to question the inclusion of potentially inappropriate, but relevant, material. To maintain its true representation she felt it was important to avoid *“sanitising”* (Patricia128) material but recognises that she is unable to prevent younger users accessing the app – *“whilst you can put an age limit on it’s only a recommendation, there’s nothing you can do to stop children accessing it”* (Patricia129). System builders must recognise that Changing Purpose is not only an element of development but also of use. System builders may find it difficult to recognise the impact of emerging needs and perceptions on the purpose of these resources. One example within this study was discussed by Patricia (A/C). Through the use of her app within an educational environment she was made aware of some users’ discomfort during use based on their own previous personal experiences and so she *“made it very clear that you shouldn’t be engaged doing that unless you really wanted*

to” (Patricia187). This may not be a salient aspect for developers if use remains remote or feedback is not invited, e.g. through user testing, and may instead lead system builders to mitigate their resources to reduce unintended repercussions of use.

### 6.3.3 Divergence in Consumer Experience

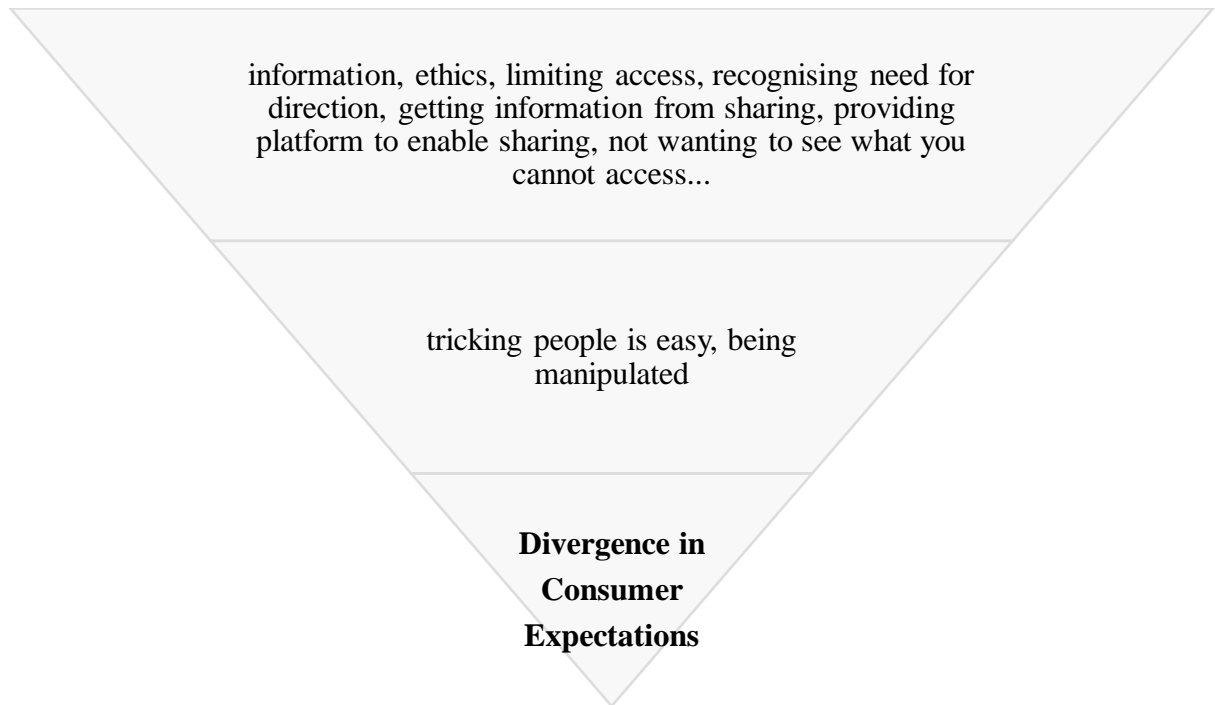


Figure 26. Showing analytical process of codes resulting in the concept of *Divergence in Consumer Expectations*.

At times within DMH, a divergence arises in the expected and actual experiences of both system builders and users. David (D) describes an evaluation done in which users identified that they received all their health information from the platform, even though as he states “*we’re not meant to be providing you with information*” (D65). He elaborates that the purpose is instead to provide a platform on which users can share information. This suggests that users may reconstruct purpose through their use of DMH resources. This further identifies a potential divergence of expectations between provision and experience that may also be influenced by

system builders. For instance, Phillip (U/P) is aware of the 2014 controversial study in which Facebook manipulated the timelines of their users to study emotional contagion (discussed in section 4.2.2.4.), which he feels exemplifies that *“it’s easy to trick people sometimes”* (Phillip696). Sean (U/D) too feels that at times technology can be viewed as manipulative, although he constructs this as improving user experience, *“you’re being manipulated all the way through, that’s what user experience is about”* (Sean259). Sharon (A/C) recognises the need for more streamlined content provision to ensure appropriate use of her platform; that *“if [users are] depressed or experiencing some kind of stress then maybe they need to be directed a bit more through a programme”* (Sharon44). These points of divergence are interesting in that they offer insight into the ways that stakeholders within DMH do and do not adapt. Jessie (U) has considerable issue with the way that she perceives DMH resources are sometimes marketed, feeling that the lack of clarity as to what they offer has the potential to cause undue distress – *“only certain people can access the professional help... I don’t think they should show it on there... Because that can make you feel really bad”* (J250). Divergence may be an element of user’s perception of purpose, constructed even prior to use, and may lead to non-use or adaptation when it occurs.



### 6.3.3.1 Marketing

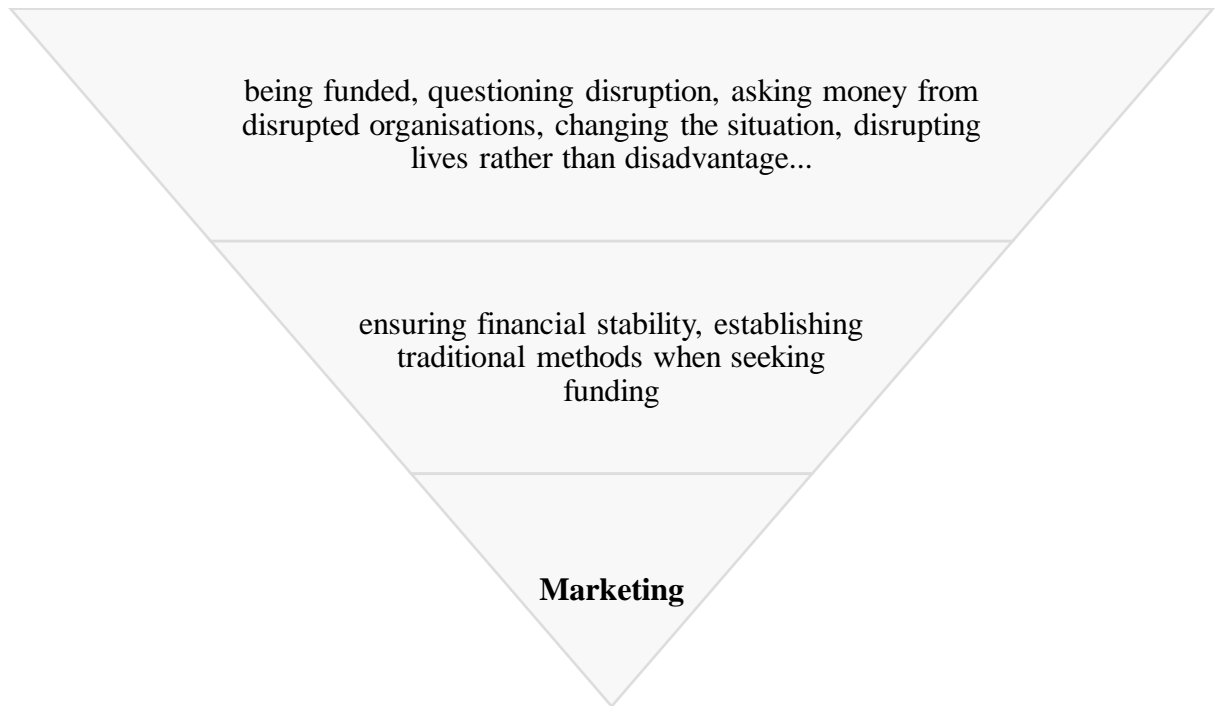


Figure 27. Showing analytical process of codes resulting in the concept of Marketing.

System builders may view the technologies themselves as a more salient source of change than users (see The User and Changing Purpose, section 6.3.1.). However, some do address the ambiguity and complexity of marketing. Sharon (A/C) discusses how, when delivering a viable resource within an existing structure (whether organisational or systematic), it is necessary not only to consider the end users but also those that are purchasing the resources – *“I have to be attractive to [providers] ... I have to be attractive and relevant to [users]”* (Sharon172). Sean (U/D) too feels that much of DMH is challenged as *“it’s extremely difficult to have a successful business model that involves disrupting your customer”* (Sean33) and that resources are *“often about disrupting the lives of the person who has the disadvantage”* (Sean427). This means that in marketing it as a service it must be framed within the existing paths of delivery; as David (D) states *“we tell them that we deliver it online in the first line and*

*you never mention it again so they can equate it to services they're used to funding” (D230).*

Sarah (U/D) identifies this as a need to market products not to the users but rather to systems as these may offer a more sustainable business model – that it’s “*very hard to get traction... it’s even harder to get scale*” (Sarah402-403). Marketing one’s product requires careful negotiation within a complex system of consumers and providers, with value constructed from both use and financial investment.

### 6.3.3.2 Divergences

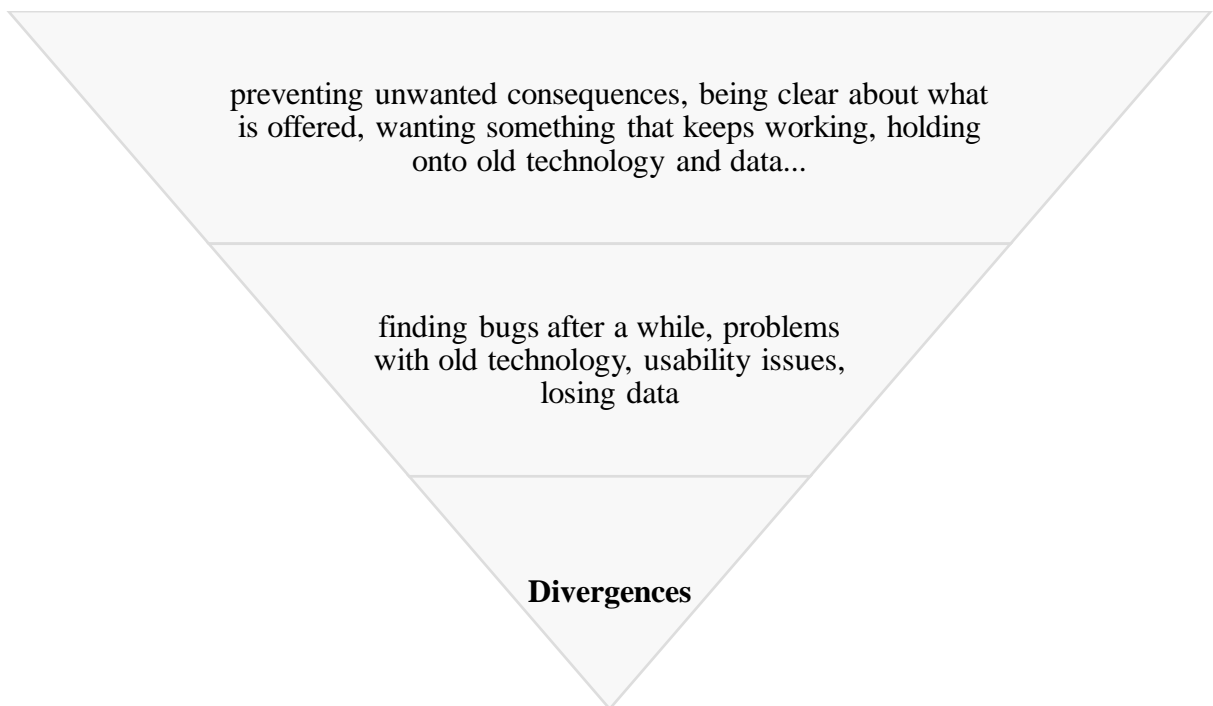


Figure 28. Showing analytical process of codes resulting in the concept of Divergences.

As divergences in expectations exist not only between system builders and providers but also their users this can challenge use in many ways. Anne (U) identifies several problems with the usability of resources – “*they’re full of bugs and they often don’t kind of quite work as well as they should*” (A11) – and devices – “*this phone is quite old, I couldn’t update... it basically wanted to wipe the whole thing*” (A103). Likewise, Jessie (U), Sam (U/D) and Sarah (U/D) all

feel that the information provided by healthcare-controlled websites are often risk-averse and so only provide ‘generic’ information. Jessie (U) discusses how system builders “*had to take away... interactions with the website because... they were worried about what the implications of that would be so they decided to make it, like, literally just factual*” (J200-201). Sarah (U/D) states that information provided on health websites “*can feel very dry and generalist and safe and it doesn’t feel like real life*” (Sarah181). This is further discussed in The Practice of Digital Mental Health (Chapter 8). For users there appears to be little salience about the potential negative impact of information, although they recognise it within the divergence of expectations of use (Impact on Users, section 6.3.2.2.). Sam (U/D) is concerned that the knowledge surrounding the impact of different resources on mental health is not well-known enough for direct implementation, that “*there are always going to be decisions made in an online design and the design programming of an application that unless a person is truly knowledgeable in health that person isn’t going to realise the impact it can have*” (Sam213). Instead, system builders need to consider and explore the experience of divergence as applied to the various mental health conditions. This may require more in-depth research than can be offered by user testing as it requires understanding the impact at the point of need, as identified by Jessie (U).

### 6.3.4 Change as Purpose

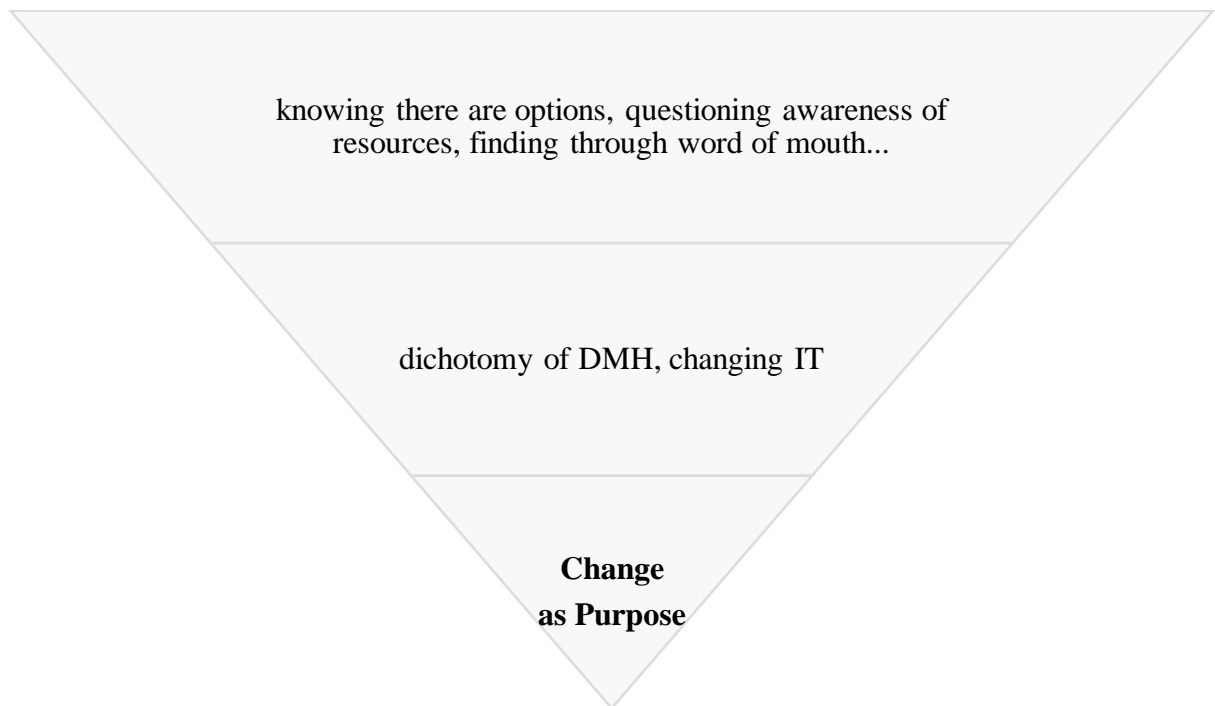


Figure 29. Showing analytical process of codes resulting in the concept of Change as Purpose.

Many of the participants, both system builders and users, shared a perception of technology as changeable. Phillip (U/P) stated that *“one thing about IT is that it changes”* (Phillip205). Sean (U/D) discussed how the representations of technology in popular media only a few years ago were now considerably outdated – *“no one has a mobile... the plots are based on the fact that people can't find out where other people are”* (Sean590). As addressed in Changing Resources and Needs (section 6.3.1.2.) an observation for many was that technology has evolved quite quickly, particularly in DMH. Sandra (U) queries this perception, wondering *“whether there's a lot more resources now or whether I'm sort of more aware of them”* (Sandra19) yet it is a concept shared by many. As previously addressed, the system builders have constructed The Interminable Product (section 6.2.2.) and users describe the evolving perception of DMH resources (The User and Changing Purpose, section 6.3.1.). However, it is important to consider

whether the change is inherent to constructs of technology or as an aspect of their constructed purpose within DMH. Sean (U/D) addresses this numerous times throughout our interview. He questions the meanings that are attached to technologies as a challenge to the list of resources that I provided to participants by stating that it was “*like asking what trousers you wear for your mental health. Anything has the capacity to contribute positively or negatively to your mental health or wellbeing*” (Sean206-207). This variability is explored further in The Practice of Digital Mental Health (Chapter 8); however, it serves to propose that the constructed meaning within the purpose of DMH may include its adaptive nature not only as an active element asserted by external actors but as a component within the objects themselves.

### **6.3.5 Summary**

In conclusion, purpose may be changed by system builders through adaptations of resources and marketing, in response to feedback from users, or their perception of such, and technological changes. Users too may change the purpose of DMH, although the role participants inhabit appears to help construct the meaning of whether adaptation is seen as novel or subversive. User perception of purpose is also changeable through their own experiences, both in everyday and within technological use, and through the interactions they have within the resources themselves. These changes exert influence on the development process when salient, as well as the choice and operation of DMH resources. The impact of this influence may potentially cause distress for existing users and lead to limited functions being introduced into resources as a way to mitigate this.

### **6.4 Overview**

This chapter brings together two categories that demonstrate the complexity of interactions between the various subworlds – particularly clinical, technical and experience of

use – that must co-exist and collaborate within the milieu of DMH. DMH as Product emphasises the need to recognise that resources are developed and produced within a business context, wherein the need for sustainability is paramount not only for system builders but also for users who rely on DMH resources. Changing Purpose demonstrates the evolving nature of resources and technologies as well as user's mental health. Both categories interact and support each other in identifying important concepts that arise when considering technology-in-practice (Timmermans & Berg, 2003) and the multiple roles within DMH.

## **7 Analysis and Findings: The Experience of Digital Mental Health**

### **7.1 Introduction**

Within this chapter several results are displayed and discussed. Please note that Participant Roles are identified through the use of abbreviations to denote the different roles – Developer (D), Academic/Contractor (A/C), User/Developer (U/D), User (U), User/Provider (U/P). This section explores the meaning that participants have constructed around the use and application of DMH resources in everyday life. It presents three categories; Freedom to Fail, Seeing the Journey, and People Like Me.

### **7.2 Freedom to Fail**

The concept of Freedom to Fail is composed of various properties, most notably autonomy and agency. However, it also necessitates that the individual's feeling of responsibility over their actions is either reduced or perceived of as controllable, and the options available from which to choose are increased. Anonymity is often used to describe the tool that helps individuals feel more or less responsible online yet it is constructed here as an element of the 'barrier of the screen'. This category is strongly linked conceptually to the Experience and Practice of DMH. It emphasises the 'freedom' of use and development in DMH. Integral to the Experience of DMH, it places the concept of self-determination as an underlying characteristic of applying DMH.

### 7.2.1 Autonomy

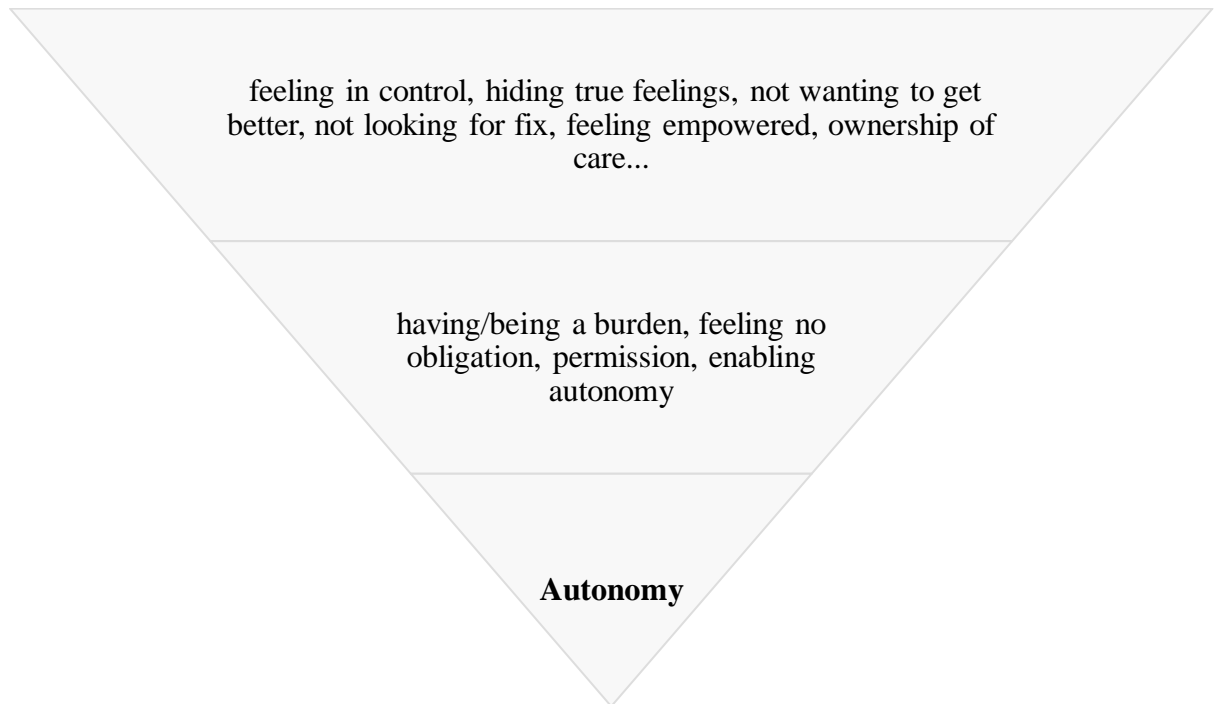


Figure 30. Showing analytical process of codes resulting in the concept of Autonomy.

Figure 30 demonstrates the analytical process through which subtitles were conceptualised. Each level represents codes assigned to lines of the interviews, becoming more relevant as it is abstracted downwards until a concept could be constructed to account for the meaning within these codes.

Sean (U/D) believes that *“if you transfer responsibility without power of choice or control you're just transferring blame”* (Sean136). Several participants discussed the burden they feel managing their mental health as directed by professionals. For Anne (U) this was constructed as a responsibility to take care of herself but that *“it's very difficult to live in the way [professional] suggest”* (A221). Sandra (U) too communicates the pressure she feels in taking care of herself – *“I got that feeling, whether it was right or wrong, that if I went back (to the GP) and the worksheets hadn't worked then it would be like 'now what do you expect?’”* (Sandra136-



137). Rita (U/P) compares conventional mental healthcare to DMH, particularly identifying the alleviation of pressure – *“there’s no obligation to do anything”* (RVW555). Jessie (U) emphasised the autonomy of those using DMH in reference to the moderation of self-harm content – *“I think you have to give people a bit of credit as well that they can deal with that”* (J192). This concept is important to consider within the category of Freedom to Fail as it suggests that for some the constructed meaning within their experience is one that contrasts the autonomy of DMH with conventional expectations in mental healthcare. This is discussed further within the Model of Compromising (section 8.2.3.).

This experience is not solely connected to expectations of mental healthcare professionals but rather can be constructed from experiences with friends and family, as well as the onus they place upon themselves. Sarah (U/D) discusses her concern prior to seeking help from friends – *“my friends would feel pressured into doing something”* (Sarah68) – and family – *“I didn’t want to put that burden on them”* (Sarah67). Anne (U) too would prefer to maintain equitable friendships – *“I’ve got great friends, [but] you don’t really want to make a friendship about something like that. You don’t want something like that to become a caring relationship, you just want it to be friends”* (A194). For Sarah (U/D) there was a recognised need to maintain certain unhealthy behaviours – *“because I was ill, I didn’t want to be intervened on”* (Sarah70) – whilst for Anne (U) the use of DMH resources can mean she *“feels like I’m helping myself”* (A194). This means an increased sense of autonomy – *“giving some sense of control to me rather than having other people... doing it”* (A200). The pressure to maintain one’s mental health is constructed as a responsibility – *“of being vigilant yourself and if you’re not then you’re not taking care... you’re not being good, you’re not helping yourself. And then it becomes a bit of a blame thing”* (A83-84). DMH may be a way to assert one’s autonomy within mental healthcare.

Information, particularly information difficult to access in traditional healthcare contexts, may support individuals seeking to assert autonomy. For example, Carol (U/P) describes seeking and finding information within the NICE guidelines for the person she cared for, information she “*would never have found out if it wasn’t for search engines*” (C137). This provided her with a feeling of confidence in requesting what was needed – “*I felt like I’ve got concrete, black and white information about what should happen; it lended [sic] a lot more weight to my argument*” (C151). The constructed meaning of autonomy within DMH appears to encompass a sense of supported responsibility towards oneself.

### 7.2.1.1 Control

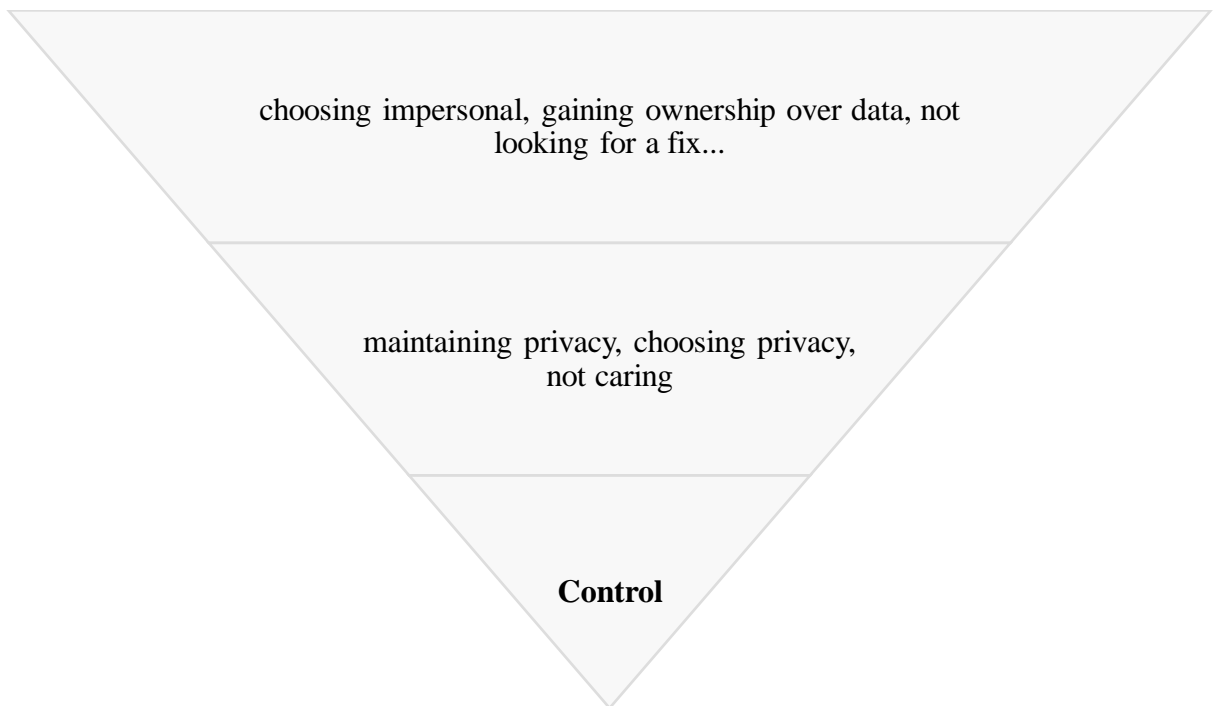


Figure 31. Showing analytical process of codes resulting in the concept of Control.

The concept of control within the Freedom to Fail can be constructed in relation to use, interactions with others, and the participant’s experience of mental health. It can support feelings of self-determination – as Sarah (U/D) states “*it does help me be a bit more accountable about*

*myself*” (Sarah218) and for Anne (U) she feels it gives “*patients and service users ownership over their information*” (A156). Privacy is a useful concept through which to explore control in relation to participants’ use of DMH. Sandra (U) feels that she is “*able to keep the things private that you want to keep private*” (Sandra178) when interacting online. For some this differs between resources. Anne (U) discusses how feedback from others is unpredictable in a forum – “*you still don’t know... what you’re gonna receive in the end and I think it’s that unpredictability that I don’t like*” (A59) as “*you’re actually getting feedback from other people that you might not want. Some feedback you might want and you might approve of but you can’t select it*” (A57-58) – whilst with apps “*you can choose to work with it and it’s kind of predictable*” (A59). Carol (U/P) and George (U) can both interact through a closed group on Facebook, ensuring that what they discuss is kept private – “*it doesn’t appear on people’s personal Facebook page*” (G43) and “*even if you write something on that page it doesn’t show up on your Facebook page... I was a bit concerned when I first joined*” (C71-72). Phillip (U/P) identifies the importance of being able to control privacy, of being able to “*keep the circle a bit more closed because with mental health... you’re very vulnerable*” (Phillip727).

Participants seem to have some awareness of the control that they have. Phillip (U/P) discusses how he has become more careful about what he shares – “*if I don’t want anything personal to be shown obviously I’m just not going to speak about it or blog it... I used to but then I’ve changed*” (Phillip714-715). However, whilst discussing the need to balance privacy with connecting to others, he also notes that “*most of the time I just don’t really care that much because I’m not gonna put anything... personal*” (Phillip712-713). Sam (U/D) constructs it as a compromise – “*they see the payoffs, for example Google knowing what you want ten seconds earlier is greater than the reward of privacy*” (Sam174-176) – and, indeed, Phillip (U/P)

constructs the use of DMH as a surrendering of privacy – *“it’s just the way it is you know”* (Phillip699). It may be that for participants this was not a salient concern as the decision to use DMH was linked to a decision to accept the removal of certain aspects of their control. Phillip (U/P) discussed Facebook manipulating user feeds to research emotional contagions (discussed in section 4.2.2.4.), identifying that technology is an easy way to *“trick people”* (Phillip696). Indeed, Sam (U/D) and Sean (U/D), two User/Developers, also discuss the role that technology may have in manipulating users. Sean (U/D) feels that it is an acceptable aspect of improving user experience – *“you’re being manipulated all the way through, that’s what user experience is about”* (Sean259) – whilst Sam (U/D) feels that without understanding the impact on mental health issues the use of design techniques in this way is concerning – *“there are always going to be decisions made in an online design and the design programming of an application that unless a person is truly knowledgeable in health that person isn’t going to realise the impact it can have”* (Sam213). This exemplifies the concerns that arise when system builders are not aware of clinical, technical and user needs (discussed within Changing Purpose, section 6.3.), and the differing meaning that can be constructed. Privacy may be a way for individuals to practice control but, as identified, can also be a way for control to be undermined; illustrating the dichotomy of meaning within DMH.

### **7.2.2 Agency**

The Freedom to Fail requires that individuals feel they are provided with choice and feel able to choose. This section will explore, within the context of DMH, the constructed concepts that both support and disrupt the individual’s experience of agency.

### 7.2.2.1 Supporting Agency

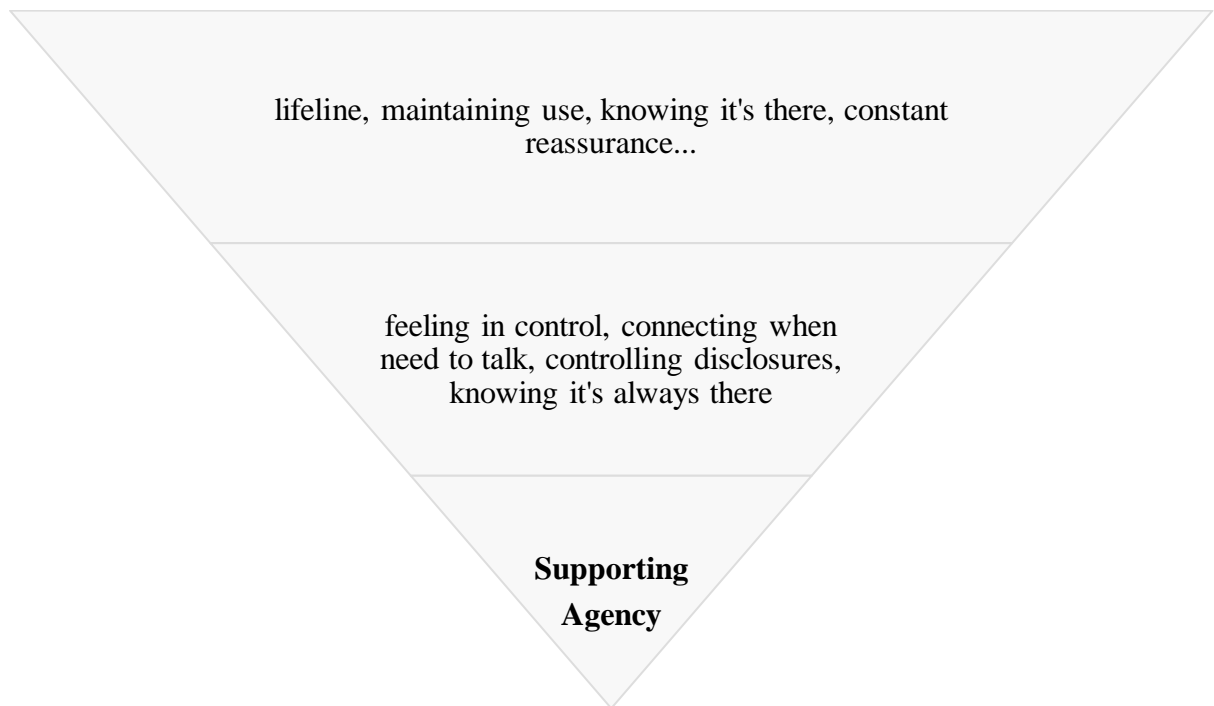


Figure 32. Showing analytical process of codes resulting in the concept of Supporting Agency.

Participants discuss the experience of both knowing that there are options and that the resources are always there, in relation to DMH. Sandra (U) identifies it as *“that constant reassurance of knowing that even if I do feel bad or if anything happens that this is where I go, this is what’s there for me”* (Sandra162-163) – that resources are available when she needs them. George (U) agrees that DMH *“has made things easier because it’s more accessible”* (G88). The options available to participants through DMH have become important aspects of their lives, whether through the multiple ways that individuals have access to resources – for instance through interactions with others or search engines – or the broader access and use enabled by its accessibility. Sarah (U/D) can access support on her smartphone when overwhelmed because *“now no one cares and everyone’s on their phone all the time so no one has to know you’re doing something therapeutic”* (Sarah280). For Phillip (U/P) DMH is also constructed as an

important element of the management of his wellbeing, particularly having it available when it is needed:

*“It really has ... I won't say saved my life but it's saved me from stress. If you have someone on the other end of a Skype... and it's free mostly... you can connect to so many people if you need someone to talk to”* (Phillip464-468).

Here Phillip (U/P) identifies the choice that is available to him, the convenience of having it accessed through a device already in his possession and the cheap cost associated with DMH.

### 7.2.2.2 *Trigger Warnings and Choice*

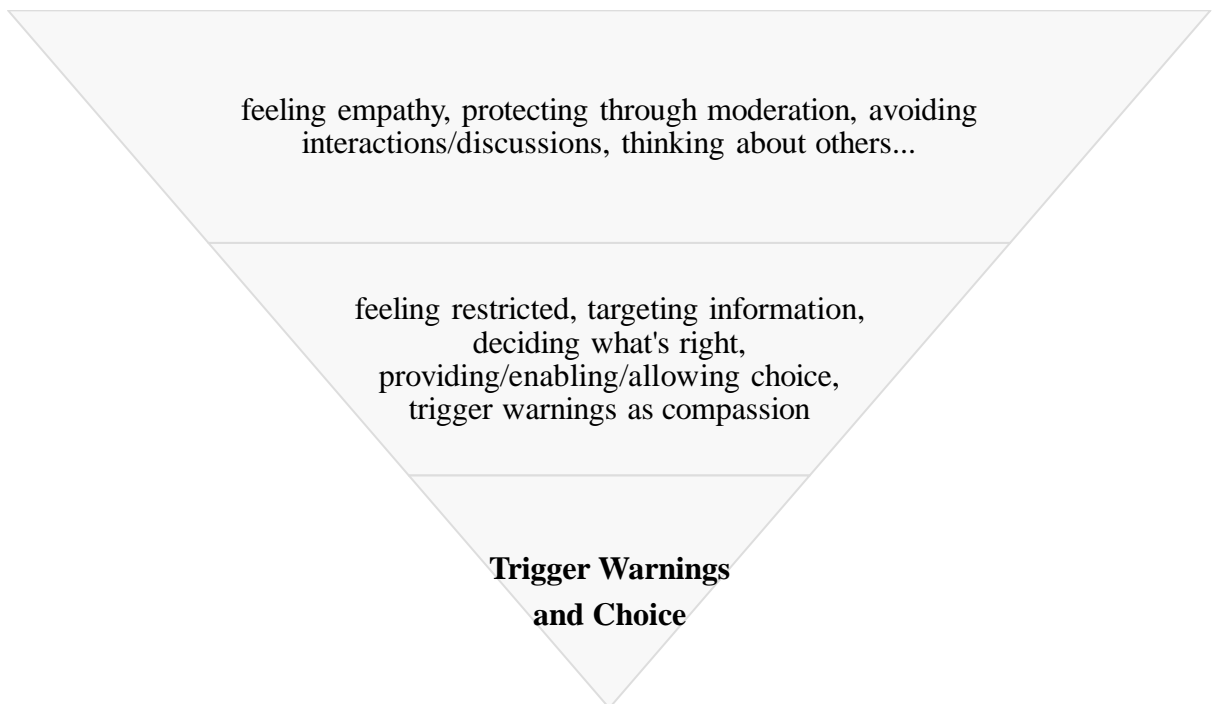


Figure 33. *Showing analytical process of codes resulting in the concept of Trigger Warnings and Choice.*

Another area that exemplifies the agency of individuals in DMH are trigger warnings. It is important to consider the potential impact of information or shared experiences on an audience

that may be experiencing considerable distress. For instance, Jessie (U) discusses the dilemma faced by both content providers – who “*had to take away any kind of... interaction with the website because... they had to have it that it was purely... facts*” (J200) – and moderators – who “*try to protect the community*” (J190). Shared experiences may lead to unhealthy decisions or traumatic responses, for instance “*if... someone went on there and went this is terrible and you shouldn't take [medication] ... it could be helpful for someone else and then they're put off taking it because of what they said*” (J203). However, Jessie (U) feels that it is also problematic to withdraw choice from individuals. With regards content she asks “*who's to say what is right*” (J210) whilst for moderation she wants to know “*if we can't talk about these things on a mental health forum with people who are experiencing similar things then where can we speak about it?*” (J183). This demonstrates a user's awareness of the dichotomy faced when providing information online. Sarah (U/D) shares her own experience of using pro-anorexia forums as a way to bypass restrictions and being able to discuss information that was potentially triggering for others – “*sometimes you need to get things off your chest or illustrate a point and I just felt that I was quite restricted in what I could say on recovery forums; I couldn't say what I had or hadn't done... because it could be triggering*” (Sarah130). However, she feels they have evolved over time to become more about giving people a choice – “*it's your choice to recover or not, we're not going to judge you*” (Sarah142). This suggests that DMH resources are engaged in ongoing processes of adaptation to the needs and challenges faced by users.

