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Understanding young adults' online engagement and health experiences in the age of social media: exploring diabetes and common mental health disorders

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Abstract

Production and consumption of text, image and video content about both diabetes and common mental health disorders (CMHDs), by individuals and organisations, has become commonplace since the widespread adoption of social media. Despite the increasing importance of these online spaces for health-related discussion few studies have fully explored people's experiences of drawing on social media content around either diabetes or CMHDs. The aim of this study was to explore the multiple ways young adults engage with health-related content online and develop an understanding of how social media are used for health information and communication. A further aim was to explore the areas of convergence and divergence between professional producers' perspectives on online resources about diabetes and CMHDs and prospective users' perspectives. To explore these issues, a qualitative study was developed. Forty young adults, aged between 18 and 30 years, and six professional producers took part in semi-structured interviews.

The key findings of the study reflect the increasing prominence of health-related user-generated content online. While continued reliance on search-engines for locating relevant content was evident, some participants discussed accessing health-related content as part of their everyday social media activity. Further, participants' perceptions and experiences of support from family, friends and formal health services appeared to relate to their online practices: those who described least supportive resources offline discussed engaging most actively in production and consumption of health-related user-generated content. Participants also discussed what limited their production of health-related content, suggesting that production of content related to diabetes or CMHDs could compromise their presentation of self online. Disjunctures were evident between the perspectives of producers and potential users, with producers prioritising dissemination of generic information and young adults emphasising the consumption of tailored content. The findings of the study suggest key opportunities for exploiting the potential of social media to engage with users but highlight potential barriers to some individuals' engagement.

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Author's declaration

I declare that, except where explicit reference is made to the contribution of others, that this dissertation is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.



Signature _____

Printed name Gillian M Fergie

1 Introduction

Since the rapid expansion of internet access in the United Kingdom (UK) in the late 1990s and early 2000s, there has been growing interest in the potential impact that accessing online information has on people's experiences of health and illness. In the UK, use of the internet to find health information has remained stable over the last decade with around 70% of current users reporting accessing online resources related to health issues (Dutton et al., 2013). Sources of health-related content online are many and diverse, and include professionally produced sources of medical information as well as lay accounts of health and illness (Hardey, 1999). Content ranges from preventative medicine and healthy lifestyle information to information for patients on chronic and acute disease management (Rich and Miah, 2009). Ziebland and Wyke (2012) provide a summary of the wide range of resources available to internet users to gain access to other people's experiences of health issues - from homemade YouTube videos to decision-making aids and consumer-review sites.

Appropriating, interpreting and contributing health-related content has been possible since the inception of the internet (Hardey, 2001). These processes, however, have become easier and more common since the proliferation of social media technologies (such as YouTube and Facebook) (McNab, 2009). Online practices also continue to alter with innovations in information and communication technologies (ICTs). The number of users who use multiple and mobile devices to access online content is increasing and reliance on search engines is decreasing, with users increasingly choosing to find information shared through links amongst their online social networks (Dutton et al., 2013). The internet, therefore, offers a dynamic range of health information which can be accessed and appropriated by a vast number of users at any time and users' practices within online spaces continue to develop. There has been limited qualitative research which explores users' perceptions of dynamic health-related content, their experiences of accessing online resources since the rise of social media and the impact of these processes on their offline health experiences.

1.1 Scope of the study

The primary focus of the study is the use of the internet and social media technologies to access varied forms of health-related content. Rather than explore these processes broadly, specific health issues and a key population group were identified to define the scope of the study.

Firstly, in order to ground the study in particular health contexts, two contrasting health issues were identified as exemplars, namely diabetes and common mental health disorders (CMHDs), such as depression, anxiety and stress. Diabetes mellitus is a chronic disease caused either by the inability of the pancreas to produce insulin or the insensitivity of cells to the insulin produced. Diabetes UK (2014) estimates that more than one in 17 people in the UK has diabetes (including some undiagnosed cases). Of these, they suggest 10% have Type 1 diabetes, with the remainder having Type 2 diabetes. CMHDs are a key public health priority across the UK. Population level estimates published by the Office of National Statistics suggests that one in five people in the UK (19%) is affected by anxiety and depression, with rates higher in women (21%) than men (16%) (Beaumont and Lofts, 2013). Increasingly online interventions and online resources are being developed by health services and organisations to support individuals' experience and management of both diabetes (Lorig et al., 2010, Mulvaney et al., 2010) and CMHDs (Postel et al., 2008). The internet also offers informal access to accounts of other people's experiences of diabetes and CMHDs, impacting users' in a range of ways which might inform their health experience and development of self-management practices (Ziebland and Wyke, 2012). By exploring how individuals with diabetes or experience of CMHDs access and appropriate health-related content, insights around the impact of online resources on people's health experiences and self-management practices were generated.

Secondly, rather than explore a wide age range, where there may be very different levels of confidence and competence in engaging with social media, the focus of this study is primarily on young adults' (aged 18 to 30 years) perceptions and experiences. This age group was selected because of their general propensity for

online engagement and use of social media. Other considerations, related to the sample and scope of the study, are discussed in more detail in the following chapters.

1.2 Study aims, objectives and research questions

The broad aim of the study is to explore engagement with diabetes and mental health content on the internet to:

- Develop an understanding of the multiple ways by which young adults engage with health-related content online
- Develop a holistic understanding of how social media are used for health information and communication currently amongst young adults and professional producers of online health resources
- Identify areas of convergence and divergence across developers', users' and contributors' perspectives on online health resources and provide insights around opportunities for future resource development in line with users' preferences
- Explore the differences and similarities between the processes and practices of engagement with content about diabetes and CMHDs, and between men and women.

The following research questions were developed to address the aim and objectives of the study:

- What are young adults' perceptions and experiences of engaging with health-related content on the internet and through social media technologies?
- How are the internet and social media technologies used by young adults in self-management of health issues? Are there differences or similarities between people with experience of different health conditions and between men and women?
- How do professional producers view the needs of potential users of online health resources and how do these views align with young adults' conceptions of the role of online resources?

1.3 Thesis structure

Chapter 2 presents an overview of some of the theoretical literature that relates to health and the internet; highlights the main themes in the empirical literature; and

provides a synthesis of literature focused specifically on social media and health, and in particular diabetes and CMHDs. Chapter 3 describes the methods used in developing and conducting the study, including reflections on my role as the researcher and my interactions with participants both online and offline. Chapters 4 to 6 report the main findings of the study. Chapter 4 provides a description of how and why the young adult participants approached online content about diabetes or mental health and how they identified and appropriated relevant content. Chapter 5 offers a detailed exploration of participants' perspectives on social media content related to their health experience, and a typology of how they engaged with user-generated content in relation to their experiences of offline support is proposed. Chapter 6 presents the professional producers' perspectives on the creation and management of online resources for diabetes and CMHDs alongside the young adults' perceptions of the limitations of online resources. Chapter 7 provides a discussion of these findings in relation to the relevant literature and details the strengths and limitations of the study. The thesis is concluded by considering issues which could benefit from future research and suggests some implications for professional producers of online resources and those considering social media as a site for intervention with young adults.

2 Literature review

2.1 Overview of chapter

The importance of online technologies in people's everyday lives and their emergence as a key site for health communication of various sorts has prompted a growing body of research literature, both theoretical and empirical. In this review of the literature an overview of some of the broad theoretical perspectives which underpin much of the research around health and the internet is provided. This is followed by an exploration of some more recent theoretical concepts which have informed the development of this study. Next a discussion of the diverse empirical literature focused on health and the internet, emanating from various disciplines and research traditions, is presented. Finally, a review of studies of social media in the context of people's experiences of either diabetes or CMHDs is provided.

2.2 Health and the internet: setting the theoretical context

The literature on health and the internet is diverse and draws on a number of theoretical interpretations of the social world. In particular, theories of the 'network society' and 'information society', and of 'risk' and 'reflexivity', underpin the growing canon of research about the presence of health-related content on the internet. After describing these concepts, the key issues which inform research on the production and consumption of health-related content on the internet are discussed. Next, sociological concepts relevant to the study of health and the internet are introduced. In particular the concept of 'e-scaped' medicine is explored, and its implications for the construction of medical knowledge and the relationships and tensions between 'lay' and professional understandings of health. Finally, the phenomenon of social media will be considered, and the implications of these dynamic facilities for the active production and consumption of health knowledge are discussed.

2.2.1 Risk

The concept of risk has informed much of the sociological literature around health, as well as policy and practice in public health. Aspects of 'risk' which are

particularly pertinent to people's use of online resources for information and communication about health include: issues of expertise and knowledge-making; and the processes of reflexivity and consumerism.

Ulrich Beck's concept of the 'risk society', a society characterised by the pervasiveness of risk, is a central concept in contemporary sociological analyses of the life world. It has been adopted and adapted within a range of disciplines as a useful tool for exploring contemporary social phenomena. Beck (1992a, 1992b, 1994) and Giddens (1990, 1991) propose a number of consequences of the pervasion of risk in society. One of these is the emergence of a culture of risk identification and calculation. Beck suggests that the processes of risk identification and calculation highlight a discord between 'lay' and 'expert' perspectives:

[...] what becomes clear in risk discussion are the fissures and gaps between scientific and social rationality in dealing with the hazardous potential of civilization. The two sides talk past each other. Social movements raise questions that are not answered by the risk technicians at all, and the technicians answer questions which miss the point of what was really asked and what feeds public anxiety (1992b: p. 30).

Despite this apparent discordance, lay and expert interpretations of risk do coalesce at particular junctures. Since many expert processes of risk calculation, such as epidemiology, are complex and produce results which can be difficult to interpret, lay people often rely on expert advice to quantify and react to risk prospects. Beck, however, suggests that the relationship between the construction of lay and expert risk knowledge is not as simplistic as this paternalistic, one-way mode of communication might suggest. Lay people in contemporary Western societies are understood by Beck as consistently offering a critique of science and expertise. This public critique stems from the high degree of contestation which is inherent in the production of scientific knowledge. Science consistently appears fallible due to regular disagreement between scientific experts and the role of science in producing controversial technologies which in themselves constitute risks (e.g. genetically modified foods). Such disputes foster public scepticism over

expert risk identification and advice, and as a result lay people's decision-making around risk is bound up with issues around information credibility and trust in expertise. Public challenges to science are regularly made visible online, where the circulation of alternative knowledge around particular health issues has flourished. For instance Kata's (2010) study of anti-vaccination content identified the existence of alternative post-modern vaccine narratives online, which she suggested cannot be adequately addressed through traditional approaches to health promotion or education because they are based on the biomedical knowledge that the users contributing anti-vaccine narratives reject.

A further consequence of the emergence of the risk society, noted by both Beck (1992b) and Giddens (1991), is the changing role of the individual in society. One of the central tenets of the reflexive modernisation thesis propounded by Beck is the notion of the 'reflexive actor', a participant in society who is characterised by his or her active decision-making and not by traditional social divisions, such as class and gender. He suggests:

Individualization in this sense means that each person's biography is removed from given determinations and placed in his or her own hands, open and dependent upon decisions. The proportion of life opportunities which are fundamentally closed to decision-making is decreasing and the proportion of the biography which is open and must be constructed personally is increasing. Individualization of life situations and processes thus means that biographies become self-reflexive; socially prescribed biography is transformed into biography that is self-produced and continues to be produced (1992b: p. 135).

Similarly, Giddens (1991, 1994) suggests that individuals engage in 'the reflexive project of the self' which involves filtering and responding to the wealth of risk knowledge in a constant process of choice to maximise the benefits for the self. The individual, therefore, is central to Beck and Giddens' concept of risk. As the risk society emerges individualisation is promoted and traditional cultural barriers reconfigured. This has a number of consequences for individuals' management of

their health. Proliferation of risks gives rise to a series of decision-making opportunities for the individual through processes of surveillance and screening, preventative medicine, healthcare, and health promotion, which allow for people's routine management of health risk in late modern societies (Bury, 2005). Hardey (1999) notes the importance of the internet in giving people access to consume information they may require for negotiating decisions and concerns about health and illness. He stresses in particular that this content could include knowledge ordinarily confined to experts as well as opportunities for peer-support. Similarly, a recent editorial by Petersen and colleagues (2010) presents a number of examples of online text, such as targeted lifestyle marketing and virtual support groups, which illustrate the plethora of direct health marketing to consumers pursuing 'healthy' lifestyles online. A number of key empirical studies explore the consumption of online health content in everyday life and allude to risk-related literature (Henwood et al., 2003, Broom, 2005b, Fox et al., 2005, Nettleton et al., 2005, Lewis, 2006a, Kivits, 2009). These studies highlight key issues related to the intersections between risk theory, health and the internet, some of which are discussed in more detail in the review of empirical literature (p. 29).

2.2.2 The network society

A further theoretical perspective relevant to the study of health issues and online technologies is the 'network society'. The internet and the creation and passage of information throughout networked societies is said to be a defining phenomenon of late-modern society (Van Dijk, 2006, Castells, 2011). In Castells' (2011) terms, the network society is defined, in part, by information and communication technologies (ICTs). He suggests that increasingly ICTs constitute the central tenet around which society's various networks are organised as well as the means by which information flows. The concept of the 'network society' is closely related to the characterisation of late-modern society as the 'information' or indeed, 'informationalized' society (De Mul, 1999). Alongside conceptualising society as a series of networks, some theorists foreground the importance of the passage of information to the everyday functioning of society. Webster (2006) contends that in the West "information and communication technologies are now pervasive and

information has grown in economic significance” as the substance and output of much employment. While the term ‘information society’ has been contested, with some theorists critical of the move to conceptualise society as transformed (in a revolutionary sense) by information networks since traditional economic and social constraints pervade (Webster, 2006), the concept of networks and importance of information has been appropriated in many disciplines.

Van Dijk (2006) provides a multidisciplinary survey of the significance of networks as they shape and increasingly structure economies, politics and societies. He suggests that the internet has blurred established boundaries in society between micro and macro (or private and public) networks and as such is a site for the meshing of interpersonal, organisational and mass communications. Similarly, Papacharissi (2010) suggests:

The evolving centrality of ICTs in the everyday experiences of the self [...] spawns a set of consequences which reposition the private individual within a globally networked society, in an organizational framework revolving around what Castells (2000) has referred to as the *net* and the *self*. Ultimately, this is a question of autonomy and control, fantasies of which online technologies inspire and sustain (p. 516).

Online technologies, which have become part of everyday experience for many people, re-position individuals as part of wider networks, which do not adhere to traditional structural and hierarchical boundaries, allowing greater freedom to communicate and engage across networks. This phenomenon has also redefined previously entrenched national boundaries providing greater opportunities for cross-cultural and cross-national communication (Golding, 2000). More recently, theorists of the network society have suggested that information technologies are being appropriated by users and are no longer provided and controlled by developers. Castells (2011) describes users who are now appropriating and altering internet technologies in parallel with developing new cultures and practices. It seems, therefore, that the blurring of boundaries of space and time, as well as technology, by individuals and networks of individuals, is a crucial development of

the network society and a concept which can be usefully interrogated within specific contexts.

The concept of the network society has prompted interpretation and analysis of the nature and impact of information and communication technology across a number of academic disciplines. Webster (2002) provides an overview of the significance of the network society in terms of medicine and health, outlining three defining features of the network society which characterise medicine and health in the late modern society: the computer dependency of biological research, which requires computer technology for endeavours such as mapping the human genome; the delivery of medicine through technology (e.g. telecare, telemedicine), which distances practitioner from patient and delocalises health practice; and the collation and analysis of risk-related information, which prompts greater lay and professional interpretation of probabilities related to individual genetic and lifestyle risk-factors. These features contribute to a re-working of the definitions of health and the body in contemporary society (Brown and Webster, 2004). They reposition the professional and the patient, and significantly alter relationships between these actors. Simultaneously, descriptions and understandings of new technologies alter conceptions of medicine in wider culture. Communication technologies, therefore, have a crucial role to play in the public's understandings of medicine, their experiences of health and illness, and their interactions with health professionals.

Nettleton (2006) identifies two further characteristics of the network/information society related to health. She suggests that the prominence of an 'evidence-based' approach to medicine coalesces with the concept, since health policy and practice are increasingly influenced by the assimilation and proliferation of information rather than clinical experience. Most notably for this study, she also suggests the growing contemporary phenomenon of 'consumer health informatics' is concomitant with the wider emphasis on networks and the passage of information in society. Consumer health informatics is the term used to describe the analysis and implementation of various approaches and strategies for supplying health information to individuals through computers. While the evolution of consumer

health informatics suggests a move toward the transparency and availability of medical knowledge, some suggest it breaks no new ground. Seale (2005) and Nettleton et al. (2005) have suggested that accessing health information online is similar to accessing health information via print media, in that websites, like newspapers, often present mainstream information most accessibly and ‘bury’ less well-accepted information. Indeed, as with print media, the internet, through search engines, prioritises certain types of knowledge (or information), often that which is biomedical and governmental. As a result, the network society, and the passage of information through online networks, cannot be seen as an entirely disruptive force to established hierarchies of knowledge within medicine. However, the significance of new information technologies and the networks they precipitate invites constant re-evaluation of this. The introduction of any innovation, particularly related to information and communication technologies, can impact hierarchies and relationships within society related to medicine and health (Brown and Webster, 2004). Indeed, the developments in users’ information-seeking practices, with increasing reliance on social networking sites (Dutton et al., 2013), is perhaps of particular interest for understanding contemporary developments in how health knowledge is constructed and communicated.

2.2.3 E-scaped medicine

Building upon conceptualisations of both the risk society and the information age, Nettleton and Burrows (2003) and Nettleton (2004) have explored the importance of information and information flows with a focus on the specific context of medicine and health. They suggest:

[...] information (or indeed knowledge) may be rationally produced in a range of locations but, within the context of the information age, it can become irrational in terms of its circulation and distribution. Knowledge flows through networks and is disembedded and detached from its source of production. Furthermore, the act or ‘reflex’ of sourcing information becomes inseparable from the act of assessing and responding to it (Nettleton and Burrows, 2003: p. 175).

This move away from carefully packaged and distributed information from known and trusted sources, facilitated by the increasing pervasion of internet technologies, raises a number of issues for the provision of medicine and health. Firstly, the array of health information available to internet users is diverse and expanding, with sources ranging from governments and charities to commercial organisations and individual users and groups of users (Hardey, 1999). Secondly, engagement with this information cannot be contained or monitored and therefore could be either systematic or fleeting, since users employ their own tailored strategies for searching (Adams et al., 2006). Online information seeking allows for different types of knowledge, created according to different criteria and for different purposes, to be available on the same terms, as information for individual assessment and appropriation (Nettleton and Burrows, 2003). This re-sites power from provider to consumer with users able to access various alternative forms of information and engage with health information on their own terms (Webster, 2002). For some medical professionals, policy-makers and academics this causes concern and has precipitated a plethora of literature on ensuring and assessing the quality of online health information (e.g. see Silberg et al., 1997, Eysenbach et al., 2002). Their concern is with the preservation of 'expert' medical knowledge or, in Foucauldian (1973) terms, with sustaining the discourse of scientific medicine. However, some suggest that the issues of sociological interest, related to health information on the internet, go beyond concerns about reliability and quality of information.

One of the wider effects of the growing phenomenon of diffuse medical knowledge, identified by Nettleton (2004, 2009), is that medical knowledge is no longer in the possession of experts alone, but is now widely available and beyond regulation and control. She suggests that this effect constitutes a new 'medical cosmology' in Jewson's (1976) terms. Jewson charted the social organisation of medicine: from the bedside, where the patient had some purchase over the medical encounter; to the hospitals, where doctors acted autonomously on coherent theories of disease diagnosis; to the laboratory, where scientists determined the origin of disease through microscopic means. To these cosmologies Armstrong (1995) added a

further shift, to ‘surveillance medicine’, by which epidemiologists characterised disease at population level. At each shift the positioning of the individual becomes more abstract, at the outset the individual is an active actor in the medical encounter, but by the advent of ‘surveillance medicine’ the individual exists as a statistic. Nettleton’s (2004) addition to this system of cosmologies is based on the shifting focus of medicine toward information and ICTs. Not only does the internet allow for the indiscriminate dissemination of medical knowledge, it provides a facility for users to consume and produce medical knowledge:

Medical knowledge is no longer exclusive to the medical school and the medical text; it has ‘escaped’ into the networks of contemporary infoscapes where it can be accessed, assessed and reappropriated. Rather than being concealed within the institutional domains of medicine, knowledge of the biophysical body seeps out into cyberspace and may be accessed and assessed by non-‘experts’ (Nettleton and Burrows, 2003: p. 179).

Nettleton and Burrows (2003) refer to this shift as ‘e-scaped medicine’, building on the theory of the ‘informatization’ of the worldview propounded by de Mul (1999). This contention suggests individuals’ realities are transformed by the information which now courses throughout society, via technology. Nettleton (2009) suggests that the emergent medical cosmology re-establishes an active role for the individual in creating medical discourse. As Jewson described the disappearance of the ‘sick man’ from his role in bedside medicine, Nettleton describes the re-appearance of sick and healthy men and women as producers and consumers of health knowledge, through networks of technologies.

Nettleton’s description reflects the plurality of health-related information available online - preventative medicine and healthy living information are both prominent, as is chronic and acute patient information (Hardey, 1999). Her description also foregrounds the diverse user group of online health information. She lists “the sick person, the passive patient, the expert patient, the inert body, the responsible and the culpable individual and the health care consumer, and more recently the ‘prosumer’” (2009, p. 636). These characterisations illuminate the diverse range of

individuals who engage directly with health information. Her list extends beyond ‘patients’, as people engaged in the healthcare system, to ‘the responsible individual’. This is perhaps reflective of the growth in individual health consciousness across the late-modern world, stemming from the emergence of cultures of vulnerability and risk (Crawford, 1987).

Furthermore, research has highlighted that some users are distinguished by their use of the internet for health information. In particular, the expert or resourceful patient, who is conscientious about being informed (Muir Gray, 2002), is at the forefront in terms of online information seeking (Ziebland, 2004). Similarly, the ‘prosumer’ (producer *and* consumer of content) is characterised by engagement with online sources of information, but in this case their engagement extends beyond merely *consuming* health information to *production* of health information, as a contributor of health-related content, typically through social media (discussed below). In recognition of the variation in individuals’ use of the internet, calls have been made for research which explores the experiences of individuals as they engage with health-related online content in everyday life, not only as a result of a period of ill-health (Henwood et al., 2003, Nettleton et al., 2005, Kivits, 2009). One potential extension of this call, related to Nettleton’s observations about ‘prosumers’ of health-related content, would be to explore the everyday lives of the individuals whose lives are now permeated with social media and mobile internet technologies and how these dynamic technologies impact their access to and appropriation of health content, and their health experiences.

2.2.4 Social media

The social media platforms by which users are increasingly producing and consuming content have also received sociological attention. From its inception the internet has provided opportunities for communication between users and informal publication of content by individual users (Hardey, 2001). However, in recent years the facilities for such activity have expanded and users’ production of content and consumption of other users’ content has increased exponentially (O’Reilly, 2005). The array of opportunities for production and consumption of user-generated

content reorient the internet as a platform by which individual users are key to creating meaning within the online environment and managing its content. The range of technologies which facilitate this user-led phenomenon is known by various collective terms, including social media and web 2.0. Throughout this thesis these technologies are described as 'social media', which includes social networking sites (such as Bebo, MySpace and Facebook), wikis (such as Wikipedia), video-sharing facilities (such as YouTube), blogs, micro-blogs (such as Twitter), and forums.

Social media technologies by their very nature are in a constant state of flux. Their content and facilities change regularly, as do their popularity and user groups, but their significance as mundane aspects of life for many people is well-established (Beer and Burrows, 2007). Boyd's (2007) ethnographic study reports on the importance of social networking in many young people's lives for the management of identity, the organisation of sociable practices, and the creation of culture. Similarly, YouTube has been discussed as an important cultural space for participation in community-based online activity (Burgess and Green, 2009). Furthermore, social media technologies have been acknowledged as crucial to the appropriation of the internet by the user. Through blurring of the boundaries between production and consumption of online content the position of the user has altered and the internet has facilitated the development of a participatory culture online (Beer and Burrows, 2010). As social media technologies have become mundane they have shaped the social lives of many people. Through repositioning the role of the user, social media facilitate a greater user presence and greater freedom to colonise online spaces and appropriate technologies.

Beer and Burrows (2007) suggest that, as social media technologies become embedded in society, they are "reworking hierarchies, changing social divisions, creating possibilities and opportunities, informing us and reconfiguring our relations with objects, spaces and each other" (para 1:2). This notion seems to coalesce with some of the issues raised by Brown, Webster and Nettleton surrounding the impact of technologies on the changing landscape of medicine and health, particularly around challenging established medical discourse and altering lay and professional relationships (Brown and Webster, 2004, Nettleton, 2004). Social

media may, therefore, have a role in informing people's experiences of health and illness and moreover, lay individuals' engagement with social media content about health issues may facilitate the construction of new medical discourses.

Lupton (2012) also suggests that social media and mobile apps can be examined for the meaning and subjectivities they assume, their implications for users and *vice versa*, the implications of users on such technologies. She suggests social media technologies such as Twitter and Facebook go some way to altering the mechanisms and structures of public health surveillance. Lupton invokes the image of the panopticon, a symbol of surveillance used by Foucault to represent 'the few watching the many'. She goes on to suggest that social media in many ways subverts this image. Through social media individuals report personal health information, for example details of blood sugar, activity and diet in the management of diabetes, to wide audiences and in so doing shift the boundaries of surveillance, thus Lupton suggests "the many are watching the few" (p. 236). This reconfiguration of the boundaries of where and how individuals' narrate their health experiences creates opportunities for research:

A space is opened up here for researchers to identify and explore the experiences of individuals as they take up (or indeed, resist) the potentialities of mobile digital devices and the new social media as they are adopted into the 'toolbox' of health promotion (p. 241).

Pre-dating Lupton's call, a number of studies have explored related issues in more general studies of the internet, which may be useful for informing empirical exploration of the role of social media in re-defining health and medicine in society.

One area of research has focused on users' health-related contributions to homepages as a point of particular sociological interest. Hardey's (2001) study of homepages containing accounts of ill-health suggests that boundaries are redefined in these spaces where sources of medical knowledge are combined and presented reconfigured. He concluded:

The question is not one of whether Internet health information is ‘legitimate’ but rather the more pragmatic one of how health and illness is understood and the forms of social relationships that stem from this. In some cases the answer may be that users gain a great deal, while in other cases the consequences may be less faith in medical care and greater exposure to risk (p. 402).

This insight is perhaps all the more relevant when considering social media, where social relationships are formed and maintained, and health professionals and sources of ‘legitimate’ medical knowledge are less well-represented. Indeed, the advent of social media in some ways exacerbates existing tensions relating to the preservation of expert knowledge online (Adams, 2010b). Through social media, communication about health goes unchecked and groups are brought together to discuss health issues and create health knowledge, without input from health professionals. Indeed, empirical work might usefully explore this repositioning of power towards the lay public, facilitated by social media, as it creates opportunities to contribute to medical knowledge which circumvent established boundaries.

An alternative starting point for empirical research on social media is to consider the design and organisation of websites and how social media feature in these, paying particular attention to conceptions of the user. In their research on medical and healthcare technologies Pinch and Oudshoorn (2003) focus on the role of the user and explore the co-construction of technologies and users. Using a similar approach to study the development of patient support websites, Oudshoorn and Somers (2006) suggested that interactive technologies are often difficult to integrate into websites created for the purpose of patient support and that various constraints shape the development of websites with little involvement from users in the design process. However, they also conclude that patient support websites can support active forms of patienthood through fostering the construction of medical knowledges online. This concept resonates with Nettleton’s (2009) image of the reappearance of, sick and healthy, men and women in medicine. Oudshoorn and Somers’ approach could be extended to explore social media facilities on health-

related websites, or indeed, the appropriation of social media by users contributing and consuming health-related content to assert an active role in health knowledge construction, beyond the confines of websites constructed for, and not with or by, users.

A related approach is described by Segal (2009) in his account of the online environment and its implications for health information. Segal concludes that “the triangle of speaker, subject matter and audience” (p. 351) is not fully accounted for in much research on health and the internet. It may then be useful to consider the priorities of both users and professional producers of online health content with regards to online resources. In particular research could explore professional producers’ perceptions of interactive facilities (e.g. social media), their conceptions of useful content and their constructions of the user in website development and compare this with users’ perspectives. This more holistic approach to research should produce findings relevant to both academic debates on online health information and professional producers of health-related content who are interested in the production of health websites and social media profiles which are aligned with users’ preferences and practices.

2.2.5 Summary of key theoretical issues

Theoretical discussions of risk in contemporary society provide frameworks to draw on and interrogate throughout empirical research on health. In particular, the notion of the reflexive consumer and the negotiation of expertise are particularly relevant to informing research, policy and practice around health issues. The phenomenon of people engaging online with health information, through passive reading or active communication, augment and illuminate some of the key theoretical issues around risk in society. The internet is a site for the dissemination and exchange of lay and professional knowledge about health, blurring the boundaries between the two and acting as a resource for the reflexive health consumer. It also provides an opportunity for individuals to connect over health issues, and share complementary or divergent view-points, as well as opportunities for challenging dominant models of health. Research can usefully interrogate these

issues, of expertise and knowledge exchange, as well as the production and consumption of online health-related content. Furthermore, research around how individuals engage online may also provide insights into online and offline cultural influences on conceptions of risk, and exploration of social media use could inform understandings of contemporary reflexive health consumers.

The pervasion of networks in society and the increasing importance of information flows, both of which are crucially dependant on ICTs, are also defining characteristics of late modern Western society. These accounts of society underpin Nettleton's suggestion of a new paradigm in medicine, which is not only centred around technologies but which features a re-ordering of hierarchies and re-positioning of agency. Her concept of 'e-scaped' medicine, which highlights "the reappearance of sick and healthy men and women in medicine", illustrates the significance of opportunities provided by online technologies. Building on this concept, the incorporation of social media technologies into the everyday lives of individuals is a dynamic and vibrant area for research, particularly the impact this has on engagement with and construction of health knowledge.

2.3 Health and the online environment: a narrative review of empirical literature

In response to the vast amount of health-related content being generated online, a diverse literature has emerged which explores various dimensions of health and the internet. The empirical literature spans a range of disciplines and theoretical perspectives and often draws on inter-disciplinary approaches. Online health-related content, and users of that content, have become subjects of much sociological research while also receiving attention from medical and public health researchers. Scholars of the sociology of health and illness have become interested in the means by which the integration and importance of ICTs impact on the construction of medical knowledge and people's experiences of health and illness (Brown and Webster, 2004, Nettleton, 2006). Research on the development of health resources and ICTs within medicine has also proved diverse and has prompted the coining of the phrase 'consumer health informatics' to describe this

area (Eysenbach, 2000, Eysenbach and Jadad, 2001). This includes research which focuses on: consumer information needs; participation in health care and health promotion through information technologies; integrating consumer practice and health provision through technologies; and the effects of interactions between health and ICTs on individuals, relationships and society (Eysenbach and Jadad, 2001).

The diverse literature, emanating from both sociological and medical traditions, includes research which explores the phenomenon of online health information from various different perspectives. The internet serves as both an ‘observational’ resource, because users can gather information from it without contributing any content (lurking), and an ‘interactional’ resource, because users can use it to communicate with other users and website administrators (Conrad and Stults, 2010). Research has examined both the ‘observational’ and ‘interactional’ features of online health resources, exploring both online content and the offline experience of engaging with such content. The following review of empirical literature will be presented by addressing three main categories of research: *the internet as an information resource* for health; *the internet as an interactional resource* about health; and *the practices, perspectives and consequences of users’ engagement* with health-related content, both information and interactional. Throughout this section, key themes, approaches and methods featured in the existing literature will be highlighted and potential areas for future research will be discussed.

2.3.1 The internet as an information resource

Much of the research around health and the online environment focuses on the qualities of the internet as an informational resource. One perspective featured in this literature is labelled by Nettleton and colleagues as ‘concerned and dangerous’ (Nettleton et al., 2005) and described by Conrad and Stults (2010) as permeated by a ‘discourse of reliability’. In general this research involves assessment of information reliability on health-related websites, utilising methods such as content analysis. Systematic content analysis of online health-related content suggests high variability of information accuracy across websites, and generally poor quality of

information (Silberg et al., 1997, Eysenbach et al., 2002, Purcell et al., 2002, Benigeri and Pluye, 2003). However, Eysenbach and colleagues (2002) point out that among these types of studies there is large variation across study methodologies and the particular criteria identified as quality markers. More recently, research around reliability of health information and social media technologies has suggested that difficulties of ensuring health information reliability are further complicated by the proliferation of social media content (Adams, 2010b). The challenges of assessing online health information in research are perhaps related to the difficulties in defining the criteria by which 'accuracy' and 'quality' are measured, given that different users are likely to access health-related content with different expectations.

Other studies of health information quality focus on the available online information around particular health conditions. For example, one study examining online information about cervical cancer reports only one of the 46 websites reviewed met credibility criteria, and accuracy varied across websites (Selman et al., 2006). A number of studies also explore quality and accuracy in websites found by particular user groups. Research by Buhi et al. (2010) reported that websites featuring sexual health content found by young people were on the whole accurate, but most inaccuracies occur in the presentation of complex material, and there was no correlation between website quality, based on a range of authorship and editorial criteria, and the presence of inaccurate information. In general, studies of information quality and reliability are apprehensive about the proliferation of health information online and convey concern around preserving scientific discourses of medicine. Attention to quality and accuracy online resonates with established concerns about information reliability online in the media and society, where the internet is portrayed as a risky environment for users (Nettleton et al., 2005). Recent work building on this area of research has attempted to unpack issues of information reliability online and the implications of misinformation for public health policy. For example, Kata's (2010) examination of anti-vaccination websites indicates a high level of misinformation but, importantly, also attempts to chart the dominant discourses used in constructions of anti-vaccine online texts to

inform future health education policy. Research assessing the characteristics of online health-related content as an information source, however, does not provide insight into users' interpretations of the array of information available and since the discussions of such studies raise concerns about potentially vulnerable users becoming misinformed, this missing perspective seems crucial.

2.3.2 The internet as an interactional resource

The internet has also been explored as an interactional resource. Rather than assessing information, this research draws on users' contributions in social spaces, such as forums, blogs or personal websites, to explore discourses around particular health issues (Hardey, 1999, Pitts, 2004, Adams, 2010a). This approach not only offers alternative data sources for accessing people's experiences of health and illness but also provides an opportunity to explore how the online environment impacts on these experiences. A number of methods of analysis are used in interpretation of this type of data. Seale et al. (2006) have used a novel method of keyword comparative analysis; Gavin and colleagues (Gavin et al., 2008) used interpretative phenomenological analysis (IPA) and other researchers have employed discourse analysis (Guise et al., 2010). Many of these studies move away from questioning the quality of medical information online and instead focus on how health and illness is understood and enacted in online spaces (Hardey, 1999, Nettleton et al., 2005).

Exploring the online publication of health narratives by users has altered over the lifecourse of the internet. A number of studies have provided insights into the earliest modes of online user contribution, the personal homepage, and the possibilities for empowerment such websites provide. One of the earliest studies, which focused on users' health-related homepages as a new site for the publication of illness narratives, explored how users drew on established medical information, personal experiences and commercial resources throughout their accounts (Hardey, 1999). The range and diversity of these accounts, highlighted by the study, suggests that the internet presents a particular opportunity for the shifting of boundaries around medical knowledge and expertise. A similar study, which

focused on women's accounts of breast cancer in online spaces, attempts to interrogate the empowering or emancipatory notion which this re-drawing of boundaries implies (Pitts, 2004). Pitts' analysis suggests that the processes of empowerment are complex and that in online spaces feminine norms are often reproduced rather than challenged. Her exploration highlights the alternative, and perhaps more realistic, portrayals of women's femininity, bodies and disease that user-generated personal websites feature, but also draws attention to the compounding of social pressures on women to portray optimistic and resilient selves. The internet as an empowering space, therefore, is a notion which can be usefully analysed through research around user-generated health content and one which has been highlighted as overly simplistic in some cases.