Sean (U/D) feels that technology is personalisable – “*digital goods and services that are adaptable to different people's wishes around their mental health*” (Sean216) – particularly as “*you never know who you're gonna trigger or what's going to be triggering to who because everyone is triggered by different things*” (Sarah149). In essence, DMH appears to be

conceptualised by users as enabling autonomy and agency with regards the information that can be accessed and tools that can be used. As Sarah (U/D) concludes, whilst trigger warnings are “*compassion for your fellow man*” (Sarah150) there are also people who will choose to be triggered – “*who if they see a trigger warning will click on it specifically because they’re trying to trigger themselves further*” (Sarah168). However, they maintain autonomy and agency in this decision. For example, Rita (U/P) describes how “*people... leave in the middle [of the virtual hallucinations tour on Second Life] coz they say the voices are too much*” (RVW179). It is seen as easier than real life by Harold (U/P) – “*you just teleport... you’re safe. So it’s actually easier to get away*” (H143-145). They can choose to remove themselves from the situation. Thus trigger warnings offer an example of the way that DMH is constructed as a tool to be used by the individual as they choose – echoing the concept of Changing Purpose (section 6.3.) – rather than a tool that is controlled externally.



### 7.2.2.3 *The Challenges to Agency*

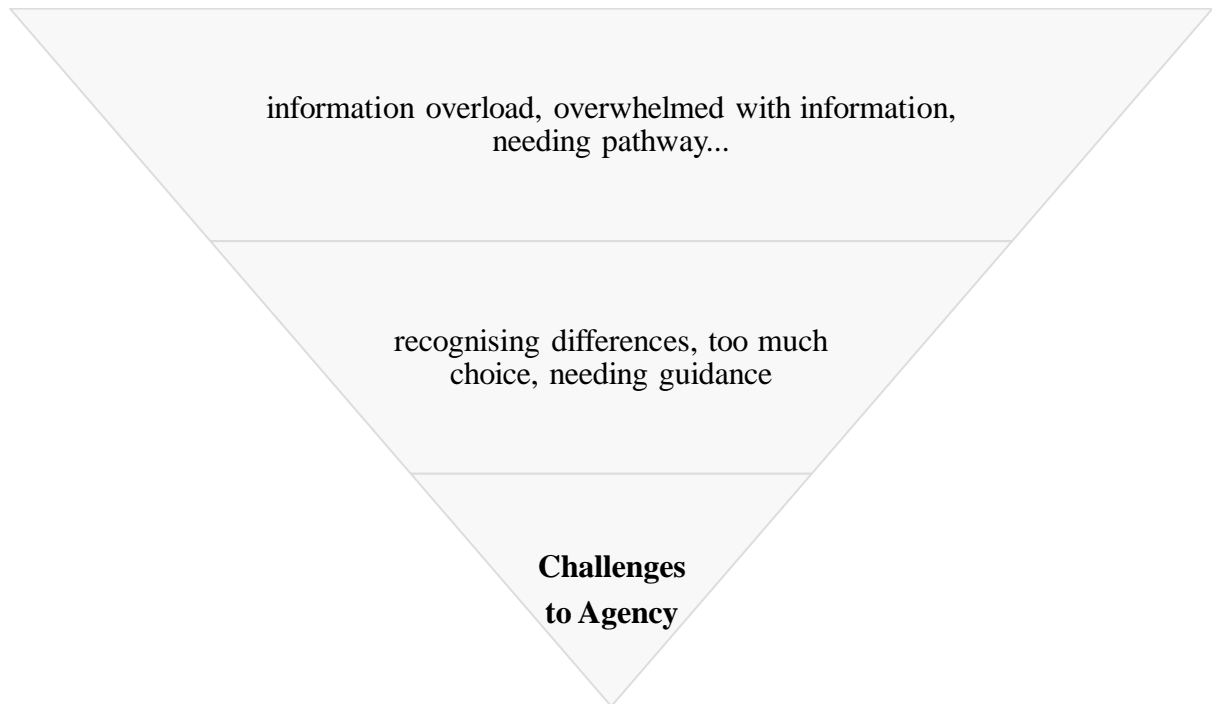


Figure 34. Showing analytical process of codes resulting in the concept of *Challenges to Agency*.

Unfortunately, agency is often challenged within DMH. Many of the participants discussed the difficulties associated with the considerable choice that was available. For Norman (U) this can be confusing – “*there are a plethora of sites and loads of information which is ultimately confusing*” (N21) along with “*so many different opinions so many different approaches*” (N22) – whilst Phillip (U/P) discusses how, at times, “*you can feel overwhelmed with information*” (Phillip567). However, it appears that the difficulty is exacerbated, as identified by Anne (U), by how it is “*hard to know which is best*” (A127) when there are “*hundreds, if not thousands of things*” (A129) to choose from. Thus, the lack of guidance as to what they seek may undermine their capacity to exercise agency. The challenges of exercising agency in DMH are discussed further in Finding What Works (section 8.4.) as an element of choosing resources.

### 7.2.3 Anonymity

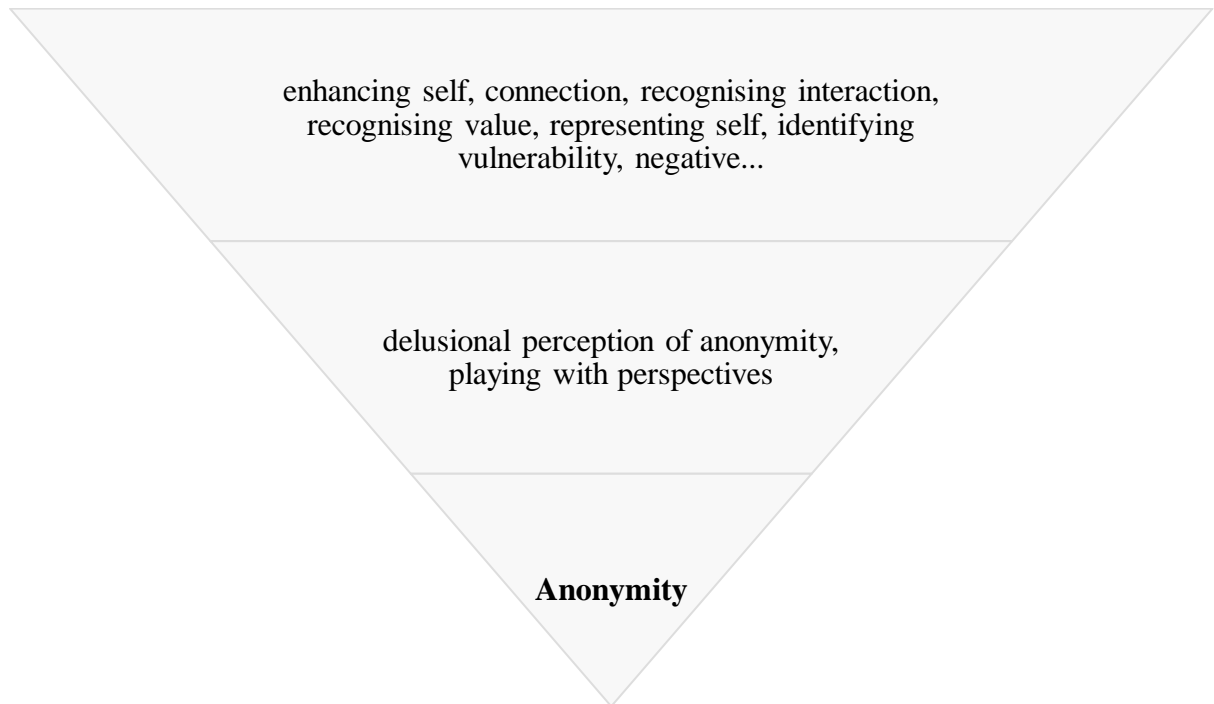


Figure 35. Showing analytical process of codes resulting in the concept of Anonymity.

Several participants discuss anonymity and the meaning they ascribe to it in DMH use. Rita (U/P) identifies the construction of anonymity online as “*a delusional perception*” (R458). She refers to it, when discussing individual’s anonymity online, as the use of “*a fake name or a fake page or an avatar*” (R460) and the expectation of privacy – the belief that “*just by having a fake name you can't find them*” (R458). Sandra (U) feels “*you get to be a bit more honest... if you can hide behind somebody else’s name*” (Sandra84). This suggests a perceived disconnect from the individual’s real world identity that may be seen by some as guaranteeing anonymity. Rita (U/P) feels this may be experienced by some people in therapeutic interactions where they may feel they can retain that disconnect – “*when you speak to a therapist there’s still this sense, even if it’s a false delusional perception, that you’re anonymous*” (R475-476). In exploring this concept further Rita (U/P) concludes that the “*delusion of perception can be a great thing when*

*it comes to stigma but it can be a very bad thing when it comes to treatment*” (R510) and relates this to her own use of a male avatar to heal – *“I needed him to heal but he was my persona”* (R512). Rita (U/P) appears to believe that this perception of anonymity, these simulated selves (see section 8.3.3.), may help individuals overcome their reticence to seek help but that it is not in itself conducive to therapy. Whilst the personas that people use online may become tools in recovery and self-management, Rita (U/P) feels strongly that they are unable to provide a solution to mental health needs. Sam (U/D) also indicates that this perception may actually lead to potentially more vulnerability as profiles or resources are able to be searched and targeted specifically, using *“tools to search and find and, if you're so inclined, analyse people's behaviour”* (Sam320) that may lead to *“revealing your vulnerability to those who are most likely to take advantage”* (Sam122). The constructed concept of Anonymity is explored further in the following section.

#### 7.2.4 Barrier of the Screen

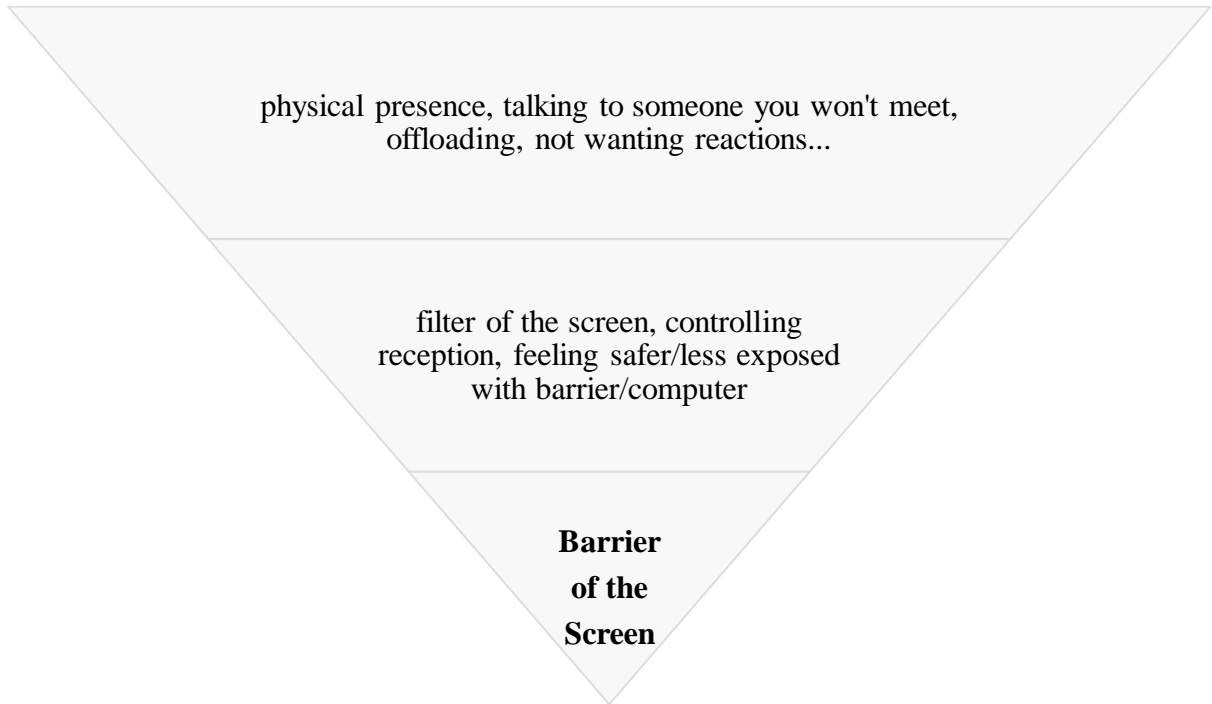


Figure 36. Showing analytical process of codes resulting in the concept of *Barrier of the Screen*.

Both Sam (U/D) and Rita (U/P) construct the device as an object that sits between themselves and their interactions online. For Sam (U/D) it is the “*filter of the screen*” (Sam80) whilst for Rita (U/P) it is a “*barrier*” (R35) or “*barrier protection*” (R79). The ‘barrier of the screen’ appears to offer some users a way to control their disclosures. Rita (U/P) describes the fear associated with accidental disclosures of her mental health – “*it’s delusional, it’s hard to separate the delusion from what’s real and in that moment in time you almost feel that it really did happen*” (R70). It is also present in the experiences of others. Carol (U/P), for instance, discusses the way “*you can talk to someone you won’t bump into necessarily when you’re out shopping*” (C35) rather than “*a friend who might not understand and then you go and see them in some social setting and it’s all awkward if you’ve offloaded*” (C37-38). Sarah (U/D) felt that opening up online allowed her to reduce the potential of real life repercussions, of people that

she knew intervening – “*it was about safety to talk about feelings without feeling like someone’s gonna do something*” (Sarah72). Much as Sarah (U/D) feels able to compartmentalise her experiences through a personal diary and a public blog – “*there are entries about things that I’ve been through that I never want to read again... those all go on a private journal that’s online.*” (Sarah310-311) – so too might participants feel they can compartmentalise their mental health and their real world interactions through the ‘barrier of the screen’. Rita (U/P) feels that it is a way of controlling people’s judgement – “*I no longer have to think are they looking at me*” (R82) – and is about “*creating this barrier. So it’s not about stigma or no stigma but rather creating this protection barrier within your mental health symptoms*” (R89-90). The barrier appears to be constructed by individuals to account for their own particular mental health needs.

Sam (U/D) recounts a personal familiarity with the technology – “*the screen is my best friend*” (Sam81). Similarly, Anne (U) feels that whilst “*relationships with people are always complicated by so many other different things... if you have a technology you can use it’s probably complex still but it would... be a constant really that you would feel able to engage with even if you weren’t well*” (A227). Sam (U/D) anthropomorphises it in describing how “*it provides me with information, it provides me with, you know, whatever I want at the touch of a button*” (Sam82). But its anthropomorphic characterisation stops there because “*it’s not a person that I have to worry about it’s emotions*” (Sam84). The device is able to support interactions through its non-human nature, which appears to be constructed as both familiar and protective.

#### 7.2.4.1 *Controlling Physical Presence*

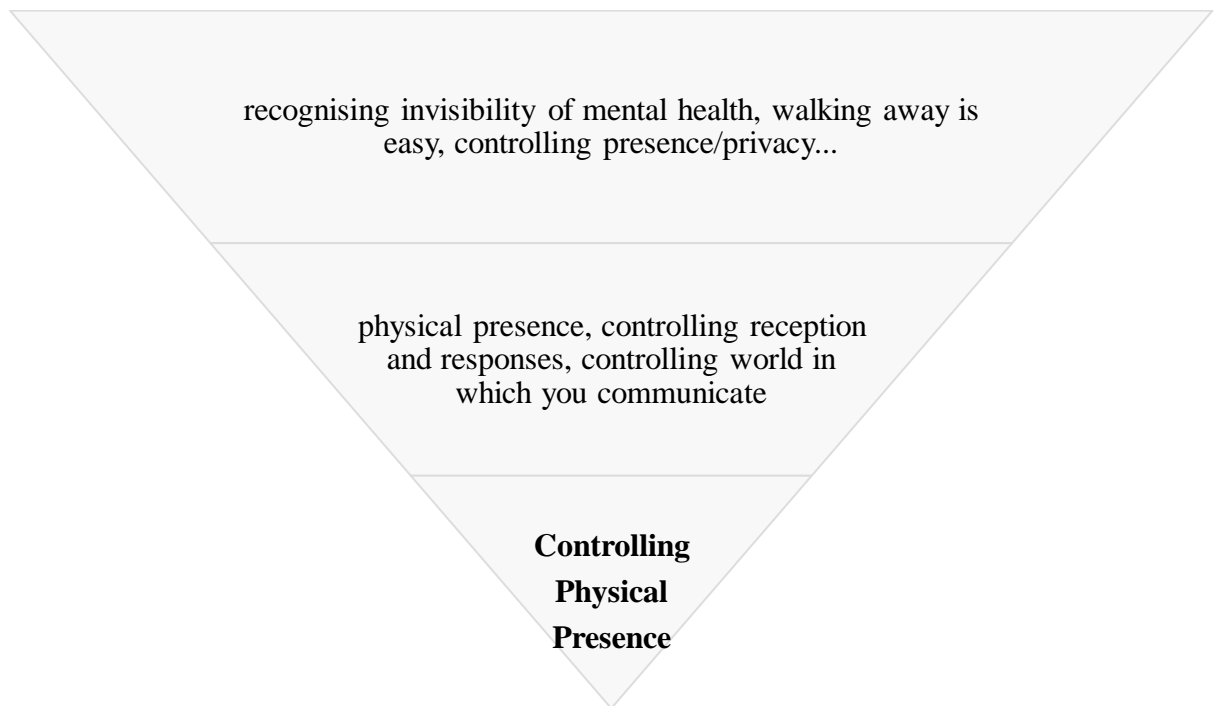


Figure 37. Showing analytical process of codes resulting in the concept of *Controlling Physical Presence*.

Rita (U/P) recognises that in the real world “*if you don’t say I have a mental illness nobody’s gonna judge you*” (R48). However, one way that the screen offers a more attractive barrier is that it removes direct human contact. Sam (U/D) discusses the vulnerability he feels when communicating face-to-face – having “*to be very emotionally vulnerable*” (Sam68) – whilst his experience of using instant messaging is one “*of being emotionally guarded by default state*” (Sam72). Both Sam (U/D) and Rita (U/P) discuss the way that they can control the interaction. For Sam (U/D) he feels that not only can he “*mute them*” (Sam70) but that “*if I don’t want to talk to them anymore I just don’t reply*” (Sam69). Rita (U/P) discusses it in relation to our interaction through Skype, she “*can still walk off from here, delete you, you never existed... I can erase you*” (R451). This suggests a feeling of control. Sandra (U) explains that when faced

with trolls in the online communities she visits the impact of their actions is lessened, whilst offline trolling “*would really upset you*” (Sandra198) she feels supported by a community of people “*who are all gonna turn around and say the same things*” (Sandra200).

When exploring this further the code ‘controlling reception and controlling response’ became linked. Sam (U/D) explains that he feels “*almost protected because I can step away*” (Sam76) and in Second Life Harold (U/P) can “*just teleport to another place*” (H144). The physical presence aspect is also important. For Rita (U/P) the body is constructed as a concern, its appearance a worry that her “*mind is struggling with*” (R87) especially through “*having direct human contact [which] creates a panic attack*” (R86), but that “*because there’s this block they don’t have to worry about that*” (R86). Sam (U/D) explains that “*having that emotionally present connection with someone, even if it’s just a showing of empathy or caring, it can be too much*” (Sam80). The barrier of the screen appears to function as a way of controlling not only one’s own physicality and presence but also that of others.

### **7.2.5 Summary**

The experience of DMH may be one wherein users perceive there to be the potential to exercise both their autonomy and agency. Whilst these are at times challenged they provide users with a sense of responsibility that is enabled by the Barrier of the Screen, a reconceptualisation of the technological object as a tool through which control may be exerted over not only the individual’s presence but also the presence of others. This control may be threatened by technology itself, although it is not a common salient aspect of the individual’s experience. The choice available online leads many users to develop heuristic methods of exercising their agency, particularly through establishing novel precepts to manage the unique challenges of digital technologies. Anonymity, whilst remaining important, is constructed as an aspect of the Barrier

of the Screen. This concept supports and underlies the category of Freedom to Fail, establishing both autonomy and agency through the control and use of the technological object. Freedom to Fail is thus constructed as the use of digital technologies within mental health to exercise control of interactions and choice within self-management in a way that may be difficult in conventional mental healthcare. It can be exercised free from judgement or feelings of responsibility to others. Although this can be used in negative ways – as evidenced by Sarah’s (U/D) discussion of people choosing to trigger themselves – the presence of this concept must be considered also for its positive aspects of empowering and supporting the individual in making their decisions.

### **7.3 Seeing the Journey**

This category considers the experiences of participants in seeking to understand mental health through DMH. It considers it from the perspective of a journey, representing their experiences in the past and those that may occur in the future.



### 7.3.1 The Past

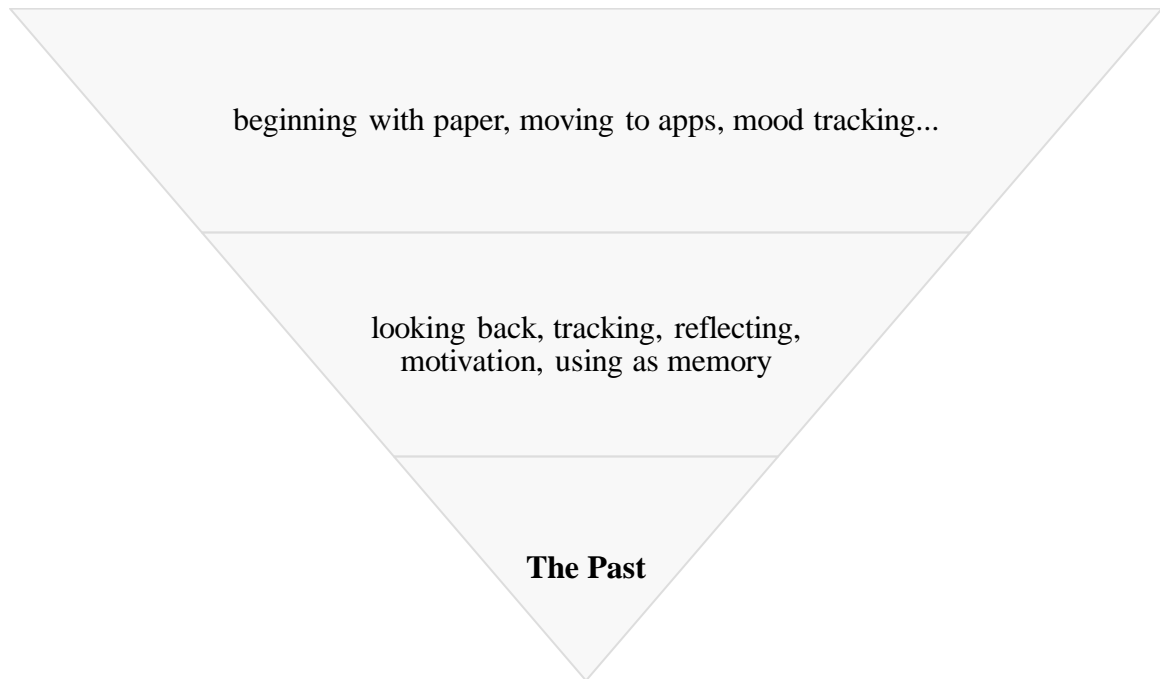


Figure 38. Showing analytical process of codes resulting in the concept of *The Past*.

To know the past is to be able to reflect on what has happened and, potentially, be part of preparing for the future.

The concept of tracking and recording one's life story is not uncommon in mental health. Anne (U) notes that her GP was the first to suggest she do so – *“my doctor... suggested that I keep some sort of mood diary”* (A3). Her use of traditional methods – pen and paper – evolved through her purchase of a smartphone which acted as a catalyst to explore DMH resources – *“since getting an iPhone... there's been a few things that I've tried to use to do it”* (A4). DMH use may be reconstructions of existing behaviours. Individuals construct tracking as a form of memory, and a way to look back and reflect on changes. It provides Sarah (U/D) with data that she can analyse – *“I can start to think if there are any patterns... could it be my PMS or something like that I hadn't even noticed”* (Sarah207-208). For Anne (U) tracking moods can

provide information that would be forgotten otherwise – “*I think I’m... interested in tracking my mood... because if I don’t then I don’t remember*” (A92) – whilst Jessie (U) emphasises that even tracking one’s mood can be difficult to remember – “*I’ve still forgotten to log my score*” (J65).

Anne (U) connects it to the Freedom to Fail and self-determination:

*“at the end you can be objective and relate it to the last time you did it, you can see how you’re feeling. It can be a bit of a spur to doing something. So if I know that aw I’m actually really not feeling good this week I can think about what’s happened... have I been exercising? Eating properly? Like, is this just something small or should I see my doctor? So it just means I can, that horrible thing when somebody else turns to you and says ‘you know you don’t seem alright, you should see a doctor or something’. I hate that! It’s horrible! So I try and avoid it. So I guess yeah it is that, it’s just kind of keeping it more to myself really. Giving some sense of control to me rather than having other people, you know, doing it. Yeah. I probably shouldn’t be so proud of it but there we go”* (A197-200)

These demonstrate the constructed meanings that mood trackers have for the participants of this study. The following concepts consider the unique functions provided by technology and the ways that users have constructed meaning around their use in recording moods and experiences.

### 7.3.1.1 Continuation

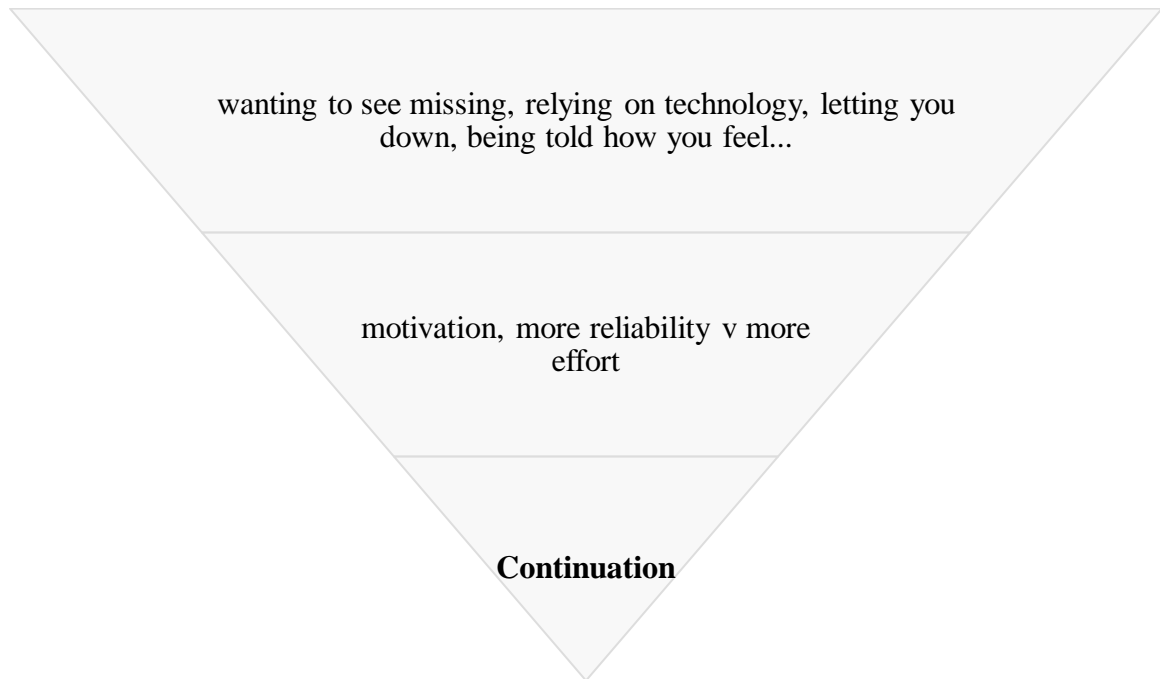


Figure 39. Showing analytical process of codes resulting in the concept of Continuation.

Jessie (U) identifies she is more likely to track her moods when feeling low – *“often it’ll be that I’m feeling bad and I’ll go back and I think I should probably like log this. But then sometimes I think that’s not right because that’s not an accurate reflection... maybe it’s not very accurate what I’m logging here if I’m only ever logging it when I’m feeling bad”* (J142-144). This demonstrates that one’s mental health may influence continuation. Relevant data requires consistent and credible input yet certain aspects of DMH may challenge the reliability of data. Jessie (U), when showing me her mood records, constructs the missing experiences where she did not record her mood as potentially being of significance:

*“But then it’s annoying because... where there’s months where I haven’t used it and when I did pay for it and I looked back I was like there’s a whole chunk of time where I didn’t*

*use it, it would have been useful to see then like what was going on, why wasn't I using it? But obviously I hadn't recorded my scores so I don't know"* (J41).

Anne (U) experiences a similar frustration but linked to the unreliability of the apps themselves – *"you feel like you've put something into something that's just let you down"* (A179). Indeed, when Phillip (U/P) was demonstrating his use of a CBT app he expected it to save his previous entries but was unable to find them – *"you can see that I've done other articles... I dunno if it does show the ones that I've done earlier"* (Phillip384-386). The unreliability of apps is given by Anne (U) as a reason *"why a spreadsheet on my computer seems more sort of usable"* (A182). Anne (U) proposes that digital resources may be able to offer an alternative way to ensure continuation, through passively collecting data *"it'll give you feedback on how you are without you realising"* (A212), whilst Jessie (U) suggests that the use of reminders may help her to ensure continuation through *"a notification type thing on your phone so it reminds you to log it"* (J68). So whilst DMH is constructed as somewhat unreliable digital resources may also offer various functions that could be utilised to aid in the continual tracking of moods.

### 7.3.1.2 *Looking Back*

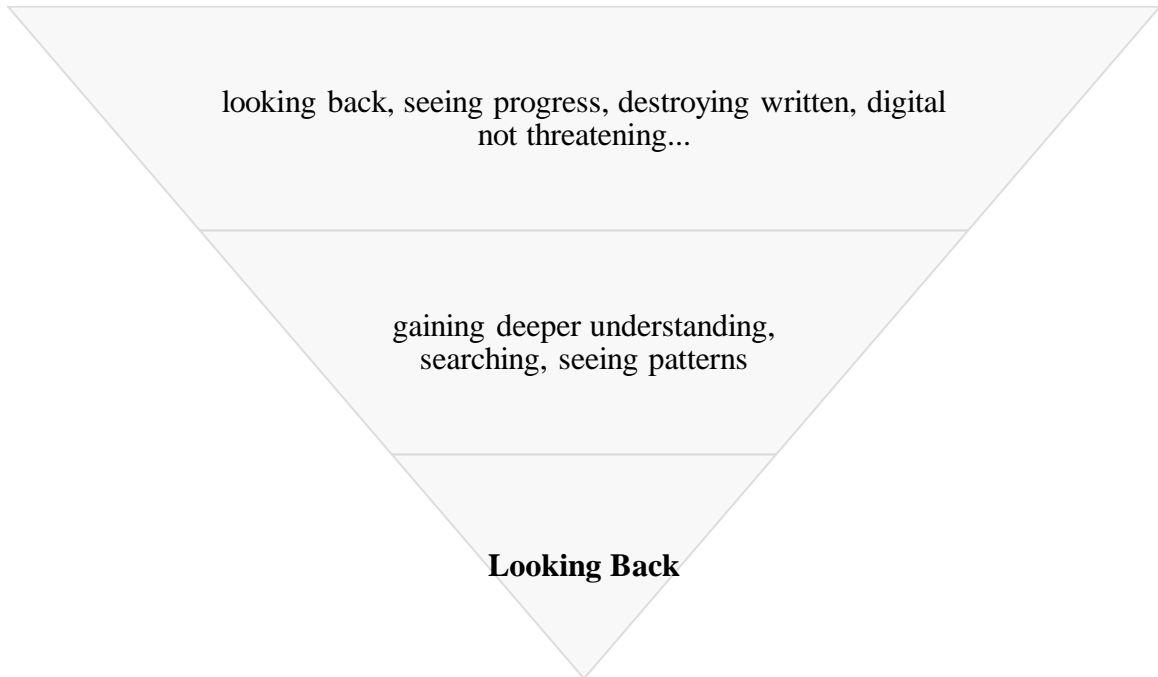


Figure 40. *Showing analytical process of codes resulting in the concept of Looking Back.*

The concept of a life story, a record that people keep for the purpose of looking back, was an important construct. For some participants this involved blogging publicly, anonymously or not, whilst others used a more private diary. Again, this is a concept that is not dissimilar to conventional mental healthcare. Sarah (U/D), for instance, identifies the way that the visual representation of mood can allow her to analyse her experiences through comparing her various selves at different points in time – *“I can look back at the negative entries and go, god I can’t believe 3 months ago I was feeling like that”* (Sarah303-304) – whilst the qualitative aspect is also important – *“how I felt in my own words, that feels more powerful”* (Sarah306). Jessie (U) gains some insights by looking back at her recorded moods and diary – *“you can see are there particular times of the year when you feel bad or was there something particular going on in your life that made you feel really bad”* (J32). Likewise, Anne (U) would like to look back but

for her it is a way to represent the progress of her illness – *“the idea that you can one day look back and hopefully your illness won’t be as bad as you perhaps might have thought initially”* (A175). However, within DMH filtering may be made possible by the technology, a function that would be difficult to replicate using more traditional methods. Sarah (U/D) describes the use of an online diary to write about experiences that she would like to keep private, experiences that even she may not wish to revisit:

*“I still have the stuff... it’s not appropriate for me to blurt at my therapist or I don’t want her to see or I want to write a long ranty post with lots of swear words... I’ve got a private journal for that... you know there are entries about things that I’ve been through that I never want to read again but at the time I needed it out of my system and I needed to vent.”* (Sarah309-310).

Anne (U) too wishes to record entries she may find distressing to look back upon – *“when I write things down I tend to destroy them later because I know at a later date they’ll be distressing”* (A234). She feels that the use of technology reduces their potential impact – *“you could write things down and store them but they’re not physical so they’re not so threatening in that way and if you want to get rid of them you can just delete them”* (A234). Anne (U) explores this further when she conceptualises a diary that would filter the entries that were more distressing – *“you could label your writing... so that the ones that I think I never want to read that again, you know you could just put a big line through and you could know not to look at it”* (A245) – and a diary that would remain private – *“in the future you could reflect back but just knowing that nobody else would access it would be great”* (A246). Filtering is a function that may be enabled by digital technologies and applicable to mental health needs.

### 7.3.2 The Future: Reducing Uncertainty

The category of Seeing the Journey also encompasses understanding one's own potential future. It is about reducing the uncertainty of the experience that surrounds mental health and a way of preparing and recognising one's needs, particularly everyday aspects that may not be part of the conventional medical information provided.

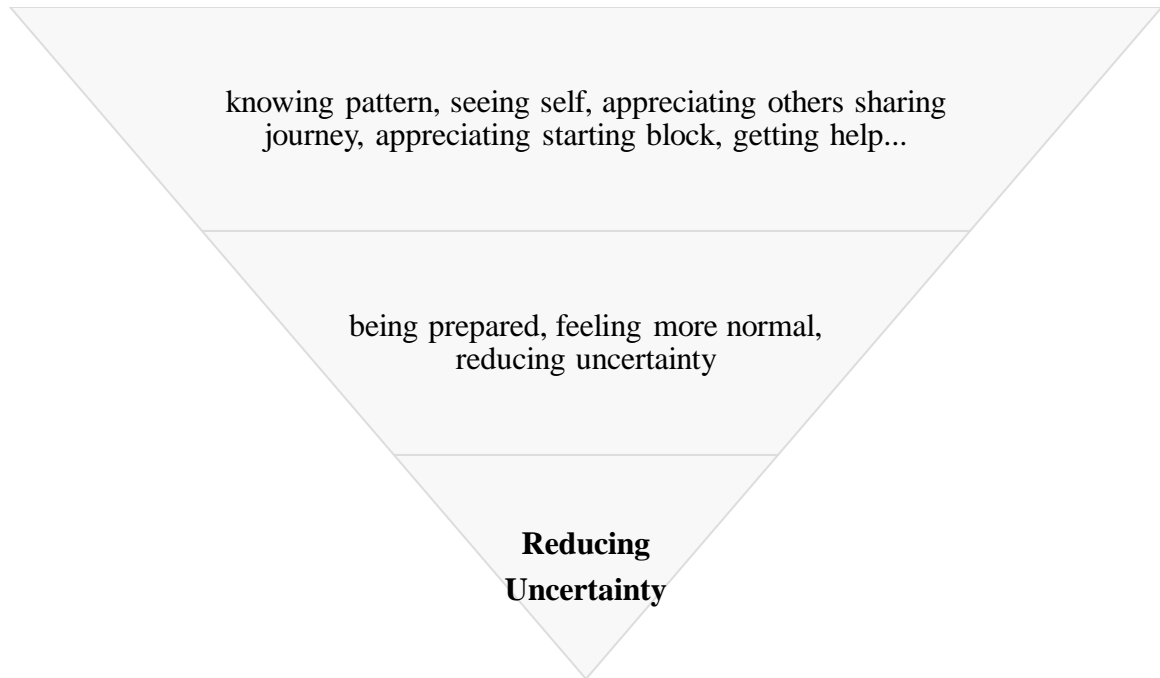


Figure 41. *Showing analytical process of codes resulting in the concept of Reducing Uncertainty.*

Reducing Uncertainty relates to an individual seeking ways to understand their potential experience in mental health. Participants construct this firstly by using tracking as a way to predict future behaviours, cognitions and moods and secondly using shared personal stories and interactions with People Like Me (section 7.4.) to alleviate the uncertainty surrounding experiences. Anne (U) constructs tracking as not only useful for detecting her past experiences but also as potentially useful in being able to predict her moods, a device or app with which “*you can sort of predict how things will be if you know what your pattern is*” (A216). Sarah’s (U/D)

interactions with experienced others gave her an understanding of what to expect when she sought help – *“I felt like I went in prepared because... I had people help me”* (Sarah175). Sandra (U) attributes seeking help to understanding herself through the experiences of others, having *“other people say ‘actually this has happened to me as well’ you start feeling things are normal... it makes it a lot easier, I think, to get help”* (Sandra155-157). Rita (U/P) too felt that other people’s experiences, as discussed further in People Like Me (section 7.4.), contributed to reducing the feeling of uncertainty she felt around her own experiences – *“somebody else felt like that too”* (R324). She feels that the experience of mental health is one with significant uncertainty, that *“the patient doesn’t know what they’re facing”* (R415). It is important to note that the potential to predict one’s mental health in the future, whether through patterns or through the experiences of others, may be constructed as a way of identifying when further support is needed. Without access to DMH resources and these personal stories, without Seeing the Journey, Sandra (U) states *“I don’t think I would have actually gone to the doctors in the first place”* (Sandra150). She calls it a *“starting block”* (Sandra151). This is discussed further in Finding What Works (section 8.4.) as an element of the process through which users engage with resources.



### 7.3.3 All Stages of Recovery

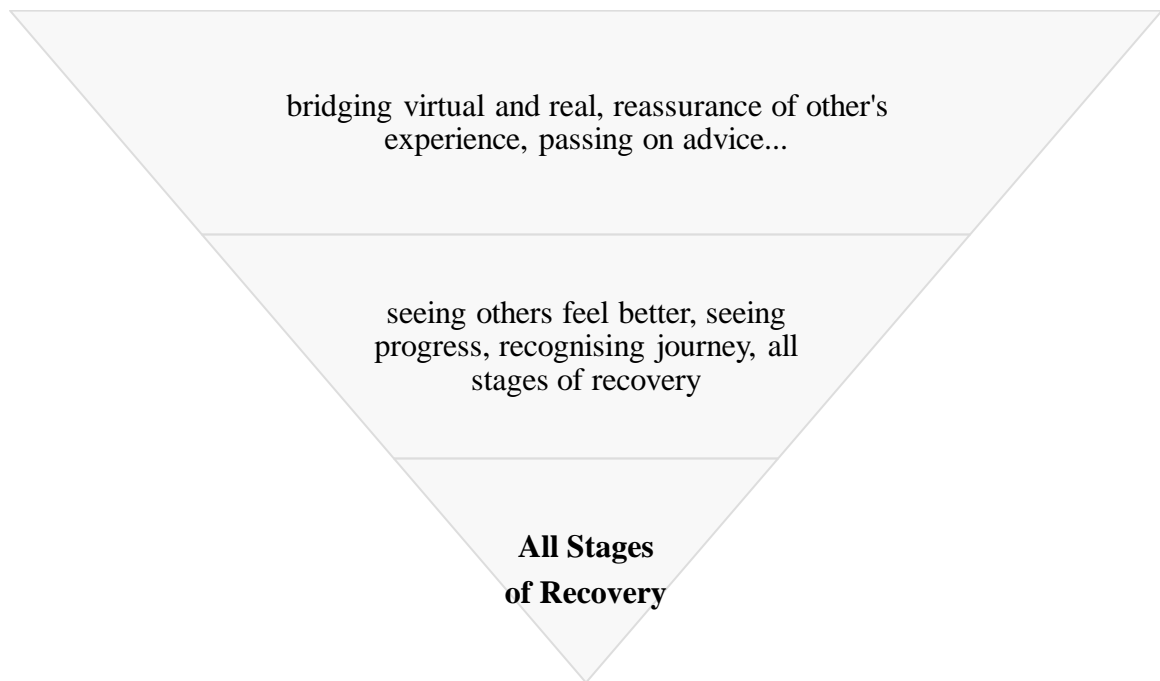


Figure 42. Showing analytical process of codes resulting in the concept of *All Stages of Recovery*.

DMH can enable individuals who share diagnoses or experiences to interact regardless of where they are in their recovery. Some people may even return to provide support to others – “*I know some people log in and support others when they’re feeling better*” (J293). This holistic representation of the journey may help individuals to construct both their past and their future.

As Sandra (U) explains:

*“I mean that constant thing of someone going “well yeah this is going on, this happens, it’s not a weird thing, it’s not new... these things happen and it’s ok”, and... then seeing people who were maybe further along starting to feel better... and seeing that progression. And then as I sort of started to feel better in myself then being able to see people coming in, again at the sort of beginning and not really knowing how to cope, and being able to then pass on advice was*

*quite nice as well. It made it feel like a proper sort of journey, that you're on a pathway. It wasn't just a random all-encompassing thing*" (Sandra102-109)

Sarah (U/D) agrees with Sandra (U), that *"most places have people at all stages of recovery"* (Sarah113). Within Rita's (U/P) support group she talked often about people who were in recovery remaining within the group – *"the people that I saw that did link it to real life and incorporated... resources, information, peer support, and a therapist; those were the people who went back to school, back to work or basically they controlled the illness"* (R530). Indeed, even David (D) is able to recognise that for users of his platform many will seek out experiences *"once they're ready to listen to the people who have been through what they're going through"* (D183). This suggests that an important component within Seeing the Journey is being able to see the experiences of others represented over time and to be able to interact with others who are at different stages in their mental health journey.

### 7.3.4 A Call to Action

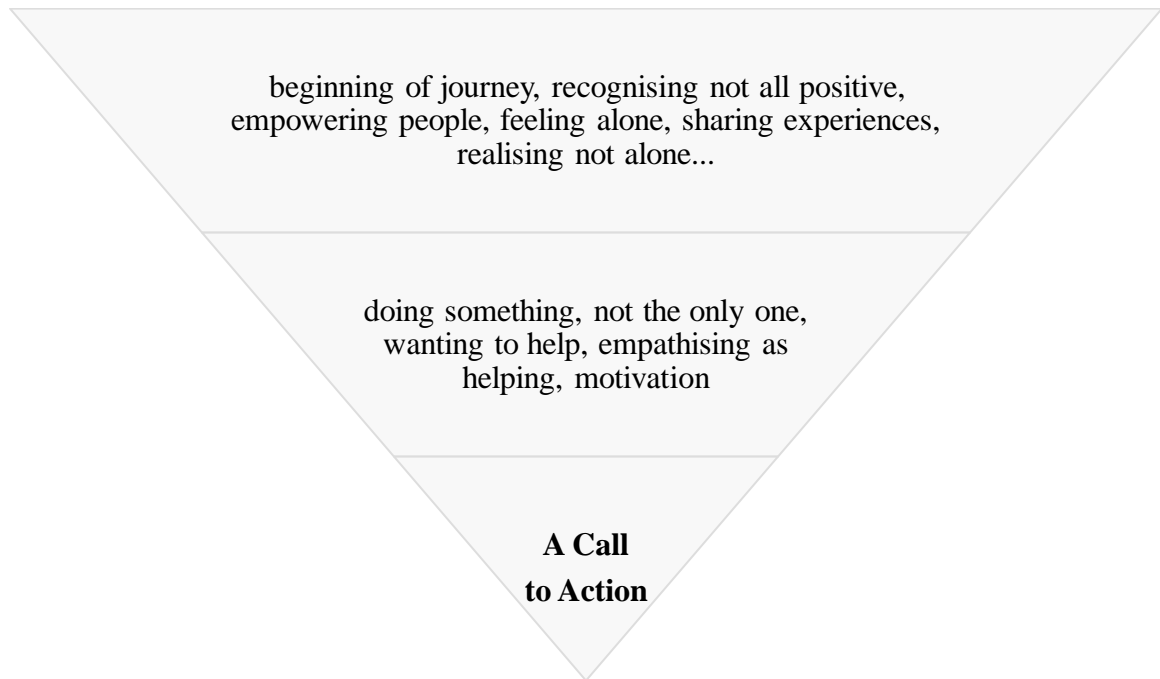


Figure 43. Showing analytical process of codes resulting in the concept of A Call to Action.

Some participants appeared to construct their own journeys as a call to action. Through recognising the experiences and challenges that they faced themselves they construct their role as a guide for others. Carol (U/P) and Phillip (U/P), both prolific bloggers, recognised that their experiences could be shared with others. Phillip (U/P) wishes to share his experience so that others might find advice:

*“Not all of it is happy stories, some of it is criticisms as well but the whole point is that it’s my story and those who are beginning their journey as a mental health carer can at least connect and pick up ideas from what I’ve experienced on my own journey”* (Phillip66-72).

Carol (U/P) finds it rewarding to share her experiences with others online – *“if it helps, if somebody else can empathise then it might help them too. So I feel like I’m doing something”* (C93-94). For Rita (U/P) her own experience seeking resources became a driver to share and

connect, enabling her to recognise the difficulties of similar others in their experience of DMH and seek to provide a solution – “*how many other people can be going through a similar situation? And that’s when I opened up a group*” (R162-163). Likewise, Sarah (U/D) began an online support group because she recognised that her own experiences were not unique – “*if I’m seeing all these other people with mental health problems online and I feel like I’m the only one in my school, I can’t be. So I started a group up*” (Sarah34-35). DMH appears to enable Seeing the Journey, which in turn can encourage reciprocal activities as individuals seek to improve their own and others’ experiences.

### 7.3.5 The System Builder Perspective

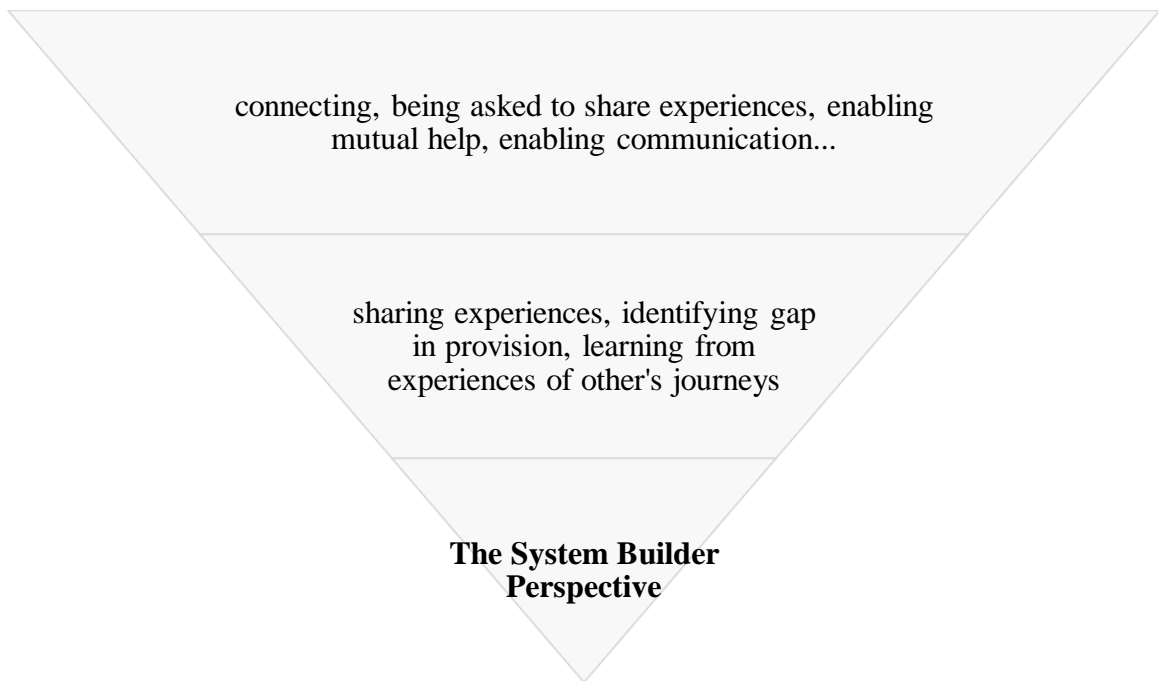


Figure 44. Showing analytical process of codes resulting in the concept of *The System Builder Perspective*.

It is not just users who recognise the role of Seeing the Journey within DMH. Phillip (U/P) discusses organisations such as Carers UK who recognise its role for users – “*Carers UK*

*heavily pushes their carers forum online so carers can communicate and help other carers”* (Phillip183-185).

### **7.3.5.1 The Future: Reducing Uncertainty**

System builders also recognise the importance of other’s experiences within development. Tom (D) feels that an important part of DMH development is to *“learn from others”* (T160). Patricia (A/C) was limited when finding that there were few people to go to when looking for advice about developing an app – *“I did try to get recommendations but again there isn’t a huge pool of people who have done this... people come to me now and ask me about developing an app”* (Patricia105). Patricia’s (A/C) experiences are valuable; they are being sought by others who are about to embark on developing an app within an academic context. One of the lessons that Tom (D) feels he has learned is *“to ask people for their advice and their input”* (T155). Likewise, he feels that his own experiences can help others – *“every couple of months or so someone will get in touch and want to talk about the work or I will recommend some of the blog posts to people”* (T14). This suggests that within DMH development there is also a drive to find people who can share their experiences, constructed as a way of Seeing the Journey, of building a resource through social learning.

### **7.3.5.2 A Call to Action**

It may also act as a call to action. Through the personal experiences of a friend, David (D) and his colleagues *“identified that there was a huge gap in provision for people”* (D12) which led to development of their forum. Sharon (A/C) recognised the additional needs of a particular user group through her interactions online with them – *“I think that... [specific user group]... need a lot more support than a digital programme”* (Sharon29). Even for system builders this recognition of shared experience, even when not their own, may become a driver to

take action and contribute within DMH. David (D) explains that it was through the diagnosis of a close friend that the platform became built – “*one of my best friends... was diagnosed*” (D3).

Likewise, it was Tom’s (D) experience as a mental health advocate that led him to his involvement in DMH development – “*I was working as a mental health advocate in the voluntary sector and I developed an interest in how technology could support people in the same way*” (T3). This suggests that Seeing the Journey also contributes within development itself by identifying areas of need.

### **7.3.6 Summary**

Seeing the Journey is constructed from the ways in which DMH can provide meaning to the individual’s own experience of mental health. It involves personal tracking of moods and records of experience that may be represented visually over time, including the potential to filter and manipulate what is viewed. It requires continuation, which may challenge its usefulness if not maintained. These representations of moods, along with the personal stories of others, may offer individuals a way to reduce the uncertainty of their experience in mental health and allow them to anticipate their potential future. Knowing what to expect may provide them with more confidence in taking the necessary steps as well as informing them of what those steps may be. What sets DMH apart in Seeing the Journey is the representation of all stages of recovery in interactions. Many of the participants appreciated the depth of information made available through access to those at different stages of recovery and through sharing their progress, providing reassurance that there is a journey. Another outcome of Seeing the Journey is recognising one’s own experience of seeking out information around mental health and wishing to provide a more suitable way of doing so. This is constructed as a call to action, the individual’s own journey becomes a driver to provide for others. In the subworld of system

builders, Seeing the Journey may provide support in an otherwise difficult area. There are similarities in the way that system builders report recording their experiences or sharing them with others so as to reduce the uncertainty of the development process. Seeing the Journey represents the meaning that surrounds the shared construction and utilisation of mutual understanding in the social world of DMH.

## 7.4 People Like Me

This category addresses the types of connections that are made by participants through DMH and their constructed meaning, particularly in relation to the others with whom they choose to interact with online. In understanding this category, several forms of support were constructed.

### 7.4.1 Similarity

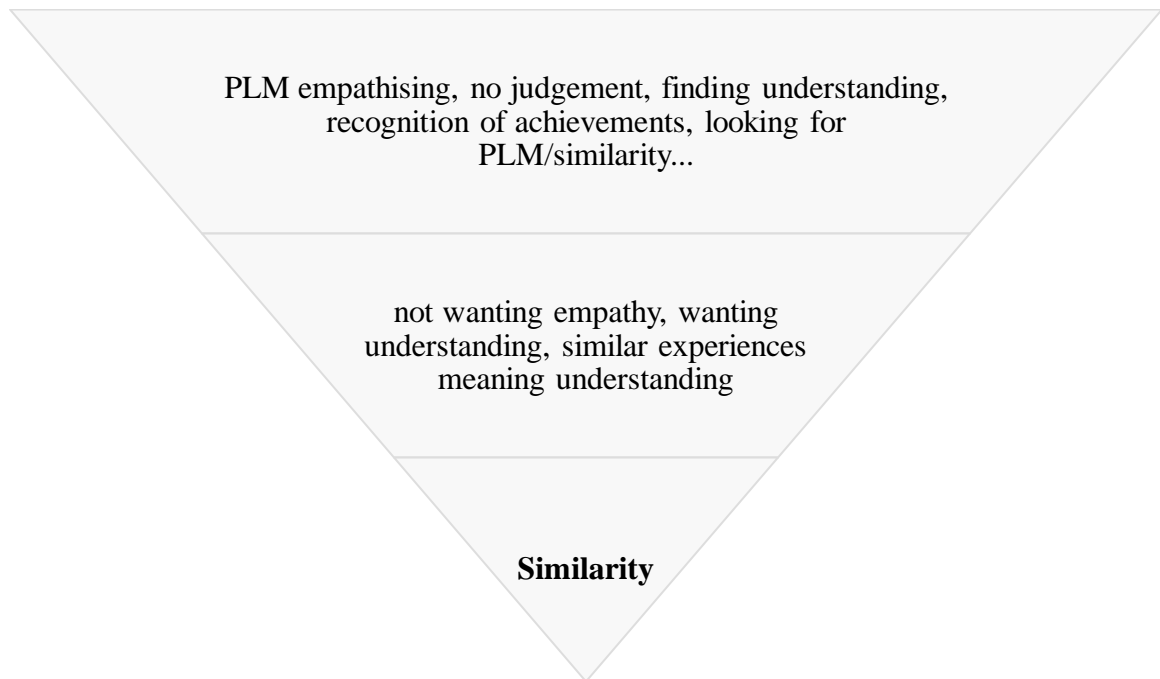


Figure 45. Showing analytical process of codes resulting in the concept of Similarity.

People Like Me are constructed by users as those who are similar. As Carol (U/P) states, they are “*people in a similar situation*” (C48) who “*have the same kinds of problems, the same kind of issues*” (C42) and “*genuinely understand*” (C43). They include, according to Sarah (U/D), those who “*had actually been there themselves*” (Sarah131) and so are constructed as having a deeper understanding. Indeed, they have a depth of understanding surrounding what individuals experience so that even when friends and family remain unaware, People Like Me can recognise “*how big a deal*” (C327) certain life experiences are. Similarly, Sandra (U) seeks out people who are “*feeling the same way*” (Sandra11). For Sarah (U/D) the similarity is made clear through others’ experiences – “*the more I read the more I identified with what I was reading*” (Sarah32). These descriptions suggest that People Like Me in mental health are identified as an element of similar experiences rather than similar diagnoses. The following sections will explore the experiences associated with contact with People Like Me in DMH.

#### **7.4.1.1 Affirmation**

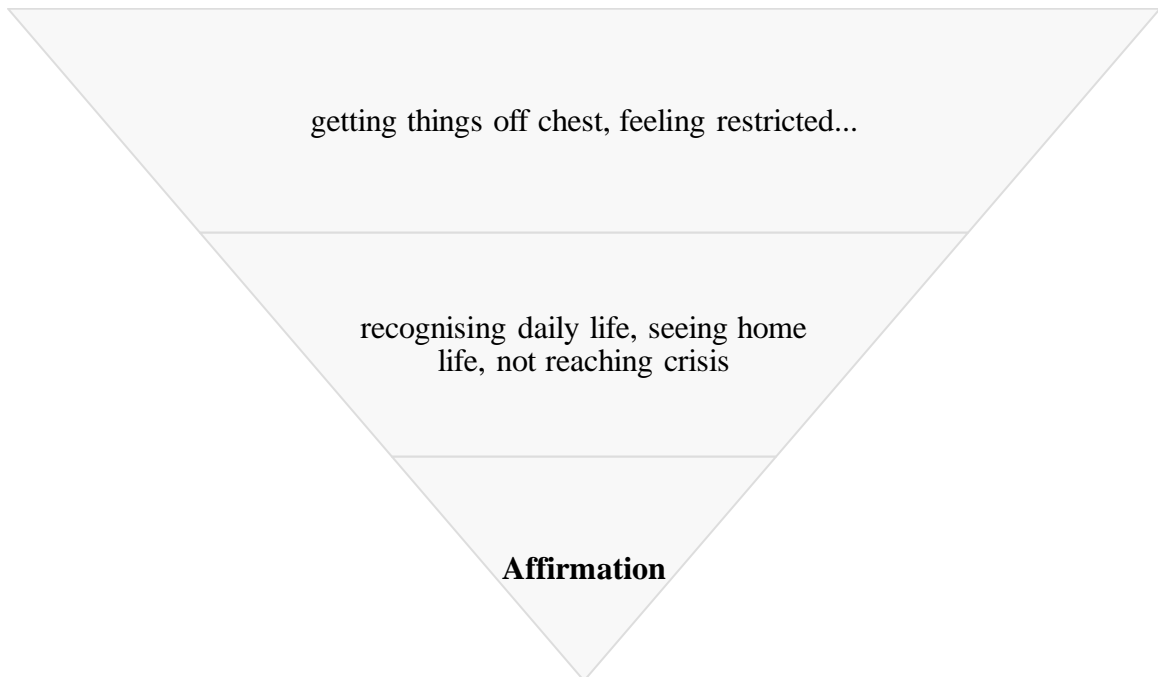




Figure 46. *Showing analytical process of codes resulting in the concept of Affirmation.*

People Like Me are constructed as those who share similar experiences. This can be constructed as acknowledgement of, and the feeling that others can understand, their everyday experiences. One concept that arose in both Carol (U/P) and Sarah's (U/D) interviews was of the 23 hours that people are outside of professional oversight – *“they don't see the other 23”* (C216) and *“they don't know what's happening at home”* (C183) – whilst People Like Me understand *“what it's really like at home”* (Sarah131). This may provide both affirmation and important information. Carol (U/P) compares her relationship with her friends, that although *“I've got a lot of very good friends... I feel that they sort of judge me”* (C44) whilst People Like Me will *“be able to relate to it”* (C51). She talks about how she is *“not judged for losing the plot because everybody knows how difficult it is”* (C67) whilst she is concerned that her friends would tell her *“you did the wrong thing”* (C81). Sarah (U/D) found that she had 24-hour access to people with whom she could talk, people who *“had actually been there themselves”* (Sarah131). She observes that *“most people don't have crises in office hours, we struggle at evenings and weekends”* (Sarah49). People with whom Sarah (U/D) interacted were able to identify her need to seek help – *“I had no idea how serious it was so I think I would have kept going and it wouldn't have been until someone in my real life picked up on it or it was a crisis point that I got treated”* (Sarah84). This suggests that an additional constructed meaning surrounding People Like Me is their awareness, acknowledgement and acceptance of the everyday experience of mental health.

### 7.4.1.2 Recognition

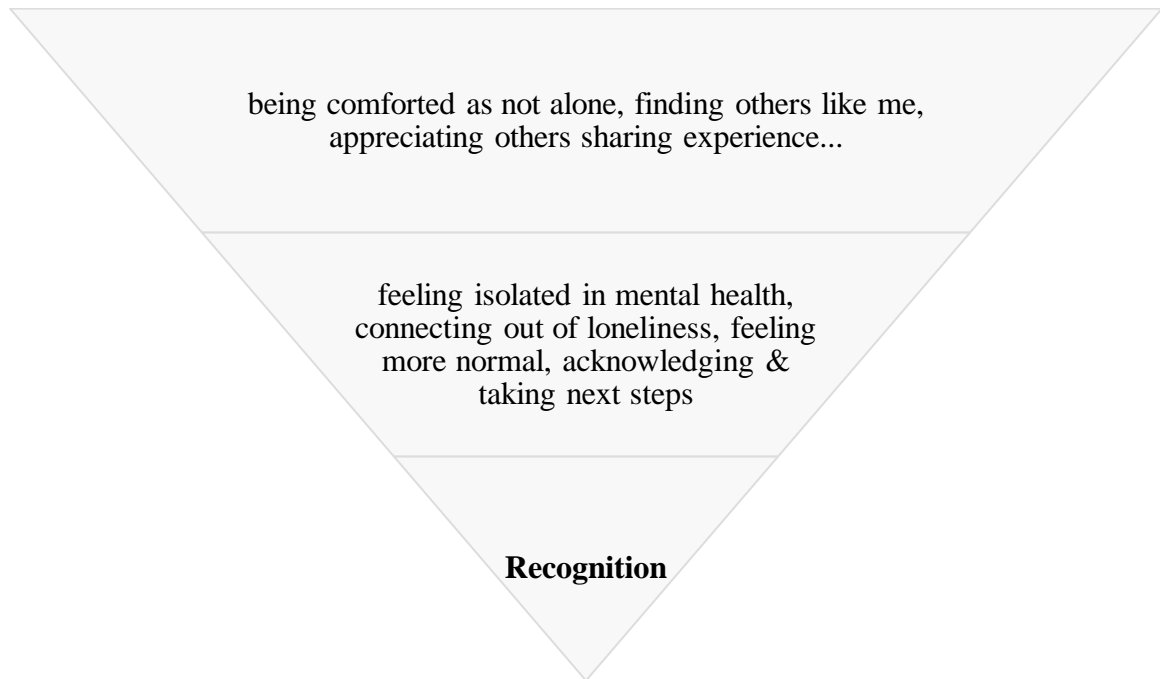


Figure 47. Showing analytical process of codes resulting in the concept of Recognition.

An important component of the constructed meaning of People Like Me is the way that it offers individuals a feeling of belongingness and validation, recognition that others too have similar experiences. Both Sandra (U) and Anne (U) talk about their feelings of isolation, connected to their experiences of their mental health. Sandra (U) identifies that *“it can be quite isolating when you’ve got mental health issues”* (Sandra12) and Anne (U) recognises that *“you can feel quite isolated day-to-day”* (A205). For Sandra (U) *“knowing I’m not alone is comforting”* (Sandra45), whilst for Carol (U/P) it was the realisation that *“it’s not just me that’s odd”* (C130). This familiarity and recognition of self within others may provide individuals with a way forward. Sandra (U) and Rita (U/P) identify it as an important step in their recovery. Sandra (U) feels when *“other people say ‘actually this has happened to me as well’ you start feeling things are more normal”* (Sandra155-156) although Rita (U/P) feels that rather than

normalising it is constructed as “*knowing that you're not alone, you're not this foreign crazy alien person*” (RVW425). This establishes a link between People Like Me and Seeing the Journey (section 7.3.).

### 7.4.1.3 Reassurance

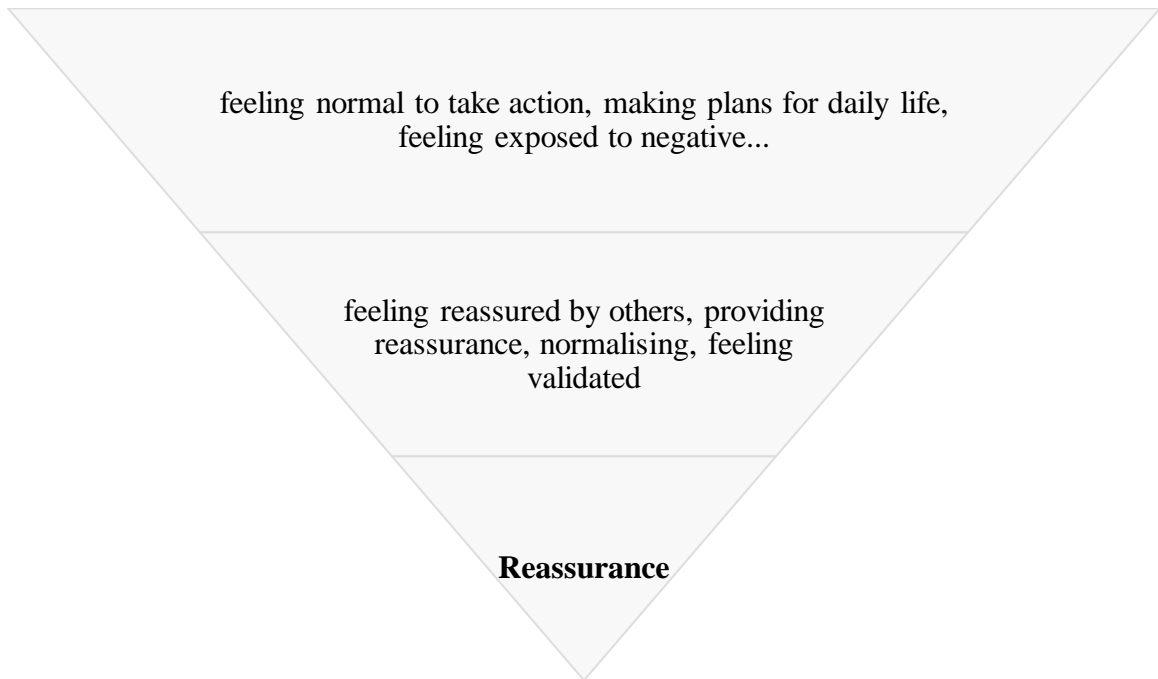


Figure 48. Showing analytical process of codes resulting in the concept of Reassurance.

Reassurance is constructed as a feeling that what they are experiencing is ok. Sandra (U) felt that contact with People Like Me was reassuring – “*this is going on, this happens, it’s not a weird thing, it’s not new... these things happen and it’s ok*” (Sandra102). Sandra (U) discusses the role that Reassurance played within her finally seeking help, needing to “*feel normal before I could feel like I could do anything about it*” (Sandra158). Anne (U), however, is reassured when she accesses information about a support group but does not then take action and attend – “*I’ve looked up a local support group... when I’ve felt a bit low... but I’ve never actually been*” (A207) demonstrating inaction through Reassurance. Rita (U/P) refers to “*the pity party*” (RVW403) that

she has experienced in online forums. This “*acknowledges that there is a problem, it acknowledges the emotions but that’s it*” (RVW404). It is a cycle of sharing, where experiences are shared but actions are not taken. Sarah (U/D) reflects on the echo chamber that at times occurs online, where illnesses may be validated and normalised – “*people will validate that it’s ok to be kind of ill*” (Sarah135). Unfortunately, she recognises that this “*probably did keep me sicker because it does expose you more to that mindset*” (Sarah135). However, she perceives this to be from seeking out validation rather than as a mandatory component of People Like Me, in line with the Freedom to Fail (section 7.2.).

#### 7.4.2 Actionable Advice

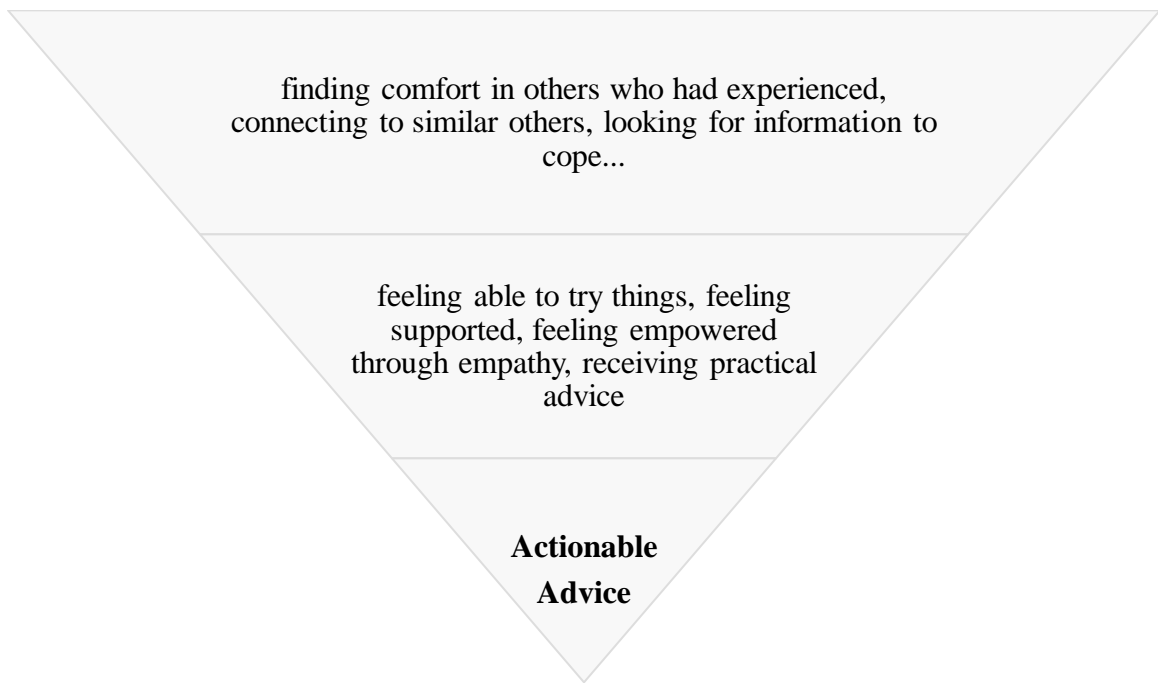


Figure 49. Showing analytical process of codes resulting in the concept of Actionable Advice.

People Like Me share advice that is relevant. Carol (U/P) explained during the interview that people who had been through similar situations were able to support her and provide the confidence she needed to put their advice into action – “*because I was getting support from other*

*people that had been through the same thing I was able to think... I'll try this... and see what happens"* (C168). Rita (U/P), Phillip (U/P) and Sandra (U) also identified the role that People Like Me played in learning that there were options available, tools and coping mechanisms that they could apply knowing that it helped others. Rita (U/P) says that viewing blogs on Tumblr led to her identifying "*what they did that helped them, let me try it*" (R324). Phillip (U/P) connected "*to others who are in that situation already*" (Phillip47) and sought "*information about how to cope*" (Phillip50). Sandra (U) discusses the role that YouTube videos have in providing "*coping mechanisms... from somebody who knows that it works*" (Sandra127-130). This identifies the role that similarity may play in recommendations (see Guides, section 8.4.5.). Rita (U/P) also addresses the advice provided as what separates "*the pity party*" (RVW403) – discussed as a component within Reassurance (section 7.4.1.3.) and illustrating validation without progress – from productive and useful information from others. Instead of People Like Me simply being to compare one's experience against they may offer advice that is more relevant, demonstrate tools that are more acceptable and guide the individual in their use. In this way the concept is linked to Seeing the Journey (section 7.3.).

### 7.4.2.1 Asking Silly Questions

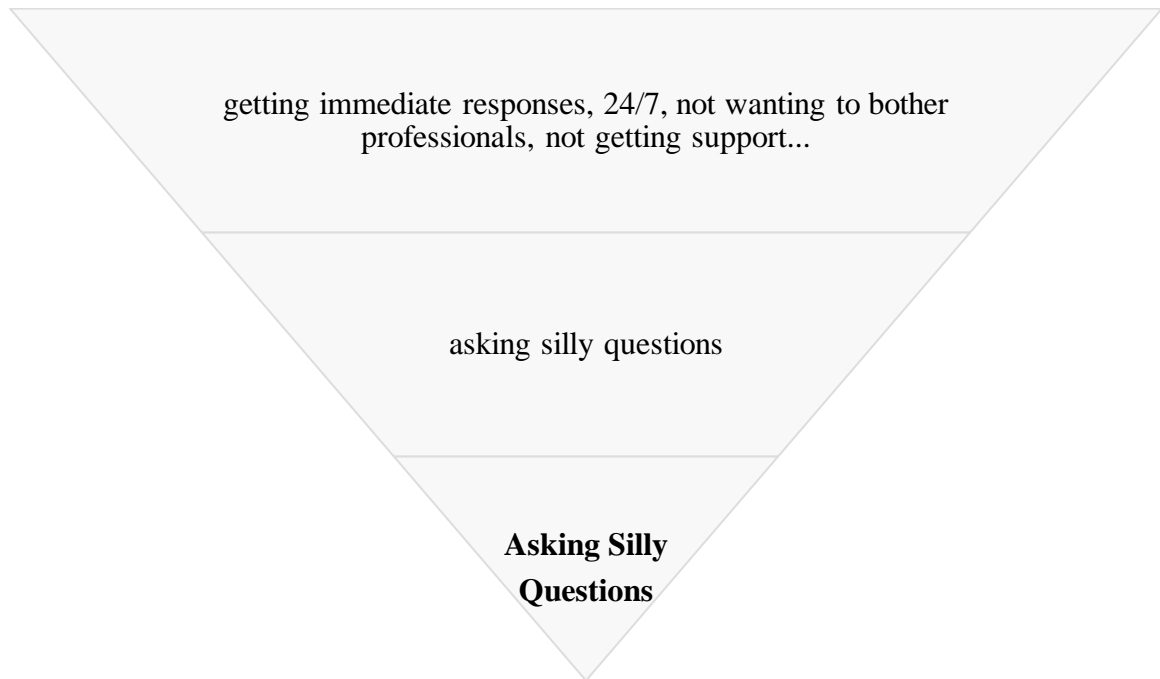


Figure 50. Showing analytical process of codes resulting in the concept of Asking Silly Questions.

Another aspect of the advice provided by People Like Me that was identified by participants was that they have privileged information that may not be easily accessible. For Sarah (U/D) this meant information that might not be easy to ask a GP, including information that was needed quickly but that seems “*like a stupid waste of everyone’s time*” (Sarah184) if you were to ask a professional. For Carol (U/P) these are questions that help make her life easier but seem silly to bother her GP about – “*3 o’clock in the morning when you can’t sleep... do I bother my consultant?*” (C320). People Like Me are able to share information that is often difficult to access in conventional healthcare. For Carol (U/P) this meant information that could aid her in being a carer, particularly as she felt that if “*you’re in services... the carer’s the person who’s not sort of completely involved so I didn’t get a lot of support for a long long time*”

(C176). Sandra (U) feels that there may also be a reticence to ask certain questions surrounding one's mental health, *"I think a lot of the time a lot of the questions that people would have about mental health and how they're feeling and things like that they worry that they're silly questions"* (Sandra90). This suggests that People Like Me may offer individuals a way of accessing relevant advice and information that may not be available or easily accessible otherwise.

### 7.4.3 Targeting

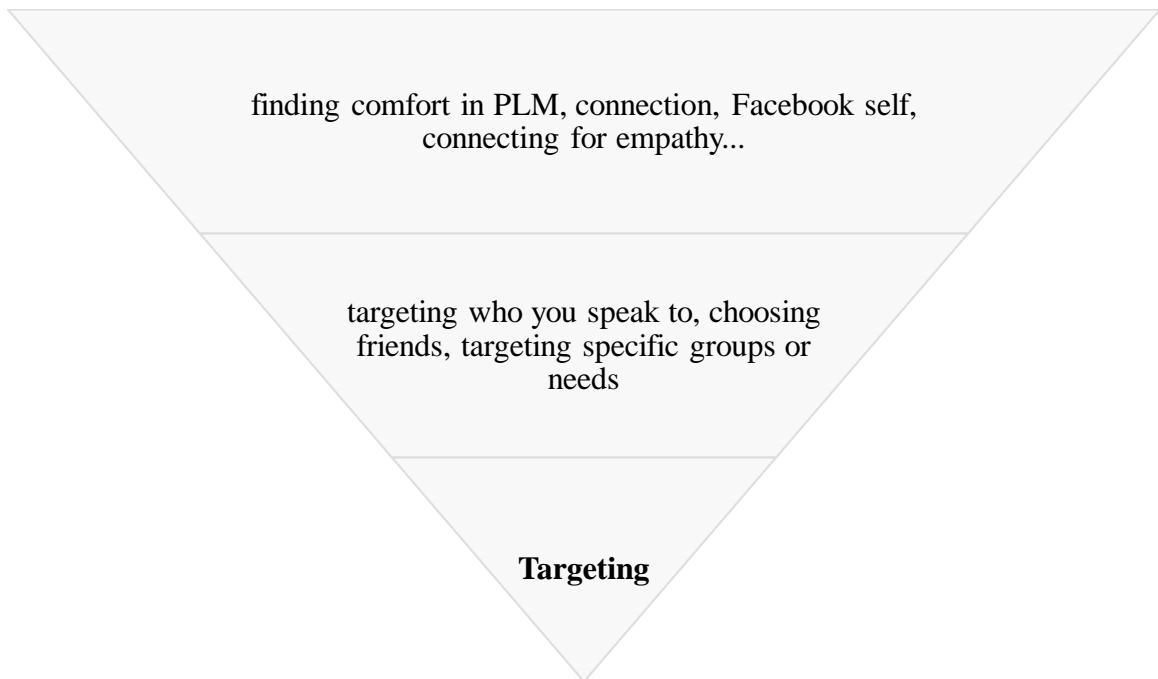


Figure 51. *Showing analytical process of codes resulting in the concept of Targeting.*

Participants appear to feel that sharing a diagnosis is not sufficient in connecting with people, for instance George (U) identifies that *"because of the nature of the mental health beast there is a lot of conflict"* (G72) in mental health support groups. DMH offers a way for individuals to seek out and find People Like Me who not only share similar experiences but also, as Sam (U/D) suggests, will respond in a positive or expected way to disclosures around one's mental health – *"you almost create assurance that your openness is going to be well received by*

*only communicating with those who will receive it well*” (Sam48). This is something that is not easy offline, as Sam (U/D) explains: *“in everyday life we don’t have so much command over who is around or who is prone to our information”* (Sam49). Communities of people with shared interests are formed through wanting to connect and communicate about specific topics as well as provide support. When Sandra (U) discusses the community she is a part of as *“an important support network”* (Sandra200). However, there is the potential for the formation of *“cliques... it’s a bit like people gang up against each other, even on mental health forums”* (J179). Both Sarah (U/D) and Carol (U/P) discuss targeting specifically:

*“you can target who you’re speaking to rather than just a friend”* (C55)

*“I can be really choosy about who I have in my life”* (Sarah92-93)

Both Harold (U/P) and Sean (U/D) identify the importance of digital technologies in improving accessibility and specificity in online communities or DMH resources. Harold (U/P) explains:

*“I might have a particular need for a support group... yet if I’m just counting on the geographic area where I’m living well there might not be enough of us, and there might not be enough of us interested in being in a group but if I could call upon all of the resources of Facebook or Second Life we may be able to get enough people”* (H72-74)

Sean (U/D) too feels that more specific needs, traditionally expensive and difficult to design for, are made easier through increased access to interested users – *“we can design really good things for really small group preferences... it doesn’t have to be massively expensive... and a lot of the time it’s just that no one has thought that your problem is important to solve”* (Sean455-459). This constructs DMH as a place that enables more specific targeting of People Like Me.