More recently, the mechanisms by which users contribute health-related content have altered. Maintaining personal websites or homepages has been superseded by the production of content through a range of social media technologies. Contemporary research which considers the internet as an interactional resource acknowledges this dynamic environment. Quantitative content analysis has been used to describe the diversity of health-related pages on Facebook, suggesting that marketing, patient awareness and information, and support are all represented on Facebook pages for a wide range of health issues, with AIDS generating the most marketing pages and cancer the most support pages (Hale et al., 2014). Furthermore, weblogs or 'blogs' have been explored for the alternative possibilities they offer to individuals interested in health and healthcare in developing understandings of their own and others' health. A preliminary study by Adams (2010a) presents two case-studies of blog-based applications utilised for health purposes, and raises a number of questions for future research and health-related policy. Her study suggests the advent of 'web 2.0' and proliferation of social media technologies make the processes of publishing health and illness accounts simpler and more accessible. This offers: diverse sources of information to users; alternative means of constructing health and illness for users; and new opportunities for health promotion and health care. Although narratives of health and illness have always been of medical and sociological interest, the shifting

opportunities presented by dynamic online technologies foster novel means of creating and disseminating these accounts which present extensions to abiding questions around identity construction, health experience and social relations.

The presentation of individuals' identities and meanings around health and illness has also been explored through interactional data from online sources. Analyses of participants' interactions within online support groups and forums have provided particularly useful insights into groups' shared understandings and constructions of health and illness in a number of contexts. Both contested illnesses, such as chronic fatigue syndrome (CFS), and culturally stigmatised illnesses, such as anorexia nervosa, have been researched in this way. Gavin and colleagues' (2008) study focused on pro-anorexia forums used by women. Their findings suggest that in the interactions they studied, anorexia was constructed as a lifestyle choice rather than an illness. The users' presentation of themselves as healthy women, striving for weight-loss, in a supportive space which was private from the judgemental public sphere, suggests the importance of improving understanding of the social pressures around anorexia and maintaining awareness of online spaces as sites where meanings and identities around anorexia are co-constructed. Alongside highlighting alternative representations of health and illness on the internet this type of research provides useful insights for practitioners, who might otherwise not gain access to these perspectives. Similarly important insights for practice are suggested by Guise et al.'s (2010) study of individuals with CFS. In this study, users posted about their experiences of interactions with health professionals. Guise's analysis suggests users discussing CFS online draw on discourses around the 'good' patient. By presenting themselves as positive and active actors in maintaining their health, forum users rejected overtly negative accounts of health professionals and, in doing so, constructions of themselves as troublesome patients. These studies suggest that research which observes online accounts and users' interactions around particular health issues, either covertly or openly, can inform the development of good practice around particular groups of patients, by emphasising particular constructions of identity and promoting sensitivity to these.

Another alternative body of research which draws on pre-existing online data, is the exploration of internet users' health behaviours through personal and social data they post online (e.g. on social networking sites). In particular this research has been promoted as a means of identifying 'risk behaviours' in young people (Pujazon-Zazik and Park, 2010). For example, Griffiths and Casswell's (2010) analysis of alcohol-related user-generated content on Bebo profiles of 16 to 18 year olds found that the online environment provided by social networking sites is permeated with references to alcohol, which may be contributing to the normalisation of underage drinking. Similarly, Moreno and colleagues (Moreno et al., 2009, Moreno et al., 2010a, Moreno et al., 2010b) conducted a series of studies into the content of social networking profiles focusing on various risk behaviours. The authors examined alcohol references on MySpace and suggested that explicit references to alcohol are commonplace on young people's social networking profiles and could, therefore, be influential across peer groups (Moreno et al., 2010a). Sexual references across user-defined friendship groups were also examined and the authors suggested that those young people who make references to sex on their profile are more likely to be friends with others who make similar references (Moreno et al., 2010b). Similarly, an analysis of blogs has been successfully used to help identify teenagers with depression, which could help engage teenagers suffering depression with social agencies (Goh and Huang, 2009). In these studies, social media have been utilised as a source of interactional data to provide insight into young people's risk behaviours particularly in relation to their social networks, made all the more visible through social networking sites.

As a result of the incorporation of the internet into people's everyday lives (Wellman and Haythornthwaite, 2002) and the increasing incorporation of social media into many young people's social lives (Williams and Merten, 2009), health interventions are beginning to utilise the interactional properties of the internet to promote young people's engagement with health issues (Hyden and Cohall, 2011). Much of the research around using social media for health interventions focuses on particular groups, which are broadly affiliated with social media technologies or have been considered 'hard-to-reach'. Indeed, some have suggested that the

potential of social media lies explicitly in addressing existing health inequalities, by capitalising on existing communication pathways within specific groups which are made visible through social networking sites (Gibbons et al., 2011). For instance Ralph and colleagues' (2011) study title, 'Finding teens in TheirSpace', reflects the intention of health communicators to relocate existing health promotion materials to sites which are more relevant to young people. Their research with low-income families in the US suggests that high-levels of internet access, high levels of presence on social networking websites, and pre-existing use of the internet for health information all point towards using social media for health information dissemination. The authors of one review synthesise a range of research literatures to suggest that social media technologies may also be a useful and socially acceptable way for young men in the UK to access to health-related resources (Robinson and Robertson, 2010).

While the potential and importance of developing a presence for health promotion in online spaces is well-noted, the complexities for utilising social media in this context are not fully explored in the literature. Studies which explore the acceptability and desirability of delivering health interventions through social media to specific target groups seem to be lacking in the literature. One of the few articles which explicitly details the process of attempting to comprehensively use social media marketing techniques for health intervention describes the process of developing and maintaining two arms of a health promotion campaign aimed at young people and men who have sex with men respectively. Gold and colleagues (2012) provide insights from their successful attempt to utilise social media which reflect the range of expertise needed and the importance of consistent evaluation. However, few studies have successfully evaluated the use of social media for health promotion and intervention.

Some of the potential opportunities for research around health and the internet build on these studies around online interaction and health. As highlighted by a number of authors, these studies do not provide insight into the offline identities and experiences of individuals (Pitts, 2004). Much of this research would be usefully complemented by studies of users' or potential users' perceptions of

content, as well as exploring the consequences of engagement with online health resources, whether professionally produced as interventions or naturally occurring in user-generated content.

2.3.3 Users: practices, perspectives and consequences

Thus far the research that has been discussed involves utilising online content as a data source, to explore information reliability, discourses around health and illness, users' interactions around health issues, or the internet as a potential site for health intervention. Further research explores users' perspectives on online information seeking and the related issues of negotiating reliability, health knowledge construction, user empowerment and relationships with health professionals.

With quality and accuracy an over-riding concern of much of the research discussed so far, a considerable body of literature on how people of all ages access and evaluate online health information has developed. The 'concerned' perspective (Nettleton et al., 2005), associated with a discourse of 'reliability' (Conrad and Stults, 2010), inherent in much of the early quality and reliability assessment research, draws attention to the prospect of users' vulnerability to misinformation on the internet. A number of studies explore internet users' practices of health-information seeking generally. One study proposes users who find unreliable information could be ill-equipped to assess and interpret it (Cline and Haynes, 2001) and another indicates gaps in key areas of information and low level of readability could prove challenging for users (Berland et al., 2001). Similarly, Gray et al.'s (2005a) focus group study of young people in the UK and US explored literacy levels through online engagement with health information. While the findings of this study suggest young people's sophisticated internet skills, they also point to shortcomings in abilities to locate, appraise and use online health information. Research has also provided insight into the processes by which people search and evaluate health information online. Eysenbach and Köhler's (2002) observational study found that while consumers indicated the importance of noting the source of medical information, in practice few checked this rigorously. These

studies suggest that while there is a wealth of information available online, users' skills may not always be sophisticated enough to detect misinformation.

Further studies go beyond characterising users' online skills and focus on the range of online practices and their offline contexts. Nettleton and colleagues (2004) study of "health e-types" draws on qualitative interviews with parents of children with chronic diseases to construct a typology of users' practices. They conclude that this range of users' practices, rather than being determined by social position, is nuanced, embedded in everyday experience and contextually specific. Typologies of users' practices have yet to be developed in relation to health information and social media, and given recent characterisations of "cultures of the internet" provided by Dutton and Blank (2013), perhaps these could be usefully re-examined.

Criticism of studies which construct the user/patient/'lay' public as a passive, and perhaps vulnerable, actor in online engagement with health-related content (Lewis, 2006b) has led to research which interrogates this notion. Nettleton and colleagues (2005) took this approach in their study of people's rhetoric around health information seeking. They found that participants regularly referred to the risks associated with information reliability online and portrayed themselves as cautious and experienced in gauging reliability when engaging with online information. This suggestion has much in common with the approach of Ziebland and colleagues (2004) (amongst others) who conceive of the internet as an everyday resource, important for risk negotiation but not as a risk-laden environment in itself. Shifting emphasis on the internet, from a site of health risk to a resource for reflexivity, indicates the movement of research towards a focus on the user.

A number of studies have explored the idea of the internet as informing, and in some cases emancipating, the user by exposure to health information and medical discourse to which they would otherwise have limited access (Henwood et al., 2003, Fox et al., 2005, Nettleton et al., 2005, Lewis, 2006a, Kivits, 2009). These studies, explore the model of the 'reflexive consumer' (Giddens, 1991, Beck, 1992b) using the internet to access expert knowledge to inform critical and rational

decision-making. Nettleton and colleagues (2005), Fox and colleagues (2005) and Kivits (2009) suggest that the internet provides a site for facilitating individuals' emergence as what has been variously termed a 'reflexive health consumer', 'lay expert' or 'informed patient'. All of these terms convey an image of a citizen who takes responsibility for self-monitoring of health and engages with expert medical knowledge. Adams (2011) attempts to address the "political dimension of reflexivity" in relation to health and the internet, by exploring the increasing opportunities for individuals to participate and engage online to give feedback or raise questions about health policy and practice. She suggests:

Mechanisms and spaces are created where patients can order their own information, and - during treatment or after a medical encounter - disclose their experiences with care services to others. Website users become information producers, changing their current roles from message recipients to message senders, and creating room for new information users to emerge (p. 1070).

Like TripAdvisor and Amazon reviews, users providing feedback on particular health services or policies, providing approval and disapproval ratings, acts as a means of 'crowdsourcing' information. The use of this secondary, aggregated information, made possible through social media technologies, is a further resource for reflexive consumption.

However, some have noted that the availability of a plethora of information through online sources can place pressure on individuals to enact the 'empowered' or 'expert' patient role (Ziebland, 2004). Indeed, Fox (2005) cautions that the entire notion might be somewhat constraining. She suggests that since online medical discourse and the activities of users are, for the most part, concordant with the biomedical model of health, alternative modes of lay expertise are less prominent online. Further qualifications to the emergence of 'reflexive health consumers' through online information seeking are suggested by Lewis (2006a) and Henwood et al. (2003). Lewis's (2006a) interview study with young people found that there were marked differences in the processes of reflexivity participants of

different social positions engaged with as they negotiated the online environment. Similarly, Henwood and colleagues (2003) suggest that the emergence of a reflexive health consumer is limited by various factors, including concerted avoidance of self-monitoring, varied information literacy levels and wariness of affecting doctor-patient relationships. While the internet may be able to provide opportunities for users to become informed, and indeed empowered (around health issues), this process is contingent and involves negotiation of both established and novel societal pressures and expectations.

As well as exploring everyday consumers of health information and those seeking information following a specific diagnosis, some research has focused on users' engagement with health-related content online at particular transitions during the lifecourse, such as puberty, pregnancy and menopause/andropause (male 'menopause'). Recent research on online interaction amongst pregnant women traces the appropriation of professional medical discourse and suggests the empowerment of users in rethinking and discussing previously side-lined issues (Cohen and Raymond, 2011). Similar themes of empowerment are emergent from studies around women's use of the internet for support and health information in mid-life (Dare and Green, 2011). This research explores the interplay between professional and lay knowledge construction and focuses on the supportive communities which permeate much of the user-focused research around health and the internet.

Related to the importance of the internet for enabling empowerment is the provision of peer support and engagement with experiential information through online technologies. Ziebland and Wyke's (2012) realist review provides a summary of the key means by which people's health is impacted by the sharing of health experiences online. By collating insights from a range of literature the authors identified seven domains: finding information, feeling supported, maintaining relationships with others, affecting behaviour, experiencing health, learning to tell the story and visualizing disease. They conclude that users' accessing other people's accounts of health and illness is a defining feature of 'e-health' and that the act of contributing health-related content profoundly influences patients'

understandings and experiences of health issues. More specifically, there has been particular research interest in the formation and use of internet support groups, also known as electronic support groups (ESGs) around health issues (Conrad and Stults, 2010). A number of qualitative studies suggest that people find specific and sustained health-related support online (Broom, 2005a, Fox et al., 2005, Bar-Lev, 2008, Barker, 2008). Supportive online communities provide important public spaces for expression of thoughts and emotions about illness and for some users can offer safe spaces in which to express alternative accounts of their experience and identity (Broom, 2005a, Bar-Lev, 2008). In some cases, online support groups, through users sharing accounts of embodied experience, enable the emergence of informed or expert patients (Fox et al., 2005) and indeed groups may go on to develop wider objectives, such as challenging medical expertise (Barker, 2008). More recently, studies have explored the use of social media for the provision of supportive communities for young people with chronic disease (Nordqvist et al., 2009, Ekberg et al., 2010). Peer-support appears to be one of the most clearly positive consequences of the emergence of the internet as a site for health-related interaction, and is recognised by both users and researchers alike. However, few studies have focused on comparing people's experiences of engaging in supportive online communities across different health issues (Chen, 2012) or whether there are differences in men's and women's accounts of engaging in such communities.

The consequences of patients' use of online health information for relationships with health professionals is another prominent issue in the literature. McMullan's review (2006) points out online information empowerment can progress patients' relationships with health professionals in a number of ways, perhaps most productively resulting in a collaborative relationship with patient and professional collating and analysing sources of information together. A more recent review suggests possible changes to relationships with health professionals as a result of active online engagement with health content (Dedding et al., 2010). Some of the negative impacts include patients delaying consultation (and therefore diagnosis), professionals feeling threatened, and patients requesting inappropriate care. Positive impacts include increasing patients' confidence in encounters with health

professionals through access to professional vocabulary, and supplementing patients' existing knowledge through health promotion materials. Relationships with health professionals are therefore likely to be impacted to some extent by users' increasing engagement with health content online, but the effects of this are neither clearly positive nor negative.

Online technologies may impact health professionals in another sense. Some social media technologies, more often associated with shopping websites, have allowed the further exertion of patient agency through contributing and sharing opinions of identifiable health professionals on user-review websites. Hardey (2010) explored the existence of such websites, which are more prominent in the United States (US) but increasingly utilised in the UK, and the type and tone of the user-generated content they feature. These facilities afford individuals opportunities to enact 'consumer' roles. They can pre-judge and select health professionals according to accounts from other users and so challenge the nature of existing professional-patient relationships. This phenomenon provides an example of how developments in users' online practices can disrupt established healthcare conventions and offline relationships. The existence of sites such as PatientsLikeMe, which allows patients to compare their treatment experiences and results with other patients, also serves to reconfigure relationships between patients and health professionals. As these websites expand, individual users contribute to projects collating health information which could also inform research and policy, further redefining relationships between individuals and health-related institutions (Wicks et al., 2010, Bletsos et al., 2013). However, despite these reconfigurations of relationships between patients and health professionals facilitated by social media technologies, some health-related social media content serves to reinforce and reproduce offline relationships with health professionals, as trusted sources of information. A recent study of 'patient-to-doctor' online communities suggests that both professional and experiential accounts are valued by users, but health professionals' contributions are viewed as the more reliable source of information for users (Vennik et al., 2014).

A subset of literature around accessing online health information is dedicated to the experiences of parents, accessing and engaging with content which relates to their children's illness. One recent study explored parents' preferences for information-seeking about paediatric cancer (Gage and Panagakis, 2012). The authors interviewed parents who said they did not seek information about their child's illness on the internet for a number of reasons. These included oncologists warning them against going online, being intimidated by the volume of information available online, fearing what they might find out, and concerns about the reliability of information. In contrast, research with parents of children with a genetic disorder suggests the importance of information-seeking online to this group (Schaffer et al., 2008, Gundersen, 2011). Schaffer and colleagues (2008) found that the appropriation of online information, from both factual medical websites and user forums, was important for many parents in producing and furthering genetic knowledge and advocating on behalf of their child. Moreover, Gundersen (2011) identified the internet as an important coping resource for supporting parents' emotional progress during the processes of diagnosis, prognosis and treatment. These contrasting experiences of accessing online resources by groups of parents encountering two different health crises indicate divergent attitudes towards the use of health information online by both users and health professionals. Perceptions and experiences of engaging online with health-related content seem to be related to contextual influences including the implications of the specific medical condition and the advice of individuals. Emotional responses therefore, seem to be supported by both using online resources and rejecting them. Similarly, exerting individual choices about engaging with information, and other users, online seems related to issues of trust and expertise, particular to specific illnesses.

2.3.4 Summary of key empirical issues

In this broad review of the empirical literature, key areas of research around health and the internet have been mapped out in brief and examples of particular research provided to illustrate prominent themes and approaches. The diversity of the literature foregrounds the unique nature of the internet as a phenomenon of interest for health-related issues. Research around illness, particular lifestages and

transitions, as well as healthy lifestyles are all represented. While some research focuses on the online environment as a rich source of data, other research explores the range of experiences of those who engage with health-related content online. Similarly, research often alternately explores the internet as a passive source or as a site of interaction, but rarely addresses both perspectives. However, despite this diversity in research subjects and approaches, a number of themes recur. These include information reliability, knowledge-making, mechanisms of support, empowerment, relationships with health professionals and opportunities for intervention and health promotion.

There are also a number of gaps in the literature. A growing number of qualitative studies focus on users' perspectives; however, few consider the impact of social media on people's engagement with health information online and the implications of this in their day-to-day lives. Similarly, and perhaps as a result of the dynamic and fast-moving nature of the online environment, few studies explore the impact of mobile internet use and always being online on experiences of health and illness. A further gap is around comparative research. Few studies compare online access around particular health issues by groups of users. Since internet use is embedded within wider social contexts, it is likely that issues relating to stigma, advice of health professionals, accessibility and indeed, health issue-specific concerns may impact users' practices and experiences.

2.4 Studies of social media related to CMHDs and diabetes

While the general literature about online and social media technologies and health remains relevant, the following section focuses specifically on studies of social media related to people's experiences of CMHDs or diabetes. The rationale for the focus on these two issues is detailed in Chapter 3.

2.4.1 Approach to literature searching

In order to locate the most recent and most relevant peer-reviewed literature on social media and diabetes/CMHDs a number of searches were conducted. Medline, IBSS and ASSIA were searched using search terms such as "social media",

“blogging”, “Facebook”, “Twitter”, “MySpace” and “social networking site” in combination with either “diabetes” or “mental health”, “depression”, “anxiety” and “stress”.

Search results were checked for relevance. The full text of papers was retrieved if the paper was deemed to refer specifically to both social media and individuals experiencing CMHDs or diabetes. Articles that were not in English or where abstracts were unavailable were excluded. Articles referring to health professionals or health policy and social media and those papers which focused solely on less common mental health disorders, including psychotic symptoms were also excluded. Methods papers about the use of social media to recruit participants to mental health-related research studies were excluded. As well as conducting searches of relevant databases, additional peer-reviewed articles and books were identified from bibliographies and citation searches. Details of the number of articles found in the original searches, exclusions at each stage and additional articles are included in Appendix 1.

The resultant literature is summarised below, separately for each health issue. Firstly, the literature around mental health and social media is described, then the literature around diabetes and social media is discussed. Areas of differences and similarities are highlighted throughout.

2.4.2 CMHDs

Online and social media technologies have been discussed at length in relation to mental health. A number of studies have attempted to explore the relationships between using online social networking sites and mental wellbeing with varied results. A recent quantitative study of college students in the US suggested frequent Facebook use is associated with increased distress, both directly, and indirectly due to lower self-esteem and communication overload (Chen and Lee, 2013). However, others have suggested that increased social network use among the same population might be linked to social support, which can contribute to users' well-being (Liu and Yu, 2013, Nabi et al., 2013, Wright et al., 2013).

Authors have also explored how social media technologies have served to re-create the boundaries around where and how mental health problems are discussed and addressed by individuals and groups within society. Grohol (2010) charts the rise of the internet as a site for mental health information, interactive resources and peer-support. He points in particular to the rise of personal homepages in the late 1990s, many of which featured accounts of lived experience of mental ill health, as a defining feature of the internet in that it allowed communication and personal information sharing beyond what was previously possible. Grohol goes on to suggest that web 2.0 and social networking make these processes even easier and offer further opportunities for the formation of support groups and blogging practices with potentially therapeutic benefits to those encountering poor mental health. The position and agency of individual users have also been described as altering with changing online practices. The advent and widespread adoption of social media have been lauded as having “upgraded Internet users from consumers into contributors in ways that many have wanted as mental health service users” (Wicks, 2012, pp. 1-2). However, Wick’s (2012) review of research around “e-mental health” also highlights the potential for more damaging health consequences related to internet use, exemplified in the ‘pro-ana’ online phenomena. It seems, therefore, online and social media technologies are seen as historically significant in redefining the position and opportunities of individuals who are experiencing mental health issues. By bringing together sources of information and support, these technologies create multiple opportunities for users to both consume and contribute mental health content.

Research on e-mental health has also explored the potential of the internet generally as a site for the delivery of interactive interventions and self-help programmes to address common mental disorders (Schmidt and Wykes, 2012). A number of papers highlight the range of opportunities for social media technologies to be used in this context. O’Mara (2012) discusses the potential of online and offline participatory action research projects to develop culturally appropriate health and wellbeing (including mental health) video content that can be disseminated throughout social networks. Similarly, Norman and Yip (2012) have

highlighted the range of opportunities social media offers for engaging with young adults on a variety of health topics, including mental health.

Much of this research alludes to the potential of social media to broaden the reach of mental health interventions. A survey of young people in rural Australia suggested that this population used online social networking sites regularly, many sought mental health information online and most would be willing to seek peer-support for mental health issues through social media (O'Dea and Campbell, 2011). Some have also suggested that interventions delivered through social media could be useful in breaking down existing barriers to engagement with mental health services in 'hard-to-reach' groups (Goodman et al., 2011).

Although assertions of the potential of social media for mental health interventions seem common, few studies have systematically evaluated such interventions. In particular, questions have been raised about the different ways by which users are impacted. Crutzen and Nooijer's (2011) assessment of the potential of 'chat'-based interventions for improving young people's mental health suggests that the approach could be useful but understanding of the differences between the impact of professional-to-individual interaction and peer-to-peer interaction online are lacking. Mohr and colleagues (2013), similarly, suggest that understandings of the structure and impact of peer-to-peer interactions facilitated through social media are poor. The complexities of how social media environments can be used to support users' mental health have been highlighted particularly in the area of self-harm. Engagement in online communities for people who have experience of self-harm has been identified as useful for peer-support, decreasing feelings of isolation (Jones et al., 2011, Powell, 2011). However, the increasing volume of social media content about the issues, particularly on YouTube has been seen as contributing to the normalisation of self-harm practices (Lewis et al., 2011). This dual impact illustrates the difficulty of understanding how social media can best be used to improve mental health outcomes. Indeed, many of the studies that focus on social media as a site for mental health interventions point to the need for more research which aims to understand how interaction in these spaces is structured, and how it impacts users.

Recent studies have also explored mental health issues utilising data captured from social media. Some studies have identified social media as a key site for display of users' mental health problems through analysis of individuals' profiles. Cash and colleagues' (2013) analysis of MySpace pages indicates that young people (aged 16-24) used the social networking site as a place to make statements about suicide. Similarly, a study of college students in the US suggests that depressive symptoms are commonly displayed by users on Facebook and that users are more likely to post such updates if they receive responsive comments from 'friends' (Moreno et al., 2011). More detailed exploration of users' Facebook practices has also been used to explore mental health issues. Park and colleagues (2013) conducted a mixed methods analysis of Facebook profiles which suggested that participants' use of social Facebook features was associated with depressive symptoms. In particular, those with depressive symptoms were less likely to participate in common Facebook practices such as location tagging and 'liking'.

Other research has explored how users construct and enact mental health issues in online communities. A review of studies of internet support groups for depression indicated that such communities could be useful for fostering social support and seemed to be appreciated by users (Griffiths et al., 2009). Blogs have also been analysed to explore the experiences of young adults with mental health concerns. Marcus et al. (2012) conducted a qualitative analysis of young adults' blog contributions. Their findings suggest that individuals with mental health concerns can feel disconnected, isolated, and powerless. They also suggest that accessing blogs can help identify the concerns of individuals not currently engaged with mental health services to inform policy and practice accordingly. Giles and Newbold (2011) comment on the tendency within community-led, mental health online forums for users to actively promote the use of diagnostic labels to define sub-groups and cliques within their communities. In a further analysis of mental health forums the same authors suggest these online communities serve to facilitate the creation of supportive interactions and offer an opportunity to construct "a set of category predicates around what might be considered 'normal' within a community that enables members to validate their credentials for

community membership” (Giles and Newbold, 2013: p. 487). This research contributes a more nuanced understanding of how online communities facilitated through social media contribute to conceptions of CMHDs and the offline experience of them - in these cases by defining experience according to diagnostic labels and community membership. However, this analysis is limited to specific community initiated forums and not mainstream social media, such as Facebook pages dedicated to CMHDs, which may function in different ways.

The visual presentation of mental health online has been explored by Thompson (2012), who conducted a discursive analysis of images of mental illness on one website (HealthyPlace). The findings of this study suggest that visual representations are used to “market” mental health as an everyday concern for individuals and highlight the use of online resources as a means of addressing poor mental health. She suggests:

Stylized stock photos of imagined community members, photos of bloggers and members within the social support network reify the connection between sociality and health; the ‘faces’ of HealthyPlace thus serve as commodities to sell sociality as a sign of health and wellness (p. 416).

This analysis suggests the importance of considering the visual dimensions of online resources, and users’ perceptions of the portrayals of health and illness in images.

Although much of the research on mental health and social media has explored online data, some studies have focused on users’ experiences of engaging with mental health-related content. Some of this work suggests the potentially positive impact online engagement, facilitated through social media, can have on individuals’ experiences. Tan’s (2008) case study of one blogger’s experience illustrates how social media practices, such as blogging as part of the social networking site MySpace, can serve as a form of self-therapy for the blogger. Similarly a study of users’ experiences of engaging with self-harm online communities found they appreciated the facility as an opportunity for peer-support (Jones et al., 2011). These studies suggest that both individual self-therapy and community-based peer-support can be facilitated through engagement with social

media. Egan and colleagues' (2013) focus group study explored a more social dimension - people's perceptions of mental health status updates on Facebook. Their findings suggested that such updates were viewed in many different ways, including as both calls for help and attention-seeking. Therefore, while there may be positive outcomes for users who actively engage with social media, other users' perceptions of discussing mental health issues on social media might be less favourable.

Broadly, existing research on social media and mental health focuses on identifying new opportunities for improving mental health outcomes through social media-based interventions, particularly with groups that have been considered difficult to engage offline. Research on both online data *and* users' experiences is limited, and raises a number of issues for further exploration. Few studies aim to understand the experiences of a range of individuals experiencing CMHDs, including both those who use social media to discuss mental health and those who do not. Furthermore, few studies explore users' perceptions of the range of different social media platforms for discussing mental health issues, or their perceptions of different types of content, including visual depictions of mental illness in images or videos.

2.4.3 Diabetes

Studies have highlighted the growing importance of social media to people's experiences of chronic disease. Findings from the 2010 Pew internet national survey suggest that one in four internet users in the US with a chronic condition, such as diabetes, uses the internet for peer-to-peer support (Fox and Jones, 2011). In relation to diabetes specifically, Jones and colleagues' (2013) recent review of the literature on social media use amongst young people and young adults with diabetes, concluded that use of social media for seeking advice about issues relating to their diabetes was widespread.

Similar to the mental health literature, some authors suggest social media offers opportunities for engaging with individuals to support their experience and self-management of diabetes. A survey of social media use amongst people with diabetes in the US, reported that the majority used social media regularly and many

would be willing to discuss their health issues online (Shaw and Johnson, 2011). This willingness to engage online about diabetes has prompted the development of a range of social media interventions. A recent review of randomised controlled trials (Toma et al., 2014) suggests that online social networking interventions improved both glycaemic control and a range of secondary outcomes in people with Type 1 and Type 2 diabetes. The authors also suggested that mobile interventions without social networking elements are generally less successful, perhaps because they lack the social dimension which facilitates peer-support. Indeed, even for those interventions that do not function through social media but on standalone websites, the importance of understanding how social networking and social media impact users' perceptions of and engagement with such resources is increasingly prioritised during intervention development (e.g. Yu et al., 2012).

As with the mental health literature, alongside intervention-related research, a number of studies have explored the features of content on particular social media sites about diabetes. A recent content analysis of social media groups set up for breast cancer, colorectal cancer and diabetes found that, of the three health conditions, diabetes had the largest number of groups on Facebook and Twitter (De la Torre-Diez et al., 2012). The study also reported that, while the breast and colorectal cancer groups were largely focused on prevention, the content shared by the diabetes groups focused mainly on research issues and supporting other users. A number of other studies have also reported on the presence of content that appears both supportive and edifying to users. Some have observed social media content about diabetes that amounts to "social learning" (Ho et al., 2014), while others note the prominence of advice and experience sharing (Jones et al., 2013) or facilitation of "patient-centred" approaches to diabetes self-management (Greene et al., 2011). Zhang and colleagues' (2013) analysis also suggests how well-organised many online communities focused on diabetes are and noted the frequency of realistic encouragement and support. User-generated content has also been employed as a data source to explore the prominence of biomedical research in accounts of diabetes. An analysis of diabetes blog content and the influence of diabetes blogs (measured by the number of links to the blog) suggests that a gap

has emerged between health professional blogs and personal blogs (Gruzd et al., 2012). While the former were more likely to cite research literature, the latter were more 'influential', perhaps as a result of users seeking more like-minded authors, providing emotional and experiential accounts rather than research evidence.

Despite recognition of these potentially helpful features of content for users, some studies have also noted concerns about the quality of information contained within user-generated content. Weitzman et al. (2011) and Jones et al. (2013) both reported variable accuracy of information and advice, while others have highlighted the presence of commercial interests (Greene et al., 2011) and inconsistent approaches to transparency in advertising (Shrank et al., 2011) within diabetes-related social media. As well as concerns about information quality, one study used quantitative cluster analysis of discussion forums focused on three different health conditions, including Type 1 diabetes, to suggest that patients' information needs seemed to change over time, with specific information required at different stages during their experience (Chen, 2012). Therefore, while social media offers useful resources for some users, there remain challenges around the management of information quality and around users locating relevant and timely information.

While these studies highlight both positive and potentially problematic dimensions of online interactions on social media sites focused on diabetes, some suggest there are outstanding issues which require research. Libreri and Graffigna's (2012) discussion of their content analysis of Italian diabetes-related user-generated content reflects on the lack of literature which goes beyond focusing on the explicit purpose and topic of content. They call, in particular, for greater exploration of how specific online contexts (e.g. Facebook, Twitter, user-led/health professional-led forums) and online practices in these contexts impact how content is constructed and responded to. Furthermore, fewer studies have explored users' perceptions and experiences of engaging with diabetes-related content on social media sites and compared these perspectives to findings from studies exploring online content. Users' perspectives on the different social media platforms and the

impact of these contexts on their online engagement and offline experience also seem under-researched.

2.5 How this study adds to existing literature

Given the increasing calls for interventions and health promotion to utilise social media as a means of engaging with people encountering long-term health issues, such as CMHDs and diabetes, and the literature which suggests user-generated content and online communities can foster social support and learning, the online and social media environment warrants further research. There are few studies in the existing literature which explore users' (or potential users') perspectives on accessing health-related content in these environments. Furthermore, neither the literature focused on diabetes nor the research on CMHDs provides a nuanced account of the ways that different social media platforms, and static websites, are viewed by individuals who are increasingly using social media both for social purposes and to engage with health information. Practices for engaging with health information online, which were researched from the late 1990s to the mid 2000s, have yet to be fully re-examined since the proliferation of social media technologies and pervasion of these into many young adults' lives. Furthermore, Segal's call for research which addresses the triangle of speaker, content and audience (2009) has yet to be explored in relation to health and the online environment. Although some studies have explored website producers' perspectives on the creation and presentation of content on standalone websites, and have highlighted some divergence in producers' and users' perspectives, few studies have compared the expectations and intentions of those who facilitate social media spaces which feature health related content with the expectations and perspectives of users and non-users of such sites.

2.5.1 Study aim, objectives and research questions

As described in Chapter 1, based on the theoretical perspectives outlined, and building on existing empirical literature, the broad aim of this study is to explore engagement with diabetes and mental health content on the internet from a range of perspectives to:

- Develop an understanding of the multiple ways by which young adults engage with health-related content online
- Develop a holistic understanding of how social media are used for health information and communication currently amongst young adults and professional producers of online health resources
- Identify areas of convergence and divergence across developers', users' and contributors' perspectives on online health resources and provide insights around opportunities for future resource development in line with users' preferences
- Explore the differences and similarities between the processes and practices of engagement with content about diabetes and CMHDs, and between men and women.

It will focus on three main areas: the online health-related content which users access and contribute to; young adults' perceptions and experiences of engaging with diabetes and mental health related online content and, lastly, the perspectives of diabetes and mental health-oriented organisations that employ social media strategies and online communication. Through comparing providers' perspectives and young adults' perspectives, these aims are informed by Segal's call for research which addresses the triangle of speaker, content and audience (2009) in relation to social media and health.

The following research questions have been developed to address the aim of the study, and some of the gaps identified in the literature around health and the internet generally, and around social media, diabetes and CMHDs specifically. The specific issues each question was designed to address are described below:

1. What are young adults' perceptions and experiences of engaging with health-related content on the internet and through social media technologies?
 - In what ways and for what reasons do young adults use social media websites for engaging with diabetes and mental health information?
 - Can social media content related to diabetes and mental health fulfil particular information and communication needs? To what extent do these complement, duplicate or contradict other sources of information?

- How are issues around information reliability negotiated in different online spaces?
 - How do young adults respond to different social media platforms, do they identify different conventions and online practice within each?
 - How is online information and communication about diabetes and mental health incorporated into offline experience?
2. How are the internet and social media technologies used by young adults in self-management of health issues? Are there differences or similarities between people with experience of different health conditions and between men and women?
- How do people use the internet in self-monitoring of diabetes and mental health issues?
 - Are there any gender differences in the way that the internet and social media technologies are used by young adults?
 - Are there differences in the way that the internet and social media technologies are used by young adults with diabetes and young adults with experience of CMHDs?
 - What are the barriers and facilitators to using the internet in self-management of health issues?
3. How do professional producers view the needs of potential users of online health resources and how do these views align with young adults' conceptions of the role of online resources?
- What are the similarities and differences between the intentions of those creating or facilitating websites and users' perceptions and experiences?
 - How do providers conceive (or construct) the user in the design and development of online health resources?
 - Are there areas where young adults' health needs are not being met that can usefully be addressed online?
 - Do social media strategies conceived by providers align with users' practices?

3 Methods

3.1 Overview of chapter

This chapter describes the processes of designing, developing and conducting the study. Firstly, the decisions I made in the planning of the project and the underpinning approach of the research are discussed. Next, the preliminary analysis of online data I conducted as preparatory work is detailed, and the key insights it provided for the main study are summarised. I then describe the primary method of data collection, my key learning from a series of pilot interviews and the developments I then made which informed the main phase of interviews. Finally, the processes of sampling and recruitment, conducting the main fieldwork and, managing and analysing the data are described. Throughout the chapter I offer my reflections on the practical, ethical and theoretical issues which I encountered during the course of the research project.

3.2 Scope of the study

3.2.1 Identifying the health issues for comparison

To focus the project, two contrasting health issues were identified as exemplars, namely diabetes and CMHDs. Entwistle and colleagues (2011) reflect that using contrasting health issues to explore people's engagement with health information provides a rich source of data because of the range of different decision-making challenges relevant to each specific health issue. A number of other health issues were considered as potential foci for the study, such as epilepsy and HPV, and a scoping review of existing online content was conducted to identify those most actively discussed online, in both professionally produced and user-generated content (see Appendix 2). The scoping study highlighted the high prevalence of content in relation to both diabetes and CMHDs.