#### 7.4.4 The System Builder Perspective

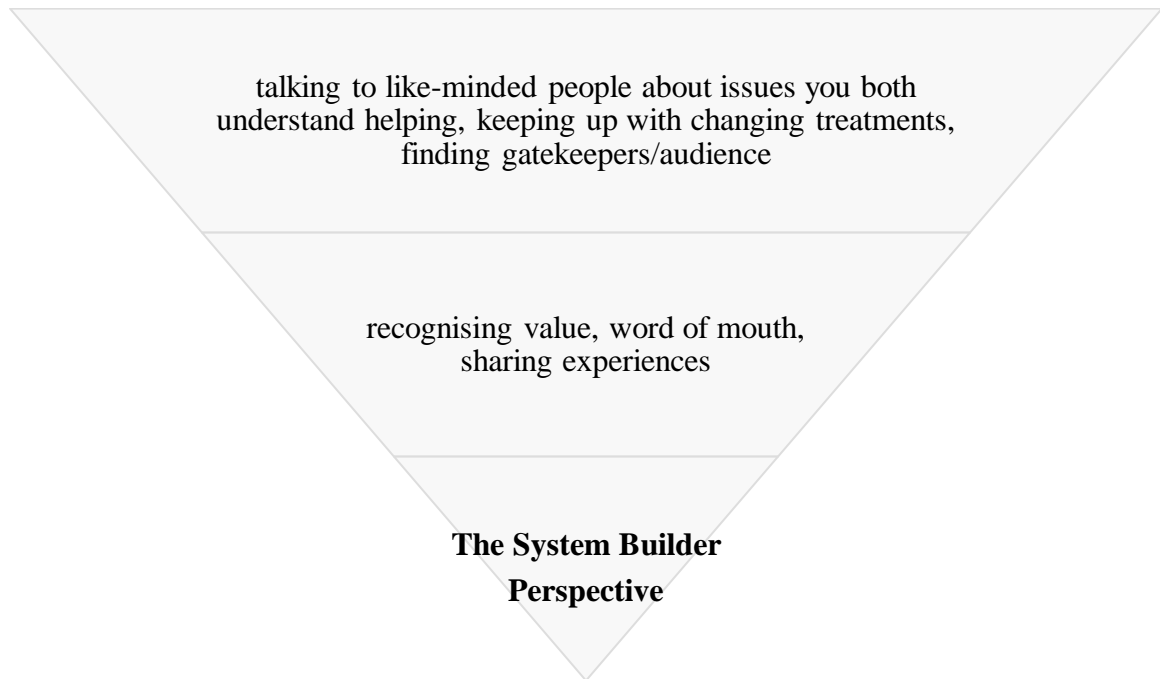


Figure 52. Showing analytical process of codes resulting in the concept of *The System Builder Perspective*.

David (D) had the most experience with this concept from a system builder perspective as he was involved in the development of a forum. However, others also discussed it in relation to their own experiences.

##### 7.4.4.1 Similarity

David (D) identifies the reason that himself and his colleagues decided to build their platform was that they “*inherently know that talking to like-minded people about issues that you both understand can help you get on with your life and help you adjust*” (D62). He also believed that “*when people get diagnosed... they go on their forums and the people who sit on those forums all day are very different to what they're looking for and actually quite scary*” (D122).

Development of a different kind of forum offered a way to support individuals in connecting to

People Like Me. For Patricia (A/C), people similar to her played a role within dissemination and marketing leading to identifying and accessing an audience more quickly. An audience with similar characteristics, such as academics, were “*a more defined audience... that we... can influence fairly easily*” (Patricia16) whilst those dissimilar, carers, were constructed as “*a much less specific audience... less single gatekeepers*” (Patricia19). The similarity of the potential audience to the system builder may impact the appropriateness of the resource and its implementation.

#### **7.4.4.2 Actionable Advice**

Another concept arising within Patricia’s (A/C) interview was of feeling that apps used by others “*for the same purpose*” (Patricia135) that “*worked in a similar context*” (Patricia137) would lead her to be more perceptive to trying them – “*it would inspire me to go and look at it*” (Patricia137) – demonstrating once again their role in recommendations (also see [Guides](#) section 8.4.5.). Tom (D) too felt that advice from others who had been through similar development processes was essential within DMH development – “*I’ve learned to ask people for their advice and their input... it’s really important at the beginning*” (T155). This suggests that the importance of advice from People Like Me is shared by others, not just users. David’s (D) Call to Action (section 7.3.5.2.) to develop a forum was influenced by his friend wanting to enable people with a condition “*to ask the naughty questions or silly questions*” (D32), echoing the concept of Asking Silly Questions (section 7.4.2.1.) that was discussed by users. It seems this is an area of need that people may construct as being answered through DMH.

#### **7.4.4.3 Targeting**

David (D) feels that the “*health model to date has felt like if you put a load of people in a room with [condition] then they’ll get on with each other but that’s rubbish*” (D181). He is

aware that users seek out People Like Me and, from his own experience – *“every time I went on that page I saw a grid of faces that I didn’t really associate with because it was most recently active”* (D164) – has built a filtering system so that *“when you first see the people on the site and start thinking about making friends with people they’ll be the people you wanted to see”* (D165). It seems that David (D) understands not only that people seek out those who are similar but that they also engage in Targeting (section 7.4.3.).

#### **7.4.5 Summary**

The category of People Like Me addresses the constructed meaning that surrounds the others with which people interact online in relation to their mental health. DMH offers the opportunity for people to exercise their discretion whilst accessing people that share similarities in experience with digital technologies allowing contact with and the formation of groups around what may be a unique experience. Within mental health this may mean disclosing online to constructs of similar others, which can provide normalisation and advice from those who are perceived to lead by example. These shared experiences and advice may provide support that has different constructed meaning for those who seek it. Individuals seek reassurance surrounding their own experiences in mental health, they seek people who can recognise their experiences and they seek people who can affirm that they are not alone in experiencing them. However, this may also lead to reassurance, affirmation and recognition of unhealthy behaviours. People Like Me requires the provision of actionable advice to be supportive of good mental health and wellbeing, along with the perceived absence of judgement that appears tied to similarity with a community of others. There was some evidence to suggest that the concept of People Like Me was one shared by system builders, who also seek out advice and use similarities with people to aid in disseminating resources. The underlying constructed meaning is that of constructing

similar others as important representations that may act not only as guides but also as a way to support oneself by seeking out acknowledgement of one's own experience in the experiences of others.

## **7.5 Overview**

The experiences shared within DMH were encapsulated within three categories that brought together different meanings constructed by the various roles of participants. Freedom to Fail (section 7.2.) constructs the ways in which participants used DMH resources to exercise autonomy and agency within their mental health. Seeing the Journey (section 7.3.) demonstrated how they could construct meaning through their interactions and the data that they recorded as a way of documenting their experience. Finally, People Like Me (section 7.4.) identifies a process of seeking out and feeling supported by others within DMH – others who share similarities of experience but not necessarily diagnosis. These categories provide unique concepts within the experience of DMH.

## **8 Analysis and Findings: The Practice of Digital Mental Health**

### **8.1 Introduction**

The Practice of Digital Mental Health links the categories within the milieu and experience of DMH to more abstracted categories that explore and describe the processes that underlie them. Finally, a category is posited that examines the process through which individuals apply DMH in the wild. Please note that Participant Roles are identified through the use of abbreviations to denote the different roles – Developer (D), Academic/Contractor (A/C), User/Developer (U/D), User (U), User/Provider (U/P).

### **8.2 The Milieu of Digital Mental Health: Compromising**

The milieu of DMH comprises two significant categories, DMH as Product (section 6.2.) and Changing Purpose (section 6.3.). Both represent a complex interplay between development and use, between the environments imagined and the environments in which resources are used. The milieu includes recognition that just as users must utilise resources developed for them by remote system builders, system builders must also contend with devices designed, and used, remotely from them. The interaction occurs without oversight and often without feedback. Bringing these two categories together offers constructed insight into the processes at play within the experiences of stakeholders within the social world of DMH. These processes are brought together within the theoretical category of Compromising. The theoretical category of Compromising recognises the mutuality of decisions that must be made within DMH, not only potential concessions made by developers with regards what is possible but also the ways in which users adapt and may at times settle for tools and resources that are not ideal.

### 8.2.1 System Builder Compromises

The limitations of DMH at times relates to the small-scale organisations of system builders. When Jessie (U) is faced with an unresponsive system she excuses it by telling me *“there’s not a lot of funding going into it and I think you can tell that quite a lot sometimes”* (J110). However, she is willing to compromise because *“they say that if you’re paying for it your payment is paying for people who can’t afford to pay to have the lite version of it so they can keep that section of it free. And that’s nice to know”* (J287). David (D), a Developer, identifies his organisation as small, constructed as *“a much more flexible space to experiment”* (D72). However, he also recognises that this requires compromising with regards the feedback they can accommodate from users – *“we’ve deliberately not opened up those feedback loops because we wouldn’t be able to process them all and we’d end up giving people false hope in being able to influence our approach when we just have a tiny team”* (D206-207).

System builders may also compromise in their management of resources. For instance, Patricia (A/C) discusses her experience with restricting development to a specific timeframe due to funding restraints – *“I also had a time restriction”* (Patricia57). The cost of development and need for maintenance is a further limitation, as identified within the concept of The Interminable Product (section 6.2.2.), whilst compromises also appear to be made surrounding stakeholder collaborations and input in development that is addressed within the concept of Human Interoperability (section 6.2.1.). System builders may make compromises that impact the user when they must ensure stability of resources. For instance, when Anne (U) must update her phone she finds that there is not enough room to do so – *“I couldn’t update it for ages... it basically wanted me to wipe the whole thing so I’d have enough space to put the new operating system on so I found for a while nothing worked”* (A103) – which necessitates a compromise

between the data she has stored on it and its usability. Improving operational usability of the device challenges Anne's (U) perception of its suitability for her needs and causes irritation. This contrasts with Patricia's (A/C) experience of choosing not to restrict the resource – or as she calls it “*sanitising*” (Patricia128) – as discussed in Impact on Users (section 6.3.2.2.). Users are subjected to numerous changes to which they must adapt (discussed in Adaptation, section 6.3.1.1.), whilst system builders may resist compromising their intended products in response to anticipated problems amongst their users.

### 8.2.2 User Compromises

Usability is constructed by users as resources that work for them, although this may require compromises in terms of cost or privacy. The expected benefit of their use of a resource must be achieved, or achievable, for it to be considered usable. For instance, Anne (U) identifies the usability of apps as a challenge – “*they're full of bugs and they often don't kind of quite work as well as they should*” (A11) – and when faced with them may choose to discard it and find another resource – “*what I've found I then do is sort of give up and think 'oh well I'll try something, I'll find something new or better'*” (A20). This is constructed by Sam (U/D) as inherent to peoples' view of technology itself, that technologies are “*quicker but they're also disposable*” (Sam240) and that “*any time or energy or effort that we put into things is easily discarded because there's no cognitive process or way we understand, well certainly my generation understands, the cost of it*” (Sam241). In this way Compromising is linked to Freedom to Fail (section 7.2.) – the choices available and the autonomy of use contributing to compromises being made within the practice of DMH.

The devices on which DMH resources are used may also bring compromises. Phillip (U/P) had recently purchased a new smartphone, a phablet, and often returned to the cost – “*I*

*still sometimes think it was a bad idea because I still think it's a bit pricey but I know I do need it*" (Phillip667). Anne (U) too spoke of her need for a newer device – *"I'd like to get a new laptop"* (A104) – and technology's high cost – *"it can be quite expensive can't it, to have all the latest things"* (A106). When recording the interviews, I found myself deleting data from my computer so as to be able to store them on the device for transcription. Rita (U/P) accesses Second Life on a slow device, leading to considerable time spent waiting for her avatar to load (also known as 'rezzing') – *"you have a fast computer! I usually take a bit... I'm rezzing"* (RVW46). Faster devices are viewed as expensive, whilst DMH offers the potential for resources with no cost. For instance, Rita (U/P) *"downloaded almost all apps that were free for moods... that were free for suicide"* (RVW372-373) and the element of cost was prominent in her decision to try these apps – *"if it's free, I mean what have you got to lose?"* (RVW371). When considering costs, it is possible that users will 'make-do' depending on how financially accessible more efficient technologies and resources are in DMH. This is particularly pertinent when considering Norman's (U) construction of an understanding as requiring *"the establishment of a real therapeutic relationship and this does not occur unless money is no object"* (N23). It may be that participants have constructed DMH as a cheap alternative to conventional mental healthcare. This is discussed in the next section.

### **8.2.3 Model of Compromising**

The challenges in accessing conventional mental healthcare are constructed by participants as making DMH attractive to potential users. Jessie (U) feels that DMH has become a necessity as it is the only place that individuals can find support – *"with offline support at the moment there's the waiting lists and cuts to services... so I think more people are turning to digital stuff because they can't access anything else"* (J245). Norman (U) turned to DMH to seek



out mental health information as a result of his perceptions of the care provided by conventional services – *“Sadly very little information is provided by GPs’ possibly due to time constraints... The NHS too are very poor at providing information and again time constraints and I understand that under-funding is a part of the problem”* (N5-10). Sharon (A/C) sees DMH as a way to mitigate the variability of support available through traditional services, an area that she had direct experience with professionally – *“the quality of the support that people got was very variable depending on the individuals that were delivering the support”* (Sharon9-10) – and her perception that *“the gap could be filled using digital technology”* (Sharon16). Both Sam (U/D) and Carol (U/P) identify that there is certain information that is difficult, perhaps even impossible, to access through conventional healthcare. For Sam (U/D) this involved information surrounding the mental health concerns of his peers – *“this wasn’t something you could freely get information from your GP for, you know, in regards to someone else”* (Sam4) – whilst Carol (U/P) *“would never have known where to start to find NICE guidelines”* (C149) without the internet.

However, DMH is not able to provide an ideal service. Whilst it may be where people turn – Sandra (U) described it as a *“starting block”* (Sandra151) – it is also constructed as wrought with its own limitations. Jessie (U) and Sam (U/D) identify these as synonymous with the limited funding available, addressing the link between investment into DMH and their own willingness to rely on it for their mental health needs. Jessie (U) warns that *“you shouldn’t see it as the sole source of your support. Well I think if more funding goes into it then potentially one day it could be”* (J264-265) whilst Sam (U/D) feels *“if I’m going to invest time in trying to use digital to maintain my mental wellbeing I think things are going to have to be different to what they are. In terms of design and technology we are behind because of the funding”* (Sam334-

335). Potentially, these constraints are replications of those found offline. For instance, Jessie (U) addresses the variable access available to users of Big White Wall – *“you can use it so long as it’s available in your area but you can’t get therapy without a referral and without your CCG paying for it so there are quite a lot of hurdles”* (J263) – which presents a limitation that mirrors accessibility issues offline.

Participants are also concerned that DMH will be viewed as a cheap alternative – *“it could end up being a cheap alternative rather than enhancing that area... it could detract from it”* (Patricia191) – or even a solution that does not consider users – *“they were interested... because they knew they should be going into the digital market”* (Sharon222), *“there’s service drive for cCBT but that’s not the same as consumer drive”* (Sean201). Sean (U/D) feels that this may lead to solutions that are *“not utilising any of the possibilities of the technology”* (Sean106) and are thus beset by the same challenges as those that already exist. He views these problems arising when *“the system that caused the problem”* (Sean156) is viewed as the one that *“has the power to resolve the problem”* (Sean156) or when the solution is *“not a solution to any problem anyone has”* (Sean200). The points at which compromises are made demonstrate areas that require careful consideration so as to understand what potential remains and what leads to these challenges.

#### **8.2.4 Bridging Virtual and Real**

*“I’d just like something where I can record and store how I’m feeling that somebody else would be interested ... That I can go to my doctor and they’ll be able to access the information somehow. They’ll be able to look at it with me. You know, somebody else will care how I’m sort of feeling day-to-day and what the pattern is”* (A215)

Compromises may lead participants away from DMH back into offline services. However, this cycle of compromising can be constructed positively by participants and represent a process that ensures a connection between virtual and real mental health resources and services, *“a bridge between real life and the virtual world”* (RVW418), is maintained. This bridge may represent a symbiotic link between DMH and conventional mental health services. For instance, despite Carol (U/P) feeling that she *“didn’t get a lot of support”* (C176) offline in her role as carer once she was provided with support online she was able to recognise *“if I step back and [the person she cares for] gets worse the GP will do something”* (C180). Rita (U/P) and Sarah (U/D) both give examples of the real world impact of what they learned online. Rita (U/P) learned grounding tools with an app in the safety of her home – *“I actually sat with my phone, ok how do I do this breathing? And I did it in a quiet space which was my room”* (RVW323) – and then how she began *“applying it in the street”* (RVW325). Sarah (U/D) felt that opening up to people online helped her to prepare to open up offline, compared to the alternative of the *“first time you ever have to open up about it is at an assessment that’s really traumatic”* (Sarah97). In this way, what people do online may help them in what they do offline. This emphasises Rita’s (U/P) perception that *“technology is only the one solution”* (R501) and Jessie’s (U) opinion that it cannot be *“the sole source of support”* (J265). As Rita (U/P) explains, *“there’s room for technology but I strongly believe it needs to be linked back to reality”* (R515). For her this means accessing a therapist because *“a peer can only do so much”* (R531). Within the group she ran she compares *“the people who were not... applying it back to real life, they did not heal, they did not make any progress”* (R530) versus those who did who she felt *“have control instead of the illness controlling”* (R531) them. For those who do not establish a bridge from the virtual to the real Rita (U/P) feels *“they end up struggling so much and by themselves*

*and that's just as dangerous because if they're struggling alone and they become suicidal, then what?"* (RVW522). This demonstrates a constructed need for a bridge between the virtual and the real to mitigate the potential compromises that already exist within both.

### **8.2.5 Summary**

Compromising may be constructed as a heuristic strategy to overcome challenges. Some areas may require compromises to be made, particularly when expectations or needs are challenged. It brings together not only elements of categories present within the milieu but also within the experience, notably Freedom to Fail (section 7.2.). Analysis of the compromises made within DMH may be complex as certain components are dichotomous in nature and dependent on context or the individual as to their presentation. For instance, user experience may be constructed both as an important element of usability and as a manipulative aspect of technological use so that users must decide whether they are willing to compromise their control for a more usable product. Within mental health these aspects are even more significant considering the potential vulnerability of users. Likewise, system builders report making compromises, which are often linked to development and the concepts discussed within DMH as Product (section 6.2.). For both users and system builders the costs associated with use and development appear significant in decision-making. Compromising may be significant in the integration of DMH into mental healthcare, particularly in aspects of self-management.

### **8.3 The Experience of Digital Mental Health: Simulating Mental Health**

The experience of DMH brings together three categories – Freedom to Fail (section 7.2.), Seeing the Journey (section 7.3.), and People Like Me (section 7.4.) – which recognise and describe the constructed meaning behind the use and purpose of DMH resources for participants. An underlying process exists alongside these conceptual experiences that individuals seek, find,

and construct within DMH; this subsumes the experiences of both mental health and technology. In this way a process can encapsulate both the utilisation and application of technology specifically for a mental health purpose. The process described here, *Simulating Mental Health*, refers to the use of technology to represent and rehearse the experience of mental health itself. The abstract category of *Simulating Mental Health* brings concepts from within *The Experience of Digital Mental Health* (Chapter 7) to explore a process exerted by individuals when using technology to represent, support, and challenge their mental health. The concept of simulation describes the representation of a situation or process via another medium, particularly through a computer model. However, it is also known for its association with deception. A simulation is often represented as a pretence, although it can have different levels of fidelity. The introduction of the concept of simulation emphasises the role that DMH can play in depicting mental health whilst constructing it not through its overall accuracy but rather through its level of fidelity as defined by the individual utilising it. A simulation is important not for its precision but rather for its authority and purpose, as ascribed by its creators and users, and potentially the aptness of the technology itself. This category identifies several properties constructed by participants and aims to explore it from the perspective of experience rather than as an absolute. It aligns the experience as an important component and function of DMH.

### **8.3.1 The Simulated Connection**

For some participants keeping a record of how one feels can provide a simulated representation of moods over time that may enable them to feel more connected to their experience. As discussed in *Seeing the Journey* (section 7.3.), this can serve as a life story or a record which participants may use to claim ownership of their past experiences. It is important to recognise its role as a simulation, a representation rather than an exact record as it often lacks

contextual cues and is affected by the need for Continuation (section 7.3.1.1.). However, it does offer individuals a way to link their everyday experiences to their mental health. For instance, several participants discussed its role as a way of capturing and communicating their everyday lives “*in-between*” (J272, Sarah212, G89) the traditional mental healthcare context. Sarah (U/D) constructed it as a way to “*support myself between sessions*” (Sarah213), as opposed to “*when I was younger I’d go on forums in between therapist appointments because I needed support*” (Sarah213). It helps her “*keep an eye on how I’m doing*” (Sarah220) and feel “*more accountable about myself*” (Sarah218). This echoes Anne’s (U) feeling that tracking her moods is “*giving some sense of control to me rather than having other people... doing it*” (A200). Jessie (U) contrasts the email function in Moodscope, which allows her to instantly email her results to a nominated other, with the apparent lack of contact or interest from therapists in-between therapy sessions – “*a lot of them are very much like you have this session once a week, no contact in between*” (J272). Both see it as a “*starting point... when you do go to the session*” (J274) that means the “*therapist knows how I’m doing when I come in and see her*” (Sarah216). Being able to simulate their everyday experiences in this way is compared to the “*snapshot*” (J267) available to therapists, it is a use of DMH that “*you wouldn’t necessarily be able to do... in an offline kind of environment with a therapist but you can with an online tool*” (J268). Whilst “*it’s not therapy... it’s helpful in the sense that it monitors each day how you’re feeling in a way that you can’t... with therapy*” (J266) and, as Sarah (U/D) points out, a way to document “*any patterns... could it be my PMS or something like that I hadn’t even noticed*” (Sarah207-208). The simulation of what is experienced may act as a tangible connection between what is felt and what is represented.

### 8.3.2 The Simulated Experience

As addressed within the categories Seeing the Journey (section 7.3.) and People Like Me (section 7.4.), personal stories are often considered to have more value in that they can provide context and privileged information about the everyday experience of mental health. Constructed here as a simulation of experience it is necessary that the context is made explicit, not only within which the author is placed but also the potential contexts of readers. The concept of information or experiences that are “*firsthand*” (RVW465, R255, H108, Sandra123) arises in several interviews. For Sandra (U) it emphasises the familiarity of the speaker with the experience, not only advice from “*somebody who knows that it works*” (Sandra130) but also the way in which she is able to access as it delineates between information that is read and information that is communicated, in this instance through YouTube – “*it’s nice to sort of hear people talking... have it firsthand*” (Sandra122-123). Rita (U/P) feels that tours available within a virtual world can provide a more immersive experience, a way to “*experience somewhat firsthand what this experience may be like for someone with these types of illnesses*” (R255). Harold (U/P) feels that the virtual world can represent real world interactions quite closely – “*a firsthand meeting of people from other countries*” (H108). It may be a simulated experience where fidelity is ascribed by the consumer’s assessment of its impact and their affinity to it. For instance, Sarah (U/D) finds considerable difference between an academic representation of experience – it “*doesn’t feel like I’m reading about myself*” (Sarah178) – and someone’s personal story which she “*can relate to... a lot more*” (Sarah178). She constructs these as having “*the kind of human things that you want to know*” (Sarah179). Likewise, Rita (U/P) explains that for professionals “*unless they experience it firsthand they don’t understand how horrible these conditions are*” (RVW465). She describes the experience of a professional colleague who when

faced with their own mental health issues turned to Rita's (U/P) support group because she felt unable to grasp the experience itself – *“Here's a person that had paperwork, that had knowledge, that had information, and she couldn't even apply it to herself because she physically didn't know”* (R176). She related this to her own experience training as an Emergency Medical Technician being strapped onto a back board so as to *“know what our patient experiences”* (R178). There appears to be a constructed discrepancy between information and a simulated experience, for participants the simulation may allow for a more in-depth understanding. Carol (U/P) provides a suggestion as to what the difference may stem from. When describing the process through which she blogs, the presence of her audience is clear:

*“it actually made me think about how I had reacted to things... gave me a bit more understanding of... how I was feeling, what I was doing... cos' I was sort of looking at it from the people who might be reading its perspective which is slightly different from looking at it from your own perspective. So it gave me a bit more insight into... other people's perspective of what I was doing”* (C105-111)

Carol (U/P) appears to suggest that by exploring her experience not only from her own perspective but through a constructed viewpoint of others' perspectives she is able to gain further understanding of her self.

### **8.3.3 The Simulated Self**

The concept of the simulated self emphasises its constructed nature, of being able to create multiple personas and simulate various attributes or address different needs with them. Different participants use the simulated nature of self online in different ways. Sandra (U) can take on other people's names through simulated profiles, giving her the security to be more open – *“you get to be a bit more honest, I think, if you can hide behind somebody else's name”*



(Sandra84). This is linked to Anonymity (section 7.2.3) and Asking Silly Questions (section 7.4.2.1.) . Harold (U/P), when discussing avatars within Second Life, emphasises that “*even if I take a particular character or role, that is just an enhancement of who I really am*” (H48). This means that “*there is a person behind the avatar, you are really talking to that person*” (H47). Although the avatar may represent a version of oneself – “*that is them but is more than them*” (H78) – Harold (U/P) feels it is important to recognise “*that this is really you inside*” (H84). Within DMH one’s represented self may not be useful in terms of treatment. Rita (U/P) addresses this when discussing her avatar which is male and her perception that if he was treated it “*wouldn’t really get to the root of my issues*” (R512). Sam (U/D) views the persona that is constructed online as often “*an over-exaggerated caricature of ourselves*” (Sam185) whilst Jessie (U) notes:

*“people come across very differently online to how they are in real life and so someone could write something that could seem like they’re in a really terrible place but then perhaps they’re just trying to express something online but they’re not actually at risk even though what they’ve written sounds like they might be. But equally at the same time somebody could really be at risk but... that doesn’t come across in what they’ve written”* (J193-194).

The simulated self may represent one aspect of self and be a way to explore that without revealing other parts of self.

#### **8.3.4 Simulated Support**

This concept explores the constructed meaning of support, particularly when devoid of direct interactions with known others. Here Anne (U) is responding to my question about the impact of DMH on her life:

*“I suppose it is in a way support if you have an app... reminding you to take medication or whatever, it feels like a support even though it’s just an app... a bit of technology... I suppose without even really thinking about it, you know, recording my mood does help me... I hadn’t really thought about it... it feels like I’m helping myself and it makes up for the fact that I feel that if I’m having a bad day I haven’t got a lot of places to turn to... I suppose using technology, it could be more so but I have felt it a little bit, it kind of helps me feel more in control” (A192-195).*

DMH provides Anne (U) with somewhere to turn, a way of feeling more in control, and it enables a function that she believes can help. This is echoed by Jessie (U) who feels that apps provide a more immediate way to access support – *“if you’re really panicking... for the instant bit that really works it being an app... if you’re in the middle of a panic attack you can’t just be like oh let me find a computer and let me log on” (J304-305)*. Carol (U/P) too feels supported through her phone – *“if I’m on a train, maybe, and sometimes I get this overwhelming feeling... I can go on there and post something on the group and there’ll be somebody there because it’s worldwide... when you sort of stop things can often hit you” (C254-259)*.

Simulated support may also be offered by others through digital technologies. For example, both Rita (U/P) and Jessie (U) discuss virtual hugs. Rita (U/P) described a campaign that was started in Second Life in which people would band together to provide support for people that posted concerning posts by leaving them a heart on their profile – *“this person would get thousands of hearts and... most of those people would come back and say ‘wow, I can’t believe I matter. I can’t believe people care’” (R365)*. She equated this to a virtual hug, *“If people hug you and are like ‘hey I’m worried about you, concerned about you’, it’s the same thing” (R367)*. Jessie (U) discusses her use of an app called Mood Panda, which offers a social

component that enables others to provide virtual hugs in response to one's mood score. However, she did not construct this in the same way as Rita (U/P) – “*it just didn't feel very, like, genuine*” (J168) questioning “*what has changed there?*” (J171). The missing element may be Actionable Advice (section 7.4.2.), as in the campaign discussed by Rita (U/P) “*people would message them finally – here's the information, here's the resource*” (R366). The fidelity of the technology itself may also contribute to the impact that virtual support offered by others has. For instance, Jessie (U) finds the limitations of the support being offered – “*people didn't write reams and reams when they were trying to support somebody*” (J175) – meant that she constructed it as platitudes rather than genuinely helpful and supportive. This was compared to forums where “*there's more space... for people to offer their insights*” (J177). It was also problematic as it allowed people to remain anonymous, “*you didn't have to put your name or anything so... it didn't really change anything*” (J170). This demonstrates how individuals may be constructing the fidelity of the simulations they access in DMH.

### **8.3.5 Appreciation Through Simulation**

One constructed meaning of simulations was that of ‘appreciation’, the deeper understanding that could be communicated through them. For many participants it was key to the building of empathy in others. Some also spoke of their own use of DMH to understand mental health better. For instance, Sam (U/D) sought to understand his friends' eating disorders through searching online not only because “*normal areas of getting understanding are very difficult to engage with when it isn't something you personally have*” (Sam5) but also because “*the communities around either forums or blogs or YouTube... had a better understanding... kind of warts and all into how someone is dealing with life... it's the best way to understand*” (Sam6-12). Carol (U/P) too used online communities to better understand what the person she was

caring for was going through – *“to see what she might be looking at so I could sort of try and understand it a bit more from her perspective”* (C127). Rita (U/P) describes bringing a group to do the Virtual Hallucinations tour on Second Life where many were dismissive despite having experienced mental illness themselves, asking *“how bad can it be?”* (R208). Once they finished the tour, Rita (U/P) snaps her fingers, *“it sinks... they have some compassion”* (R217-218). For her *“because it’s not physical people can’t see, but when they experience it through a virtual world they’re like ‘wow... I can’t believe this is what people are going through’”* (R220). These examples show that simulations may offer individuals a way to gain a better understanding of mental health.

Participants also spoke of using DMH to offer further insight to professionals. Carol (U/P) emphasises the roles that simulations have in offering professionals access to *“what actually happens at home”* (C214) as those that seek out information from groups online gain a better understanding - *“The people that try and look outside the sort of clinic – we will see the patient for an hour – and come online actually get a better insight because they get a chance to see what it’s like from the patient’s perspective or the carer’s perspective”* (C219). Phillip (U/P) constructs the insight possible online as a rationale for why professionals may find an appreciation through simulation – *“patients... tend to talk more openly amongst themselves and can be more critical of the mental health profession and they’re more likely to rant and rave about what they’re going through”* (Phillip247-249). DMH can help *“health professionals who might not understand [mental health]”* (Phillip174).

Rita (U/P) feels that simulations offer professionals a way to *“relate to how bad it is”* (R193). She compares reading *“it in the book”* (RVW464) where *“they don’t understand it, there’s a lack of compassion and empathy”* (RVW468), to the understanding they get when *“they*

*experience it firsthand*” (RVW465). This is “*not just being able to put yourself in someone’s shoes, it’s about having compassion about what they experience*” (RVW469) so Rita (U/P) feels strongly that “*professionals should go through a simulation... they might start to understand it a bit more than just by reading*” (RVW481). When discussing what this understanding might entail she relates it to her experience of slowly beginning to apply coping skills to her daily life and the expectation of the therapist that it would be easy – “*they ask have you tried... going outside... and if you say no? They’ll automatically judge you*” (RVW479) – but for Rita (U/P) it is “*debilitating*” (RVW479) and she describes the process of “*opening up the door... am I going to face anxiety*” (RVW480). Through a deeper understanding gained through simulation Rita (U/P) anticipates that professionals will be able to comprehend these difficulties better.

### **8.3.6 Bridging Virtual and Real**

Harold (U/P) constructs Second Life as a place for people to practice, having the Freedom to Fail (section 7.2.), and a way of using their simulated self to understand themselves better before applying it to their real world selves – “*because of the anonymity on Second Life they tried it out, they practiced it and they gained a lot of confidence and a lot of feedback from other people. And they took that confidence and then translated it into real life*” (H66). These simulated selves offer individuals the potential to consider what is most important in their representations – “*I think that people very quickly gravitate to kind of that wishful dream – if I could remake myself in any image what would it be? And then live through that*” (H51). This he relates to the therapeutic practise of self-actualisation where people can question “*what is standing in the way of those potentials?*” (H59) and that “*people get an opportunity in Second Life to kind of try out those potentials*” (H60). In this way Harold (U/P) is constructing the simulated self as a process through which individuals can play with different aspects of

themselves, potentially using it to understand how others might react and respond to their disclosures and behaviours relating to mental health.

Simulations may form a bridge between the virtual and the real. Here, my own experiences with digital resources is important to consider. As addressed within Chapter 5, participants were interviewed in four different environments – Skype, Second Life, email, and face-to-face. These involved different experiences, connections, and representations of self. The face-to-face interview was conducted with David (D) in a windowless room, across a table on which sat a recording device. One comment made during the interview stood out for me – *“I always talk about walking into a room and I look at people’s shoes... and the people with the coolest shoes are the people I’ll want to talk to”* (D180). Whilst this comment over Skype would have aroused no particular thoughts, because I was sitting in a room with David (D) I began to wonder how my shoes were being judged and whether it might affect his willingness to open up within the interview. When conducting the interview through Second Life a similar interaction occurred. Rita (U/P) and I were discussing the marketplaces on Second Life where commodities such as clothing are available. She compared her own rather dapper grey suit to my generic avatar’s restricted clothing choice – *“one set of clothes... there’s not much variation and, I’m sorry, but they’re ugly right?”* (RVW94-96). Immediately, I was made aware of my presentation of self. Rita (U/P) had previously talked about the fear that came with exposure to real life, where those who are socially anxious use the Barrier of the Screen (section 7.2.4.) so they *“no longer have to think are they looking at me? Are they judging me? Are they... looking at my clothes...?”* (R82-84). Yet I felt that in the moment this barrier did little to protect me from questioning my choice of apparel. Whilst a barrier may be possible to construct I found myself acknowledging a bridge between the virtual and real that existed within my simulation of self. In

both the virtual and real world a comment about how people represented themselves had drawn my attention to my own representation and, in both instances, I continued the interview with a passing moment of unease. For me this suggests that the simulation requires a connection between the virtual and the real.

Throughout my tour of Second Life my responses to the environment were stronger than I had expected. A good example is my interaction with Rita (U/P) before and after the Virtual Hallucinations tour:

*RVW130: there was a time I came and it was very triggering.*

*Interviewer (RVW131): Really? But then I suppose it must be, like especially with your avatar that you've embodied for so long. To go through something, it must be totally different to, I mean I've embodied this avatar for very little time so it's not as connected to my sense of self really.*

...

*RVW165: Ok, so what did you think?*

*Interviewer (RVW166): That was, yeah... it's quite intense, isn't it?*

*RVW167: Now you've just said something prior. You haven't been in this body for so long so you may not be as immersed but even though you're not as immersed in the game you can still experience that right? It was still intense for you. So it shows how you don't have to be immersed in your avatar, this can still be educational...*

Rita (U/P) is here showing me that my initial expectations that there would be little impact were challenged by the intensity I felt during the simulated experience. Jessie (U) showed me Moodscope, demonstrating inputting her mood score where she chose to flip “a random one” (J106) when choosing cards, presumably to minimise time, and was faced with frustration when

it failed to work – “*it’s not letting me click on ones here so there’s clearly a problem with the website... it’s not working*” (J106-108). This drew her back to the reality of the resource, where she attributed its failure to the fact that “*there’s not a lot of funding going into it*” (J110). She has constructed Moodscope not just as providers of DMH but as a real-world company with associated challenges, demonstrating that the virtual and the real may be bridged through challenges in usability (see Compromising, section 8.2.).

### **8.3.7 Summary**

Participants spoke often about the time outside of mental healthcare – the time between therapist session and the everyday experience rather than that experienced within a healthcare context. This arose within the ‘silly questions’ that they wanted answered and the moments when they sought guidance for everyday problems. Within these moments participants live a life that they feel is unrecognised by the medical profession, or at least little understood. They are tasked with understanding – with recording and seeking out experiences that will help them make sense of their experience. They also construct DMH as offering those who care for them, clinicians and therapists along with system builders, a way to empathise with their experience. This, they feel, can lead to more effective and compassionate care and resources.

## **8.4 The Practice of Digital Mental Health: Finding What Works**

Previous categories have explored the variability of experience and complexity of the milieu within DMH. This final theoretical category proposes a model to represent and encapsulate it within the concept of a process that demonstrates its practice within the social world. Finding What Works represents not only the process through which resources are accessed and used but also the way that participants explore their own needs and mental health



using DMH. This theoretical category identifies the processes involved in the practice of DMH from the meaning participants construct in its use and application within an everyday context.

#### **8.4.1 Trying Different Things**

When asked what advice they would give to those considering using DMH resources, participants advised them to “*try lots of different things*” (A252). This was constructed in a number of ways. The following excerpt from my interview with Tom (D) illustrates these concepts:

*“try stuff out and see how it fits into your life. You should get any use from it, not everything suits everyone and the world is quite full of mental health apps at the moment so go and try stuff out and through doing that I think you probably learn more about what is useful or what you find a good experience to use. My own experiences with apps on my phone is I try, if I'm interested in something, try out a few things around it to get a sense of what actually is any good. Because there is stuff out there, it can be quite hard to decide what to use”* (T165-168)

Individuals explore the many DMH resources to find what fits with them personally and through this they may learn not only what constitutes a suitable resource but also what is useful for their own mental health needs. Tom (D) relates this to his own experience of apps more generally but it is certainly present within the interviews when participants are asked about DMH. Jessie (U) feels “*it is kind of about testing out different things and finding out what's right for you*” (J262) whilst Sarah (U/D) suggests that people “*shop around*” (Sarah413). Participants appear to give advice that emphasises the exploration of resources rather than providing examples or suggestions of specific use.