Diabetes and CMHDs were also considered useful comparators because they involve different considerations for people in relation to: diagnosis, treatment options, information needs and decision-making. Both diabetes and CMHDs involve some

degree of self-management, a concept traditionally associated with chronic diseases such as diabetes but which has also come to be associated with mental health (Sterling et al., 2010). Information-seeking online can be seen as a key element of self-management. Furthermore, concerns about stigma in relation to mental illness have been discussed in detail (Goffman, 1963, Wright et al., 2000) and online resources are often seen as a means of overcoming stigma-related barriers to help-seeking (Sánchez-Ortiz et al., 2011).

3.2.2 Identifying the key population of interest

Young adults are of particular interest to this study because of their life-stage and their potentially rich online experience. The life-stage of young, or ‘emerging’, adulthood has been characterised as distinct from both adolescence and adulthood and identified as an important period of transition (Arnett, 2000). It has been suggested that this might also be a group which have unmet health needs (Marshall, 2011). In terms of online health information seeking, Dutton and Blank (2011) state that 57% of students reported actively seeking health information on the internet. Furthermore, young adults (16-24 years) are more likely to use the internet for social networking, at least quarterly, than all other internet users (96% vs 69%) (Ofcom, 2014). Indeed, young adults are some of the most avid users of social media websites, and the opportunity to post, comment, respond and ‘like’ have become important expressions of personal and group identity for many, with some theorising that this is not without social and political consequences (Papacharissi, 2010). Furthermore, in relation to the use of online support groups, a review of research on online communities for supporting experience of depression suggests users’ ages ranged from mid-20s to mid-40s (Griffiths et al., 2009). By identifying young adults as the population of interest, the focus of the study was narrowed to individuals who might share a common awareness and experience of engaging with social media technologies.

3.3 *Disciplinary and epistemological considerations*

This study aims to use qualitative methods to explore the role of online technologies, and social media in particular, in contributing to constructions and

experiences of diabetes and common mental health issues, and associated processes of self-management. Timmermans' (2013) recent commentary entitled 'Seven warrants for qualitative health sociology' identifies several types of questions which can be uniquely answered by qualitative rather than quantitative methods. In particular, he identifies the power of qualitative methods in "illuminating the constructions of medical beliefs" (p. 2). By exploring habits, influences and context in relation to health through qualitative research, insights can be generated around health beliefs beyond established biomedical presumptions. Timmermans (2013) also draws attention to the opportunity to identify "unfulfilled promises", that is, using qualitative methods to identify disjoints between the intentions of health interventions and the complexity of people's experiences of them. By exploring young adults' practices for engaging with online content about diabetes and CMHDs this thesis should contribute to both these objectives of qualitative health research.

Like much qualitative work in health research, the study is underpinned by an interpretivist approach, in that it focuses on the meaning of phenomena for people and seeks to explore their understandings of the world (Green and Thorogood, 2013). This perspective shares some tenets with social constructionism, which recognises phenomena as socially produced by individuals and groups within a specific cultural context (Berger and Luckmann, 1966). Schwandt (1998) elucidates these perspectives:

The world of lived reality and situation-specific meanings that constitute the general object of investigation is thought to be constructed by social actors. That is, particular actors, in particular places, at particular times, fashion meaning out of events and phenomena through prolonged, complex processes of social interaction involving history, language and action (pp. 118-9).

This perspective, therefore, prioritises understanding individual experiences and seeks to identify patterns within these subjective experiences rather than surveying large groups of people and discerning trends in behaviour (Broom and Willis, 2007). Conrad and Barker (2010) suggest that adopting more constructionist and

interpretivist ways of thinking has impacted health policy-making by prioritising critical reflection on the definition of health ‘problems’ and related ‘solutions’. By developing this study within an interpretivist tradition, I aimed to prioritise the perspectives, definitions and concerns of participants and avoid common assumptions around both practices of internet use, and experiences of health issues and self-management.

Rather than adopt a particular approach, such as Grounded Theory or Discourse Analysis - both of which are relevant to this study, and conform to that tradition throughout the development of the research, I developed the study iteratively and drew on a range of methodological influences. This type of approach is sometimes termed ‘bricolage’, in that it attempts to explore “phenomena from multiple, and sometimes competing, theoretical and methodological perspectives”, and employs “practices explicitly based on notions of eclecticism, emergent design, flexibility and plurality” (Rogers, 2012: p. 1). Denzin and Lincoln (1994) suggest that the advantage of the ‘bricoleur’ who works across paradigms, perspectives and methods is that they are able to explore phenomena both thoroughly and systematically: “The combination of multiple methods, empirical materials, perspectives and observers in a single study is best understood, then, as a strategy that adds rigor, breadth and depth to any investigation” (p. 2). This approach also broadly aligns with the account of the foundations of qualitative research given by Ormston and colleagues (2013), who suggest an interpretivist stance allows pragmatic decisions to be made about methods. In line with this approach I considered a range of qualitative methods and data sources during the design phase of the study, with the aim of maximising the perspectives explored.

Although the study did not follow a traditional Grounded Theory approach, it is inductive and aims to suggest tentative theoretical conclusions. Such conclusions are potentially useful because this study relates directly to contemporary innovations in health communication and may offer insights for the development of particular communications policy and strategy. Many authors have commented on the need for policy-related research, to produce context-specific interpretations

rather than detailed description, to be of practical use in policy development (Pope et al., 2000, Kearney, 2007).

3.3.1 Researching and reflexivity

One of the key considerations for undertaking qualitative research is the principle of reflexivity (Green and Thorogood, 2013). This involves considered reflection on the experiences of the researcher in the field and the dynamic relationships she has with the research participants and setting of the research and has become a common feature of accounts of qualitative research (Matt, 2004). Foregrounding these aspects of research, or ‘outing’ the researcher in Finlay’s (2002) terms, constitutes reflexivity in research. The neutral, absent researcher is the product of a positivistic model of research (Mauthner and Doucet, 2003), and has been critiqued by those who emphasise that knowledge is not ‘discovered’ but ‘made’ (Latour and Woolgar, 1979). As a result, acknowledgement of politics, cultures and ideologies have become crucial throughout the research process in order to situate claims as partial interpretative perspectives (Harding, 1986, Haraway, 1988). Furthermore, reflexivity can also be understood as ‘a confessional account of methodology’, with details of decision-making reported as means of maximising the transparency of the research process (Finlay, 2002). A reflexive approach to the research was important over the course of this study. By reflecting on research relationships in the different environments of data collection and analysis and the dynamics of power, agency and identity, I was able to attempt to address inequalities and imbalances. In this study, which includes both interviews with young adults and interviews with individuals in a professional setting, these considerations varied. Reporting of the researcher’s contributions to the research in the field and in interpretation also allows for situating knowledge claims (Finlay, 2002). Throughout the reporting of the research process, and in the findings chapters, I attempt to provide detail on the specific context of participants’ comments, and my role in their construction.

3.4 *Specific issues to consider for internet research*

As well as interpretivist and ‘bricoleur’ approaches the research design draws on online research methodologies (see Fielding et al., 2008, Markham and Baym, 2009) since the study aims to explore an online social phenomenon. In particular, Hine (2009) and Orgad (2009) recommend considering both the online and offline contexts of social phenomena. They suggest that investigating engagement with health online requires crossing boundaries between online and offline environments throughout the research process to reflect on the phenomenon in both contexts. Therefore, in this study a key aim of the research design was to allow for a shifting focus, between the online content and its creation and the offline experience of interpreting it.

3.4.1 Opportunities and challenges of internet research

Although researching online phenomena has become commonplace since the rise of everyday internet use by the public, a number of opportunities and challenges specific to internet research have been noted. Firstly, the complexities of the online environment pose new challenges to established theoretical interpretations of media that have implications for research. Livingstone (2004) draws parallels between audience reception research focusing on television and more recent research on new media, but adds that the terminology and roles of the audience are less well defined in the case of new media. Varied labels have emerged to identify the ‘audience’ in new media research, with references made to both the ‘user’ and ‘consumer’ of online content, which require further consideration. Indeed, Lievrouw and Livingstone (2002) suggest new media and internet research could draw further on audience reception literature to recognise the complexities of the audience as situated within a particular context. In order to explore this complexity in the current study, young adults have been identified as the user group, or audience, of interest, and the specific content areas of diabetes and mental health specified, to create boundaries within which these ‘users’ (or audience) can be described and analysed.

Das (2011) suggests a further challenge of internet research is negotiating the tension between drawing on established theoretical interpretations of media, whilst maintaining an awareness of the dynamic environment under study. Indeed, the importance of paying close attention to the evolution and development of online communication, particularly in relation to social media, has been stressed:

[...] the rise of ‘pull’ rather than ‘push’ forms of consumption such as RSS feeds [format for distributing frequently updated content], the development of spaces for content sharing such as YouTube and Flickr, are all in the process of changing long-established media theories about producers and audiences and the relationship between them, and indeed about the very nature of ‘text’ itself (Bachmair and Bazalgette, 2007: p. 82)

The dynamic online environment is central to this study and the development of interactive content and users’ practices are important concerns of the aim and research questions. In a bid to keep abreast of developments in online practices and understand the impact of changing communication technologies on health issues, I inhabited online spaces regularly, throughout the length of the study, and maintained links with specific online communities. Despite this, researching the dynamic online environment remains a particular challenge of internet research generally, and this study in particular, given the speed at which users’ practices and social media platforms develop.

3.5 Research design

Based on the research questions and the various perspectives and issues outlined above, I developed the research iteratively. In particular, the study design was informed by calls for research which investigates online phenomena from multiple perspectives. As discussed in Chapter 2, Segal (2009) has called for internet research to address the triangle of speaker, content and audience, and suggests the development of studies that are holistic and involve all three perspectives, which has rarely been done. More holistic analytical approaches have also been recommended by Beneito-Montagut (2011), who calls for research which attempts to investigate how “social information and communication technologies operate

within society in everyday life” (p. 716). In particular she suggests that exploring multiple data sources is valuable since, by focusing on isolated snapshots of online text and disregarding primary data collection with users, much research fails to explore the complex interplay between online and offline existences. Rather she proposes researchers employ “a multi-site, multi-media and user-centred methodological approach” (Beneito-Montagut, 2011: p. 720) to more fully explore the impact of online communications. With these recommendations in mind, and the lack of literature explicitly exploring users’ experiences of engaging with social media content about diabetes and CMHDs, I developed the study to address the phenomenon of engagement with health-related online content to explore both online and offline perspectives.

The study was designed with three phases, which overlapped and informed each other over the course of the research process. These are outlined briefly here and described in more detail in the following sections.

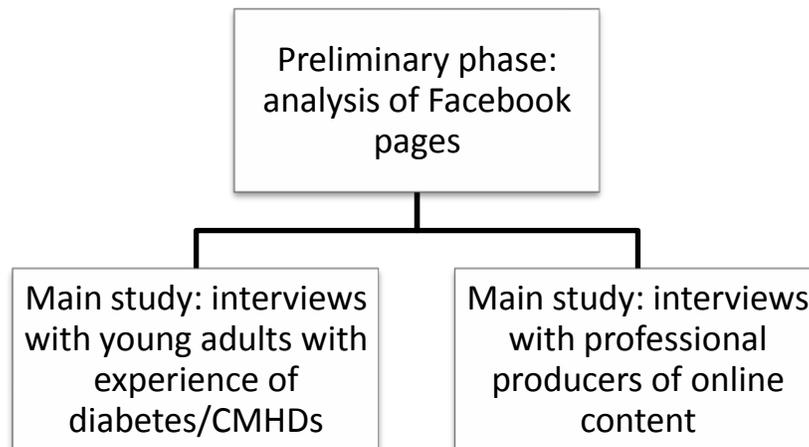


Figure 1: Overview of research design

Figure 1 illustrates how the phases of the study were conceived, with a preliminary, exploratory phase designed to inform two phases of the main study. The preliminary phase was designed as an opportunity for me to develop my understanding of the landscape of user-generated content related to diabetes and CMHDs. In order to explore how these issues are discussed online by users and professional producers of online content I collated and analysed a sample of naturally occurring online data, relating to each of the health issues. This

use of social media platforms, and users' responses to both professionally produced and user-generated content. This focus on social media is concomitant with its growing presence as a tool for public engagement with health issues and calls for further research around its use as a means of communicating with publics (Thackeray et al., 2012).

3.6 Preliminary phase: exploring online content

As a means of 'entering the field', a process described by Lincoln and Denzin (1994) as getting familiar with the spaces and actors which the study is concerned with, I spent a period of time exploring the generation of content on social media sites related to either CMHDs or diabetes. In order to understand more fully the framing of health issues in these spaces, as well as observing users' practices, I conducted a preliminary analysis of the user-generated content featured on four Facebook pages.

This preliminary phase of data collection and analysis was originally conceived of as a stand-alone discursive analysis, and a larger element of the study, for comparison with the interview data collected. Analysis of online texts created by users was deemed useful to the study for two main reasons. Lupton (1992) comments that important insights can be gained in public health research from exploration of the discursive practices used in conversations between lay people about health issues. The online environment and its increasing participatory and contributory culture provide an opportunity for gaining access to day-to-day conversations and debates about health so that constructions of particular health phenomena can be analysed. Secondly, user-generated content is a source of information for other users and warrants analysis in the same way that print and broadcast media do. Many researchers have pointed to the need for examination of media representations of health and illness since they are one of the most prominent sources of expert and lay accounts of health (Bury and Gabe, 1994, Stockdale, 1995, Lupton, 1999, Lyons, 2000). In particular, studies which explore linguistic and visual framing of health issues can identify the narratives of particular health phenomena that are available for the lay public as consumers of mediated information. Media representations of

health issues also serve to mirror or reflect back people's established constructions of health issues. Indeed, as Lyons (2000) suggests, "critical examinations of media representations provide valuable ways of incorporating and explicitly analysing the social and cultural context into the study of health and illness" (p. 355). Health issues are represented frequently and broadly online and the rationale and methodologies used in the analysis of traditional media can also be applied to social media. Indeed, textual and linguistic approaches such as content and discourse methods are increasingly used for analysing online texts. Analyses have been conducted of patient support group forum threads (Guise et al., 2010) and blogs (Keelan et al., 2010) around particular health issues. In online spaces we are granted a view into public debate, removed from individuals' motivations and experiences but which can provide an insight into the multiple discourses which are drawn on in the construction of health issues and accounts of the experience of them.

3.6.1 Defining the scope

Having explored a range of social media sites, including Twitter, YouTube and blog sites, the difficulty of defining boundaries around the analysis of online health-related content became apparent. Rather than conduct a full discursive analysis of user-generated content related to both health issues, I decided to conduct a focused descriptive analysis of a small sample of Facebook 'community' or 'group' pages in order to inform the development of the main study. Facebook was identified as particularly useful because of its large number of users (over 845 million in 2012), the volume of content shared on the site (four billion pieces per day) and the interest it has generated as an important source of insight and data for contemporary social science (Wilson et al., 2012). Furthermore, due to the number of users and the volume of content produced on the site, group pages hosting interaction about the experience of both diabetes and CMHDs were easy to find and many were well-used.

In order to collate data for analysis I performed searches within Facebook with search terms such as 'diabetes', 'mental health', 'depression' and 'anxiety' to

identify pages focused on these health issues. These ‘community’ pages offer spaces within Facebook for bringing together users around a particular issue of interest, rather than reflecting established offline social networks. On these pages users can contribute various types of content, including images and videos, as well as links, and post comments that other users can respond to. Unlike users’ profile pages, the content on these pages is often entirely public. ‘Community’ Facebook pages can be created and managed by anyone, and are utilised by commercial and charitable organisations, as well as individuals, for creating networks of users to disseminate information and promote engagement.

From the search hits a purposive sample of ‘community’ pages was selected. In order to ensure the pages explored were not atypical and were relevant to, at least some, users’ experiences, inclusion criteria were developed. Firstly, pages had to be currently active (with daily contributions from users up to the search date) and secondly, pages had to have gained a substantial number of ‘likes’ (over 200). The ‘like’ function is a feature of some social media technologies which allows users to express their approval for various types of content, such as comments, images, videos, events, and commercial, community and charity pages. The action of clicking the ‘like’ icon associated with a particular section of content is then recorded on the user’s profile page, published to their friends and contributes to a total number of ‘likes’ which is then displayed alongside the respective content. Previous research (Fergie et al., 2012) indicates that some users appreciate these features of social media as indicators of credibility and rely on these markers in navigating social media content. Pages were excluded if the health issue was not the primary focus of the page, with the aim of limiting content not relevant to the research questions.

In order to maximise the type and tone of content included, the origins and administration of the ‘community’ Facebook pages were considered. For each health issue, one page was included in the sample which was professionally created and managed by a high profile charity and the other created by a Facebook user or group of users without corporate branding or input. The two charity pages included were the *Diabetes UK* page and the *MIND* page and the two user-generated pages

included were entitled *Diabetes - the patient experience*, and *Depression*. These pages featured a large number of posts on varied subjects. On each page user-generated posts appearing between 1st June 2012 and 31st July 2012 were examined. In order to explore interactive elements of the user-generated content featured on the pages, only those posts which had generated three or more further comments from other users were extracted for further exploration. Rather than preserve this content intact, the text from these interactions was copied and pasted from the Facebook pages into word documents. Although details about the number of 'likes' for each comment were available, this process reduced the multimedia content to textual data. In total between 15 and 25 interactions (original posts with subsequent comments) were extracted from each page and collated for analysis.

Literature on online research ethics stresses the need for specific ethical consideration for different online contexts (Eynon et al., 2008). The user-generated content collated in this project was considered according to Elm's (2009) 'public/private continuum' which is based on how easily accessible content is and how public or private users understand their contributions to be. Only content deemed public according to these criteria was included in the study and therefore consent from contributors was not sought.