There are some key questions that become apparent as a result of this advice. If individuals are to seek out and find resources that are personally rather than broadly applicable,

this will likely require considerable energy. Patricia (A/C) talks about her own experience looking for apps that she could use as examples when developing:

*“there are tonnes and tonnes of apps out there but I don’t think it’s possible to determine very easily what they need to do, where to find them, it’s very hit and miss. It’s very sort of word-of-mouth or, if you go looking for something, it’s chance whether you land on one that’s any good or not. You kind of have to download it, have a look at it. It’s quite a lot of effort to invest to determine if it’s going to be any use to you. There isn’t really a straightforward cataloguing system that can outline it”* (Patricia112-116)

This constructs two challenges for those seeking DMH resources. One is the issue of finding them – and the energy required to try them – and the second is knowing which are of a high standard. This also appears to require being “*open-minded*” (J253, A253) and having “*a natural curiosity*” (N13). The application of DMH resources may be challenged as it was noted by participants that they are “*disposable*” (Sam240). Sean (U/D), in advising to “*try stuff and see if it works for you*” (Sean431) adds that “*if it does work for you keep going with it. If it doesn’t work for you opt out of it... most people vote with their feet*” (Sean431-435). David (D) reinforces this with his belief that “*if someone doesn’t like something they won’t come back*” (D200). This suggests that in Finding What Works individuals must engage for extended periods of time to heuristically assess whether a resource is of benefit. As Anne (U) identifies “*I think if I engaged more... with forums, I might find it a bit more helpful*” (A255). The importance of Ensuring Engagement (section 6.2.3.1.) is emphasised by users when considering the perseverance needed in assessing the impact of DMH use.

### 8.4.2 Struggling

Both Norman (U) and Jessie (U) construct the point at which individuals seek DMH resources to be one associated with distress. Norman (U) explains that *“seeking help through technology can be a distressing experience especially when it is the only support there is, and there is no one to offer any balance... Trying to find a way through the overwhelming amount of information is particularly difficult when the ‘seeker’ is unwell”* (N64-66) whilst Jessie (U) identifies that *“when people are struggling, and that’s when they’re gonna be accessing these things for the first time, you aren’t normally ‘oh I’m feeling really good I’m going to go look up mental health digital support’, you’ll be feeling really really bad and that’s why you’re accessing it”* (J282). Whilst some apps such as Moodscope are *“things you can use every day whether you’re struggling or not”* (J290) resources such as *“Big White Wall I wouldn’t sign into unless I was struggling”* (J291). This is supported by Sandra (U) who states that her use of DMH was through *“having episodes of bad mental health and then Googling things to do with it, just to look up things to help really”* (Sandra2-4). It is proposed that it is at the point of need, when the exertion involved to find is least welcome, that users will be engaged in exploring the resources available to them. Indeed, Sandra (U) discusses:

*“at the start when you really struggle, when I couldn’t find anything that was useful, it does make you feel quite isolated and then you can’t find somebody to talk to you but when you eventually sort of made headway, and actually realised there are things there for me, it had such a big impact on me... I think that pulled me out a lot more than even going to the doctors did”* (Sandra226-232)

These struggles are echoed by others. Patricia (A/C) states that she *“struggled to find a good example”* (Patricia144) whilst Anne (U) discusses the *“ongoing struggle... to find*

*something useful*” (A135). But it is important to note that Sandra’s (U) perseverance led to a satisfying resolution which she compares favourably even to conventional healthcare.

### **8.4.3 Searching**

The process of searching for resources, particularly at first, may be challenging. Norman (U) explains that not only is the action of searching unpredictable but that choosing and filtering the results can be a difficult process:

*“finding the websites that I have tried to use has always been by accident – the use of a search engine brings up thousands of sites and that is really overwhelming. Having found a particular website there is often another hurdle to overcome in trying to sift through everything in order to find something that is of particular relevance and that can resonate”* (N69-70)

Many others discuss the challenges they faced when first seeking DMH resources. George (U) felt he didn’t know where to begin – *“I’ve used a computer but I didn’t know the right place to look or how to look”* (G19). Anne (U) *“just looked on the app store and then it’s not specifically for mental health”* (A120). Rita (U/P) was unaware of apps until she found them advertised on Second Life – *“I learned about apps coming here... that’s how I started using apps”* (RVW362). Even Patricia (A/C) when seeking examples of apps from which to draw inspiration had difficulty and suggested it may *“have been that I lack the skills to do an effective search”* (Patricia145). Sandra (U) identifies that for her it was:

*“doing really broad searches and seeing what comes up and then eventually you start picking up the bits that work and then you go down those channels and find more and more stuff. That was the initial thing, was again finding the things in the first place, finding the information that was actually out there”* (Sandra141-147)

For Phillip (U/P) the process is similar – *“someone just tells you go Google it... that’s the first point of contact; just type in mental awareness into the Google browser and it just trawls through a vast array of different sites and different platforms to provide you with that information”* (Phillip497-503). Norman (U) relates how difficult this can be when *“it is available in huge quantities and that... is not necessarily a good thing, it requires enormous energy and patience just to sift through and find that which is relevant”* (N74).

For Phillip (U/P) it is a process of finding resources that are most relevant, not just through search but through asking others – *“I always try and find things that are most relevant for me... others would as well and they don’t just search, they ask and they go on forums and they’ll see countless posts on forums asking ‘where can I find information to help me tackle a particular subject in mental health’ and then some will say ‘well these are some sites you can use”* (Phillip569-575). This may be a useful way of identifying resources but necessitates that connections have already been made to individuals who can provide this advice. As Sandra (U) relates it can be difficult at those initial stages to even know what to look for. Thus the advice that participants shared was to persevere in searching. Sandra (U) advises *“keep searching because there is definitely something out there and it’s just a case of deciding what works for you and not being put off if you can’t necessarily see it on the surface. There’s so much out there and I think a lot of it is becoming a lot more visible... just keep looking”* (Sandra202-206). Sean (U/D) too feels that it requires perseverance – *“there’s stuff you try and then try a few times, that just doesn’t work for you. And that doesn’t necessarily mean there’s something wrong with you, it just doesn’t work for you”* (Sean447-448). However, the process of finding resources may be one associated with considerable disillusionment if faced with DMH resources that are unsuitable. This is discussed further in the next section.

#### 8.4.4 Engaging for the First Time

DMH was constructed by various participants as the first way that information and resources surrounding mental health are accessed. Jessie (U) feels “*that is the first thing... they go online*” (J208) and Sam (U/D) also sees it as “*the first place that they seek information or seek connection with anyone around mental health*” (Sam40). Jessie (U) explains why this might be – “*if you’re using a forum it might be that you don’t have anyone else to talk to about these things*” (J206). Sandra (U) echoes this when she describes her initial difficulties in finding information around mental health - “*then the hard bit was making that initial connection with people when you don’t want to talk to anybody, to actually find out about these things. It’s quite hard to start looking*” (Sandra25-26). This first experience may have considerable impact. As Sam (U/D) states:

*“I think our first impression of mental health treatment is probably the most important and how we see things in the future. If that’s a very shoddily put together CBT programme online because it was a free intervention, I think that could definitely have a negative impact on peoples’ help-seeking behaviour in the future”* (Sam358)

Similarly, Sarah (U/D) feels that the first experience of mental healthcare offline can have a significant impact:

*“you don’t know what’s going on, what you really don’t want actually is a medical professional in a maybe half an hour appointment telling you some big scary sounding words and talking about some acronym of a place you’ve never heard of and it’s all very formal... if that’s your first introduction to mental health services and mental health that is very scary. Whereas for me I felt like I went in prepared because... I had people help me”* (Sarah173-175)

She was prepared through her online interactions with people that could support her in Seeing the Journey (section 7.3.). Jessie (U) also feels that for “*someone who has experienced something for the first time and they log in and those interactions about what they’re experiencing could shape completely what they then do*” (J206). Sam (U/D) feels that “*it will taint how you seek help in the future*” (Sam105). This emphasises the importance of providing a suitable entry point via digital technologies. However, Sam (U/D) feels that information is geared towards those who may “*traditionally be referred to services or might have already had contact with services, just in terms of the language of it*” (Sam345) which may challenge people’s understanding. Jessie (U) also warns of the potential for a service to not be explicit enough in what it can offer, “*that right from the beginning people know what that service is about because... if you go into it thinking it’s one thing and you’re really struggling and then you find out that it’s not then that’s going to make things even worse*” (J283). If DMH is constructed as an entryway to help-seeking in mental health it is important, as noted by Jessie (U), that information is presented well but also, as emphasised by Sam (U/D), that their first experience of seeking help is positive.

#### **8.4.5 Guides**

Some of the participants proposed the use of guides. Norman (U) feels there are “*so many opinions so many different approaches and no one to help keep the focus*” (N22), and that “*to have someone guide and encourage would I believe have helped me enormously. To be self-taught is commendable but to have the experiences of other to guide... would be a better way*” (N49-50). Anne (U) would like “*something that was almost like approved of by the NHS, you know that the doctors would be interested in as well. Because I think I would probably be more encouraged to use something like that*” (A134). However, when I ask Sam (U/D) about strategies

that might help individuals in using DMH resources he stated *“I don’t think there’s any way of sorting it... any pathway to advice... there isn’t any kind of assured way of knowing what you’re doing is right. Because I think in general we don’t know what is right”* (Sam360-364). Some participants discuss the role apps play as guides. When comparing the Australian and American versions of PTSD Coach Rita (U/P) talks about how *“the Australian version actually guides you through breathing”* (RVW311) leading her to choose it over the American version. Another app she chooses to use is SAM – *“it’s very detailed... it guides me through breathing... it guides me to change my focus”* (RVW378). Anne (U) also suggests that apps *“could actually have a little character there who could say... who they are. We are this company... and we produced this to help you”* (A30).

Others were more successful through *“word-of-mouth”* (Patricia113), Sarah (U/D) found that *“other people’s experiences are a really good way of finding”* resources (Sarah416) whilst George (U) relates that *“I’ve found things useful and I’ve passed it on”* (G22). Sandra (U) too discusses how it has become easier to find DMH resources as she knows *“people who work in mental health... other people who have had experiences and then they’ve suggested things... so you start hearing about more”* (Sandra20-22). David (D) believes that decisions are now made by *“triangulating... formal reviews, expert opinions, and then relevant personal experience, and the closer the personal experience is to people you recognise the more you’re gonna go for it”* (D136-139). Patricia (A/C) too feels that choosing a resource is predicated on the experiences of others who have used it for a similar purpose *“because sometimes they are quite context defined”* (Patricia138). Users too discuss the importance of others in deciding to use a DMH resource, George (U) states *“I’ve found things useful and I’ve passed it on”* (G22). Sarah (U/D) felt that good reviews from others would incite more trust than professional appraisals, *“I would trust*



*something far more if five people had given it five stars and said this is great and this is why, rather than something that was top of the list and had the five-star evidence base” (Sarah257).*

This demonstrates not only the influence that ratings have over research (section 6.2.3.) but also illustrates how some individuals identify People Like Me (section 7.4.) as important in guiding them to resources that may ‘fit’ to their needs.

#### **8.4.6 Finding What ‘Fits’**

Sarah (U/D) notes the difficulty she has identifying an app that she perceives as ‘good’, despite having experience with “*such a range*” (Sarah247) – “*it’s really difficult to know which are the good ones, and I don’t mean that just clinically but I mean the ones that you actually want to use as a patient*” (Sarah247). Despite her encouragement that individuals “*shop around*” (Sarah413) and that “*you’re kind of an expert by experience so find something that works for you*” (Sarah414) she is still unsure of how to initially assess an app for quality. Anne (U) is challenged by the number of resources available – “*there’s almost too many things you can use... and it’s hard to know which is best*” (A128). Yet Carol (U/P) constructs the options available as enabling people to explore what works for them – accepting of potential differences – but also advises that individuals must persevere when they are faced with a DMH resource that does not work:

*“I would say dip your toe in to find what works for you because different things work for different people. And you can sort of just do a little bit and think well actually that doesn’t work and find something that does work, so just because one online media thing doesn’t work don’t dismiss it all because another one might work for you” (C343-346)*

Sean (U/D) warns of challenges to perseverance when apps do not work – “*that doesn’t necessarily mean there’s something wrong with you, it just doesn’t work for you*” (Sean448). So

long as individuals can recognise this, and are willing to persevere, it may lead to individuals seeking out and adopting resources that work for them personally. For some this perseverance is constructed positively. Rita (U/P) discusses how apps are *“to your preference. There's so many apps to choose from that you can search for what fits with you, with your lifestyle and with your mentality”* (RVW366) and that she *“would personally love to try them all”* (RVW369). She shares her process – *“when I downloaded [PTSD Coach] into my phone and saw that there was different versions I downloaded all versions”* (RVW358). She then *“went through all of them and found which one was best for me and then I keep only that one app that works for me”* (RVW372). This demonstrates a process of exploration within finding what fits.

In choosing resources there appears to be an intuitive process with regards the meaning of ‘fit’. Sarah (U/D) believes *“it’s about finding one that’s sticky for you”* (Sarah200). Rita (U/P) feels that DMH *“provides you with information and you apply what you feel resonates with you. There's no obligation to do anything”* (RVW556), echoing Sarah’s (U/D) use of ‘sticky’ with her use of ‘resonates’. This supports the concept of Ratings Over Research (section 6.2.3.), that individuals rely on their intuitive fit rather than more clinical assessment strategies. Again, the process of trying is emphasised but the changing nature of mental health needs is also recognised. Sarah (U/D) relates how she *“used to use a sleep tracker but then it started telling me what my sleep debt was at the end of the week and then I started getting anxious about how much sleep I was losing so I stopped with that one”* (Sarah198) showing that she is aware of the negative impact, which in turn led her to recognise that she tends *“to kind of use some sporadically”* (Sarah199). Anne (U) is also aware of the impact of resources on her mental health, noting that she questions *“is this gonna make me feel worse than I already feel today”* (A54) leading her to *“sort of feel suspicious”* (A52) of forums. Not only must resources fit to her

mental health needs but they must fit to her needs within that moment. For example, in her use of medication reminders – *“if I’m feeling a lot better I’ll just get a bit lax with it and that’s when I tend to put the reminders on. So I turn them on and off as I feel it’s appropriate. So you need an easy facility to be able to do that”* (A63-65). This echoes Sarah (U/D) and Jessie (U) who both refer to their use of DMH resources as changing dependent on different needs – *“I use different places for different things”* (Sarah308), *“they’re kind of different at different times”* (J292). This echoes the discussion in Changing Purpose (section 6.3.) and Continuation (section 7.3.1.1.) in which participants discuss the impact of mental health on use.

#### **8.4.7 Establishing an Ecosystem**

Both Carol (U/P) and Jessie (U) discuss being able to identify the types of resources, through use, that did not fit for them personally as a component of *“find(ing) what works for you best”* (C337). Carol (U/P) states *“the apps didn’t work for me and... some people find mental wellbeing apps really good”* (C338) whilst for Jessie (U) *“I tried forums... and that really wasn’t right for me... but then other people find forums really really helpful”* (J261-262). Even Anne (U) recognises the benefit *“that some things suit some people... but it won’t suit other people”* (A170) from her own experience of forums – *“I didn’t necessarily find it personally helpful to me... but I know it helps a lot of other people”* (A37-41). This acceptance of differences contrasts with the perception that the *“NHS seems to have developed a ‘one size fits all’ attitude to most mental health problems which does more harm than good”* (N15) but is challenged by the need to identify resources that work. As identified by Sandra (U), there may not be a single resource that is suitable for all the individual’s mental health needs – *“there are certainly so many different facets of how people can feel... that you can’t just say well here is a fix-all site go on there, because it is different for everybody and some people like to have general positive*

*messages all the time... whereas other people like to give other people a feeling of how they're feeling*" (Sandra208-213). Sarah (U/D) agrees – *"apps aren't one size fits all"* (Sarah232).

Indeed, these differences in what 'fits' is an important component of DMH.

Participants appear to construct two separate types of 'good' resources. They seek a DMH resource that can be a solution but they also seek a collection of resources that can be accessed when needed. Anne (U) relates how she would like to *"recommend one thing but I've yet to find something that's really worked for me consistently"* (A256) whilst many of the others express their frustration with not having found a single resource that can provide them with what they need. Carol (U/P) relates how, in reference to apps, she hasn't *"found anything like that that really works for"* her (C248). Sarah (U/D) too is *"not sure I've found the perfect thing for me yet"* (Sarah201). A single 'solution' may have alluded them but this does not mean that they are without a toolbox of resources that can support them in managing their mental health.

The type of use that appears to be constructed by participants as being currently satisfied is that of resources that fit into certain areas of their lives, a suite of apps *"that work with your life"* (Sean452). Sarah (U/D) relates how *"there might be apps that I use for individual purposes and there might be tools that I use in my everyday life to look after my wellbeing"* (Sarah245). Sean (U/D) uses *"a variety of different sites for a variety of different purposes and different points... It depends what's happening on that particular day and it depends what I'm doing"* (Sean214-215). Others support this type of use. Jessie (U) uses mood trackers *"every day whether you're struggling or not"* (J290) but for forums like *"Big White Wall I wouldn't sign [in] unless I was struggling"* (J291). Rita (U/P) returns to apps to relearn grounding techniques:

*“I usually use it when I need to go back and figure out what's a good grounding technique. Maybe breathing isn't working for me so I'll open it up and find other tools that I may have forgotten. Because there are so many tools you can use.”* (RVW341-344)

Sean (U/D) explains it when he says the following:

*“it's having a bash at stuff and not just limiting yourself to mental health stuff when you look at things that might be helpful. It's about working out how you use digital things and working out whether something works for you. It's like an ecosystem”* (Sean439-443)

This concept of an ecosystem emphasises the ways that individuals integrate various DMH tools into their lives, applying them dynamically to needs at different times and in different places.

However, it also challenges the use of DMH in isolation, which is discussed in the next section.

#### **8.4.8 Bridging Virtual and Real**

The ecosystem of DMH resources – a suite of apps and forums applied to different needs – may be constructed as a bridge between the virtual and the real. Participants report applying what they have learned online to real world contexts, as discussed within Bridging Virtual and Real (section 8.3.6.). When individuals use a DMH resource it becomes a component of their self-management ecosystem. However, this does not just include DMH resources but is rather part of a much wider support system. Anne (U) feels the ideal resource would be *“like a lifestyle management thing, just something to help with daily life”* (A221) and further clarifies *“that it could be... not the main support in your life because it wouldn't replace people but just it could be that sort of completely... not a judgemental thing, it's not difficult”* (A226). Similarly, Rita (U/P) believes *“there's a therapeutic aspect to professional psychologists... I kind of think technology is only the one solution”* (R501). Jessie (U) also views DMH as something other than therapy – *“it's not therapy but it's helpful in the sense that it monitors each day how you're*

*feeling in a way that you can't be with therapy*" (J266). Sarah (U/D) constructs DMH as aiding professionals, it *"makes their patients realise that treatment and getting better is not just the hour a week in a room with them. That's the backup, that's the clinical backup but actually it's you that's got to make the change"* (Sarah291). Jessie (U) states *"I don't think you can use it as a sole source of support, it's more something to back up whatever you're doing like outside... offline"* (J265) whilst for Phillip (U/P) *"social media is to support what I'm doing outside"* (Phillip169). Norman (U) struggled using DMH – *"having tried to use technology as therapy I feel it is extremely difficult"* (N62) – and yet feels it has a role *"as an aid, a resource to enhance and supplement"* (N63). Participants felt that DMH was integral to their daily lives but still recognised the importance of other forms of support in self-managing their mental health.

DMH is constructed as a way to support self-management alongside other types of care. It provides options, an important component within recovery, and yet is unable to provide a clear way of assessing those options. It is constructed as supporting change yet requires self-motivation. It is a supplement that may provide *"other ways of helping [people] look after their health"* (A144). It enables *"lots of different paths to the same outcome depending on your preference"* (Sean360). But without the bridge to real mental healthcare, to professionals who can help guide and support, it appears to fall short. Rita (U/P) strongly believes *"there's room for technology but... it needs to be linked back to reality"* (R515). Whilst there are challenges within conventional mental healthcare it does appear that DMH may offer tools that support individuals not only in their daily lives but also in their interactions with professionals.

#### **8.4.9 Summary**

Finding What Works is presented below as a model that integrates several categories together in a complex process illustrating how individuals autonomously practice DMH 'in the

wild'. This category has addressed the processes through which individuals integrate and apply DMH to their everyday lives, constructing it from participant's recollections of their initial use through to their existing. It integrates meaning from both user and system builder perspectives to identify and give voice to the challenges as well as the successes. Constructing the process of Finding What Works within DMH not only aligns the various categories within a model of use, as shown in Figure 53, but also identifies heuristic strategies that users and system builders apply to ensure that resources that personally fit are adopted.

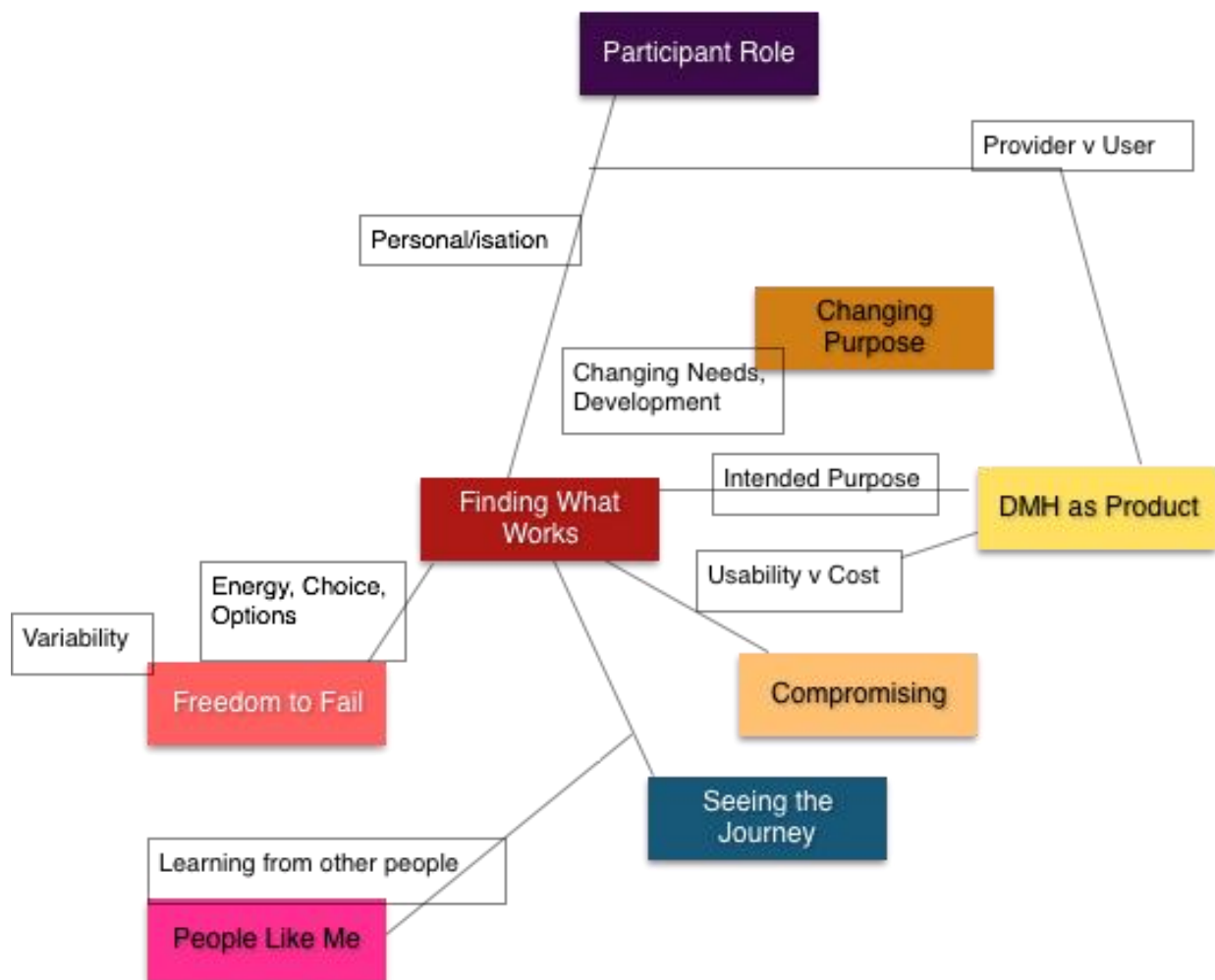


Figure 53. Model showing interrelationship of categories within Finding What Works.

## **8.5 Overview**

This chapter brings together the categories that relate to the practice of DMH within everyday life and the constructed meaning of how it is applied. Compromising (section 8.2.) identifies the difficult interplay of needs and demands within both actors and actants that co-exist within DMH. Simulating Mental Health (section 8.3.) constructs the representative nature of DMH as enabling different mental health needs to be met. Finally, Finding What Works (section 8.4.) brings together the categories into a process that encompasses DMH as a toolkit or ecosystem that can support individuals in self-managing their mental health. Throughout these theoretical categories the concept of a bridge between the virtual and the real, between what is represented and the representation, demonstrates the importance of not viewing DMH in isolation but rather constructing it as part of a system. People do not construct meaning in DMH separately from their mental health experience.



## **9 Discussion and Recommendations**

### **9.1 Introduction**

This study has focused on the meanings that are constructed through the application of DMH within everyday life. It explored the meanings not only of those using but also those involved in development and research. These actors, that participate in broad substantive yet related areas, are representatives of their social worlds yet also engage with DMH in roles that shift, reorganise and realign (Clarke & Star, 2007). This is important to recognise as it accepts the fluidity of roles within the present study as an aspect of the complexity that is inherent to the arena in which DMH social worlds co-exist and interact.

The structure of the discussion chapter closely follows that of Chapters 5, 6, 7 and 8. This is done so that the reader can more easily reference back to these chapters and clearly link the results to the discussion. It will address the roles within which participants were constructed and the importance of recognising the position of system builders within DMH research. Findings constructed within the categories of the milieu, the experience and the practice of DMH are discussed with reference to present research. Finally, recommendations are made. In particular, the future of DMH is anticipated and an abstract concept constructed from the categories within this study. Technology-as-advocate is an abstract idea – the beginnings of a theory – that can help support the application and practice of DMH. The limitations of this study are also discussed clearly and concisely.

### **9.2 Participant Roles**

When Timmermans and Berg (2003) explored the concept of ‘technology-in-practice’ it was to include technology as a component within the networks of healthcare treatment with emphasis on the importance of development and implementation. Approaching and including

system builders within sociological research is highlighted as important as an area of future relevance (Timmermans & Berg, 2003), demonstrating considerable overlap between the Social Worlds Framework (Clarke & Star, 2007) and the perspective of technology-in-practice (Timmermans & Berg, 2003). This study is novel in its inclusion of multiple roles, including system builders, to explore constructed meaning in DMH.

### **9.2.1 Roles**

The Social Worlds Framework addresses not only those actors or actants that are present but also those that are implicated (Clarke & Star, 2007). For instance, system builders may develop for an imagined user or users may position system builders as implicated actors. Rather than configuring users and system builders, I attempted to construct roles alongside participants. This led to roles that encompass the meaning that participants have as representatives of subworlds to which they feel they belong, but also recognises the potential for these roles to shift.

#### **9.2.1.1 Users**

Users are often involved in development, implementation and research, however their influence is variable. The role of user has been conceptualised in various ways within digital mental health research. These include:

- Potential users, usually individuals identified as having a specific mental health condition (e.g. bipolar disorder; Todd, Jones, & Lobban, 2013)
- Participants recruited to use a specific resource (e.g. in RCTs; Gilbody et al., 2015)
- End users, usually framed by developers or researchers as the ideal user (e.g. I-methodology; Vennik, Adams, & Putters, 2015)

However, there are interesting concepts within digital health that begin to expand these roles to recognise the autonomous nature of ‘consumers’. Deborah Lupton has sought to recognise these digitally engaged patients within the structure of the patient role, where there is constructed pressure from healthcare providers to engage in self-care (Lupton, 2013). This demonstrates additional constraints within their roles that may be difficult for system builders to configure.

Within this study, participants constructed as users demonstrated their active participation within both development and use. They provided novel applications for existing resources, demonstrating support for what Lindsay (2005) has termed their ‘ontogenetic’ role. It is also important to consider the role of User/Providers in future research, as they appear able to offer insights into the complexity of use from a moderator or advisor role that can contribute to the understanding of DMH in an everyday context.

#### ***9.2.1.2 System Builders***

System builders, although influential throughout use, often inhabit an implicated role in research. The role of system builder within the literature appears often to be constructed as entirely external (Proudfoot et al., 2003), unfamiliar to collaboration (Bergin, 2015; Topham et al., 2015) or to be framed within the construct of their users (Martin & Barnett, 2012; Money et al., 2011). System builders are an important component within DMH research. They are considered to have a central role (Woolgar, 1994) and, indeed, this was supported within the findings. However, despite their conceptual significance in the construction of meaning their position was not salient among users. Instead their role was very much as an implicated actor (Clarke & Star, 2007), not always voiced but often referred to obliquely when users faced challenges. Some of these, particularly usability issues, may be constructed through the ways that users are configured and through the pressures and problems that they face. It is unlikely that

without giving voice to those creating, marketing, and implementing DMH resources that its true potential could be achieved.

Within this study system builders were given a voice and contributed not only to their own construction but to that of the experiences surrounding the use of DMH. Academic/Contractors were reflective of the participants within Proudfoot et al. (2003) and Topham et al. (2015) and demonstrated the conflicts that can arise when cooperation is needed between technical and clinical paradigms. System builders also discussed the need for financial stability over an extended period of time, which has implications not only for use of DMH but also for research. Finally, the role of User/Developer echoed Clarke and Star's (2007) 'entrepreneurs', individuals who are deeply committed and active within a social world. These participants aligned the technical and clinical paradigms to the everyday practice of DMH and constructed rich and in-depth meaning around their experiences. In future research and development, the potential conflicts within the different roles of system builders and the richness of data from those immersed in the field are posited to be important considerations.

### **9.3 The Milieu of DMH**

The milieu of DMH refers to the overlapping boundaries of subworlds that interact, converge and diverge to produce meaning. It positions the contextual aspects of constructing DMH as a product that is given complexity through its changeability by and through use.

#### **9.3.1 DMH as Product**

In constructing DMH as a product, the challenges faced by system builders are recognised and their meanings help to co-construct its benefits and limitations alongside those of users.

### 9.3.1.1 *Human Interoperability*

Co-production is important within research addressing the use of technology in medical contexts (Gulliksen et al., 2003; Martin & Barnett, 2012; Shah & Robinson, 2007). The concept of Human Interoperability was constructed to recognise the broader implications of the need for stakeholders and technological systems to cooperate and coexist within multiple social worlds.

This was constructed through two main concepts:

- Conflicting Paradigms (section 6.2.1.)
- Involving Stakeholders (section 6.2.2.)

The insights of both system builders and users within the construction of meaning that surrounds co-production were sought within this study. As within the reviewed research, where Proudfoot et al. (2003) presented their experience as Academic/Contractors, there appeared the concept of ‘conflicting paradigms’. This addressed a lack of cohesion between the technical and clinical paradigms necessary to produce DMH resources. Developers constructed the conflict as one surrounding resource needs so that involvement of stakeholders was dependent on the resources available to them (also see The Interminable Product, section 9.3.1.2.). This is also recognised within the literature (Money et al., 2011; Shah & Robinson, 2007). For Academic/Contractors, the commercial nature of developers presented a challenge as they felt that the “*potential pitfalls*” (Patricia99) were not communicated to them as they were not “*incentivised*” (Sharon197) to do so. There remains a gap in technological research as to the impact of technological functions on mental health, whilst in health research there remains a gap in comprehending the complexity of translating practice into digital formats. This may lead to stakeholders remaining within their own fields rather than seeking to bridge the professions in a meaningful way. There is a need to understand these conflicting paradigms in more detail and to

consider the construction of relationships between and within the various disciplines that must be negotiated throughout development. User/Developers constructed meaning as a paradigmatic synchronicity, recognising the need to understand DMH as a system that integrates several knowledge-bases that are all essential. By involving stakeholders and encouraging cross-disciplinary co-production the impact of resources is considered not just within use but as an element of a system, which can potentially improve the application and implementation of resources. It is through these processes that innovations occur.

### ***9.3.1.2 The Interminable Product***

The Interminable Product is a concept related to the need for DMH resources to be maintained over time, requiring a sustainable business plan and with particular consideration of the reliance on resources that individuals with mental health needs may have. A product within DMH does not often stand alone. Various devices are used to access DMH resources and by necessity system builders must ensure they are kept updated, a requirement not only of the device manufacturers but also of operating systems and their security. Users must also be aware of the need to update, and be capable of doing so. As a result, DMH resources may fail, whether due to difficulties maintaining the product or through a significant change in the capacity of devices. Sustainability is an important concept that must be recognised within DMH research, particularly as it also relates to resources that have been created through academic research and disseminated.

The low cost of DMH is often cited as a facilitator to its use (Horgan & Sweeney, 2010; Proudfoot et al., 2010). Participants discussed their use of free apps as Supporting Agency (section 7.2.2.1.) and as an element of User Compromises (section 8.2.2.). Participants, particularly system builders, were conscious of their limited resources and this need for

sustainability potentially impacts the experiences and perceptions of users. If a product is not maintained the user may be faced with a DMH resource that no longer works, due to bugs or a failure to update. For users who are reliant on a product, or who may use it to track sensitive information, this aspect has the potential to cause considerable distress. This is an area that appeared to be little discussed within the literature, perhaps because the majority of resources were developed and sustained throughout the research trial. An app reported as downloadable from the app store and no longer available (BinDhim et al., 2015; no longer available on UK App Store as of 23.03.16), demonstrates that even for researchers there may be a failure to sustain products past the initial development and research cycle. This appears – for the participants in this small study – to be as a result of limited resources, particularly ongoing funding. The concern that users feel towards the continuation of resources may be a considerable barrier to DMH resource use and reliance for mental health self-management. Another side to this dilemma is that of users and the devices that they access resources through, some of which may be relatively outdated. Considering the cost of devices, which may be inaccessible to some, and the need to update operating systems for security reasons, there must be more discussions surrounding the ethical quandaries of providing DMH resources to users within unsustainable business practices. In countries where healthcare is provided free or is subsidised there may be a need for evidence-based DMH organisations to be financially supported in their provision so as to ensure that users have access to low-cost or free resources that are effective and likely to be maintained over time.

### ***9.3.1.3 Ratings Over Research***

As addressed within [The Interminable Product](#) (section 9.3.1.2.) there is a need to ensure sustainability in DMH. Participants appeared to equate this to a drive towards acceptability over

effectiveness, whereby the commercial nature of products led to resources prioritising consumer engagement. Likewise, consumers may be unsure how to assess the effectiveness of resources prior to use and instead consider their engagement as an indicator of such. As identified in previous research developers may construct those who purchase their resources as consumers even when they are not the end users (Money et al., 2011; Shluzas et al., 2011). This creates a rift for commercial system builders between appealing to a user, which may be more associated with the design of a resource, and to healthcare professionals who place more value on clinical efficacy. A resource that remains unused, even when clinically effective, is not one of value. A problem arises when funding is sought through clinical arenas that emphasise the need for efficacy but may not recognise the impact that usability and design can have on use. Mental health conditions bring a range of motivational difficulties (Barrett et al., 2008; Nicholas et al., 2010; Stjernsward et al., 2012), as does human nature, that must be accounted for when considering use. This demonstrates the need for DMH resources to be clinically rigorous whilst remaining usable.

Within conventional mental healthcare systems professionals recognise the clinical need for evidence and develop criteria for decisions based on their clinical knowledge and understanding of the integration of technologies into existing pathways of care. However, DMH is a complex marketplace in which end users with autonomous access to resources may rely on heuristic assessments of value for personal use. DMH resources may be influenced by several factors that have the potential to impact on whether they are subjected to rigorous research. There may be uncertainty for system builders as to what evidence is needed or how technically capable the end users will be. The source of funding may lead to resources prioritising certain functions, for instance if funding is provided for social impact this will be the measure of success



(Bergin, 2014). It is also important to consider the speed of technological development. Long RCT processes can delay dissemination of evidence-based apps whilst those that are commercially produced are able to go to market sooner and utilise the research as proof of efficacy. These challenges have significant impact on users who are faced with large numbers of DMH resources from which to choose (IMS Institute for Healthcare Informatics, 2015; Research2Guidance, 2016) and it may lead to a marketplace that prioritises ratings over research.

#### **9.3.1.4 Summary**

In summary, DMH as Product reflects the constructed meaning that surrounds the positioning of DMH within a system of need that acknowledges that when resources fail, users are failed. People must work together to support each other and the sustainability of resources over time. Users rely on the whole system to work – from devices all the way to the effectiveness of a resource – particularly when risk is constructed as part of innovation. By constructing DMH as a product the link is made between the consumer and the producer, and the need for Human Interoperability is made salient. The Interminable Product emphasises the needs of both users and system builders as connected to the continuation of resources. Finally, Ratings Over Research presents a potential challenge within the future of DMH wherein the commercial-nature of resources is prioritised over the establishment of evidence due to users' prioritisation of ratings or usability and system builders' economic response to this.

#### **9.3.2 Changing Purpose**

The category of Changing Purpose constructs DMH resources and their use as evolving in meaning and adapting, or being adapted to, existing and expected needs. This study focused on change as a component of system builder and user interactions with technology and so the findings are restricted to these subworlds. However, the role of technology within change is also

discussed and emphasises the complexity of “technology-in-practice” (Timmermans & Berg, 2003) wherein actors and actants (such as devices) influence meaning. Thus the interpretative flexibility (Bijker et al., 1994) of DMH resources is acknowledged and incorporated into its understanding.

### ***9.3.2.1 The User and Changing Purpose***

Purpose is fluid within DMH. There appears in the experience of users to be movement between and within different resources as they construct different meaning in response to changes of function and purpose as ascribed by system builders. Whilst the parallel of users influencing the resource’s development is not clearly apparent within this study, and could actually be considered absent past initial stages, they are certainly involved in utilising resources in novel ways. These changes, instigated by users to adapt functions to their needs, appears to disrupt the intended purpose of DMH resources. Within Science, Technology and Society studies, researchers recognise the ontogenetic role of users – their capacity to appropriate and reconstruct technologies (Lindsay, 2005). Researchers of new digital technologies recognise the fluid and diverging ways that users can appropriate the same technologies to personal needs and present contexts (Barkhuus & Polichar 2011) – the interpretative flexibility of technology (Pinch & Bijker, 1994). This echoes the concept of ‘making-do’ proposed by de Certeau (1988). Many users in DMH research consider personalisation an important component of resources valued as engaging (Bendelin et al., 2011; Gerhards et al., 2011; Lal & Adair, 2014; Schrank et al., 2010) supporting the experiences of participants in this study who often reported making changes to the resources they used. For system builders in mental health this may cause concern as the structured and expected use, the ‘intended use’, may be disrupted by the user. This opacity is a further issue as system builders will likely be unaware of how users have adapted their resources.

Adaptation as reported by participants within this study also suggests that users may at times alter the use of certain resources that do not have a primary mental health purpose to fit within their self-management. It may be that these uses are no different whether they are for mental health or for their original purpose. For instance, a calendar's purpose as a reminder may be applied to tracking moods or for appointments. However, other adaptations may be specific to a mental health condition. One such instance, discussed by participants, is the use of calorie counters by those with eating disorders. This conflict of purpose as ascribed by user may be unanticipated by system builders until the resource has been disseminated for some time. Whilst they may be able to make changes through updates it is unlikely that the necessary changes to mitigate that risk will be clear. Involvement of stakeholders throughout development and implementation may help to account for unintended use and adaptation (see Human Interoperability, section 9.3.1.1.).

Participants reported that their previous experience at times affected their use and perception of DMH resources, suggesting that the construction of meaning is fluid and influenced by both use and the user. Along with perceptions and purpose, resources may also appear to change over time when new types are developed or they may alter how they are presented. These concepts were not recognised within existing research. Another area that needs further investigation is the impact that context has on the effectiveness of DMH resources. When these are accessible on the go, whether on a bus or a train, the impact on its effectiveness is little understood. There may also be privacy issues, for instance when health data is accessed through public Wi-Fi. Another aspect that may alter the effectiveness of a resource is the device through which it is accessed. Participants discussed the differences they had found between the same platform available through a browser or through a smartphone, and questioned whether the

reduced functions within the app could impact its effectiveness. Although the concept of access anywhere and at any time is reported within the literature (Bradley et al., 2012; Lillevoll, Vangberg, Griffiths, Waterloo, & Eisemann, 2014; Pretorius et al., 2010), recognition that the situation in which someone accesses a resource may influence its use is not yet part of the research. Future research must consider not only the ways that users can adapt resources but also how the context of use, whether changes in device or environ, can alter and influence the constructed purpose of DMH resources.

### ***9.3.2.2 System Builders and Changing Purpose***

Many of the system builders within this study were aware of the potential for user adaptation, and some were concerned about the unintended consequences of use. The literature has demonstrated that resources can be developed for a constructed user but produce a resource with very different meaning for the actual user (Livingstone, 2007). Adaptation (section 6.3.1.1.) and Changing Resources and Needs (section 6.3.1.2.) are concepts that recognise the potential for users to reconstruct purpose, not just reinterpret the information that is presented. Technology itself, through contextual factors, may also play a role in reconstructing meaning. System builders must decide whether to mitigate these factors without bowdlerising their resource and are faced with technologies that are difficult to ‘sanitise’. For instance, although it is possible to place an age limit on an app it is very difficult to ensure that children do not have access.

System builders may also exert more control in Changing Purpose. Throughout the development lifecycle, dissemination, and even once downloaded, system builders can update and alter their products. When change occurs before dissemination the process may be reconstructed as a way of understanding the resource’s position within a suitable environment, system or care pathway. Participants discuss changes made once a product has been disseminated

as a response to users and to perceived gaps or issues within the resource. However, it is unclear whether these users are actual or configured (Oudshoorn & Pinch, 2005; Woolgar, 1990), with the potential that system builders are tempted to respond to market forces and be influenced by resource limitations (see DMH as Product, section 9.3.1.). Even when responding to users there is a complexity in adaptations, made by system builders, to both individual and technological needs. These are changes that seek to respond to, rather than disrupt, use and yet may be limited to the perceived needs of users as constructed by system builders and may not be sought by all users. These transitional moments are an important area for further study to explore users' responses to changes within existing resources.

### ***9.3.2.3 Divergence in Consumer Experience***

System builders may construct their DMH resources differently to their users, creating a potential divergence between the expectations of users and their experience, between developers and its use, and finally between the user and the developer. For instance, Facebook users agree to the platform's terms and conditions and so it can conduct research without asking for explicit consent as it is a commercial entity (Guillory et al., 2014; Kramer et al., 2014). Yet users of Facebook are unaware that it is both a social network and, apparently, a source of research data for the emotional contagion effect. At times developers may attempt to guide users through resources, which may be viewed as restrictive (see also Guides, section 9.5.3.5.). There appears to be frustration among potential users when access is limited, e.g. through pay walls. What effect this has on adherence and perception, considering The User and Changing Purpose (section 9.3.2.1.), is an area in need of further research. The knowledge gap and hardware bias discussed within the literature review may also lead to expectations being challenged

surrounding the purpose and use of DMH resources (see [Inequalities in Accessibility](#), section 2.7.1.1.1.).

The presentation of resources is important for several reasons. System Builders may exaggerate its potential due to [Ratings Over Research](#) (section 9.3.1.3.), feeling there is a need to be attractive to consumers. If resources are not presented transparently it may cause distress for users who are faced with a product that they have invested in that may not be able to offer what has been promised. There is a potential return to ‘quackery’, where resources are marketed fraudulently as evidence-based or effective. This also illustrates the difficulties associated with selling to different stakeholders, as addressed within [DMH as Product](#) (section 9.3.1.). If the consumer is being disrupted the sustainability of a product may be challenged. By presenting the resource as a component within a current service its potential may be restricted, by exaggerating or undermining what is possible. Users are challenged by divergences including within devices and the resources themselves. There appears to be a dislike of generic information, which for many feels irrelevant (see [Seeing the Journey](#), section 9.4.2.) even though it is recognised that it is necessary to at times sanitise apps due to unintended consequences. But through doing so it potentially limits the engagement that individuals feel to the resource. The building of trust through satisfaction of expectations appears to be a more successful strategy for system builders to adopt.

#### **9.3.2.4 *Change as Purpose***

Many of the participants were accepting of change and constructed it within the purpose of technology as a whole. Whilst it did mean that they were faced with challenges they also saw the changeable nature of DMH as positive. For instance, change has led to more resources becoming available. It is also an aspect of the literature, the interpretative flexibility of

technology (Bauchspies et al., 2006; Bijker, 1994). Users and system builders alike are aware of the fluctuating meaning around DMH, relating how they adapt and mitigate. Technology is constructed as changing over time, which aligns to the ways in which people change so that, within mental health, the individual's present needs are satisfied through use of DMH that is adaptable.

### **9.3.2.5 Summary**

Technology can be understood not only as a bridge or boundary object (Clarke & Star, 2007) between system builders and users – one that can bring together either convergences or divergences of expectations – but also as an actant in itself. Not only can developers and device manufacturers change software remotely through digital means but users too can be faced with changes instigated by themselves, possibly through mistakes, and even apparently by the technology itself if issues such as bugs are to be understood as such. Change comes from the individual also through their use or their evolving needs and must be recognised as inherent to human nature. It is a complexity that must be understood within DMH research to a greater extent as it has the potential to disrupt much of what is accepted knowledge in conventional treatment. Regulations within DMH remain at an embryonic stage, although in recent years there have been numerous high profile attempts to establish guidelines that can account for the complexity of both technology and mental health. However, this has proven difficult. For example, the FDA published guidelines that differentiated health apps from wellbeing apps, which would not be regulated (Food and Drug Administration, 2015). It is my understanding that a considerable challenge lies in the use of the term 'intended use or purpose', which attempts to limit the use of resources to that marketed and presented by system builders. The category of Changing Purpose constructs DMH resources and their use as evolving in meaning and adapting,

or being adapted to, existing and expected needs. This study focused on change as a component of system builder and user interactions with technology and so the findings are restricted to these subworlds. However, the role of technology within change is also discussed and emphasises the complexity of “technology-in-practice” (Timmermans & Berg, 2003) wherein actors and actants (such as devices) influence meaning. By recognising this the purpose of DMH resources is viewed as transformative and thus challenges the view that DMH is static and/or predictable in its application.

## **9.4 The Experience of DMH**

This section addresses the constructed categories that surround the experience of DMH as a component within one’s everyday life. It recognises participants’ autonomous use and the constructed meaning which they find within their appropriation of DMH.

### **9.4.1 Freedom to Fail**

There are two underlying constructs within the category of Freedom to Fail that must be understood in the context of DMH, that of autonomy and agency. The research suggests that technology may be a way to exercise control within mental health; choosing how, when and where to get help as well as who to tell (Cheek et al., 2014). The latter part is discussed within People Like Me (section 9.4.3.). The capacity to exercise control over one’s mental health through choice appears to be inherent to the category of Freedom to Fail, which is constructed around the individual’s feelings not only of control through their autonomous usage but also through the agency they can exercise with access to a variety of options. This alleviates the pressure surrounding their choices and enables them to explore what might best work for them. This links the category Freedom to Fail to Finding What Works (section 9.5.3). It also addresses



the concept of the Barrier of the Screen (section 9.4.1.4.), a reconstruction and reinterpretation of the meaning behind anonymity as addressed by participants within this study.

#### **9.4.1.1 *Autonomy***

Autonomy is constructed within this study as the capacity to control and direct one's own use and experience of DMH, including their mental health more generally. Some research suggests that digital technology provision may challenge the individual's perception of control over the self-management of their own mental healthcare and their identity as independent (Sanders et al., 2012). Whether the responsibility of self-management is constructed as supported may be of importance within DMH as users of cCBT have constructed it as both enforcing autonomy and providing control (Knowles et al., 2014). Whilst in conventional mental healthcare the narrative often surrounds concepts such as empowerment and active patients (Coulter, 2002; Vermeulen et al., 2014), the experience within DMH is affected by its remote accessibility and minimal professional involvement. The impact this has potentially reconstructs these concepts within the experiences of users and system builders alike. Many of the participants compared DMH favourably to offline experiences with regards their autonomy, discussing the expectations and obligations they felt to manage their mental health in conventional services. Online appeared to be constructed as a place that enabled autonomy but also allowed for more control, thus negating the disadvantages associated with the responsibility of taking care of one's mental health. It is important to note that participants perceived professionals as having an expectation of them to retain responsibility for their own mental health. DMH is accessible and engaged with at one's own pace, and this is proposed to foster a feeling of control over involvement within the literature (Pretorius et al., 2010; Rennick-Egglestone et al., 2016).

Additionally, participants appear to wish to keep relationships with family and friends free of a feeling of responsibility. The role of family and friends was discussed within the literature and posited to be supportive of recovery and use (McClay et al., 2013; Wilhelmsen et al., 2013). However, research also suggests individuals have a desire to avoid reliance on, or feeling like a burden to, others as well as wanting to maintain secrecy around their condition (Drake et al., 2013; McClay et al., 2013; Pretorius et al., 2010). The perceptions of the small group of participants within this study mainly echoed a desire to separate their mental health needs from their interactions with known others. Within the literature review wanting to help oneself was constructed as a barrier to help-seeking and was reported amongst many of those with mental health conditions (Andrade et al., 2014). Participants reported being able to use DMH to enable them to feel that they were in control; to use it to support themselves and to avoid relying on others. It may be that instead of DMH encouraging people to take care of themselves away from conventional services it is a tool with which they can alleviate some of the associated pressures.

Control was constructed as having the authority to make decisions, even when in areas that are challenging to understand. Participants often discussed the concept of control with regards to privacy. Within the literature the concept of managing one's privacy was perceived as an aspect of controlling one's mental health (Bradley et al., 2012) which supports its role in this study. Privacy can be controlled by participants through understanding the settings on various platforms or resources but also through control over their disclosures. There is the potential for negative repercussions but participants appear to develop strategies to protect themselves. Indeed, the literature has also shown that many feel there is more control over this aspect online, particularly through anonymity, although they also caution that some individuals may not be

aware of potential repercussions (Brady et al., 2016). Additionally, it appears from discussions with several participants that a certain level of risk to privacy is acceptable (see *Compromising*, section 9.5.1.). It is also pertinent to consider that few users felt unable to control their privacy. Instead it was those with experience in development that were conscious of the need to recognise potential threats if privacy is not taken seriously. It may be that for many participants this was not a salient concern as the decision to use DMH was linked to a decision to accept the removal of certain aspects of their control, discussed further in *Compromising* (section 9.5.1.). The impact of technological control was also little discussed. For instance, some platforms ask for data that is then shared with third parties. This type of activity may jeopardise the control they feel they have over their disclosures online, although it was not reported by the participants within this study. Unfortunately, this is an area that remains unsaturated as it may require more in-depth and specific user testing in real time to understand the individual's response. It may also require more explicit explanations to individuals as it does not appear to be an experience that is easily identifiable through use alone.

### **9.4.1.2 Agency**

The *Literature Review* (Chapter 2) showed that for many accessing conventional services there are limitations to that access. These limitations include long waiting lists and inconvenience but also being unable to access the service that they want, not being offered a choice of services, and a dissatisfaction with prior or current experience (Ellis et al., 2013; McClay et al., 2013; Mind, 2013; Tubaro & Mounier, 2014). DMH was constructed by participants as a place that was always accessible, “*a lifeline*” (Sandra169) that offered a range of options. The ubiquity of technology also supports this constant and instant access as people

engage with their smartphones often and unobtrusively. Participants felt that this meant access could remain discrete.

Despite the appeal of information that is personal (see Divergences, section 6.3.3.2.) and a range of options to choose from, participants still recognise the importance of moderation. They are aware that certain information about mental health experience may trigger others. Participants in the literature discuss the impact that similarity of experience can have in triggering distress and identify strategies, such as avoidance, that help mitigate this (Schrank et al., 2010). However, participants within this study discuss the complexity of deciding what might be triggering and construct discussions that are seen as negative as potentially helpful. They emphasise that often what is triggering is subjective. Use is supported by trigger warnings that identify the potentially distressing topics in content. This provides participants with the freedom to choose whether to access a resource that could be potentially triggering, which some may do, but also allows them to feel safe whilst exploring. A safe environment is constructed as one that allows them to both exercise choice and remain relatively protected. The discussion of Second Life included the concept of teleporting away from situations that were uncomfortable; individuals are able to quickly and effectively remove themselves. However, this does not mean that they will have avoided the situation entirely. It is important to consider also that trigger warnings may be used by some as a way of seeking out negative content as they are searchable online.

The amount of choice available online appears to be constructed as a dichotomy, much like the paradox of choice (Schwartz, 2005). Within the literature there are more positive constructions such as viewing it as a way of ‘window shopping’ or exercising a ‘pick and mix approach’ (Advocat & Lindsay, 2010; Donkin & Glozier, 2012) but there is also recognition that

there is little support that aids individuals in choosing (see [Choice](#), section 2.7.1.2.2.). Similarly, participants discussed the “*plethora of sites*” (N21) and information that is available, considering this alongside the range of opinions that could be found online. These challenges are explored further within [The Practice of DMH](#) (section 9.5.3.) along with strategies that participants develop to overcome these challenges.

#### **9.4.1.3 Anonymity**

In much of the literature the concept of anonymity is raised. It is often perceived as a reason to use DMH, meaning a reduction or avoidance of the stigma associated with more visible access of services offline (Kauer et al., 2014; Lal & Adair, 2014; Pruitt et al., 2014). However, little research directly addresses the meaning of anonymity as constructed by individuals, and in relation to its use online rather than in comparison to offline services. Within this study, participants demonstrated a rather nuanced view of anonymity. Remaining anonymous online enabled them to feel more open, comparable to their construction of autonomy and control. Identifying the conceptual gap between privacy and anonymity was made possible through Rita’s (U/P) discussion of “*a delusional perception*” (R458) of anonymity. This suggested that remaining unidentified online is more difficult than it is constructed to be and the profiles created may become as identifiable as they are in person. Whilst individuals may use the term ‘anonymity’ it appears to deserve a more in-depth exploration of meaning, particularly with regards the experience online. This was done under the auspice of a constructed barrier, discussed within the next section.

#### **9.4.1.4 Barrier of the Screen**

This concept offered a way to explore and reconceptualise the constructed meaning that anonymity plays within individual’s use of DMH and when interacting via digital technologies.

Participants constructed interactions with and through digital technologies as different to those offline. For some it was a way to maintain interactions even when unwell. For others it formed a barrier that allowed them to control their own and others responses. As with Trigger Warnings and Choice (section 7.2.2.2.) they are able to walk away from an interaction, allowing them to feel separate and yet still connected when they choose to be. However, using technology in this way may, much like the Online Disinhibition Effect (Suler, 2004), bring about a depersonalisation of the other. In so doing, the interaction through technology becomes a reflective medium that can reinforce one's own thoughts and feelings. Although the 'barrier of the screen' may help people to open up – offering a way of controlling reception and responses – by doing so it can potentially become a way of reinforcing pre-existing beliefs.

Research has often focused on the visibility of accessing offline services (Pruitt et al., 2014). By constructing a barrier in one's interactions online, participants reported feeling more capable of preventing accidental disclosures; able to reduce the potential of real life repercussions, and able to exercise control over people's judgements of themselves. When one chooses to disclose offline they are typically physically present. One way the Barrier of the Screen is attractive is that it removes direct human contact. When communicating there is a vulnerability that is discussed by participants, whether due to their concerns over how they are representing themselves or the consequences of their disclosure, which can be controlled more immediately online. They can control the reception – often through Targeting (section 7.4.3.) – and their own responses when interacting with others. For those with more visually or identifiable stigmatised conditions (Goffman, 1963) this may be a preferable way of communicating certain aspects of their condition or receiving advice. However, it seems equally advantageous for participants with less visible conditions – particularly as they appear to

construct their body language as potentially revealing their mental health. Within the literature there are elements of the Freedom to Fail offered through digital technologies and an experience synonymous with the Barrier of the Screen. Several studies report that participants felt better able to interact and share their experiences when free of personal contact or personal connection to what is shared (Brady et al., 2016; Schrank et al., 2010). This supports the proposal that certain interactions in mental health are made easier when conducted behind the Barrier of the Screen.

Some of the participants prefer not to interact with others through DMH resources due to the negative behaviours that they expect. DMH offers a way for individuals to connect without other people, accessing information and interventions without the need to speak to anyone. The predictability of an app may make it preferable when participants do not feel capable of controlling interactions with others, and are concerned about the response to and reception of what they discuss. Within the literature, participants also report negative expectations and experiences such as a wariness of interacting with others online (Rennick-Egglestone et al., 2016; Sanders et al., 2012). Other participants, however, experienced these and felt able to mitigate them. This would suggest that the Barrier of the Screen is a tool that can be used but must also be constructed as such. Whether this is as a result of previous experiences, as discussed in Changing Resources and Needs (section 6.3.1.2.), or an element of the individual themselves, including their specific condition, is unknown and would require further research to explore individual differences in how the barrier is constructed and experienced.

### **9.4.1.5 Summary**

Freedom to Fail establishes processes and strategies that are used within DMH, such as the Barrier of the Screen, as well as conceptualising the meaning of use as a way for participants

to exercise autonomy and agency in their self-management of mental health. It enables them to explore and practice a range of coping skills and resources that may or may not support them, but with the confidence that if not successful they will be able to find more. They are free to fail. DMH becomes constructed as a way to exercise autonomy, similar to the everyday practice referred to by de Certeau (1988). This is done in what is perceived as a safe environment due to the Barrier of the Screen – the positioning of technology between themselves and their actions. This barrier enables them to exert control over their presence, not only how they are represented to others but also the immediacy of contact. Through the constructed barrier participants reported feeling more comfortable in exploring their mental health experiences.

#### **9.4.2 Seeing the Journey**

This category illustrates how DMH has been constructed by participants as a way of understanding their mental health journey. Whether through documenting their experiences or having access to the experiences of others, it provides them with a way to recognise and represent their mental health.

##### **9.4.2.1 *The Past***

The concept of tracking moods is not one that exists solely within DMH (Drake et al., 2013), although tracking through digital technologies appears to be constructed differently. A notable challenge in mood tracking is the need for regular input for it to be an accurate representation of the individual's life story or mental health. In DMH this is linked to Changing Purpose (section 6.3.), through either the reliability of the resource or fluctuations within the user's priorities or mental health. Some addressed the impact that their mental health had upon their use, for instance being more likely to track moods when feeling unwell. The impact of moods on use is suggested within the literature also (Drake et al., 2013; Nicholas et al., 2010) as



is concerns about the accuracy of data (Case et al., 2015). Others were faced with the loss of their data through the unreliability of the resource. This suggests that whilst difficulty inputting moods regularly is one area that disrupts the continuation of these records, the other challenge is the technology itself – a concept linked to DMH as Product (section 6.2.). However, participants viewed DMH resources as capable of offering ways to remind them about the need to record data through notifications or able to passively track their moods. Digital technologies potentially offer functions that can be used to simplify the process of recording one's life story. Recording one's mental health utilises either qualitative records and/or mood trackers where the data must be inputted and explored by the individual, often requiring considerable effort. DMH resources can offer a way to link both qualitative and quantitative aspects of one's mental health in a single place using a visual representation generated from input rather than from the individual's analytical effort. This can aid people in recognising patterns and contextualising them using qualitative information. These records can then become not only a way to look back but also a way to reflect on patterns and experience. DMH can potentially make the process easier and simpler, enabling participants in capturing different aspects of their experience. System builders must recognise the role that technology could play in encouraging and simplifying this. Indeed, research has suggested that DMH has the potential to be personalised to individual needs (Bendelin et al., 2011). However, there appears to be difficulty in envisioning what that might be past the passive tracking and use of notifications previously mentioned.

For participants the capacity to look back at their life story was constructed as positive, enabling reflection, but also with the potential of causing distress. With regards the former, participants discussed the way that they could detect patterns within the data that they collected, whether through the Triggergram on Moodscope that presented a word cloud of positively and

negatively associated words or the comprehension of factors that may influence their mental health, for instance the time of year. There was also discussion within this study of wanting to record the more difficult moments, feeling that some entries they would not want to return to. This does not seem to be a salient concept within existing DMH research. Online diaries were constructed as a way to exert more control over what is, and is not, read – a way to compartmentalise the more negative experiences. It is constructed as a way of being able to ensure privacy whilst also being able to “colour code” (A245) the entries so as to know which ones to avoid. In many ways this reflects the research finding that DMH resources can offer people more control of their mental health through enabling privacy management, although this tends to relate to determining with whom to share treatment (Cheek et al., 2014). This suggests that it can act in much the same way for the individual with regards the management of access to their own past disclosures, and there are links to the discussion of Trigger Warnings and Choice (section 7.2.2.2.). People are enabled to autonomously explore their past experiences within online entries where they can be filtered so that potential distress is minimised.

#### **9.4.2.2 The Future**

This relates understanding what might happen, whether through the predictive nature of patterns in moods or the sharing of experiences from similar others providing information of what can be expected in one’s mental health journey. Participants reported feeling able to predict the future through the patterns that they identified within their tracked moods. The experiences of others, shared through online forums, also offered a way to conceive of a potential future. For many this enabled them to feel prepared. Within both this study and the literature there is a suggested link between DMH and increased confidence in seeking further support (Fleming et al., 2012). It is possible that by reducing the feelings of uncertainty around what comes next that

participants felt better able to access support. This is discussed in further detail within the category of People Like Me (section 9.4.3.) as an element of other people's experiences.

However, it is important to consider the role that seeing one's mental health journey can have and the potential impact on access to further support when it is needed. Within the literature it is proposed that DMH may act as a 'stepping stone', a first step or choice in seeking help (McClay et al., 2013; Pretorius et al., 2010; Rennick-Egglestone et al., 2016). Whilst this is discussed in some detail within Engaging for the First Time (section 9.5.3.4.) the emphasis here is on the proposed concept that shared experiences and detection of patterns in past moods can help people to reduce the uncertainty surrounding the initial process of seeking help. Other people's experiences can offer individuals a way of not only understanding themselves but also what to expect from their mental health journey (Ellis et al., 2013). Participants construct this as an important component of DMH.

#### ***9.4.2.3 All Stages of Recovery***

Further to the concept of access to other people's experiences through DMH resources is being able to connect with others who are at different stages of recovery. For participants within this study this holistic representation of the mental health journey was reassuring. It enabled them to maintain helpful connections even when recovered; recognising the fluidity of their mental health, the potential for relapse, and the need for continued support. For those who wished to seek out support relevant to specific stages of their recovery the representation of mental health over time allowed them to find others at different stages. This demonstration of progress and capacity to remain linked at every stage of their mental health is present also within the literature (Drake et al., 2013). For many being able to see the journey at all stages may offer

support that is more relevant to their needs than traditional support groups in which the emphasis may be placed on those still in recovery rather than those who are recovered.

#### **9.4.2.4 A Call to Action**

Within this study there are several participants who felt that their own journeys could be constructed as a way to provide guidance to others, as a way of “*doing something*” (C94). The event ‘People Driven Digital Health and Wellbeing’ also offered insights into those who feel they can contribute in DMH (Betton et al., 2015). Some participants reported doing so through blogging honestly about their experiences whilst others chose to do so through provision of resources such as online groups. For system builders their own experiences as well as those of others also offered them a way to identify areas of need. This suggests that individuals with lived experience may at times feel motivated to help others through DMH and their own experience. Participants also discussed those who return to forums even when recovered to provide support to others. However, due to the nature of DMH it may not be clear that advice is being provided by those who have recovered. Individuals must seek out ways of establishing trust in their audience if they wish to help support others. This is discussed further as a concept within People Like Me (section 9.4.3.).

#### **9.4.2.5 The System Builder Perspective**

Participants noted that many organisations sought to provide a platform that could enable individuals to seek out and connect with each other through their experiences of mental health. System builders also used their interactions with potential users to identify appropriate areas of development, linking Seeing the Journey to DMH as Product (section 9.3.1.). The central concept of reducing uncertainty around one’s experience was also present as was the importance of other people’s experiences of development within DMH. By connecting to others it was a way

to learn from them, suggesting there is a drive towards sharing experiences when building resources as well as when using them. There is a scarcity of literature exploring the experiences of system builders in DMH which appears to challenge the development process for both Developers and Academic/Contractors who seek to build relationships with others who may be able to offer advice and support. They wish to learn from the journeys of others.

#### **9.4.2.6 Summary**

For the participants within this study their experience of mental health was not always one that they wished to revisit. It was still important for many to maintain a life story – a record that could represent and allow them to explore their journey. For some it acted as a form of memory – a way of recording what would be forgotten otherwise. It also provided participants with a way to overcome the uncertainty they felt surrounding what might happen next, allowed them to feel confident and informed. By recognising their mental health journey through DMH participants constructed it in a way that was reflective about their own experiences. This acted as a call to action for many participants, including system builders, who acknowledged that they were not alone in their experiences and sought to help others. Seeing the Journey offered a way for participants to understand their own journey, to construct mental health as a journey, and for some it was important in constructing the meaning and expectations of their experience. System builders also recognised the role that the experiences of others could play, demonstrating that, although not saturated, it may be a theoretical concept that is present not only in use but also potentially within development.

### **9.4.3 People Like Me**

This category explored the constructed meaning surrounding the role of others, particularly as discussed in [Seeing the Journey](#) (section 9.4.2.). It constructed what other people's experiences meant for participants and addressed the ways in which they were used.

#### **9.4.3.1 Similarity**

When participants discussed the role of others in their online interactions their shared experiences were often constructed as important. As in the DMH literature other people's experiences can help individuals to understand their own experiences as well as what to expect (Ellis et al., 2013). Much has addressed the role that online peers have with regards their promotion of community and engagement (Balatsoukas et al., 2015; Pfeiffer et al., 2011). However, the similarity referred to in this study exemplifies the ways that individuals construct People Like Me not just through shared diagnoses but through a shared mental health journey. The purpose of connecting with People Like Me is explored through three different types of support that can be constructed through their similarity: affirmation, recognition and reassurance. The construct of People Like Me is potentially a concept in flux (see [The Simulated Self](#), section 9.5.2.3.), reflecting how one feels in that moment or potentially influencing how one constructs their experience. Finding People Like Me online offers individuals a feeling of understanding, particularly in areas not easy to communicate within conventional mental healthcare contexts, for example their experiences within the home. This understanding led some to identify People Like Me as capable of ascertaining when help is needed, particularly as they are accessible at all times. It may be that the immediacy of contact allows individuals to share their experiences more clearly and doing so with those who they feel have been through similar can aid in promoting a feeling of affirmation. Understanding of everyday experience can be aligned to the concept of

universalisation – the feeling that others share similar concerns and feelings (Pfeiffer et al., 2011).

Many of the participants discuss others offline and the perception of stigma, or judgements, that can be expected even from those close to them. People Like Me can be sought as non-judgemental alternatives that can enable them to feel free of this stigma. The Freedom to Fail (section 9.4.1.) is linked in terms of the absence of personal connection in the real world (Brady et al., 2016; Schrank et al., 2010) and the ability to access free of judgement (Bradley et al., 2012; Horgan & Sweeney, 2010; McClay et al., 2013; Pretorius et al., 2010). There is a concern that people will respond badly to disclosures surrounding their experience but People Like Me are constructed as having a deeper understanding that facilitates honesty; there is an expected response. By Targeting (section 9.4.3.3.) those who they expect will understand them, they can potentially avoid the stigma that is anticipated from others. People Like Me may be those that are identified through this initial drive to disclose. This can potentially help them to understand themselves better through validation even of those experiences around which they feel shame, but is also restrictive as it is driven by their constructed needs. It is important to consider the simulated aspect of online connections, discussed further in Simulating Mental Health (section 9.5.2.).

Recognition from People Like Me promoted a sense of belonging that led to a reduction in feelings of isolation, as reflected in Pfeiffer et al. (2011). Knowing that others can recognise one's experiences leads to the realisation that they are not alone and can provide a sense that what they are feeling is normal. The reassurance that participants felt knowing that others were like them normalised their experiences and provided some with the confidence to seek further help. However, reassurance also acted as a way of avoiding action, particularly through

validation of unhealthy behaviours, as identified within Daine et al. (2013)). This discouragement of disclosure and the normalisation of unhealthy perceptions appears to be sought by participants purposefully. This links to the Freedom to Fail (section 9.4.1.) - that individuals are free to choose resources that are unhelpful and can seek others who reinforce unhealthy cognitions and behaviours. The autonomy that DMH enables, rather than DMH itself, appears to be the driver with regards to positive and negative applications or adaptations. Whilst this type of support does not offer practical advice, it may serve to provide individuals with a way of understanding that their experiences are aligned with others and not aberrant. Not all support from People Like Me is reassurance, but rather is one facet. Reassurance is an inactive form of support although it may contribute to help-seeking behaviours. Thus, reassurance may be sought as a way of purposefully exacerbating distress or it may be sought as a way to normalise behaviours and cognitions. If the individual seeks this within a productive community who offer advice, this may give them the confidence to seek further help. Otherwise it may simply provide them with a way to validate behaviours they know to be unhealthy.

#### ***9.4.3.2 Actionable Advice***

Participants constructed the helpful component of People Like Me, a way to overcome the potential normalisation of unhealthy behaviours or postponement of help-seeking, as their capacity to provide actionable advice. Whilst those who seek out ways to sustain more negative thoughts or actions are able to find these, the addition of helpful advice can be seen to move individuals towards recovery through its relevance to their needs. DMH has been constructed within the literature as a potential source of learning and strategies that can be applied in mental health self-management (Anderson et al., 2016; Gega et al., 2013; Schrank et al., 2010) and the participants within this study discuss the benefit of doing so through People Like Me. Knowing



that similar others have applied these strategies successfully can encourage individuals to do so too. People Like Me are viewed as more knowledgeable through their relevance and may act as a way to motivate people to begin applying what they have learnt to their own experiences. Not only can individuals seek out actionable advice but for many their access to People Like Me offers them a way to ask questions that they may feel are unsuitable or inconvenient to ask mental health professionals, particularly surrounding everyday experiences and not necessarily just those viewed as taboo. By asking these of People Like Me they are more confident that they will be considered important and that the answers provided will be relevant.

### **9.4.3.3 Targeting**

Another property of People Like Me surrounds the way that individuals can seek out others that not only share experiences and similarities with regards their mental health but also in other areas that may not be possible within conventional mental healthcare. Whilst offline individuals may meet others with similar mental health conditions through support groups, these are restricted geographically and often associated with a mental health label. Participants construct DMH as a way to access and target those with whom they share an affinity, not just a diagnosis. In this way it is linked to the Freedom to Fail (section 9.4.1.) as they are given choice over who they interact with. Participants also discuss the way that targeting can help in communicating with others where there is a guaranteed positive or expected response. This may enable individuals to feel safer in their disclosures (Gowen, 2013). The creation of communities may also lead to individuals feeling excluded but the choice available indicates that other groups may be sought, although for some this may be a difficult adjustment to make. Other participants discuss the capacity of DMH to enable the formation of groups around a specific need that is

perhaps less common, particularly as it is not confined by geographical location and can be done so for niche areas of interest or need.

#### ***9.4.3.4 The System Builder Perspective***

People Like Me is also a construct within the interviews with system builders. Some recognise that individuals seek out similar others who can share information that is more targeted, supportive and complex. The developers' centrality within the resource (Hughes, Rouncefield, & Tolmie, 2002) suggests that this is an important concept. System builders also construct People Like Me as potentially aiding them in development through the value of similar experiences. Some feel that it is easier to identify potential user groups if they are similar. By sharing resources with each other, system builders explore the purpose of People Like Me within the context of development. People Like Me can offer system builders a way of understanding and feeling supported in much the same way as it appears to for users.

#### ***9.4.3.5 Summary***

Participants constructed People Like Me as those with similarities in their experience, not just as a component of their diagnosis but within their everyday lives. This recognition of self within others enables, at times, more actionable advice. It reassures them that if People Like Me have been successful then so will they. By constructing a group with similarities in this way they are better able to target who they interact with online and it is extended beyond geographical or temporal limitations. In identifying People Like Me, individuals may seek out others who they perceive to be free of judgement, who through their own experiences can recognise and understand in a deeper and more meaningful way their everyday life.

## **9.5 The Practice of Digital Mental Health**

The Practice of DMH refers to the processes involved in applying resources to everyday life. It echoes the title of de Certeau's (1988) book, *The Practice of Everyday Life*, as well as the concept of 'technology-in-practice' (Timmermans & Berg, 2003) and attempts to capture the contextual, experiential, and heuristic strategies of use as they are constructed within the data collected in this study.

### **9.5.1 The Milieu of Digital Mental Health: Compromising**

This theoretical category recognises the interplay of the different subworlds within DMH, including the complexity of interactions that occur through often implicated or hidden processes. The category of compromising has similarities to 'satisficing' (Simon, 1991) – that rather than seeking the best solution individuals compromise – and 'making-do' (de Certeau, 1988) – using what is available even when not optimal – within research. Barkhuus and Polichar (2011) use the concept of 'seamfulness' – where seams refer to technical issues and seamfulness is the user's awareness of them – to explore compromising as a neutral component of smartphone use rather than problematic. Compromises are described as exposed seams, where users must adapt to the inherent problems of the technology they use. Whilst there are similarities, the category of Compromising within this study explores the constructed meaning of the concept within DMH specifically, taking considerable note of how 'making-do' or exposing seams may differ in those with lived experience of mental health conditions. It also considers Compromising as not limited to the technological experience.

#### **9.5.1.1 System Builder Compromises**

System builders are faced with compromises that stem from organisational issues, resource management, and their use of ubiquitous yet commercial devices. Compromises must

address the priorities of participants within the various subworlds and, as identified within DMH as Product (section 9.3.1.), those of system builders revolve around the sustainability and maintenance of resources. This necessitates that organisationally they remain streamlined and must consider the value that additional components can add. For instance, users discuss the compromises they make in response to a perception of ‘smaller’ developers, making allowances for limitations in functionality. Compromises also exist within the management of resources. This includes balancing the perceived value of time, energy and cost against the potential outcomes within the system. It appears from this small sample that these compromises can impact the usability of DMH for users. Large technology companies may require device software to be updated regularly, potentially disrupting usability and compatibility for users and system builders alike. This element of compromising is a top-down process in which system builders at different hierarchical levels may be affected more. For system builders, unless connected to large technology companies, development is restricted to commercially available devices, which are ubiquitous and easily accessed by users. Thus, system builders may feel that changes are compulsory so as to ensure their resources remain functional. This is a further element of The Interminable Product (section 9.3.1.2.), where it is discussed in more detail. The role that change plays within development is also emphasised, as outlined within the category of Changing Purpose (section 9.3.2.). Compromises are made by system builders when considering the ongoing costs and maintenance needs of their products (DMH as Product, section 9.3.1.), as well as the requirements of devices and expectations that individuals have of the functions available within resources.

### **9.5.1.2 *User Compromises***

Many of the participants discuss their mental health as a variable component of their everyday life that can at times be difficult to manage. Not only must they deal with the challenges that come with mental health concerns, but they also appear to accept responsibility, and the potential discomfort, of managing those concerns themselves. This can make it hard to feel motivated. Motivation may be seen as an element of Compromising in that individuals seek ways to reinforce their behaviours but can also choose to interpret challenges as a reason to discontinue use. The usability of resources and the choice available to individuals, as discussed in the category Freedom to Fail (section 9.4.1.), align the personal nature of use with the technological demands of DMH. Within the research the concept of seamfulness is used to address when usage is challenged, often leading to the disposal of the resource (Barkhuus & Polichar, 2011). If the purpose of a DMH resource is not perceived to be achievable users may find it easier to move on than to ‘make-do’ (de Certeau, 1988). Also known as conflict situations (Jarvenpaa & Lang, 2005), these are likely to cause frustration, particularly as users may make decisions which affect their ability to manage their mental health. Participants appeared to negotiate their use in response to challenges, demonstrating that compromises are not always constructed as a reason to discontinue use. Some are willing to ‘make-do’ even when they find it difficult, particularly when compromises are made with regards the device. However, when challenged in their use by a DMH resource there appears to be less loyalty or perseverance, perhaps as a result of the user’s Freedom to Fail (section 9.4.1.). Thus, although compromising within the literature may be synonymous with ‘satisficing’ (Simon, 1991) it is challenged here by the constructed separation of device and resource, where devices are seen as expensive whilst DMH resources are free and available in large quantities. When considering use it is important to

address the deeper meaning that participants have constructed for not only resources but also the devices on which they are used.

### ***9.5.1.3 Model of Compromising***

It is of note that compromises may be made in relation to conventional mental healthcare also. Many discuss the challenges associated with access, including long waiting lists and limited choice, as well as difficulty accessing information. These are present within the literature also (Lal & Adair, 2014; McClay et al., 2013; Mind, 2013; Powell et al., 2011; Pretorius et al., 2010). DMH appears to be constructed as both convenient and autonomous for many of the participants. However, whilst DMH may offer a solution to the compromises within conventional mental healthcare there also appears to be a construction of similar challenges present that indicate a replication of existing problems. For instance, Jessie (U) discusses the limitations in access of a DMH platform that requires residency in certain areas ([J263](#)). Funding is restricted not only in conventional mental health services (Martin & Barnett, 2012) but also online. Whether these issues remain due to the porting of existing systems to digital or as an inherent aspect within mental health treatment is unclear. When participants compare offline and online resources the constructed meaning surrounding convenience of access was challenged within the literature as individuals felt that time was difficult to find (Bendelin et al., 2011; Boggs et al., 2014; Dennison et al., 2013; Hind et al., 2010; McClay et al., 2013; Wilhelmsen et al., 2013). Offline services offer less choice and are not as immediately accessible (Mind, 2013). However, the choices available and immediacy of access to DMH resources was constructed at times as being overwhelming. Whilst participants may have the Freedom to Fail (section 9.4.1.) this also brings more responsibility. Knowles et al (2014) identified the concept of ‘enforcing autonomy’ as cCBT treatment provided without support challenging its effectiveness. Both participants within

this study and those in others see it as potentially a way of services cutting costs (Rennick-Egglestone et al., 2016). Users may construct DMH as a way to begin the path to recovery, a “starting block” (Sandra151) or a “stepping stone” and useful for those who are desperate to access and engage in treatment (Rennick-Egglestone et al., 2016). However, compromises online may bring them full circle back to more conventional resources. What appears to be constructed by the participants within this study is that the compromises lead to a cycle between and within conventional and digital mental health services, alongside their own self-directed self-management of their mental health. This is illustrated in Figure 54.