3.6.2 Coding and analysis

The processes of coding and analysis were informed by Willig's (2003) six stages of discourse analysis. However, since a full discourse analysis was deemed beyond the scope of the current study, these stages were not followed to their conclusion of linking discursive constructions to power relations. Firstly, the collated texts were read carefully and coded line by line to highlight language use, describe the thematic content of the texts and identify constructions of 'diabetes' or 'mental health' and related issues such as diagnosis, self-management and secondary health issues. Codes were also developed as the coding progressed for constructions of other issues not anticipated by the research questions, such as 'relationships' and

'stigma'. A set of questions was developed to aid and focus coding, based on the research questions and relevant theoretical and empirical literature. These were:

- What is the apparent/explicit purpose of this contribution?
- In what ways are the specific health issues constructed?
- How are the processes of diagnosis and treatment constructed?
- What identities (e.g. patient/survivor/sufferer) are represented?
- What references are made to research evidence in constructions of the health issue?
- What references are made to advice and/or information from health professionals in constructions of the health issue?
- What references are made to experiential evidence in constructions of the health issue?

During this process of coding, notes were taken and codes separated into sub-codes and drawn together into over-arching themes to suggest particular perspectives or angles which individual contributors chose to draw on in their content. The data collated from users' posts around mental health issues were coded first. The diabetes data was coded subsequently. Attention was paid to codes that were concordant across both analyses and codes that were unique to either data set. As discussed, fully developed findings were not produced, however, a summary of descriptive codes and related discursive constructions for each health issue is provided in Figure 3.

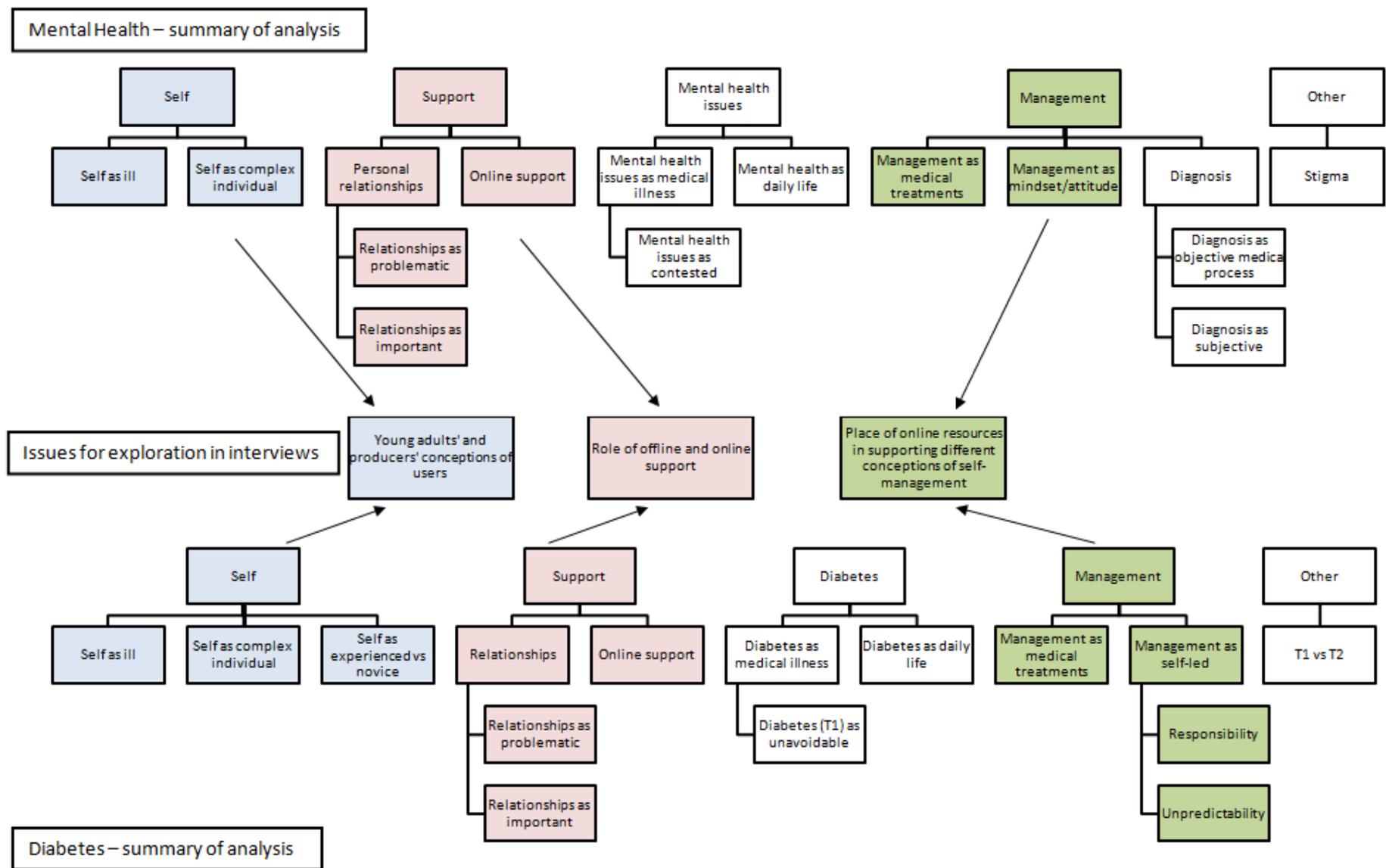


Figure 3: Summary of analyses of diabetes and CMHD related content on Facebook

The analysis of Facebook interactions highlighted the complexities and nuances inherent in users' contributions to health-related social media spaces. Although the analysis did not produce extended findings that linked the constructions of health issues online to wider political discourses, the exploration of online content was useful for informing the development of the study in a number of ways. Insights from the analysis informed the development of the research primarily by suggesting key issues for exploration in the interviews with young adults and professional producers as highlighted in blue, pink and green in Figure 3. Systematic exploration of the Facebook pages also encouraged me to explore online health content more broadly. Through firstly exploring Facebook communities, I became aware of the range and diversity of social media spaces inhabited by individuals and groups generating content related to both diabetes and common mental health issues. This exploration also highlighted the integration of social media platforms and the complexities of defining boundaries around social media for the purposes of qualitative research. Nevertheless, I continued to inhabit social media spaces throughout the course of my PhD, following links and visiting sites, pages and online events related to diabetes and CMHDs hosted on various social media platforms. Mostly, this involved me 'lurking' on pages, reading and recording content rather than contributing any. I produced fieldnotes, describing the communities and spaces where content was being produced, to create an informal record of the opportunities available to users to engage with diabetes and mental health-related content. Although some content on Facebook, and most on Twitter and YouTube, is freely available without logging into an account, throughout the study I was logged into my personal social media accounts. My lack of visible engagement with health-related content was, in part, related to concerns about my personal Facebook 'friends' seeing evidence of my engagement with this content. Indeed, throughout the course of the study I was faced with similar concerns to those raised by many of the young adult participants related to compromising my online identity.

3.7 The main study

In order to understand the perspectives of both young adults and professional producers of online resources about diabetes and mental health issues, semi-

structured, in-depth interviews were conducted as the main method of data collection. Interviews have long been established as a fundamental method of qualitative research and they are employed usefully in a range of approaches. In this section, I discuss the use of the interview in qualitative research broadly; situate the interview as the key method of data collection in this study, concomitant with the approach and research questions; and give details of the two sets of interviews I conducted.

3.7.1 Rationale for interview method

Interviews have become an important feature of contemporary day-to-day life, as a key mode of communication in both professional practice and mass media (Gubrium and Holstein, 2002). In the social sciences, the interview aims to develop our understanding “by means of conversations with the human beings to be understood” (Kvale and Brinkmann, 2009). By conducting qualitative interviews with participants, the researcher seeks to elicit participants’ perceptions, experiences and understandings of the phenomenon of interest (Nunkoosing, 2005). As qualitative research has come to prominence, the interview, alongside qualitative methods generally, has been variously problematised. In particular, the roles of the researcher and the participant, and their relationship during the interview event have been discussed. Within the constructivist paradigm, both researcher and participant are conceived as active agents, as Holstein and Gubrium (2004) state: “Both parties to the interview are necessarily and unavoidably active. Meaning is not merely elicited by apt questioning, nor simply transported through respondent replies; it is actively and communicatively assembled into the interview encounter” (p. 141). This has led to an understanding of the researcher and participant as co-constructing data during the interview, with the subjectivities and biases each brings to the interview and the interview process being as important as the data produced (Fontana, 2002).

3.7.2 Interviews for data collection with young adults and professional producers of health-related content

In order to access multiple perspectives on the processes of engaging with health-related content online, two distinct groups were of interest to this study.

To access the perspectives of potential users of health-related online resources, a series of interviews with young adults was conducted and to access the producers' perspectives, professional producers of online resources related to either diabetes or common mental health issues were also interviewed. By describing these two groups and related considerations around collecting data for each, a rationale for using interviews to generate qualitative data from both perspectives is detailed.

The focus of the study on the perceptions and experiences of young adults, as discussed in the Chapter 1, relates to their life-stage and their online experience. As potentially active users of social media technologies, young adults are likely to be familiar with the range of available platforms and have experience of engaging with them to generate or consume content. It is this potential for familiarity and mundane use of social media that is useful for exploring, through discussion, individuals' experiences of searching, exploring and inhabiting online spaces and the dynamic social practices that surround social media. Indeed, previous similar studies have successfully used interviews with young adults exploring their interpretations of social networking sites broadly (Das, 2011).

Also important to the study aims was gaining an understanding of how online resources are accessed in relation to people's experiences of diabetes and CMHDs. The aim of interviews is to gain a deep understanding about participants' lived experience and to allow participants to prioritise issues as they arise for them (Johnson, 2002). Indeed, Nunkoosing (2005) suggests that all stories participants prioritise are equally important in that they reflect some aspect of that individual's lived experience. Therefore semi-structured interviews were considered an appropriate means of exploring individuals' lived experience of diabetes and CMHDs and the role of online resources in this context.

During the formative stages of the research, focus groups were also considered as a method for data collection with young adults. Focus groups are particularly well-suited to generating data around group perceptions, interactions and experiences (Marshall and Rossman, 1995) and provide access to thought

processes and social meaning-making which are often otherwise implicit (Kitzinger, 2004). This method may have been useful for exploring social practices online, and the community and network features of social media technologies, with the group setting allowing for individuals to discuss similarities and differences in the ways they interact online. Previously I had employed the method in an exploratory study of young people's engagement with general health resources online (Fergie et al., 2012). Focus groups in this case were useful for generating data around engagement with non-specific health-related content, but did not allow for exploration of more sensitive accounts of personal experiences of particular chronic or long-term health issues. For this larger study I decided that, rather than facilitate further focus groups, conducting semi-structured interviews offered an opportunity for a personal narrative of health experiences to be constructed during the more private interview interaction with references to the significance or insignificance of a range of online resources to personal experience.

Secondly, in order to address my second research question: "How are online resources and users conceived by professional producers of online content and potential users?", I also conducted a series of interviews with professional producers of online content. The participants in these interviews were professionals from diabetes and mental health charities and organisations, who devise social media strategies and/or maintain the organisations' online presence (e.g. communications officers, online officers, website developers). Semi-structured interviews were conducted to explore the organisation's and individual's intentions for and perspectives on providing health-related content online and facilitating platforms for consumption and production of user-generated content. In many ways this type of key informant interview is similar to those which have become commonplace in health policy research, through which key stakeholders' positions on policy design, implementation and consequences are explored (Sofaer, 1999). From a pragmatic perspective, interviews were thought to be the easiest method of generating rich data from professionals working in health-related organisations since they had busy schedules but were familiar with the interview format, particularly since the interaction was similar to that of a professional meeting. Similar studies,

exploring various aspects of online health resources, have also used semi-structured interviews to explore the perspectives of professional producers and creators of online resources. Livingstone (2007) used interviews as a productive method of data collection with website producers in her study. Similarly, Oudshoorn and Somers (2006) used interviews with website producers from patient groups to supplement their analysis of 'project plans' for creating online resources. Through interviewing they explored the processes of creating sites and the constructions of users and patients embedded in these processes and resultant resources.

3.7.3 Ethics

In order to ensure that the processes of fieldwork were conducted to the highest research standards, the study was reviewed by the University of Glasgow, College of Social Sciences, Research Ethics Committee and ethical approval was granted prior to fieldwork commencing. Issues around anonymity, confidentiality and the consent process broadly were important considerations in planning the main interview phases of the study. Any young adults or producers who expressed an interest in the research were invited to take part on the basis that their contributions were confidential and anonymous and that any data gathered were recorded, transcribed and stored securely. Further description of how this was carried out in practice is included throughout this chapter.

3.8 *Piloting the methods*

Having developed a rationale for using interviews to collect qualitative data, I conducted a small scale pilot study with the aim of gaining insights to refine the design of the main study: by testing the proposed method of data collection (semi-structured interviews with young adults and professional producers of online content); refining the interview topic guide; and beginning to create networks of contacts for recruitment. These objectives are common across various types of qualitative pilot work (Sampson, 2004). The pilot was also designed to produce data which would be suitable for preliminary analysis to suggest themes for further investigation in the main phase of data collection. Specific questions the pilot was designed to address were:

- Which organisations (if any) might be happy to assist with the project, in terms of recruitment and participation?
- What might be the challenges of recruiting participants with experience of diabetes and common mental health issues?
- Are there differences between young mens' and young womens' accounts, or between the accounts from diabetic participants and those with experience of CMHDs?
- How are online technologies, and social media specifically, perceived and how important are they to personal experience? Are individual interviews an appropriate method of collecting people's accounts of using online resources?
- Are social media websites useful stimulants for discussion?

For the pilot I conducted four semi-structured interviews with young adults, two who had diabetes and two who had experience of a CMHD. Given the relatively short time frame for the pilot study, and the longer lead time required to create networks of contacts to support sustained recruitment all four participants were recruited through contacts in my personal and professional networks. At this pilot stage, no professional producers were recruited. This was due to initial difficulties creating contacts within organisations and concerns that early piloting might reduce the pool of potential participants for the main study. Details of the characteristics of the young adult pilot participants are listed in Table 1.

| Pilot participants | | | | |
|-------------------------|--------|-----|--------------|--------------------------------------|
| Participant (pseudonym) | Gender | Age | Health issue | Level of health-related internet use |
| Young adult (Sarah) | Female | 22 | CMHD | Frequent |
| Young adult (Nicola) | Female | 28 | Diabetes | Moderate |
| Young adult (Daniel) | Male | 25 | CMHD | Infrequent |
| Young adult (Fiona) | Female | 22 | Diabetes | Previously frequent |

Table 1: Pilot participants

To guide the progress of the interviews I used a flexible interview schedule, which included topic areas for discussion, some open-ended questions and potential probes (see Appendix 3). At two points during the interview I introduced examples of websites and social media sites using a tablet computer, firstly so participants could explore relevant health related content on social

media sites and later so participants could browse interactive self-management tools.

By reflecting on the process of data collection, my field notes and preliminary analysis the plans for the project and the processes of data collection were refined. The main insights gained from the pilot work are detailed below.

3.8.1 Lessons on recruitment and sampling

Snowballing from personal and professional networks was successful for recruiting young adults to the pilot. However sustained recruitment in this way was unlikely to be feasible since these networks could soon be exhausted and would not have provided a diverse sample. At this stage, further recruitment strategies, including making contact with organisations who could act as gatekeepers were deemed necessary to recruit the numbers needed for the main study. Given that I only recruited one young man to the pilot, and that people with experience of common mental health issues were more challenging to identify and contact, the pilot study informed my decision to prioritise making contacts with gatekeepers to these groups for further recruitment. In particular I attempted to make contact with men's health charities, with a focus on mental health.

The pilot sample consisted of three young women and one young man, with two participants having experience of each health issue. The participants varied by age, stage of health issue and frequency of online health information access. The different perspectives that this variety brought was evident in the data collected. Sarah inhabited online spaces related to her experience of mental health issues regularly. By seeking information relevant to Scottish health policy and joining Facebook groups set up by local support groups, the online information and peer-support she sought was embedded in her offline experience. In contrast, Fiona sought information online intensely for a period of time around her diagnosis, particularly around approaches to self-management and drew on various diet and exercise advice, from national and international resources and users, to suit her lifestyle. Daniel, however, reported that he had never used online resources to support his experience of depression and during the interview he responded negatively to online resources

and criticised the generic nature of information. He also suggested other people's experiences were unlikely to be relevant to his and so saw little value in engaging with them. These diverse experiences of engaging with online resources, evident even within this small pilot, suggested the importance of maintaining a wide-ranging approach to recruitment, to recruit both heavy users and non-users of health-related online resources in order to explore the differences in these perspectives.

3.8.2 Lessons on method choice

After having completed and explored the data collected from the four pilot interviews with young adults, I decided that this was an appropriate method of data collection for the main study and hence decided not to proceed with focus groups as an alternative method of data collection. The data collected in the pilot interviews included personal reflections on the lived experience of diabetes/CMHDs that participants may not have felt comfortable sharing in a group setting. For example Nicola commented on the impact of diabetes:

[...] it completely affected my life, I was just starting to drink and go out with friends and I just rebelled completely, I just didn't give a shit, sorry, so I just used to drink myself into a stupor and pass out and things like that (Nicola, diabetes, 28).

These types of comments from participants provided context for understanding participants' perceptions of online resources and helped me to relate participants' comments to specific experiences or time periods in their life. My analysis of Facebook interactions highlighted many examples of constructions of the 'good' diabetic as someone who is responsible and conscientious about self-management. These comments from Nicola are not in keeping with this idealised image and she may not have shared these in a group setting with other diabetics, considering the dominance of this construction of the 'good' diabetic.

Furthermore, in most of the interviews trust seemed to be built over the course of the interview and participants became increasingly open towards the end of the interview. For example, Daniel was much more reflective in the closing stages of his interview and made illuminating remarks which provided further explanatory, contextual data:

I mean, I think, if they told me to maybe use it [online resource for depression], like say if I was coming away from like a therapy session or whatever, like “you should try that out”, I’d maybe use it but be incredibly cynical through it, I dunno I’ve just never found myself that convinced with that sort of stuff I don’t know I just, yeah like I dunno I, part of my problem is I almost see myself as this completely unique, like, problem that only someone that focuses completely on me could help, I don’t know why, it’s maybe a bit of like of an ego or something, I, I [...] it’s just because it’s aimed at everybody, trying to help, but then it’s kind of missing everybody at the same time, or that’s kind of how I would see it, because it’s missing me (Daniel, CMHD, 25).