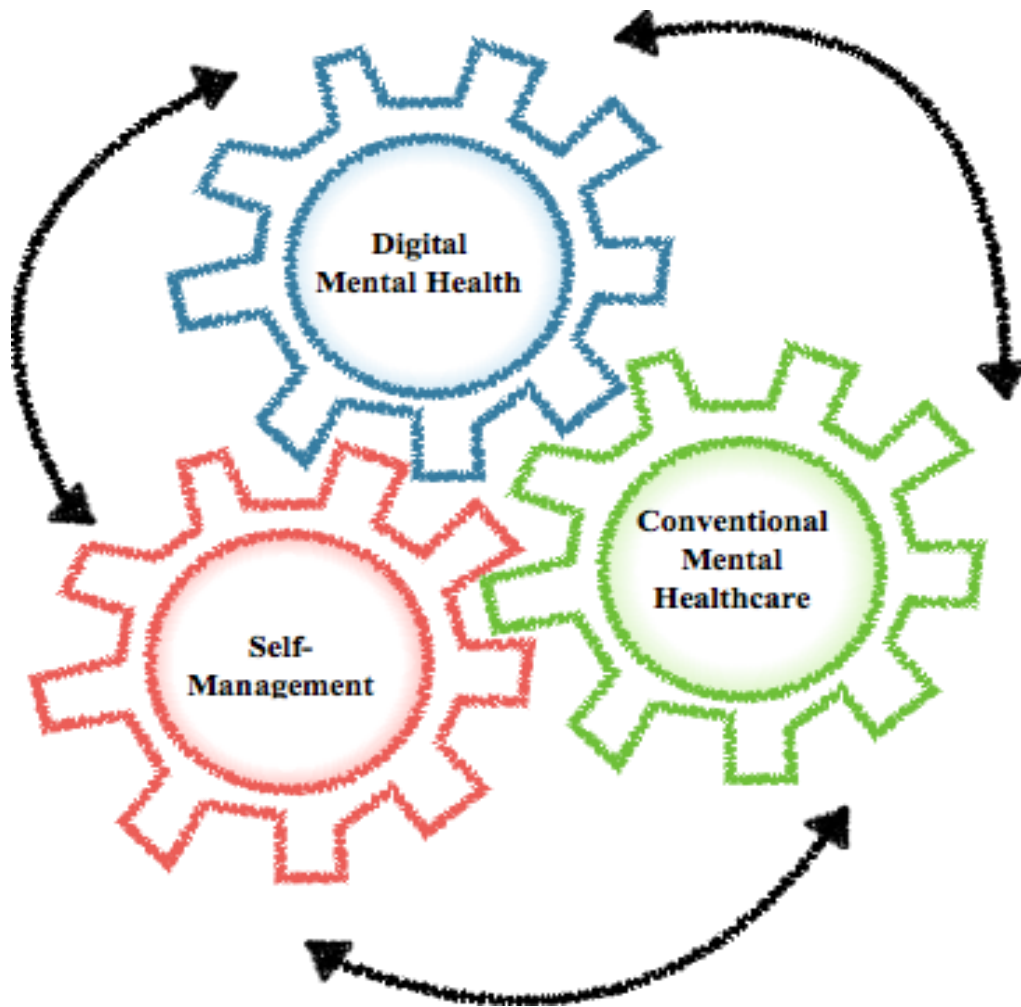


Figure 54. *Model of Compromising.*

#### **9.5.1.4 Bridging Virtual and Real**

This concept considers DMH not as an alternative to conventional mental healthcare, but rather as a supplement. It constructs the cycle of compromising as one that promotes a bridge between the virtual and the real, emphasising the benefits of maintaining a connection between them. Participants often construct this positively. Consider, as in the literature (Ellis et al., 2013; Rennick-Egglestone et al., 2016), the way that participants discuss turning to DMH as a way to learn and identify their mental health needs, the proverbial “*starting block*” (Sandra151). It has already been discussed that interactions online can encourage further help-seeking, as can the capacity to see one’s own mental health journey ([Seeing the Journey](#), section 9.4.2.). Several participants discuss being able to apply what they have learned online – of being able to bring back new tools to their offline interactions – leading to more meaningful and mindful interactions with conventional services. Through the virtual they are able to practice and learn in a more flexible environment before applying it to the real. The participants within this study emphasise the importance of applying what is learnt back to reality, so that not only does conventional mental healthcare support their use of DMH and self-care but that DMH and self-care can support their use of traditional services. DMH may offer individuals a toolbox of resources that can improve their offline interactions and practices within the mental healthcare context.

#### **9.5.1.5 Summary**

Compromising is here constructed not simply as technological but rather as a process that exists within the social world of DMH, one that crosses between what is viewed as virtual and as real. Compromises are a part of everyday life. Within DMH they are constructed within both use and development and also within the boundaries and dimensions that exist within and between



the technical and clinical subworlds. In this way it has similar meaning to the ‘seams’ of technology (Barkhuus & Polichar, 2011), which are sited at the edges. By existing where worlds overlap, the challenges and compromises that individuals face can propel them from one world to another. Thus, compromises in participants’ use of DMH pushes them towards conventional mental healthcare where further compromises lead them once again to return to self-management of their mental health. They enter these worlds at their boundaries and moving between them, learning and applying skills and strategies throughout. The compromises that push them towards another social world may be overcome or mitigated by what is learned through this process.

### **9.5.2 The Experience of Digital Mental Health: Simulating Mental Health**

This theoretical category addresses the processes underlying the experience of applying and utilising DMH through three categories – Freedom to Fail (section 9.4.1.), Seeing the Journey (section 9.4.2.) and People Like Me (section 9.4.3). Simulating Mental Health aligns the virtual practice of experiences to the individual’s reality of mental health. This category constructs the experience of DMH as one that simulates mental health, whether through purposeful representation or through the virtual nature of the medium. Participants produce meaning in a variety of ways through their actions and interactions, often co-constructing it with the technology itself. Simulation refers to the virtual aspect of DMH, particularly the way it is used in representing mental health-related concepts.

#### **9.5.2.1 The Simulated Connection**

This relates to the record or life story discussed within Seeing the Journey (section 9.4.2.). By representing their moods over time in this way it can enable participants to feel more connected to their mental health. It is a simulation of their experience but it does not appear to require a high level of fidelity. Rather it acts to link their everyday experiences to their mental

health and this, by enabling an understanding of that cohesion, leads to more connection with their reality. One important concept present within this study was the concept of “*in-between*” (J272, Sarah212, G89) moments. Rather than isolating their experience to mental health alone they feel it is important to encompass a more holistic understanding, one that can provide them with feelings of support and accountability. They compare it to the traditional view that therapists have of their experience, which is limited to set appointments and more retrospective reflections. DMH connects the actuality of everyday experiences, when used to record or track, with the reality of living with a mental health condition. The connection that individuals feel to their mental health, their awareness and acknowledgement of it as a component of their everyday experiences, appears to be improved through the simulated connection of daily life and elements such as their moods. This may also be constructed as beneficial to the therapeutic relationship by providing a link from the everyday to the conventional mental healthcare context.

#### ***9.5.2.2 The Simulated Experience***

The personal stories of others, as addressed within [Seeing the Journey](#) (section 9.4.2.) and [People Like Me](#) (9.4.3.), offer participants a way to access more contextualised and privileged information regarding the everyday experience of mental health. Personal stories can be constructed as simulations of other’s journeys. Indeed, many of the participants discuss DMH as offering “*firsthand*” (RVW465, R255, H108, Sandra123) information. This emphasises the intimacy that the reader has to that which is communicated and the proximity that the medium can provide to the information or experience. The fidelity of the simulation is not provided by any truth-value inherent to the author or simulation itself but rather is ascribed by the reader’s own affinity to the information or experience being communicated. Participants feel they find a deeper understanding, one that is more closely linked to their own experience through

recognition of the everyday. It potentially illustrates that for participants they will seek out information and experience that feels closer to their own rather than attempting to negotiate experiential information from a credibility perspective. Within the research there was a clear discrepancy between assessment of expert and experiential information (Lederman et al., 2014). References were sought when information was perceived as authored by experts whilst crowd consensus was important for information presented as experiential. This suggests that, when exploring a simulated experience, participants may seek to align themselves, for instance to People Like Me (section 9.4.3.), and the virtual representation perceived to be produced not from reality but from a simulation of such. One proposed reason for its appeal is that when communicating through digital mediums authors are aware of the potential for a much wider audience and so multiple perspectives must be taken. Thus, when presenting information or experience they not only construct it through their own reality but also in light of the expected realities of their audience. This reflection of other's perceptions of one's own self may lead to a broader consideration of information or experience.

### ***9.5.2.3 The Simulated Self***

The Simulated Self is associated with the Freedom to Fail (section 9.4.1.) and emphasises the constructed nature of digital selves, that of creating multiple personas with various attributes and needs that can be controlled through variations in their prominence. (Turkle, 1984). Participants report feeling more secure, feeling able to protect one's real world identity, as well as the use of simulated selves for the purpose of healing. Here the capacity to create an online self, a simulated version, emphasises the ways in which it can be used as a component of self-management in mental health. Rita (U/P) uses her avatar on Second Life not as a Simulated Self to heal but rather as a way to heal (R512). Jessie (U) reinforces this concept when she discusses

the way that people present themselves online, that they may be representing themselves as at-risk not because they are but rather because this is an element that they wish to express and be responded to (J193-194). This suggests that the Simulated Self may act to enable exploring, it can represent an amplified version of oneself or what one is concerned about, particularly when considering the concept of the Barrier of the Screen (section 9.4.1.4.). The Simulated Self can be used to play out different needs through the Freedom to Fail (section 9.4.1.), which enables them to explore different representations through their own and others' eyes without repercussions or the need for fidelity.

#### **9.5.2.4 *Simulated Support***

How participants construct support through DMH is illustrated here. Its meaning can be found not only within interactions with others through digital mediums but also through the resources themselves. Participants know that these DMH resources are there when they are needed and they have immediate access to information and tools for self-management. It is a support that they carry with them 'on the go' (Dennison et al., 2013), for instance through their smartphones, and have control over when and where it is accessed. This means having access to support when it suits them rather than when it suits others. The support provided through digital resources is at times constructed as similar to real support – for instance, virtual hugs are “*the same thing*” (R367) as when given a real hug – but they can also be constructed as technological. Different mediums may provide individuals with different depth of support based on their pre-existing use and connection to the resource. But rather than constructing this around the type of support that can be found, this concept emphasises the simulated aspect and its purpose as constructed by participants.

#### **9.5.2.5 *Appreciation Through Simulation***

The concept of simulating the experience of mental health is constructed as more about providing an understanding than providing information. Not only does appreciation through simulation potentially offer insights into the actual perceived feelings and experiences of those who are simulated but it may be used to access those who are traditionally difficult. Information is constructed as separate from the experience and participants emphasise the role that empathy and compassion play, viewing simulations as a way of providing these. The simulation of experience can lead to a greater understanding being communicated, constructed through its application to those without experience of a specific mental health condition. Participants construct DMH as a way of building empathy, particularly through sharing experiences. They also discuss their own use of DMH as a way of understanding and empathising with others better, such as in areas of mental health that they do not have direct experience of. It appears to be constructed within this study as particularly useful for professionals, a way to provide them with insight into the everyday experience of mental health. Due to the Barrier of the Screen (section 9.4.1.4.) it is proposed that users will be more open and more accessible. It can provide them with a way of relating to the experience through more immersive mediums such as virtual worlds, promoting compassion through the actual perceived feelings and experiences. Thus, it is about providing an understanding or appreciation through information and simulation.

#### **9.5.2.6 *Bridging Virtual and Real***

As previously addressed within The Simulated Self (section 9.5.2.3.), the participants discussed their active use of multiple personas to act out different aspects of themselves. It is suggested that the act of simulation can at times serve as a bridge between the virtual and the real. Whilst the Barrier of the Screen (section 9.4.1.4.) may provide participants with a feeling of

security, their presence within the interaction and use of DMH remains consistent. Likewise, when their use is challenged participants discuss the real world organisations that sit behind the resources they use. Although these simulations act as ways for participants to practice or represent different aspects of experience there remains a close link to the real world practices that they seek to represent. My own experience drew my attention to how I was represented, both within the real world and the virtual. How I chose to represent myself became an important connection between the simulated and the real. DMH also appears to engage participants with the everyday practice of strategies and skills that they have learned through provision of a simulated exploration of how they feel, how they appear, and how they must act. Before these are brought into their real world experiences they are able to practice them in the virtual.

### **9.5.2.7 Summary**

Simulating Mental Health refers to the representations of mental health made possible using digital technologies. These can include visual representations of one's own moods, blogs describing one's experiences, or even simulations utilising virtual reality; all of which can be used by participants to better understand their own and other's experiences. Key to this concept is recognising the role that these simulations have for users. Participants constructed it as a way of connecting their everyday experiences to that of mental health, enabling them to represent certain elements in an environment that reduced the potential impact of aspects such as disclosure. It also identifies the simulated component of DMH, emphasising the ways in which participants construct interactions with information, other people, and even technologies themselves in a virtual context. Rather than seeking credibility it is a process that appears more intuitive, based on an empathic understanding. The connections, experiences, and support found online are understood to be simulations of such by participants but they are constructed as

purposeful and usable even so. Simulating Mental Health offers a deeper understanding for professionals and users alike, despite its low fidelity.

### **9.5.3 The Practice of Digital Mental Health: Finding What Works**

This final theoretical category aims to construct the processes involved in the practice of DMH as a component of everyday experience and the milieu in which resources exist. The need to try different things appears to stem from the variability in personal experience. The choice available and Freedom to Fail (section 9.4.1.) mean that individuals are able to explore their needs free from pressure or judgement. However, this choice and availability also challenges use as resources are constructed as disposable. Variability and variety mean that individuals have options that can fit with their needs but also means they must explore, try, and discard to find what is right for them. People Like Me (section 9.4.3.) can offer a way of identifying resources that may be of use, particularly when experiences are shared (Seeing the Journey, section 9.4.2.) and simulated (Simulating Mental Health, section 9.5.2.). Seeking out resources requires considerable cost in terms of energy but users appear to bypass financial costs through their use of free to access resources. Avoidance of payment means challenges for system builders in establishing DMH as Product (section 9.3.1.), particularly in ensuring that resources are maintained. Building trust in a product means that resources must consistently deliver what they are expected to, with the potential result that users may become frustrated or distressed if their use is challenged (Changing Purpose, section 9.3.2.). However, users are also faced with compromises which must be either overcome or accepted (Compromising, section 9.5.1.).

Key to this final category is understanding that the participants of this study are engaged in a new and emerging area of mental health self-management, that of DMH. Not only must they negotiate the large numbers of resources available (IMS Institute for Healthcare Informatics,

2015; Research2Guidance, 2016) but they must do so with little understanding of what is most effective. As a result, they have developed their own strategies to overcome these challenges, processes that emphasise their autonomy and their own personal needs. A consistent concept within the data was that of “trying”, coded in various ways to reflect the exploration, the discarding and adopting that is significant within the use of DMH. This brings the categories together to reflect what is recognisable as a ‘reverse salient’ (Pinch & Bijker, 1994), an element of the system that has not developed as quickly as the other components. However, participants have constructed it as a way to explore their needs and establish pathways to recovery, although it may be challenged by their personal experiences of their condition. For system builders the practice of DMH appears to be an obstacle to the application of their resources. This model seeks to represent the complexity of the everyday practice of DMH within the often chaotic social worlds of autonomous individuals who seek to construct meaning through exploring.

#### ***9.5.3.1 Trying Different Things***

When asked what advice they would give others seeking to appropriate DMH most of the participants advised trying lots of different resources as a way of exploring what was available but also finding what fits with them personally. Not all resources suited all participants. Researchers have termed this a ‘pick and mix’ approach (Advocat & Lindsay, 2010), as well as ‘window shopping’ (Donkin & Glozier, 2012), yet for participants this concept was associated with the Freedom to Fail (section 9.4.1.), with being able to learn through using and applying different DMH resources.

#### ***9.5.3.2 Struggling***

However, the energy required for this strategy may be considerable. The literature addresses user’s frustration and difficulty when seeking the information they need (Gowen,



2013; Kauer et al., 2014; Powell et al., 2011; Schrank et al., 2010). This study draws attention to an additional consideration, that users will be at a point of need when they are seeking and accessing DMH resources. Some participants relate their distress when attempting to seek out and find tools to utilise as a struggle not only with the options available but also with themselves when they are unwell. The concept of a ‘struggle’ is used and appears to indicate that it is not a process that is currently facilitated or that is easy when doing so with poor mental health. This may mean that the resources found will be influenced by their present distress, an area that will need further research to fully comprehend. It is important to consider the concept of engagement as addressed within Ratings Over Research (section 9.3.1.3) – a focus on usability may be more appealing than resources that have prioritised effectiveness.

### **9.5.3.3 Searching**

Seeking out resources in DMH may be a difficult and challenging process as there are large numbers of heterogeneous mental health resources (Ashford et al., 2016; IMS Institute for Healthcare Informatics, 2015) and an over-reliance on search engines to find mental health information and support (Neal et al., 2011). Within this study, participants mainly appeared to access DMH resources most successfully through word-of-mouth, although a more popular strategy was to engage in broad searches that became narrowed down over time. A challenge was still presented by those initial stages of search where participants were unsure what might be available or where to find them. A search engine may be able to present a list of results but it necessitates that the correct search terms are entered. Participants reported that seeking resources became easier when connections had been made to People Like Me (section 9.4.3). To begin searching they appeared to construct it as a time of uncertainty, one that required perseverance in

the face of what was at times overwhelming information. The potential to be disillusioned at these early stages may be higher.

#### ***9.5.3.4 Engaging for the First Time***

Within the literature researchers discussed DMH as potentially a first step (Ellis et al., 2013), or stepping stone (Rennick-Egglestone et al., 2016), in seeking help. Whilst this was supported by the participants in this study it raises a number of possible areas of concern. Some participants addressed what impact these initial experiences of mental health, accessed through DMH, might present. Offline experiences can be difficult when one is unprepared, when asked to open up to someone for what might be the first time. Likewise, it may be that people have no one to speak to offline and so turn online as a way of exploring what is happening to them. In this way the experience they have may affect their future help-seeking behaviours, the way that they understand their mental health, and the choices they make in their treatment. This was also discussed as an element of Freedom to Fail (section 9.4.1) but here it emphasises how important it is to recognise the strategies that individuals are using to access DMH for the first time.

#### ***9.5.3.5 Guides***

Following on from the previous section, several participants suggested that a guide would be useful in their appropriation of DMH. Without formal screening (Rennick-Egglestone et al., 2016) or the oversight of professionals these guides are constructed as those that could help sort through the often considerable number of options available. There are many resources to choose from but little support provided in making a choice (see Choice, section 2.7.1.2.2.). For some a guide was constructed as experienced others – indeed concepts within both Seeing the Journey (section 9.4.2.) and People Like Me (section 9.4.3) suggest that they can at times act as guides – and yet there were some who felt a professional body would be more appropriate for signposting

to resources that were trustworthy and effective. This is challenged by the concept of Ratings Over Research (section 9.3.1.3.) which suggests that engagement is prioritised over evidence.

Some also felt that it is not clear how to guide individuals within DMH as it is such an emergent field. However, others constructed resources themselves as potential guides, able to conduct users through their use.

#### **9.5.3.6 *Finding What Fits***

Trust in online information appears to be low and yet information from an expert is assessed differently to that based on experience (Lederman et al., 2014). It is further confused by the impact of individual differences, for instance different resources may be suitable at different stages of treatment (Jones & Ashurst, 2013; Pretorius et al., 2010). Participants reported feeling confident in their capacity to make decisions about their mental healthcare but felt that the difficulty arose in knowing what a ‘good app’ might encompass. Whilst they are able to seek out those that best fit with their needs it is not always immediately clear whether they will be effective. As with the concept of Trying Different Things (section 9.5.3.1.) it becomes a case of exploring through the options available and, often, identifying those that do not work. Certain types of resources appear to work for users whilst others do not. Amongst the participants in this study there were some who found forums ‘fit’ whilst others preferred the use of apps. For them it was the acceptance of differences in DMH, the capacity to use different types of resources and the Freedom to Fail (section 9.4.1.), that was useful. Rather than viewing what fits as a single resource they often discussed the need for variability not just amongst users but even within their own use. Exploring various DMH resources led to a narrowing down of those that fit them best.

Choosing a resource appeared to be an intuitive process amongst participants. This echoes the concepts of Freedom to Fail (section 9.4.1.) and Ratings Over Research (section

9.3.1.3.), where users are free to access outside of clinical effectiveness. They develop and discard heuristic strategies depending on their needs, understanding through the impact of change whether a resource is helpful or distressing. The flexibility of applicability means negotiating a variety of resources at any one time. It also required the participants to rely not only on the resources but on the platforms and devices through which they access. Their instability (see [Compromising](#), section 9.5.1.) may lead participants to seek out a range of resources rather than a single solution. It may also reflect their changing needs (see [Changing Purpose](#), section 9.3.2.) and the way that DMH can be appropriate not only for individuals at specific stages of their recovery but at all stages.

#### **9.5.3.7 *Establishing an Ecosystem***

Two types of resources are constructed as good. Whilst some seek a solution the majority have found a collection of resources that can be accessed when needed to be more applicable to their everyday experience. These provide a toolbox of resources that can support the management of mental health through their appropriation within certain areas of their lives rather than as an all-encompassing solution. This means being able to return when certain components are needed. Indeed, the research supports this type of use in its construction of e-attainers, those that adopt and discard technologies specifically to achieve goals (Christensen & Mackinnon, 2006; Martinez, 2003; Nicholas et al., 2010). However, this research suggests that rather than individuals simply having single resources that can provide support when needed that there is an ecosystem of apps and resources that they have downloaded and saved to their devices. This may be an element of the more personal nature of smartphones and other research does suggest that apps which are more adaptable to needs are more likely to be kept (Anderson et al., 2016). It also identifies a lack of continual use that may challenge existing methods of research.

### **9.5.3.8 *Bridging Virtual and Real***

The ecosystem of DMH resources can be constructed as a bridge between the virtual and the real. It offers individuals a way to learn strategies for managing their mental health online before applying them offline and enables them in returning to tools that may need further reinforcement. Participants discuss the role of DMH not as a solution but as one component of their daily life, not just their mental health. Whilst it is not always considered therapeutic it does offer support in the lived experience of a mental health condition. It is constructed as a supplement, not one that negates the use of conventional mental healthcare but one that helps support its use. This may explain why some researchers found users were fearful that their current service would be disrupted (Sanders et al., 2012). There is a concern amongst participants that it will be seen as a replacement. Instead they have constructed it as a way of bridging the daily aspects of their experience, their everyday, with the more clinical contexts of mental health. The potential lies, it appears, not within its replacement of conventional mental health services but rather in its capacity to contribute to their efficacy and efficiency.

### **9.5.3.9 *Summary***

Finding What Works demonstrates several strategies that participants have constructed in their practice of DMH within their everyday lives. It identifies the chaotic process that individuals must engage in to find resources that work for them, a process that is both difficult and inherently positive as a result of its exploratory nature. By encouraging a process of seeking out and trying, participants are constructing Finding What Works within DMH as a way to discover not only resources that may help support them in managing their mental health but also as a way of learning more about their needs. Whilst accessing resources can be difficult, and requires considerable engagement over time, the ecosystem that is established can provide

participants with a toolbox of resources for a variety of needs that can be accessed when and where they are needed. This challenges the concept of continual use but provides a way to understand the heuristic methods that participants have constructed to establish DMH resources in their everyday self-management of mental health. They are challenged by the limited research in DMH but have overcome this through access to [People Like Me](#) (section 9.4.3.) and via [Seeing the Journey](#) (section 9.4.2.). It is also important to consider that DMH may be the first experience that many have of finding out or opening up about their mental health, it may be the first experience individuals have of mental health treatment. This emphasises the importance of DMH as a new area of enquiry. Participants use a suite of resources that can be adapted to their variable needs. How this affects engagement, often used to measure efficacy, is difficult to ascertain and requires novel ways of constructing people's use of DMH resources that explore how they are integrated into their lives rather than considering them as standalone elements of mental health self-management. Considering them as an ecosystem rather than individual components necessitates understanding and recognising the complexity of needs for individuals. It must also be recognised that in development and use whilst change is inherent to both there is an external element, linked to the devices themselves, that is activated by separate organisations such as technology companies.

### **9.6 Bridging Virtual and Real**

By positioning DMH as a bridge between the virtual and the real, particularly with regards the theoretical categories of [Compromising](#) (section 9.5.1.), [Simulating Mental Health](#) (section 9.5.2.) and [Finding What Works](#) (section 9.5.3), its role and purpose is constructed. Although this research has consistently been challenged through its complexity, through the understanding of multiple and chaotic constructed meanings between and within social worlds,

the concept of a bridge supports the interpretation of the experience of DMH as communicated by users and system builders alike. A bridge suggests that it can connect together areas that may otherwise be viewed as incompatible. Indeed, within all three theoretical categories it demonstrated that by connecting the virtual to the real, and vice versa, through technologies for, or repurposed as for, mental health that participants could engage in helpful strategies. For instance, learning within the virtual world had numerous applications to the real world including as a way of exploring and identifying their needs within conventional mental healthcare.

Likewise, it provided a way to establish and gain confidence in specific aspects of their mental health identity. Constructing DMH as a bridge means that participants can bring components of their experience, such as Freedom to Fail (section 9.4.1.), and the milieu, such as Changing Purpose (section 9.3.2.), from virtual to real and back again. This bridge presents an important ‘place’ though which to construct how participants exercise and appropriate DMH in their everyday experiences as it is the point at which exploration appears to be most salient for users and system builders. This suggests that more research should focus on both conventional *and* digital mental healthcare, rather than one or the other.

### **9.7 Recommendations**

DMH is a new and emerging way to self-manage mental health. However, whilst it provides options, it does not inform as to how to choose and, whilst it supports change, it is not in itself motivating.

**Both the clinical and technical paradigms need to be addressed within DMH, and the perspective of users recognised for their importance. Users may not have technical or clinical expertise but they do have lived experience and understand how DMH works within their everyday lives.**

- Policymakers need to be conscious of ensuring that policies address all areas – clinical, technical and user-based.
- Developers should involve clinicians and users in development and dissemination, but also throughout the resource’s implementation, to ensure that resources ‘fit’ into the everyday practice of self-managing mental health.
- Users should be encouraged to provide feedback directly to developers about their use and engaged in conversations about their experiences. System builders should be considerate of their users’ needs and encourage their involvement.

**When DMH products no longer work this can cause distress for their users. A resource that no longer works is one that is not usable, not useful or no longer available. This is also relevant to encouraging users to engage with apps over extended periods of time.**

- DMH resources should only be developed by those who are proficient in the area that it serves. Involvement of those proficient in technical areas supports the resource’s continued usability, those with clinical expertise support its effectiveness and user involvement ensures its usefulness in the everyday management/experience of mental health.
- System builders have a duty of care to be transparent in what they offer and to ensure that the resource is sustainable past a single point of development. For instance, users should be offered copies of any data that they contribute as a way to mitigate the potential impact of DMH resources no longer being available. Any significant changes to resources should be communicated in advance and older versions should remain available to users for a set period of time.



- Policymakers need to ensure that funding or income streams are available that can match the needs of DMH companies and ensure that they are sustained past development.
- Researchers should explore the transitional moments in DMH, for instance when interface design is significantly altered, so as to better understand the impact on users. These changes can be driven by resources but also by operating systems, so it is important to consider devices as well as software.
- Commissioners and those recommending DMH resources must ensure that the system builders can continue to offer the same high quality product. This can be done through funding or appraisal of sustainable income generation, e.g. through in-app purchases.
- Users should ensure that they keep back-ups of all their data, especially if it supports them in self-managing their mental health. Resources should be designed to help them in taking ownership of their digital self-management with information and advice about how to effectively and safely use DMH tools..

**DMH resources may run on third-party devices. This can influence the design, usability and sustainability of DMH resources.**

- Developers need to recognise the differences in operating systems and mitigate any disparities between different devices/systems. This will ensure continuity of use.
- Regulators, Commissioners and Policymakers must be aware of the differences in operating systems also. The requirements on different devices and across different systems can lead to variability in experience, security and design. For example, some

devices cannot update to newer operating systems, which can jeopardise data security.

**Placing the user at the centre of design is recognised as integral to good quality development (Gulliksen et al., 2003; Martin, Clark, Morgan, Crowe, & Murphy, 2012).**

**Within DMH it is essential. Who the user is and where the user is using the resource can have considerable impact. However, restricting use is not the answer as the adaptability of DMH is viewed positively.**

- Developers must be aware of the different contexts in which a user can use their product and be clear if there is likely to be an impact on its effectiveness.
- To support developers in this, researchers must understand how different contexts could impact use.
- Users must also consider how appropriate their use is in different contexts. They should understand why using a therapeutic tool in certain situations might limit its effectiveness.
- The impact that the following have on use of DMH resources must be explored:
  - a. Environment e.g. home, bus, school, etc
  - b. Mental state e.g. when distressed or not distressed
  - c. Mental health conditions e.g. depression, anxiety, etc
  - d. Devices e.g. Apple or Samsung, mobile or PC
  - e. Design e.g. HTML or operating systems

**If DMH resources are to be regulated or recommended it is essential that there are clear distinctions made between products that can cause harm and those that are inherently**

**harmless. Security rather than mistreatment appears to be far less salient for users and thus, has more potential to cause harm.**

- Regulations and recommendations must focus on ensuring that DMH resources are secure for their users. This means involving system builders not only in the development of regulations/recommendations but in the ongoing monitoring of updates as well as changes to operating systems.
- Operating systems and devices offer different functionalities and are regularly updated. In regulating/recommending it is essential that the differences between and within these areas is understood – they cannot be generic across different systems.

**DMH offers users a supplement to traditional mental health management and treatment.**

**Stakeholders must recognise the importance of supporting self-management in multiple ways so that people feel they have options in dealing with their mental health. Provision of online and offline services in a seamless way to promote prevention and deliver interventions that can help mitigate the issues associated with provision of a single service.**

- Clinical moderation of online services supports a space in which users can talk safely and openly. Rather than inhibiting conversations, clinical moderators can help to identify when users are in need of more direct face-to-face support, ensure that all participants are positively engaged, and promote actionable advice.
- Providing users with different options if DMH resources are not sufficient is essential. Although this may be challenged by remote provision it is necessary to explore ways of integrating DMH into existing clinical pathways and ensuring that users are aware of alternatives and their capacity to choose.

- Clinicians must be trained in how to support their patients in the use of DMH resources, not only in a clinical way but as a form of self-management. This means understanding how appropriate its use is in the individual's everyday life.
- Commissioners should understand how DMH can be integrated into clinical pathways not as an alternative but as a supplement. For instance, DMH resources may be offered alongside offline services so as to provide for both online/digital users and non-users.

**Free to use DMH resources are clearly preferable to those that must be paid for.**

**Healthcare systems must understand how they best incorporate DMH resources appropriately within delivery whilst recognising the cost to the end-user and balancing that against the need for sustainability.**

- Users need to be made aware of how their compromises, e.g. free apps over paid apps, might impact their mental health as well as the quality of the resource. They may expend considerable energy to identify a DMH resource that is usable, useful and is free.
- Databases of recommended DMH resources can aid users in identifying what will work for them. However, it is also important to address what might be more or less so through recommendations from people that are recognisable to them, e.g. People Like Me. Profiling, recommender systems and other functionalities can help in identifying resources that will help support similar users.
- Curated DMH app stores, whether patient or professional-facing, must consider not only how they help users to 'Find What Works' but also how they can support system

builders. For instance, user insights might be shared to improve recommendations and functions alike.

In understanding the role of DMH it is essential to consider it alongside existing mental health prevention and management. Many of the participants identified the difficulties and challenges of managing their mental health with only traditional tools and interventions available, and how DMH offered additional ways of doing so. Additional does not infer superiority, but rather extra methods that may suit the individual better.

**Users find DMH invaluable. For instance, it provides them the Freedom to Fail – it is a place where they can exercise autonomy and agency in choosing how to manage their mental health. However, it is necessary for all stakeholders to address ‘unintended consequences’.**

- Users may make riskier decisions online, particularly when disclosing their mental health status. Although changes to laws (e.g. General Data Protection Regulation) have been put in place to support individuals better, it is important that they are also kept informed. Users need to be aware of the potential repercussions to their personal and professional lives, and recognise that they are aligning their identity to something that may be perceived as vulnerable. Digital identities are becoming increasingly linked to our real-world selves and the confidence of participants in their ability to use online personas anonymously may increasingly be challenged. DMH resources should identify these concerns clearly in their user agreements.
- Users must be supported in understanding how technologies, such as cookies, are being used by companies and third parties. For regulators this is an area that could potentially hold significant value if they are willing to protect DMH users. Facial and

voice recognition and insidious tracking online are two areas that must be addressed to ensure users retain confidence in DMH going forward. Whilst some users will not wish to be protected, for those that do the availability of ‘data advocates’ (people with expertise in ensuring data security) may be advisable.

**Users are integrating DMH into their everyday lives as a way of supporting themselves – these tools are available at the point of need. It is also a way of compartmentalising their mental health and their real world interactions.**

- Understanding how to link the virtual and real for those using DMH tools is essential. Rather than viewing them as separate they can be seen as supportive of mental health in an everyday context. For instance, by discussing how they feel online they can be encouraged in sharing their feelings offline. When integrating DMH into mental health interventions or clinical pathways, stakeholders should recognise how they can work together and encourage amalgamation.
- Clinicians should encourage patients to share whether they are using DMH resources and support them in understanding how best to integrate these into their self-management of mental health.
- In regulating/recommending it is advisable not to solely consider DMH but rather incorporate real world tools as well. For instance, recommendations can be made using existing models such as Five Ways to Wellbeing (Marks, Cordon, Aked, & Thompson, 2008) with both digital and real world components.

**Trigger warnings and clear terms and conditions should be used as they give people the choice in engaging. However, they should not be used to enforce certain choices and must be clear enough for their target audience.**

- If functionality is lost when terms are not agreed to this must be fully justified as part of that functionality. Developers need to be clear and transparent.
- If DMH is to be used as part of mental health provision and management, it is essential that commissioners and policymakers ensure system builders use clear and easy to understand language when asking for permissions or seeking agreement to access data. Whilst this will not stop system builders from restricting access when users do not agree, it will at least provide a clearer outline of what they have agreed.
- In some mental health conditions there may be changes to the individual's cognition or behaviour. It is advisable that system builders integrate ways of ensuring that consent is still valid on a regular/continual basis.

**Individuals who use DMH can connect to people that they relate to – People Like Me – and this can give them confidence through seeing their experiences and journey reflected in others.**

- Users should be wary of aligning themselves strongly to the digital identities of others. Just as they will likely play with different perspectives and not wish to represent themselves truthfully, so too might others.
- Policymakers and regulators should support and enable user autonomy by negotiating how they approach the area of 'truth' online. Regulation and moderation of DMH resources should be a process informed by their users, where rules are implemented and altered over time in an iterative way that responds to experiences.
- Clinicians and other healthcare professionals should consider how DMH can be used to educate not only users but also themselves. Simulations can help to bridge the

otherwise invisible experience of mental health by representing how one feels and what one deals with in the everyday.

**The concept of similarity and People Like Me may be used to manipulate users through, for example, false reviews or selling products.**

- Policymakers need to be aware of online dynamics and how system builders incorporate functionality. Whilst moderation may help mitigate this it is also important to advise users on how to identify when they are being manipulated. Much like strategies used to teach people about scams this would involve clear guidelines on how to identify reliable sources.

Users feel supported by DMH. Understanding how this can supplement the existing treatment and management of mental health is essential. One key area is addressing the opportunities provided by the simulative functions of new technologies and how mobile technologies have enabled these to become part of the everyday lives of so many people.

**People rely on heuristic strategies to find DMH resources. These include word of mouth but more commonly is one of searching, filtering and choosing.**

- It is essential that going forward providers of healthcare recognise the need for guides or databases that enable users to find DMH resources that can help them. This may require working more closely with existing systems such as search engines to better understand how potential users can be supported.

**DMH may be the first place that people seek help for their mental health. It is important to recognise that when first seeking DMH users are at a point of need and this distress may influence what they choose. They may also not be those diagnosed or who have accessed**



**services previously, so they do not have the same clinical language to describe what they feel or need.**

- System builders must be clear in what they offer and avoid using clinical language.
- The absence of clinical language should not be a reason for a DMH resource to be excluded from regulation/recommendation, rather the outcomes of resources need to be considered.
- Users should be supported in their use of all mental healthcare if recommended DMH resources. This includes advice and information about accessing both online and offline services.
- Better ways to provide support for those seeking DMH resources or mental health-related information should be considered by popular search engines and personal assistants (e.g. Siri). The use of algorithms or natural language processing may help enable users in accessing the resources they need, much like interventions provided in response to searches related to suicide (Miner et al., 2016).

**Users do not appear to use single DMH resources but rather develop a suite of apps that support them. Some may be used indefinitely whilst others will be used when needed.**

- For regulators/recommenders and policymakers, it is essential to recognise how DMH resources work together. This will entail understanding the different types of tools and how they are used, as well as how they are applied.
- Researchers must address the use of DMH in everyday life. This will require novel and innovative forms of research and the involvement of system builders, clinicians and users. Researchers should also consider the use of new technologies in research

and new frameworks, such as ResearchKit (an Apple product for researchers developing apps for research).

**Finding what works is a laborious process that requires perseverance, as is managing one's mental health. The way that DMH resources 'fit' involves personal satisfaction, flexibility, usability, and incorporates a range of options to suit different needs at different times. But when users must 'fit' to the resources themselves, this challenges their usefulness. Instead, how we make apps fit to the user is the crucial next step in DMH research.**

- System builders must begin developing DMH resources that can be used to support users throughout their mental health journey, adapting to and anticipating their needs. Please see section 9.7.5. for recommendations.

### **9.7.1 Development of DMH**

The development of successful DMH resources should be supported through the encouragement of close relationships between clinicians and system builders alongside the existing prioritisation of user-centred design (Gulliksen et al., 2003; Martin, Clark, Morgan, Crowe, & Murphy, 2012). This can be provided by DMH funders, recognising that it requires financing throughout the development lifecycle and across implementation and application. System builders who develop for more basic technologies must also be supported so as to provide resources for users without access to top-end devices. Technology companies should also consider maintaining support for outdated devices or software, acknowledging users who find it difficult to update and may lose important data, causing considerable distress for those with mental health concerns. Transitional moments where operating systems and resources are updated or changed are important to DMH research and of great interest. By exploring how users

and system builders respond, a greater understanding of the potential impact and consequences of changes can be achieved. The potential impact on an individual's use must also be considered if practitioners are to utilise DMH resources within mental health treatment.

Stakeholders are advised to maintain up-to-date standards in DMH, addressing both clinical and technological advances. These must be communicated into the respective fields quickly so as to ensure that resources are safe and secure, which may require interdisciplinary teamwork that is financially supported. Considering the increasing commercialisation of DMH and digital health there must be a balanced emphasis on ensuring both a clinical evidence-base and clear guidelines surrounding the design of resources to increase engagement. This requires further research to explore how technological design can improve, or challenge, the user experience for those with mental health concerns.

### **9.7.2 Researching DMH**

The issue of new research methodologies that can match DMH evidence-seeking to the speed of technological development is one that must be further addressed. It is advisable that new digital technologies are utilised, and areas such as Citizen Science are pertinent as more people turn to heuristic methods such as rating systems, or 'technologies of choice' (Graham, 2014), to identify resources. When conducting research in DMH it is advisable that researchers acknowledge the prior experiences and existing technical expertise of their participants. When selecting participants, it is important to consider whether their existing knowledge impacts their usage. Context is also significant. Users can engage with DMH resources in environments that are unusual in current mental health treatment, meaning it is necessary to apply DMH research to these milieus, exploring how use can differ when access to an intervention is anywhere and at any time.

### **9.7.3 Regulation of DMH**

DMH regulations must also account for user and system builder adaptations. Understanding that changes can easily be made at any stage presents a challenge when the concept of ‘intended purpose’ is used in regulations (Medicines & Healthcare products Regulatory Authority, 2014). System builders may make small incremental changes or can choose to make more drastic modifications to their apps. Likewise, the devices themselves run operating systems that can require significant changes to be made by users and system builders alike. It is important to consider public use of ‘clinical’ resources ‘in the wild’. The way that resources are marketed is significant, with unworkable devices challenging adherence and engagement. The use of resources across different devices, say through the browser and on mobile, can mean a discrepancy in utility that should also be addressed. Finally, the difficulties associated with the use of digital technologies, including ‘bugs’ or required updates, can lead users to face distressing cessations of function. Stakeholders must seek to reduce the impact that unusable devices or resources can have on users with mental health conditions, even when these are not specifically applied to mental health. Understanding how individuals with mental health concerns adapt and apply mainstream resources, such as calorie counters, can help in identifying guidelines for system builders.

### **9.7.4 Supporting Users of DMH**

Trigger warnings were a useful example to emphasise the very personal ‘triggers’ that individuals can have, and participants expressed the desire to filter their experiences online. Various platforms offer ways of doing so, for instance Twitter allows people to filter the tweets they see using certain words. It is important to consider how those with mental health needs can be taught these functions so as to personally enable them in using digital technologies and media

positively. Stakeholders should recognise that the presentation of mental health information online has the potential to reduce uncertainties surrounding the help-seeking process as well as helping individuals to prepare for what is to come. Participants discussed their frustration at being limited in the information that they could access or contribute as they recognised the value of their own personal experiences. They often developed their own solutions, such as setting up online groups where they could speak freely. However, the veracity of information is not clear in these situations (Lederman et al., 2014). By constructing these experiences and stories as one element of need and providing assessment tools, users can be supported in exploring what helps them personally.

The concept of People Like Me appears to be magnified through the access and targeting made possible via digital mediums. For those with mental health conditions, seeking out similar others may provide them with affirmation, recognition and reassurance. However, system builders should recognise that the value of People Like Me lies in their provision of actionable advice. Platforms which connect individuals to similar others who can provide a variety of strategies and approaches to self-management will potentially lead to more positive outcomes.

Individuals appear to construct identities online that can enable them in exploring and playing with different perspectives, meaning comments and interactions may not be a true representation of how someone is feeling. Participants constructed similar others as more credible, whilst still able to understand that what they found online was a simulation and so assessing their impact accordingly. Even stories or apps that were seen as having low fidelity and credibility could be perceived as useful if they offered the individual what they needed. Veracity appears to be a malleable concept online so it is advisable to enable individuals to interact safely within this uncertainty. This supports them to play with perspectives concerning their condition

in ways that may not be possible offline, helping them to autonomously realise their personal needs.

The issue of disclosure online is important in DMH. For participants within this study the devices and digital technologies they used appeared to offer them a way to understand the potential impact of their disclosures better. They felt better able to control not only their interactions but the responses of others and their reactions to them. This is potentially important to consider if providing therapy via digital mediums, as users may feel more comfortable communicating through a range of channels. Disclosure of a mental health condition online may not be easily retracted if one's needs change.

Simulations of mental health conditions and challenges also appear to be a useful way to provide others with information and encourage empathy. Those involved in raising awareness should consider the use of simulation, whether through new technologies such as virtual reality or simply through personal stories.

#### **9.7.5 Technology-as-Advocate – “one size does not fit all”**

Users seek out DMH resources because of the freedom that they provide; they know that there are options and that they are always there. Individuals feel they have more freedom to fail - more freedom to try different strategies - because if one does not work there are others to try. This is also characterised by less reliance on friends and family, which can be a motivator for individuals who wish to compartmentalise their mental health needs from their relationships and thus feel able to maintain control and responsibility oneself.

However, recognising the difficulty of Finding What Works in DMH is paramount to its success in the future. Understanding the processes that individuals engage in when seeking out resources to use will help to provide platforms that can support them in identifying those that are

most suitable. Current research has not clearly stated what types of DMH resources are most suitable for whom and yet this is important in helping individuals choose what to use. The participants' drive to try different things and find what fits demonstrates a desire for personalisation. Both system builders and researchers must work together to build knowledge around not only what is clinically effective but also what is engaging. A better understanding of users is also advisable so that profiles can be utilised to support individuals in finding the best DMH resources for them whilst still allowing exploration of the options available. Recognising the role of DMH as a toolkit of resources is essential. No single app or website will provide a global solution in mental health; rather an ecosystem of technologies, strategies, and interventions are needed alongside current provision and treatment.

The majority of participants in this study reported finding resources through two major strategies – word-of-mouth and through broad to narrow searches. Understanding the types of resources that are found in these ways is essential. It is important to consider what results search engines show when words associated with mental health, not just specific to conditions, are used. Participants reported that they felt that the internet was increasingly becoming the first place that individuals with mental health concerns turn. They also posit that this will continue to impact on their help-seeking behaviours. It is advisable that researchers explore these first experiences to understand how they can be improved and work alongside search engine companies to establish strategies that support people.

It is suggested that the future of Intelligent Personal Assistants (IPAs), which are expected to become more ubiquitous over the next decade, bring potential as well as serious questions around agency and autonomy, security and ethics, as well as personalisation (Cohen, Cheyer, Horvitz, El Kaliouby, & Whittaker, 2016). First generation IPAs such as Siri, Alexa and

Google have begun appearing on the devices that we use and are aimed at learning how to help us in our everyday lives. It is important to consider how that can be applied in areas such as mental health. Advocate is a term often applied to the role of an external actor who is actively involved in supporting the decisions of another who perhaps is unable to or at a disadvantage when doing so themselves (Minoletti, 2003). Current models of healthcare are viewed as encouraging the active participation of patients in their own health (Lupton, 2012; Nettleton, 2004). As such, advocates may become more necessary in supporting patients to deal with an increasing responsibility for their own self-care. IPAs have the potential to become advocates for those with mental health issues.

Technology may also be viewed as a tool. When finding People Like Me (section 9.4.3) and the right language, as well as the strength to seek help, individuals are using technology when it is needed. However, when we consider Freedom to Fail (section 9.4.1) and Finding What Works (section 9.5.3) I think we see technology acting as an advocate by enabling the individual, and not just as a tool but as a source of empowerment. When individuals seek out and find ways to self-manage or learn about their condition through a search engine they are being supported by the technology itself. It is not inherent to the technology or its use but can be applied through improvements to the processes involved. It is a purpose to which it can be supplied by system builders and applied by users. Technology-as-advocate is a way of framing these new technologies for the future – a purpose which can be encouraged and improved upon.

Implementing the concept of technology-as-advocate to the new generations of IPAs will, I believe, bring positive improvements to future development. However, automating the encouragement of ‘positive’ activities – whilst perhaps beneficial – also needs careful consideration. Alluding to the concept of Freedom to Fail, a removal of contextual understanding



and individual differences is the opposite of empowerment. Being an advocate and empowering the individual to speak for themselves also carries less risk, particularly if that individual changes their mind. The future is not one where ‘technology knows best’ but rather one where ‘I know best’. Yet, there are challenges. If IPAs are to take the role of advocates they must provide the individual with enough information to enable them to make an informed choice, and must provide them with the support to speak up or act, whilst remaining neutral. This is not easy, particularly when an individual’s decision-making power is undermined in some way. This may be due to external forces, others who enforce their power over the individual, or it may be internal to the individual themselves due to specific needs, e.g. the very young or certain conditions such as dementia or mental illness (Batchelor et al., 2012). Using the participants within this thesis and their own journeys using technology, I have explored how these technologies could act, and have acted, as advocates and how the neutrality of technology has been challenged as well as the difficulties surrounding decision-making at various times throughout the participants’ journey.

For Sarah (U/D), who discussed her experience using technology whilst having an eating disorder, there was a clear assertion that she had control over her use. When she was ill the technology presented a way to reinforce negative behaviours, a time when her decisions were influenced not by the desire to manage but the desire to get worse. This begs the question of whether we can remove the autonomy bestowed upon individuals by access to technology. For Norman (U) his experience of DMH without guidance left him feeling overwhelmed. Anne (U) actively used technology for her bipolar disorder but wished that it could do more – that it could be her voice when she was not able to speak and help her understand herself. She also recognises that it can have a negative role in her moods and that she feels better with some disconnect. If

technology advances to become our ‘personal assistant’ this begs the question of whether it can help with that disconnect. Rita (U/P) discussed how certain apps were there to return to when she needed to remind herself about coping strategies. If the concept of Technology-as-Advocate is to be successful the technology must be able to ‘understand’ both these moments and the individual, however this is challenged through what participants have identified as a gap between the quantitative expertise of digital and the qualitative needs of mental health. This in many ways echoes the difficulties within DMH as Product (section 9.3.1.) as paradigms conflict, and suggests that strategies aimed at interoperability of systems *and* their users will be necessary.

There is some evidence that users within this study actively self-advocate *with* DMH resources. This includes Seeing the Journey (section 9.4.2.), accessing People Like Me (section 9.4.3.), but more specifically it is encapsulated within the concept of Bridging Virtual and Real (section 9.6.). By learning through virtual means and then realigning oneself with the real, participants use DMH to safely explore their mental health needs. The meaning of DMH is constructed as supportive and empowering. Patterns are detected through devices and connections made between everyday experiences and mental health. This has potential not only in therapeutic interventions but also within diagnosis as it may offer a more holistic and whole-person view of a mental health condition through the collection of data from their daily life rather than solely retrospectively or within a healthcare professional’s office. System builders within this study construct their products as neutral and yet identify them as having purpose, so challenging this position. This suggests that it is at the point of use that divergences occur and yet this disregards their input, even the presence of bugs and glitches, within the development of resources. If technology is to be constructed as an advocate there must be considerable focus on the contributions made to resources by system builders throughout development, as well as the

programming itself. Essentially, Technology-as-Advocate reconstructs an evolving product, DMH, as a tool that can help people to help themselves.

### **9.7.6 Future Research**

The concept of control in DMH needs further research to explore the complexity of how actual security of devices aligns to a person's perception of such, with the concept of disclosure through technology also requiring exploration, particularly over one's lifetime (Brady et al., 2016). Existing DMH research does not account for the breadth of recovery, focusing mainly on individuals with a current diagnosis (Fulford et al., 2016) yet the role that individuals in recovery can play for those still in distress is an important finding in this study. Access online to individuals at all stages of recovery and distress is constructed by participants as important in their understanding of it is a journey. Whether there are similarities online and offline should be explored further so current practice may guide system builders in building supportive relationships online.

It appears that an external provider, like a system builder, has considerable influence within the experiences of users and, without recognising this and addressing that role, they may often be considered superfluous. It is my recommendation that as mental healthcare evolves there is a need to broaden research from looking within the system or service to understanding it from a more development-based perspective, considering it across a lifecycle of change and dynamic processes rather than as a static entity. Policy-makers will thus be in a better position to explore how these services can best be utilised going forward. This study demonstrated the potential uniqueness of DMH 'in the wild' in contrast to its use within structured interventions, a finding suggested by the concept of e-attainers but little explored in current research (Christensen & Mackinnon, 2006; Martinez, 2003; Nicholas et al., 2010).

It is essential to also recognise the role that DMH plays in easing the strain on existing mental healthcare services by providing individuals with a way to access information that is considered important to their quality of life but not necessarily relevant or pertinent with regards their treatment. Stakeholders must begin to integrate DMH within existing models of mental healthcare and understand how the issues in different areas can be supplemented by the benefits in others. Rather than viewing self-management or digital resources as external to the existing mental healthcare system (Lal & Adair, 2014) they should be drawn together and recognised as symbiotic. By constructing it within a model of compromising, where challenges faced in access or use of one area lead the individual to access and use of another, can help identify where DMH can help support mental health treatment.

### **9.8 Limitations**

Charmaz (2014) offers several questions for the researcher to assess their Grounded Theory (GT) study. These enable the rigour of the methodology to be tested by assessing the credibility and originality. A constructive GT study is not intended to follow the scientific method of testing a hypothesis, a method that cannot account for the complexity of meaning-making in the formulation of a theory to understand an experience. Instead it must be rigorous and relevant. GT is constructed through sustained involvement with participants, returning to concepts and repeatedly engaging. This ensures familiarity with the topic. The research was conducted in an emerging field where change is inherent but I felt able to respond to the data collected through my inclusion of different subworlds. However, there will always be limitations within research of this kind as there are necessary restrictions placed by the time span of a PhD and the need to work alone. It is important to consider whether the data collected was sufficient to merit the claims within the research (Charmaz, 2014). It can be argued that the small sample

size challenges the credibility of the findings within the present study, although it is not dissimilar to other theses that apply Grounded Theory Methodology (GTM) (Baker & Edwards, 2012; Soklaridis, 2009) and this is discussed within Sample Size (section 4.2.5.1.2.). However, strategies were utilised to ensure that findings were confirmable and defensible, therefore improving its credibility. The application of abductive analysis (see Chapter 3) and the use of triangulation between different methods and types of informants (Shenton, 2004) ensured there was a systematic process through which links between the data and analysis were made. This was further reinforced via an in-depth examination of my beliefs in Chapter 3 and a complete description of both methodology (Chapter 4) and the analytical process (Chapters 5-8), that can act to demonstrate the ‘audit trail’ and allow readers to scrutinise the integrity and application of the results (Shenton, 2004). Finally, a group of homogeneous stakeholders were presented with initial findings to allow invested others to appraise and challenge these results.

It is important to recognise this research not as being representative or statistically significant but that its value lies within the co-construction of meaning between myself and participants who are experts in their experience and provided rich in-depth data. Solipsism was recognised as a potential challenge but the presentation of data and inclusion of the participants’ voices meant that I had to engage in a reflective process when engaged in meaning-making. The participants themselves were often self-selecting, except where signposted. As this research explores the salutogenic nature of DMH this was not considered a challenge to the credibility of the findings.

Recruitment was a challenge within this study. Digital resources were approached as potential sources of participants but were reluctant to act as gatekeepers (see section 4.2.5.). Many of those who expressed interest failed to engage in the research, potentially due to the

nature of initiating contact through emails. I believe that in future it may be important to include more participatory observations, for instance examples of user testing, as these may offer insights that were limited when only engaging via an online medium. The strengths within this study lie within the analysis, where triangulation across and between participants (see section 5.9.) helps to ensure credibility and confirmability of results (Shenton, 2004). Considering the constructivist nature of the research my transparency regarding the analytical process (Chapters 5-8), and my own perspectives (see Chapter 3), aids in guiding the reader through the initial data to the findings.

A further limitation that I experienced was that of including external documents within the findings and results sections. Traditional PhD thesis structure is to reference external sources within the Literature Review and to maintain the results as only data collected, either quantitatively or qualitatively, within the research. As such it was a challenge to include the observations and documents without them being viewed as more appropriately placed within the Literature Review. Many were moved. Many were avoided. Those that were included show how they contributed but it can be argued that the Literature Review itself also played a significant role within the construction of categories as external documents were found, coded and analysed alongside the participant interviews. Similarly, my own observations at conferences and events were important as data and also within analysis itself. I do not feel that I have found a satisfactory solution to this dilemma and feel that this is a significant limitation as, although I am happy to provide the raw data which clearly shows my analytical process, the scarcity of observations and external documents within Chapters 5-8 would suggest that they played only a small role.

## 9.9 Summary

In conclusion, this discussion has explored the meanings constructed within the various categories and finished by addressing two important considerations that have arisen. These are constructed as a way to explore the potential of DMH within the everyday lives of system builders and users. First, this study has highlighted the need to consider not only the users but also the technologies and their development in DMH research, particularly when recognising their consumerisation (Piwek, Ellis, Andrews, & Joinson, 2016). Understanding their integration as part of a system means understanding the fluidity of meaning in development and use. Second, the analysis has identified the purpose of DMH resources as a way of introducing simulative and virtual aspects of learning in mental health. They can offer a bridge that supports and empowers individuals to practice and then apply what is learned to real life. Existing research has struggled to capture the integration of DMH into everyday life (Fulford et al., 2016; Hollis et al., 2015; Lal & Adair, 2014; Leigh & Flatt, 2015; Torous & Powell, 2015) but this study has demonstrated various ways forward for researchers and policy makers in establishing DMH ‘in the wild’.

There are several recommendations in this study, most important of which is how technology can be utilised in mental health more effectively in the future. This led me to construct the concept of Technology-as-Advocate, a constructed role for DMH resources that aims to empower individuals with mental health concerns in decision-making. It reinforces their capacity rather than removing it. This is extremely significant when recognising the rise of autonomous decision-makers and intelligent virtual agents, functions that can be used either to guide individuals positively or in ways that could disregard their independence – particularly if their behaviours or cognitions are considered unsuitable in current mental healthcare.

Technology has the potential to support individuals when they are mentally unwell. Providing safe environments so that individuals can explore different ways to self-manage and understand their mental health should therefore take precedence over using technology to enforce ways of thinking, learning or understanding.



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## **11 Appendices**

## 11.1 Participant Information Sheet

**Title:** A look at the experiences of people using digital mental health

**Researcher:** Aislinn Bergin

**Institution:** University of Chester

You are being invited to take part in this research study. It is important that you read and understand what the study will involve and why it is being done before you decide if you would like to take part. Please read everything carefully and feel free to discuss it with family or friends. I will also be available to answer any questions. Thank you for taking the time to read this.

### **Purpose of the Study**

Digital mental health describes the use of technology in the area of mental wellbeing. This study is part of a three year PhD where the experiences of those using digital mental health will be collected, through interviews and observations. At the end these experiences will be used in the researcher's thesis and the findings should help those who are using, developing, creating or implementing digital mental health resources.

### **Why have I been chosen?**

You have been chosen because of your experiences using digital mental health.

### **Do I have to take part?**

It is up to you if you want to take part. If you do decide to take part you will need to sign the consent form and fill out the list of digital resources that you have used and send it to the researcher. You are free to withdraw from the interview at any time.

### **What will I be asked to do?**

The researcher will ask to arrange a short introductory meeting first, where you can ask any questions you might have. This will usually take 15 minutes and is not part of the main study



so you will not be recorded. It will also be an opportunity for the researcher to make sure you understand what the study is all about. Once you are happy to continue a longer, 60 minute, interview will be arranged. The interview can be conducted over Skype, using video and/or audio. If we are conducting the interview over Skype you will need to read “So, you want to use Skype?”.

**What kinds of questions will I be asked?**

During the interview you will be encouraged to talk about digital mental health, your experiences in the past and present as well as what your thoughts are about the future. You will have the opportunity to show the researcher an example of a digital mental health resource or activity that you use, but only if you feel comfortable doing that.

There may also be a follow up interview. Please indicate to the researcher if you are unwilling to be contacted for a further interview.

**What are the possible disadvantages and risks of taking part?**

There is no foreseeable risk involved in this study. However, there is the chance that some of the subjects we discuss might cause you some distress. For this reason you will be provided with a list of services that may be of help. The researcher wants to make this as comfortable for you as possible so as soon as you feel uncomfortable it is important to make that known.

**What are the possible benefits of taking part?**

It is important to understand the experiences of people using, or intending to use, digital mental health. This can inform future development and also will help insure that it remains of benefit to the users. The focus is on ensuring that it is recognised for what it can do and that the future of digital mental health remains safe, secure and helpful for the people who use it.

**Will it be confidential?**

Notes, transcripts and recorded audio and video will only be accessible to myself or to you if you choose to request it. The data will be used in such a way that no one will be able to identify you from it. This will be done by ‘anonymising’ the data and changing details like

names and events. I will do everything in my power and according to the Data Protection Act 1998 to keep the data secure for 10 years, at which point it will be destroyed.

### **Review for Protection of Participants**

The research study has been reviewed and approved by the Health and Social Care Review Board at University of Chester. In the event of a complaint, query or concern regarding an aspect of the research the Executive Dean at the Faculty of Health and Social Care can be contacted:

Prof. Annette McIntosh-Scott

Executive Dean, Faculty of Health and Social Care, University of Chester,  
Riverside Campus, Castle Drive Chester, CH1 2SL

Email: [a.mcintosh@chester.ac.uk](mailto:a.mcintosh@chester.ac.uk) Telephone: 01244513380

If you are harmed by taking part in this research project there are no special compensation arrangements. If you are harmed due to someone's negligence (but not otherwise) then you may have grounds for legal action, but you may have to pay for this.

### **Who can I contact if I want more information?**

If you would like more information about the research before you decide whether or not you would be willing to take part, please contact: Aislinn Bergin: [a.bergin@chester.ac.uk](mailto:a.bergin@chester.ac.uk)

## 11.2 Skype Information Sheet

### So, you want to use Skype?

#### What you will need

Do you have the following?

- Internet connection (not GPRS)
- Speakers
- Microphone
- PC running Windows 7 or higher
- Or Mac running OSX 10.5.8 or higher
- A quiet place free of distractions (for interview)

For more information about connecting using a mobile, tablet or other device please go to <http://www.skype.com/en/download-skype/skype-for-computer/>.

#### Using Skype

If you are new to using Skype please follow the steps below. For those with a Skype account already go straight to the next section.

1. Go to <http://www.skype.com/en/anddownloadSkype>
2. Install Skype on your computer. You will need to use your email address to set up a Skype account.
3. If you need help with setting Skype up go to <https://support.skype.com/en/>. This will also give you information about how to make sure your Skype is set up privately.

#### Introductory Meeting

During our first meeting we will go through the details outlined below in more detail and I can answer any of your questions. This is a practice run that will allow us both to get used to using Skype – and get to know each other! This is when we will also arrange the dates and times of our next interview so please bring your diary.

#### Considerations

### Technical Difficulties

The fact that computers, the internet and Skype can go pear-shaped will come as no surprise to anyone. If you aren't able to make one of the interviews because of this just let me know in good time and we can arrange a different date and time. There is always the option of meeting face to face. If we are mid-interview we will try to sort it out for 5 minutes but if we fail we can arrange it for another day or alternatively arrange to meet face to face.

### Security

Make sure your computer software and anti-virus programmes are up to date. I have a password on my computer and I use appropriate anti-virus software as well as a firewall to make it as secure as possible. Unfortunately I cannot be responsible for the security of your computer but Skype has some suggestions you can follow if you are unsure <http://www.skype.com/en/security/>. No matter how secure we try to be there is a remote possibility that someone can still access our Skype session. You need to be aware of this and consider the risks associated with this. We will discuss this in more detail at our introductory meeting.

Please also be aware that any damage to your computer is your own responsibility.

### Confidentiality

I will make sure that when we are talking there is no one who can hear us and I hope that you can do the same. I will be recording the audio of our conversation but no one else will have access to this unless they go through the rigorous ethics process at the University of Chester. It will be stored in a secure place and any identifying information will be removed. If you ask me to leave out something you say I will attempt to erase it fully from the recording and if you decide you don't want to be included in the study I will erase the full recording. You can also have a copy if you like.

### Comfortable

Please make sure you feel comfortable with Skype before choosing to use it for the interviews. If you decide that face-to-face would be better at any point we can arrange to meet instead.

### Informed Consent

During the introductory meeting we can discuss any questions you may have but please feel free to ask anything in the first few minutes or at the end of the interview slots as well. There is a chance that some of the subjects we discuss in the interviews could be quite sensitive. If this happens and it causes you any distress please let me know and we can terminate the interview immediately if you wish. I will provide you with a list of contact numbers that you might find helpful but I would also ask you to provide me with the contact details of someone close to you who I can call in an emergency. These details will be destroyed as soon as the final interview is over.

### **Skype Privacy**

Skype can only collect information that you share with it. Please be aware that Skype collects data about:

1. Who you are e.g. name, address, age
2. What you do online e.g. through cookies and your IP address
3. How you use Skype e.g. who you call, where you call from
4. The content of your messages e.g. Instant Messages

They will only share this if there are legal reasons and for the security or protection of themselves and their customers. However, they may share some information with their partners but only if those partners comply with European Data Protection (for US services they must be signed up to the Safe Harbor framework).

Personal messages are kept by Skype for between 30 and 90 days. If you would like them to delete your data you have the right to ask them to remove your data and your profile. They will usually do this within 14 days unless there are legal reasons not to.

For more information: <http://www.skype.com/en/legal/privacy/>.

### 11.3 Consent Form

**Title of Project:**

A constructive grounded theory study of the experiences of autonomous users of digital mental health.

**Name of Researcher:**

Aislinn Bergin

Please initial box

- 1. I have read and understood the participant information sheet and have had the chance to ask questions.
  
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
  
- 3. I understand that with my permission the interview will be audio-recorded, and the screen videoed.
  
- 4. I agree to take part in the above study.
  
- 5. I understand that the data will be written up as part of a report and that I will not be able to be identified in the report.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Researcher	Date	Signature

#### 11.4 List of DMH Resources

Do you use or have you used any of the following to maintain positive mental health and/or wellbeing? Please tick those that apply:

- Text Messaging
- Emails
- Computer Applications/Software
- Videos
- Audio
- Virtual Reality
- Augmented Reality
- Sensors
- Wearables
- Smartphone Apps
- Websites
- Web Apps
- Social Networks
- Forums
- Blogs
- Search Engines
- Games
- Instant Messaging
- Podcasts
- Other (please specify)

### 11.5 Assessment of Compliance

1. They have experience of at least one digital mental health resource or activity.
2. An adequate grasp of English. Participants verbal skills will be assessed alongside competence, see number 5.
3. Excluded if under the age of 16. Participants' age will be assessed visually. If they appear under the age of 16 they will be asked to demonstrate proof of age.
4. To ensure informed consent an assessment of competence will be made:

Using the British Medical Association's Mental Capacity Act tool kit (British Medical Association, 2007) this list of criteria will be used in the Introductory Meeting to assess competence of the prospective participant to provide rich and detailed data regarding their experience using and accessing digital mental health. Because of the need within GT to capture in-depth the complexity of this experience (Charmaz, 2014) those who are assessed by the researcher to be unable to comply with the following criteria will be considered unsuitable to proceed with the research.

The assessment will be repeated at the Interview if the participant shows signs of diminished capacity.

The participant must be able to:

Understand the information relevant to the decision.

Can you tell me in your own words what this study is about?

- Technology and mental health
- My experiences

Retain the information relevant to the decision.

What is your understanding of what I will be asking you to do and the kinds of questions I will be asking?

- An interview
- Showing you an example
- Questions about my experiences past, present, future



Use or weigh the information (to make the decision).

I'd like you to tell me what the risks are. What made you decide to participate even though there are risks?

- To help future research
- To help users, developers, creators or implementers
- Specific example of someone who it might help i.e. a developer of an app or people who use internet forums

Communicate the decision (by any means).

(assessed through signing the consent form)

The decision is taken to be 'participation in the named study'.

Criteria are taken from P.10-11 of the BMA Mental Capacity Act tool kit.

## **11.6 Interview Guide (amended)**

### **Topic 1: Focused Life History**

The purpose of this is to look at the context of the participant's experience, to assess the 'why' by enquiring into their past experience with technology and mental health, both together and separately.

#### Areas of Interest

- Past experience with technology
- Past experience with health and wellbeing
- Past experience with digital mental health

#### Question

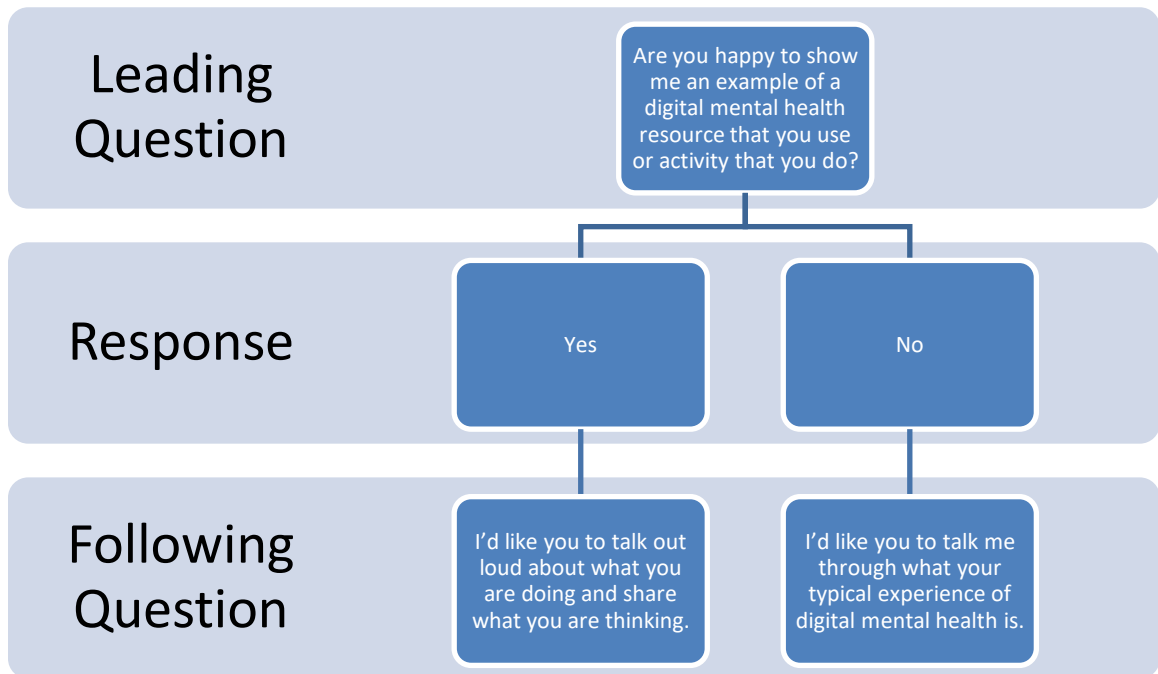
1. How did you come to start using digital mental health?
2. Could you describe the different resources you've used and how you've used them?

### **Topic 2: Details of Experience**

The purpose of this part of the interview is to bring their experiences into the present.

#### Areas of Interest

- Information pertinent to their usage – when, frequency, etc
- Their choices
- Benefits and concerns



Question

3. Are you happy to show me an example of a digital mental health resource that you use or activity that you do?

If the participant responds Yes they will be asked to demonstrate an example of digital mental health that they use. If they agree they will be asked to ‘think aloud’. This brings the experience into the present and helps to capture their experience of using digital mental health.

Question

4. I’d like you to talk out loud about what you are doing and share what you are thinking.

If the participant responds No they will be asked to instead speak about an everyday experience of digital mental health.

Questions

5. I’d like you to talk me through what your typical experience of digital mental health is.

**Topic 3: Reflection on the Meaning**

This will address the more reflective aspect of their experience. It is an opportunity for the interviewer to ask questions that clarify the meaning of topics/words that have arisen as a result of previous questions, capturing in more detail how the participant constructs their understanding/experiences. It is also an opportunity to allow the participants to reflect on their intentions within the use of digital mental health and to offer advice around its use.

### Areas of Interest

- Purpose
- Intentions
- Future use

### Questions

6. Are there any specific experiences associated with the resources we've just spoken about that you would be happy to tell me about?
7. How has using digital mental health impacted your life?
8. Could you tell me in more detail what you meant by....
9. What advice would you give to someone who is thinking about using digital mental health?

### Conclusion

10. Would you like to tell me more about anything that we have discussed or ask me any questions?

### Areas of Theoretical Interest

- The mental health journey and where these resources are placed
- Empathy and what that means to them

## Digital Mental Health in the Wild

- Different types of support
- Choice and how decisions are made
- Anonymity and what that means to them
- The burden of an illness

11.7 Extant Documents

	mHealth App Developer Economics 2014	mHealth App Developer Economics 2015	mHealth App Developer Economics 2016	Patient Adoption of mHealth
<b>How are texts written?</b>	Professional, statistical	Professional, statistical	Professional, statistical	Professional, statistical
<b>How are texts read?</b>	Report – access restricted	Report – access restricted	Report – access restricted	Report – access restricted
<b>Who writes them?</b>	Not clear	Not clear	Not clear	IMS Institute for Healthcare Informatics
<b>Who reads them?</b>	App developers	App developers	App developers	App developers, researchers
<b>For what purposes?</b>	Informative, instructive	Informative, instructive	Informative, instructive	Informative, instructive
<b>With what outcomes?</b>	Economic awareness	Economic awareness	Economic awareness	Educational, establishing IMS

<b>What is recorded?</b>	Survey results	Survey results	Survey results, appraisal, research
<b>What is omitted?</b>	Viewpoint of users and funders	Viewpoint of users	n/a
<b>What is taken for granted?</b>	Understanding of mhealth economy	Understanding of mhealth economy	Understanding of mhealth economy
<b>What do readers need to know in order to make sense of them?</b>	Research2Guidance offer consultancy in digital health and so produce these to demonstrate insights into why app developers might need them	Research2Guidance offer consultancy in digital health and so produce these to demonstrate insights into why app developers might need them	IMS produce a number of reports using big data in the arena of healthcare

	<b>Clare Rose Foster's Blog</b>	<b>Innovation Labs' Blog</b>	<b>I tried to fix my mental health on the internet</b>
<b>How are texts written?</b>	Familiar, first person	Familiar, first person, informative	Familiar, first person

<b>How are texts read?</b>	online	online	online
<b>Who writes them?</b>	Clare Rose Foster	Joe Roberson, Lucy Simons, Scott Hague, Mark Brown	Joe Madden
<b>Who reads them?</b>	Healthcare professionals, bloggers	App developers, researchers, healthcare professionals	General public
<b>For what purposes?</b>	Informative, instructive	Informative, instructive	Informative, instructive
<b>With what outcomes?</b>	Awareness, establishing self	Awareness, educational	Awareness
<b>What is recorded?</b>	Own experiences and thoughts	Own experiences and thoughts	Own experiences and thoughts
<b>What is omitted?</b>	n/a	n/a	n/a
<b>What is taken for granted?</b>			
<b>What do readers need to know in order to make sense of them?</b>	Clare works on contracts so relies on her blogs to generate interest in what she can offer	Innovation Labs were funded during development of 7 mh apps alongside young people, no longer operating	Joe is a freelance journalist. I cannot find any other articles relating to mental health



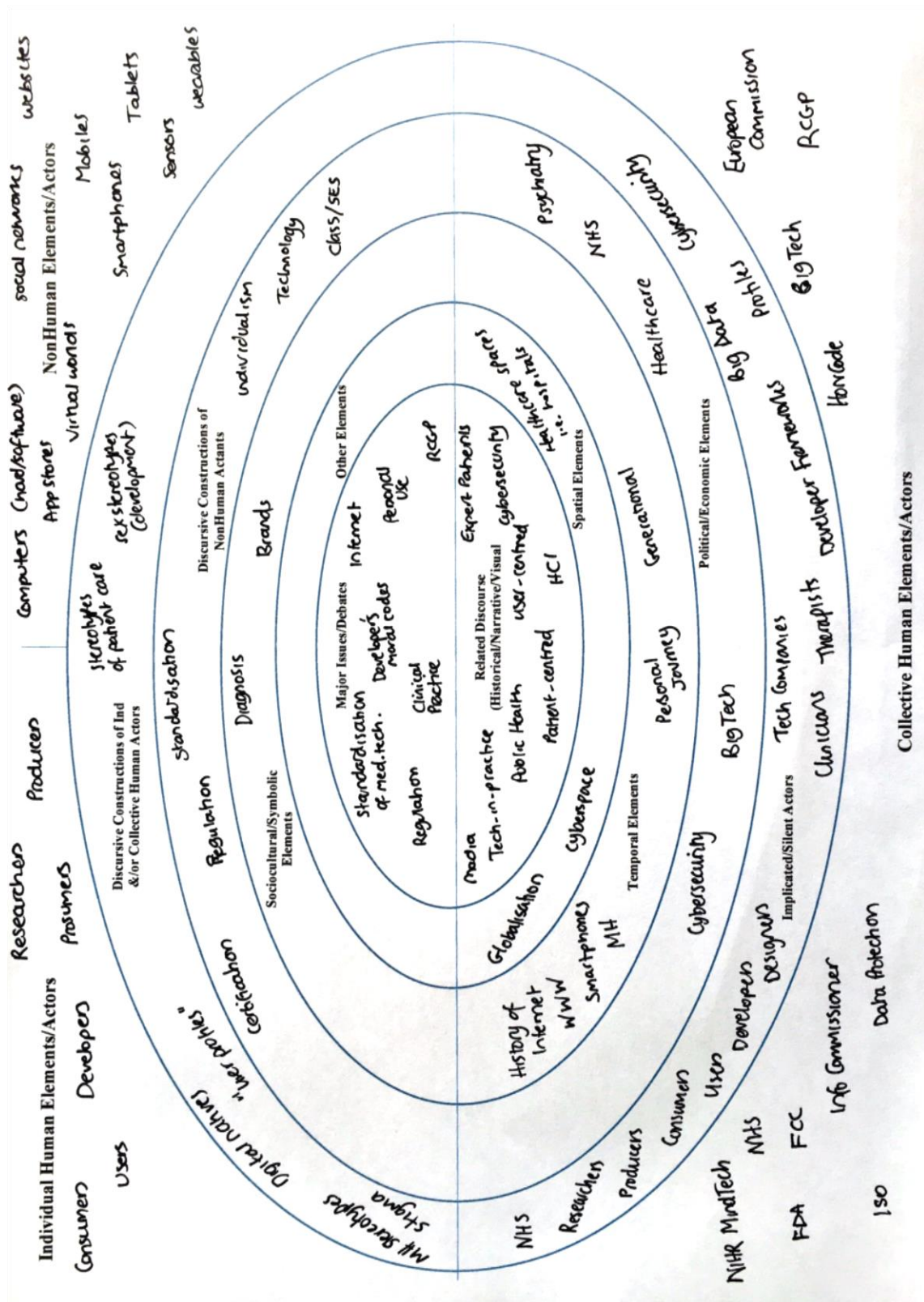
	<b>Games and Mental Health (Video)</b> Christos Reid and Zoe Quinn	<b>The Digital Human (podcast)</b> Aleks Krotoski	<b>State of Mind (podcast)</b> Claudia Hammond
<b>How are videos presented?</b>	Familiar	Professional	Professional
<b>What format are they?</b>	Interview	Interviews, presentation of facts	Interviews, presentation of facts
<b>Who listens/ watches them?</b>	Gamers	General public	General public
<b>For what purposes?</b>	To raise awareness of mental health amongst gamers, to discuss own experiences of mental health and use of own experiences in development	Explore the digital world, how people interact with technology	Explore mental health in the UK and how it has evolved over time

What is recorded?	Own experiences and thoughts	Others' experiences and research	Others' experiences and thoughts
<b>What is omitted?</b>	Places to seek help		
<b>What is taken for granted?</b>	Video games are an effective way to communicate mental health		
<b>What do readers need to know in order to make sense of them?</b>	Zoe Quinn was at the centre of Gamergate when her game DepressionQuest received positive reviews and gamers accused the reviewer of impropriety because they were in a relationship. This led to horrendous online abuse of women in video games. Christos is from the UK and has developed a number of apps that aim to show people what it is like to live with OCD	The format is often around exploring what people are doing in relation to specific questions or issues in the digital world. Many of these relate to the ways we communicate, feel, experience, etc through and with digital technologies.	This podcast sometimes covers the way mental health treatments are prescribed, how people experience them, and the way that society constructs mental illness.

### 11.8 List of Events/Observations

Event	Notes	Article	Report
IT Tools for Psychological Therapy Services			
European Telemedicine Conference			
EHI Live Conference 2013			
Technological Innovation in Mental Health			
Design for Health and Wellbeing			
Recent Developments in Digital Health			
Playing games, using apps, promoting wellbeing			
Big Data in Mental Health			
EHI Live Conference 2015			
People Driven Digital Health			
Technology for Wellbeing			
Mood Disorders and Technology: Understanding and Meeting the Unmet Need			

### 11.9 Situational Analysis



### **11.10 Memo**

10<sup>th</sup> January 2015: DMH as Self-Care

Are the people I'm interviewing using dig mh as an element of their self-management? Or do they identify with an online existence? Most forum interactions are about medication, side effects and experiences, rather than self-help. Are they just trying to gain control over their experience with the healthcare system? Is there more meaning to it i.e. a desire to 'cope', to become self-sufficient, or is it just them attempting to reassert control that they feel they have lost, to reassert some certainty in the face of the uncertainty of their experience? The neurodiversity movement came about as a result of online groups (Jaarsma and Welin, 2011) and it challenges the status quo. Foucault talks about 'madness' as though it is a construct of society, perhaps in much the same way these online groups are constructing alternatives to the way it is viewed by society? If this is the case then how do I realign the viewpoint of self-management for an experience and it being a construct of the experience itself? Need to distance myself from presuming digital mental health is a form of self-help.