The build up to these reflections was slow and I think it is unlikely that Daniel would have reached these more critical conclusions in a focus group session where discussion is wide-ranging and not focused on the individuals’ lived experiences.

The tablet computer also worked well as a stimulus for discussion during the interviews. During all four interviews participants were confident using the tablet to access pages which I had loaded as tabs in the browser and explored these pages by scrolling through content and clicking on links. In two of the interviews (Fiona’s and Sarah’s) the tablet was used more frequently, with the participants using the browser to demonstrate their searching strategies as a means of answering my questions about information seeking practices. As well as continuing to use interviews for the remaining fieldwork, I decided to extend the use of the tablet in future interviews where appropriate by loading further social media websites for discussion and making it available to participants throughout the interview should they wish to show me any sites, or demonstrate online practices.

3.8.3 Lessons on interview schedule

Analysis of the pilot data suggested some differences in interviewees’ perspectives that appeared to be related to the health issues that they had experience of, although the size and diversity of the pilot sample means these conclusions are particularly tentative. The participants put forward different

conceptions of the importance of disease-related communities and shared experience, and different conceptions of individuality. Both participants with experience of CMHDs stressed the importance of individuality when describing the problems they faced and in thinking of ways to manage and address them. However, both diabetic participants mentioned the value of accessing an online diabetic community for sharing experience and advice. This informed the development of questions in the interview schedule around how individuals' experiences related to accounts of other people's experiences online and what the advantages and disadvantages of groups and communities of users with a particular health issue coming together online are.

Related to pilot participants' conceptions of the individual and the community, differences were also notable in how they discussed the advantages and disadvantages of online resources. The participants with experience of diabetes (Nicola and Fiona) were generally more positive about the range of diabetes-related content available and the potential of social media as a resource. Both suggested new opportunities for online resource development which they envisaged might support young adults' self-management. However, while the participants with experience of CMHD (Sarah and Daniel) did suggest some benefits of online resources, they often used the caveat of 'different things work for different people' and seemed to find it more difficult to identify useful examples of online content or resources. They expressed concerns about social media generally and Facebook in particular, suggesting that use of the sites can have a negative effect on people's emotional wellbeing. Following the pilot interview with Fiona I wrote in my fieldnotes:

It seems really interesting that Fiona has so few concerns about privacy and social media compared to Daniel and Sarah. They seemed so cautious about Facebook, both saying things like 'well, Facebook's a funny one' and describing it as a 'negative' space whereas Fiona seems to see no problematic issues for using it in a health context, despite having raised the issue of stigma earlier.

Fieldnotes, interview with Fiona, 13th November 2012

At the pilot stage the similarities and differences in the way the participants conceived online resources in terms of the health issues they had experience of was particularly pertinent to the research questions. The differences in participants' accounts confirmed the importance of ensuring the interview schedule allowed for systematic comparison of participants' accounts of how they incorporated online resources into their own experience of a particular health issue.

Another key issue for further examination highlighted in the pilot was my conception of 'users' and 'non-users' of online resources. During the pilot interviews I noted that, within this small group of participants, there were not clear distinctions between 'users' and 'non-users'. Although all of the participants were familiar with the internet and used it every day, the extent to which people engaged varied hugely. For instance Daniel reported consuming a limited amount of mental health content from professionally produced websites, whereas Sarah discussed consuming a range of content tacitly from mental health-related social media sites. Furthermore, three of the participants described their changing online behaviours over time, dependent on their attitudes and needs. For example:

I don't use [the internet] as much now, I found I used it, in that first year a lot more, than I do now, cos I feel like I've got the answers and I don't need it. Every now and again, say before my test for my blood sugars I'm like oh maybe I should check kinda thing, but I use it half the amount now, and I feel that's cos I feel like I've got my cure, well not cure but feels like I've got like my Metformin, my pill, emm I do my exercise and stuff, so I feel like I've got my answers (Fiona, diabetes, 22).

Similarly Sarah described changes in her use of Facebook over time and her changing attitude to posting and 'liking' content related to her mental wellbeing. These nuances in participants' descriptions of their patterns of use seemed important issues to consider including in the main study, by adding questions about changes over time in use of the internet, and being mindful of changes over time in online practices in subsequent analysis.

3.9 Main study: interviews with young adults

3.9.1 Sampling

For the main study the sampling strategy was guided by key principles in qualitative research. Mayan (2009) suggests that the most appropriate sample is one which includes those individuals who can provide best insights on the issue for research. In order to maximise the richness of the data gathered, I chose to restrict the sample to young adults aged between 18 and 30 years old, due to their general propensity for online engagement. Furthermore, the sample included only those with experience of either diabetes or a common mental health issue, which meant individuals' insights were related to their lived-experience and a particular online context. The sample was purposive in that the participants I sought to include were individuals with specific insights on the issues of interest to the research (Ritchie et al., 2003). Table 2 (p. 89) provides details of the 40 young adults who participated in the study.

In order to ensure the study included a diverse range of perspectives and to allow for comparisons by gender and health issue, participants were recruited according to a number of criteria. In line with these criteria, the eventual sample included similar numbers of men and women to allow for gender comparison, and individuals from a range of geographical areas and socio-economic backgrounds. Since interviewing gives access to both dominant and alternative narratives, I wanted to include individuals who had different experiences of the health issues being studied. Nunkoosing (2005) suggests that there are “voices that are typical of the experience of chronic illness, as well as voices that are unique to different illnesses and personal experiences of individuals” (p. 702). In a bid to capture accounts featuring different experiences, I aimed to include participants who were at different stages of their illness trajectory, including some with a number of years of experience and some who were relatively newly diagnosed as diabetic or first experiencing CMHDs.

Based on preliminary analysis of the pilot and initial main study interviews, I identified a further dimension on which to sample and recruit young adults. This process was similar to theoretical sampling, more commonly associated with

Grounded Theory (Glaser and Strauss, 1967), which involves seeking out individuals who can further contribute to themes and issues which have arisen in earlier interviews, but not been fully explored therein. As the fieldwork progressed, I sought to include participants who could support my growing interest in individuals who had adopted online technologies wholly into their daily lives. Eleanor, the seventh person to be interviewed in the main study, was recruited through an online support forum for young people experiencing CMHDs in Scotland. She discussed her experience of depression almost entirely in terms of her online engagement. Her presence online was foregrounded throughout her account, she suggested that it impacted her interaction with health professionals, how she decided on treatments, how she approached self-management, and how she shared her experiences and supported others. As a result of this narrative, which was in contrast to the six interviews that had preceded hers, I identified heavy users of online resources as a particularly important group to include in the study.

3.9.2 Determining the sample size

At the outset of the project, I identified that around 40 interviews with young adults would be a useful target to ensure that sufficient perspectives were included. Morse (2000) suggests that the sample size should be guided by a number of factors, including: the scope of the study; the nature of the topic; and the research design. In terms of the research design, in order to allow for comparisons between the groups (according to health issue and gender) in the study, similar numbers of participants with experience of each health issue and similar numbers of men and women were included. These comparisons relate specifically to the research questions around the differences and similarities of engagement across different contexts. As the research progressed, it became clear that 40 semi-structured interviews with young adults would generate a manageable amount of usable data around the topic and maximise the perspectives included, in line with Morse's (2000) recommendation for studies using semi-structured interviews. Furthermore, towards the end of the fieldwork period ongoing analysis suggested that salient ideas and constructs were being repeated, and I had begun to discern key themes, and sub-themes for data analysis.

3.9.3 Recruitment

A number of different recruitment strategies were used to recruit young adults with experience of either diabetes or CMHDs to the study. Details of how each participant was recruited are included in Table 2 (p. 89). During the pilot phase I recruited participants through personal and professional (PP) networks in order to gain access to a number of individuals relatively quickly. Whilst this method of distributing information about the study was useful in the early stages, I was wary about using it for the main study so as not to interview any individual with whom I had, or might develop, a personal relationship. The key strength of this approach was the speed with which recruitment information could be distributed; however, since such networks are quickly exhausted and recruiting too many people in this way may have restricted the range and diversity of the sample, other strategies were required.

A more consistent strategy, which continued throughout the study, was snowballing from participants. At the end of each interview, when I was thanking the participant for taking part, I mentioned that if they knew of anyone else who might want to take part, they should feel free to pass on my contact details and information about the study. This was a particularly useful way of contacting individuals with experience of CMHDs (and the means by which I recruited seven out of the 20 participants with experience of CMHDs). Ritchie and colleagues (2003) have suggested this type of recruitment is particularly suitable when the sampling criteria are based on sensitive issues and the desired characteristic not regularly divulged. Therefore, it is perhaps not surprising that the approach was successful in this case, since mental health remains a sensitive issue and these participants would have been more challenging to identify or target through other forms of recruitment.

Another important means of recruitment was through gatekeepers. In the pilot phase I attempted to make links with a number of local and national organisations supporting young adults with either diabetes or experience of CMHDs. In order to contact potential gatekeepers, I systematically drew up a list of potential target organisations and contacted them by email with a follow up phone call. Although this was not always successful, a number of organisations expressed interest in the project and indicated that they were

willing to help. In most cases I met with a representative from the organisation prior to them distributing any information so that I could identify myself and establish a trusting relationship. Where organisations were happy to distribute information about the project, I sent this both electronically and in the post so that they could pass on my details directly to potential participants, or display leaflets and posters, or distribute information electronically to groups of potential participants. In particular, one local organisation with an interest in social media and online technologies, was very interested in the project and was able to put me in touch with a number of enthusiastic participants. The nature of this relationship and sustained contact with the gatekeeper also meant that I was invited to attend a meeting with other stakeholders in their online projects and contribute some insights from previous research (Fergie et al., 2012) relevant to the redesign of their website. While this relationship was particularly productive, making contact with gatekeepers was a time-consuming approach to recruitment. Although initial meetings were often useful and insightful, the process of recruiting participants was lengthened by the introductory stages of email contact, phone call follow up and face-to-face meeting. Sometimes this investment of time did not pay off: in two cases, despite initial meetings and willingness on the part of the gatekeeper, no participants were recruited.

Throughout the project I also contacted various student support officers in universities and colleges across Scotland and the north of England. By email, I introduced myself and the study and requested their assistance by displaying posters, which contained information about the study, in key sites where students might look for health or social support information. This too was not a particularly productive way to attract participants. Despite sending out posters to five universities and six colleges, only two participants were recruited after seeing the information displayed in such spaces. This is perhaps a fairly passive method of advertising research and seemed a less successful strategy than other approaches I pursued for recruiting young adults with experience of diabetes or CMHDs.

In order to satisfy the theoretical sampling strategy I identified in the early stages of the project, I also advertised the project in various online spaces with

the aim of recruiting heavy users of online support resources. With administrators' support, I posted information about the study on popular online support forums for either diabetes or CMHDs. Generally this generated a small amount of discussion which offered an opportunity to communicate more details about the aims of the study to interested users. Compared to poster advertising, this was a much more successful way of distributing the details of the study and engaging with potential participants without directly approaching them. Five participants were recruited through these online channels, four of whom were male. Although based on relatively small numbers, this suggests that online strategies may be a useful means of recruiting young men with experience of particular health issues to qualitative research studies. Based on this assumption I also advertised the project on a number of generic online forums hosted by magazines aimed at men, under topics like 'health' or 'support'. This also succeeded in attracting another two male participants. In line with expectations, the five participants recruited through these specialist forums were indeed heavy users of online health resources and were therefore able to offer interesting perspectives based on their experience.

Facebook support groups and community pages were also useful sites for posting information about the study, as recommended by other researchers recruiting young adults with diabetes (Balfe et al., 2012). A further three participants were recruited after seeing information posted by the administrator of a popular support group page. Support and assistance from administrators of the forums and Facebook groups was key to ensuring the post about the study was as visible as possible and drew attention from members. These administrators were also gatekeepers in many ways, and required the same level of information and discussion prior to assisting with the research as traditional gatekeepers. However, communication and relationships with these online gatekeepers were conducted via email or Facebook messaging. Recruitment information was also distributed through networks of Twitter users, by employing hashtags commonly used by online communities linked by an interest in a particular health issue (e.g. #gbdoc refers to GB Diabetes Online Community).

The recruitment information distributed through these strategies was consistent. The information included: details of the project focus; a description of the

participants' role in the research; clear statements about anonymity, confidentiality and use of the data; details of the voucher (£25.00, Love2Shop voucher, redeemable in many high street shops) offered to participants for their time; and a range of ways of making contact with me. When young adults responded to recruitment information (either by telephone or email) I provided further information (see Appendix 4) and invited them to take part in the study at a convenient time and location.

Recruitment information was only distributed at times when I had the capacity to conduct interviews within a few days of contact, since this seemed the most effective means of retaining potential participants' interest. I refined the recruitment strategies over time, targeting my efforts broadly at first and more specifically as the project progressed. Figure 4 shows the timing of each strategy.

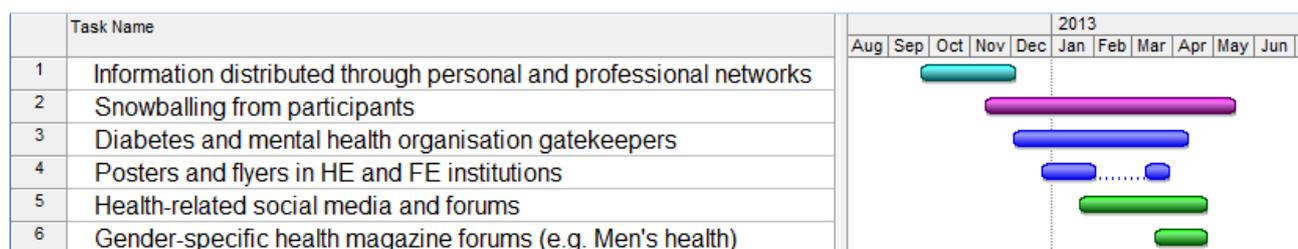


Figure 4: Extract from project Gantt Chart - timing of recruitment strategies

By developing recruitment strategies responsively over the course of the study, I was able to target particular groups in order to satisfy the sampling criteria by including a range of individuals with different online experiences and similar numbers of men and women.

3.9.4 Characteristics of the sample

Between November 2012 and May 2013 40 young adults from across the UK were interviewed (see Table 2). The sample consisted of equal numbers of men and women. At the time of interview 37 were either in employment or full-time education, one was seeking employment and two participants were out of work due to ill health. All participants were White European. Half of the sample had experience of CMHDs and half diabetes. Participants varied considerably in their health experiences. Most of those participants with experience of CMHDs described experiencing depression or low mood, although some also described experiencing anxiety. A small number mentioned other diagnoses - Josh had

been diagnosed with post-traumatic stress disorder (PTSD), Sarah and Liz had both been diagnosed with anorexia nervosa and Paul had experienced a gambling addiction. Of those participants with diabetes, most had Type 1, with only Ingrid having Type 2 diabetes. Many had several years experience of either diabetes or CMHDs, but some were much less experienced. The sample also included participants with a range of experiences of different treatment and self-management strategies. For example, amongst the participants who identified as having experience of depression, several were receiving drug treatment while others were receiving different forms of counselling. Similarly, of the participants with experience of diabetes, some were using insulin pumps to manage their blood glucose, while others were following either a flexible or fixed insulin injection regime. Further details of the sample and the interviews are provided in Table 2 and further details about each individual's background and health experiences are provided in the brief participant profiles (Appendix 5).

| Gender | Health issue | Pseudonym | Age | Date | Interview setting | Recruitment | Location |
|--------|--------------|-----------|---------|------------|-------------------|--------------|---------------|
| Female | Diabetes | Bronwyn | 28 | 15/1/13 | Home | PP network | Glasgow |
| | | Fiona* | 22 | 13/11/12 | Home | PP network | Edinburgh |
| | | Freya | 19 | 18/1/13 | University | PP network | Glasgow |
| | | Ingrid | 23 | 12/12/12 | University | PP network | Glasgow |
| | | Jill | 24 | 27/3/13 | Home | Snowballing | Glasgow |
| | | Leanne | 23 | 4/4/13 | Cafe | Snowballing | Edinburgh |
| | | Mhairi | 28 | 20/3/13 | Cafe | Social media | Dundee |
| | | Nicola* | 28 | 12/11/12 | Home | PP network | Glasgow |
| | | Penny | 27 | 3/12/12 | Home | PP network | Leuchars |
| | | Poppy | 30 | 15/2/13 | Home | Social media | Sheffield |
| | CMHD | Debbie | 30 | 18/3/13 | University | Poster | Glasgow |
| | | Eleanor | 26 | 6/1/13 | Home | Forum | Paisley |
| | | Fran | 25 | 11/3/13 | Cafe | Snowballing | Glasgow |
| | | Leah | 26 | 17/4/13 | Cafe | Snowballing | Motherwell |
| | | Liz | 19 | 3/5/13 | Cafe | Gatekeeper | Inverness |
| | | Mia | 20 | 4/3/13 | Cafe | Gatekeeper | Inverness |
| | | Sarah* | 22 | 9/11/12 | University | PP network | Glasgow |
| | | Simone | 25 | 12/3/13 | University | Snowballing | Glasgow |
| | | Sylvia | 26 | 12/4/13 | Cafe | Poster | Inverness |
| Tara | | 21 | 17/4/13 | University | Poster | Glasgow | |
| Male | Diabetes | Andy | 22 | 19/3/13 | Cafe | Snowballing | Edinburgh |
| | | Anthony | 28 | 2/4/13 | Cafe | Forum | London |
| | | Blake | 27 | 4/5/13 | Home | Snowballing | Aberdeen |
| | | Byron | 18 | 31/5/13 | Home | Social media | Edinburgh |
| | | David | 29 | 20/2/13 | Home | Forum | E. Kilbride |
| | | Leon | 22 | 8/5/13 | Cafe | Snowballing | Paisley |
| | | Max | 29 | 15/3/13 | Cafe | Forum | Wolverhampton |
| | | Ronan | 28 | 29/4/13 | Cafe | Snowballing | Glasgow |
| | | Rory | 30 | 19/2/13 | College | Snowballing | Paisley |
| | | Tommy | 28 | 11/3/13 | Cafe | Snowballing | Glasgow |
| | CMHD | Alistair | 21 | 26/4/13 | University | Snowballing | Glasgow |
| | | Daniel* | 25 | 13/11/12 | University | PP network | Glasgow |
| | | Euan | 28 | 24/4/13 | Home | Snowballing | Glasgow |
| | | Fraser | 28 | 27/4/13 | Cafe | Snowballing | Oban |
| | | Joe | 28 | 15/4/13 | Cafe | Forum | Dundee |
| | | Josh | 27 | 22/4/13 | University | Poster | Inverness |
| | | Mike | 30 | 3/4/13 | Cafe | Forum | London |
| | | Paul | 30 | 27/2/13 | University | Forum | Glasgow |
| | | Peter | 19 | 12/5/13 | Home | Gatekeeper | Galashiels |
| Simon | | 30 | 21/3/13 | University | Snowballing | Glasgow | |

Table 2: Participant information and interview details

*denotes pilot participants

Although the characteristics of the participants, in terms of gender and health experiences, were relevant to the research questions, the sample had a number of limitations. Most of the young adults (31/40) had received or were currently working towards degree-level qualifications and most (37/40) were either employed or in full-time education. Furthermore, all participants had daily

access to online technologies at home and most had smartphones. This limits the extent to which analysis of their accounts can contribute to ongoing debates about 'digital divides' based on socioeconomic status and the impact of social position on information-seeking practices. Furthermore, the sample was not ethnically or culturally diverse, therefore there could be a number of perspectives which are not represented in the data generated and subsequent analysis.

3.9.5 Interview setting

Much qualitative methodological literature notes that the environment of the interview impacts the data collected and the research relationship (Britten, 1995). As detailed in Table 2, the interviews were conducted in a variety of locations for the convenience of participants, including participants' homes (n=12), university buildings (n=11) and cafes (n=17). In all cases I asked participants where they would prefer to meet for the interview, and suggested I could come to their home, they could come to the university building that I was based in or we could meet somewhere public, such as a community centre or cafe. Participants commonly suggested meeting in public spaces, such as quiet cafes, perhaps since meeting in that kind of environment seemed less intimidating and more informal. When participants chose to be interviewed in more public locations, I tried as far as possible to limit the background noise and to ensure spaces were as private as possible to maximise participants' comfort in the interview setting. However, in some cases this was not straightforward. Some interviews were conducted in public spaces which played music and while this did not seem to impact participants' responses it meant a small number of recordings were very difficult to transcribe.

During the interviews conducted in the university building, I was concerned that the formal setting of the Unit might be intimidating for participants. As a workplace with prominent indicators of the professional environment (buzzer entry system, office furniture and notice boards), this setting may have made participants feel less comfortable and made my role seem more professional, perhaps creating a greater power differential between interviewer and interviewee. In particular some early participants interviewed in the building appeared concerned that I might have been a proponent of the websites and

resources I was using as examples for discussion in the interview. I took care to make it clear that this was not the case during these interviews and continued to stress this throughout the following interviews.

In contrast, the less formal setting of participants' homes may have meant participants were more relaxed from the outset, and perhaps redressed any power imbalance since I, as the researcher, was in the unfamiliar environment. This setting also offered further background insights into participants' lives and circumstances. By entering people's private spaces I was able to get a sense of where they spent their time when online and where the computer and other online devices featured in their home. In particular, some of the heaviest online users, such as Eleanor, had computers in the centre of their living space and used them to illustrate issues we discussed.

Cafes also provided less formal settings for interviews and were perhaps the most neutral environment for the interview, in that it was a place that neither I nor the participant was entirely familiar with. Although I was initially concerned that this type of venue might not be private enough, all of the participants I interviewed in cafes seemed happy with the choice of venue, perhaps because it seemed like a more natural place to meet someone you did not know. However, although none of the participants interviewed in cafes showed obvious concerns about the interview setting, this public nature of the venue could have impacted the data since participants may have avoided discussing particularly sensitive issues.

3.9.6 Conducting the interviews

The interviews varied in length between 40 and 90 minutes, with most lasting around an hour. All interviews were recorded electronically with the participants' permission. As described earlier, I made a number of revisions to the interview schedule following the initial pilot interviews; the interview guide used in the main study is shown in Appendix 6. While the course of the interviews generally followed the interview schedule, the semi-structured nature meant that in some instances participants digressed according to issues they prioritised. Below I describe how the interviews typically progressed and reflect on my interaction with the participants and the issues we discussed.

After welcoming the participant and ensuring they were comfortable I gave the participant a number of documents. These included the information sheet (Appendix 5), the consent form (Appendix 7) and a voucher receipt form. At this stage I made informal conversation before giving the participant the opportunity to read the information and fill in the forms while I busied myself with loading websites on the tablet. I ensured that participants were given plenty of time to read the information. I then told them about the types of questions I was going to ask and that they should feel free to not answer or leave if they felt uncomfortable. I also stressed that there were no right or wrong answers and that anything they could tell me was useful for the project. I also wanted the participant to have possession of the shopping voucher at the outset, both to show my appreciation for their time and allow them the freedom to leave at any point if they did not wish to continue with the interview, without having to ask for a voucher. After the participant had had the opportunity to ask questions and given their written consent, I turned on the recorder.

To open the interview, I asked participants to tell me a bit about themselves. At this stage it was often useful to give examples of the kinds of things the participants might want to tell me, for example: “what you do, what you are interested in, what are your living arrangements - that kind of thing?” I felt that by contributing some examples at this early stage I was able to make the participants feel slightly more at ease with the interview process. Next, I asked questions around the participant’s experience of either diabetes or CMHDs, particularly around first experiences of symptoms or the process of diagnosis, treatments, contact with health professionals and self-management. In response, some participants provided a brief description, whilst others, particularly Mia and Max, told detailed stories about their life and health experiences up to this point. Although participants’ responses varied considerably in length, these questions provided valuable contextual data.

After these introductory questions, I invited the participants to explore examples of health-related content on various websites and social media sites relevant to diabetes or CMHDs on a tablet I had brought with me (see Table 3).

| Bookmarked examples of social media websites | |
|---|---|
| Diabetes | CMHD |
| Diabetes UK Facebook page | Mind Facebook page |
| Diabetes - the patient experience Facebook page | Depression Facebook page |
| Twitter #gbdoc search | Twitter #depression search |
| Twitter #diabetes search | Twitter story about depression |
| Youtube - diabetes blog | Youtube - depression blog |
| Youthhealthtalk Diabetes Type 1 | Youthhealthtalk Depression and low mood |

Table 3: Examples of websites and social media sites discussed by young adults during interviews

These examples included some of the pages that I had analysed in the preliminary analysis of Facebook pages. Others were identified through following links or by early participants, who highlighted them during interviews. The pages were selected to represent different aspects and facilities available online; in particular I included examples from the three most popular social media sites YouTube, Facebook and Twitter, as well as one more traditional professionally produced website with embedded social media links. These sites were selected to illustrate some of the different ways that users are generating content and connecting with other users online to support self-management.

Stimulus materials are often used in qualitative interview studies, as noted by Törrönen (2002):

The use of the stimulus text channels the interviewees [...] to identify and interpret whether the stimulus text represents the phenomena under examination truthfully and credibly. At the same time data are obtained which describe the manner in which the interviewees position and identify themselves with the situations, processes and/or actors in the stimulus text (p. 354).

The examples of social media I used in the interviews served a similar purpose. For each example I asked participants to say what they thought of the site, if they had come across it specifically or similar content before, what they liked about it, what they disliked about it, what they thought of the content and how reliable they thought it was. For each site, I also asked participants to talk about the specific social and interactive practices associated with the sites - i.e. 'liking', commenting, responding, sharing, posting (links, videos or pictures), hashtags and 'mentions'. The social media sites could potentially be described

as ‘microcosm’ stimuli because, as well as being examples of the phenomenon of interest, they include constructions of the relevant illness and support resources from a particular perspective (Törrönen, 2002). Indeed, the use of examples of social media sites as stimulus texts functioned simultaneously to provide concrete examples of resources for participants to discuss and critique descriptively and to introduce particular portrayals of health and illness, which they were also able to respond to. For instance, when I asked Byron about a particular social media resource, he commented:

I probably wouldn't use it¹ [Facebook group page for diabetes], no [...] Cos this is like, this is sort of like - because my dad was in the Army, there's a lot of, like, support pages, and, British Army pages, and then there's the naff army pages, where, like[...] It's just - there'll be pages where - it's normally really cringe mums, like, 'showing the support for our boys!' and - it's just awful. And people always post embarrassing stuff (Byron, diabetes, 18).

By referring to other sources of user-generated content and making comparisons, Byron provided insights into the range of ways health-related content related to his wider consumption of social media content and online practices. Responses prompted by specific examples of social media sites generated some of the richest data around participants' considerations when navigating and engaging online. Different online spaces provoked participants to reflect on their considerations around anonymity, identity, reliability, media, online conventions and relationships to offline life as they explored those environments during the interview. Although accessing these online resources worked well, one challenge related to the use of the tablet was ensuring the availability of internet access. Most often I used my phone as a hotspot to connect to the internet and in general this worked well, however, on two occasions there was no network coverage. In these instances participants immediately offered their own smart phone as an alternative means of accessing the examples of content. Although this took slightly longer, since pages were not already bookmarked, the participants' smart phones provided adequate access and indeed, their swift

¹ Byron was browsing a Facebook page initiated and used by a group of diabetic Facebook users to exchange emotional support and advice about their experience of diabetes.

response reflected the ubiquity of mobile internet access for many of these young adults.

The next section of the interview generated data around participants' perceptions and experiences of online resources more broadly. Rubin and Rubin suggest phrasing interview questions in terms of a 'tour' as a means of encouraging participants to talk through thought processes (2005). This was useful in exploring processes of navigating online content. Questions such as 'Tell me how you would go about finding information about...' prompted reflective responses on the mundane aspects of online information seeking. For example when I asked Mia to tell me about the strategies she had used to find helpful information, she responded:

I don't know. Like, if I was feeling absolutely desperately unhappy I'd maybe type in 'what to do when you're feeling desperately unhappy'. Like, do literally the most basic thing in the world, and I'd probably read the first, like, I don't know, few pages, just glance at them, and then think 'this is the most embarrassing thing ever,' [...] it's just the same thing you read every single time. Like oh symptoms and all that, like, I don't care about the symptoms, I want, like, motivational, like, that's, like, stuff, like just stuff that'll, like, make me feel instantly happy (Mia, CMHD, 20).

In this response, Mia talks both about the processes of information seeking, such as searching and assessing search results, but also about how the activity made her feel, and what she thought would be a more useful resource. Similarly, asking about experiences of information seeking over time and how the internet featured in early experiences of health issues was a useful way of understanding the context of people's use of online resources.

Immediately after the interviews I wrote a summary of the process in a fieldnote book. I described both the topics covered in the interview and my initial analytical thoughts on the content of the discussion. This provided an opportunity to generate initial concepts for further analysis, but also an opportunity to reflexively scrutinise the research process and engagement with

participants. In line with the interpretivist approaches to research (Charmaz, 2006), I continued this process throughout analysis and writing.

3.9.7 Reflections on my position as researcher

My experience of interviewing young adults with diabetes or experience of a CMHD was mostly very positive. Generally participants were of a similar age to me, although some were younger, and this was useful for building rapport and not appearing too threatening or expert. However, as someone who does not have experience of either diabetes or CMHDs, I was concerned that my lack of lived experience might impact my ability to empathise with participants and so might inhibit frank discussion. Johnson and Rowlands (2012) have discussed in detail the advantages and disadvantages of the researcher's position as novice or expert interviewer. In this study, my position was clearly that of novice. I made sure I had a basic understanding of diabetes and a range of CMHDs and had been immersed in social media focused on both diabetes and mental health before beginning the interviews, but I was keen to learn from participants about their experiences. Using my 'naïve' position I was able to encourage participants to tell me about the mundane aspects of their experience and this often led to reflection on daily experience.

Throughout the interviews I attempted to prioritise the key concerns of the qualitative interviewer, that is, listening, questioning and clarifying, but on a few occasions during interviews I inadvertently took on a more knowledgeable role. For instance, during Paul's interview, in which he had been discussing his experience of depression and a gambling addiction, I mentioned Cognitive Behavioural Therapy (CBT) which the participant had never heard of. In this instance I felt embarrassed to have brought up something I did not feel knowledgeable enough to describe to the participant. However, the technology available meant that together we looked up CBT on Wikipedia and browsed some online resources, which I made sure not to express an opinion on. Throughout the interviews the nature of the discussion around innovations in online resources for self-management meant I had to be particularly careful not to act with authority on the subject. However, I was able to use my naïve position to good effect in these instances to probe on how resources could be used rather than in any sense promoting their suitability or otherwise for participants.

3.10 Interviews with professional producers of online content

3.10.1 Sampling

In order to gain insights into the production of online resources and the facilitation of issue-focused social media sites, I identified communications specialists within UK-based health charities and organisations as key informants for this phase of the study. The participants were approached as representatives of organisations that have developed or are developing an online presence around either diabetes or mental health issues. These organisations were identified at the outset of the study, when I was scoping diabetes and mental health-related online content and analysing Facebook user-generated content. In total seven individuals were interviewed in six interviews, with two representatives from Diabetes-1 participating in one interview. Details of the producer participants and the organisations they represented are described in Table 4.

| Producer participants: organisations, roles and online resources | | | |
|--|---|---|---|
| Organisation | Producer participant's role | Description of primary website | Social media resources |
| MH-1 Mental health charity | PP-1 Communications and operations manager of charity | Website containing an array of content around mental health issues, updated regularly with news items and longer opinion pieces | Twitter account |
| MH-2 Mental health service provider | PP-2 Health professional and creator of resource | Website containing multimedia content around stress, including information, practical exercises and an online quiz | None |
| MH -3 Mental health research group | PP-5 Academic and creator of resource | Website containing an online course to support wellbeing and cope with the challenges of day-to-day life | Twitter account and Facebook page, managed by another team member |
| Diabetes -1 Diabetes charity | PP-3 Chief Executive of patient advocacy group | Website containing a range of policy/practice related information for people with Type 1 diabetes. Maintain a Facebook group, Twitter account and YouTube channel | Twitter account, Facebook group and YouTube channel |
| | PP-4 Communications Officer of patient advocacy group | | |
| Diabetes-2 Diabetes service provider | PP-6 Technical Consultant | Website containing general diabetes information and access to personal records, test results and other information held by health professionals | Twitter account and Facebook page, managed by another team member |
| Diabetes-3 Diabetes charity | PP-7 Project Officer and Youth worker | Website targeted at young people with Type 1 diabetes, with content on health issues and social life | Twitter account and Facebook page |

Table 4: Producer participant details

The producer participants represented various perspectives as providers of online resources. Three were associated with mental health resources and four (two from Diabetes-1) with diabetes resources. Some were solely responsible for developing a site and its content, whilst others were jointly responsible for managing one section or function of a site. The producer participants expressed a range of perspectives on the use of social media, with some managing various social media channels as part of their daily workload and others rejecting the use of social media.

3.10.2 Recruitment

As far as possible, named individuals, who were described as being responsible for online strategy for their organisation, were approached using publicly accessible contact details. The first contact was made by email; which gave details of the project and myself as the researcher and indicated that there was a possibility of participating in the research. If there was no response to this initial email, I followed up by phone if telephone contact details were available. A record of all contact attempts was kept and updated to ensure timely follow-up and avoid re-contacting people unnecessarily. I also made sure to contact organisations sequentially, to avoid over-recruiting. If organisations and particular individuals indicated that they were willing to take part, I sent further details by email, explaining the study and the process of participating in more detail (see Appendix 8).

Initially, I found recruitment of key informants from diabetes and mental health charities very challenging. Beginning with cold contact emails, particularly when the target address was generic (e.g. info@charity.org.uk) meant I often received no response to my first approach. However, when I followed up these emails with a phone call it was useful to be able to refer to a previous email. My next line of contact by phone or direct email was usually more successful in making contact with individuals within organisations, although these individuals sometimes proved difficult to recruit. A number suggested that they were not the correct person to be talking to, perhaps reflecting a trend for managing online content and social media to be distributed across a range of individuals' roles within an organisation. A more successful, though lengthy, strategy,

involved approaching organisations to discuss my research interests in informal face-to-face meetings. At these meetings I introduced myself and my research more personally in order to establish relationships with potential participants based on shared professional interests. After each of these meetings I was then able to recruit a participant to the project and in some cases, people recommended other individuals whom it might be useful to contact or approach to participate.

An unanticipated challenge of recruitment was the wider financial context. Throughout recruitment, and indeed during interviews with producer participants, lack of funding and resources for online development work was regularly mentioned. During the recruitment phase, two community based mental health organisations which I contacted were interested and enthusiastic about the project but their funding had ceased and they were in the process of closing their services.

3.10.3 Conducting the producer interviews

Interviews were facilitated at a time and location suited to the individual to cause minimal disruption to their work schedule. Since the producer participants were more identifiable because of their roles as key informants, issues of anonymity and the potential for deductive disclosure were discussed with participants. However, I assured each participant that all attempts would be made to ensure their anonymity in the presentation of their contributions. After this discussion interview recordings began as soon as participants had provided written consent (Appendix 9). All but one of the interviews were with an individual; the one paired interview reflected the participants' shared responsibility for online communication. The impact of this paired interview was that each participant responded both to my questions and the each others' responses, creating more interactional data, similar to that produced in focus groups. The interviews lasted between 45 minutes and two hours.

Like the young adult interviews, the interviews were semi-structured and aimed to explore the participants' perspectives on the construction of online resources and online communication. Using an interview schedule (Appendix 10), I asked open-ended questions but also encouraged the key informants to discuss issues

that they prioritised, since this often revealed key insights into their particular perspective. My opening questions were broadly about the work of the organisation and the participant's role within it. The questions then focused on social media strategy development, implementation and maintenance, and on any particular challenges faced around online communication. In some interviews, if it seemed appropriate, we jointly browsed their organisation's websites and those of other organisations, as well as extracts of user-generated content. Although this was often impromptu, the availability of devices to access online resources was useful throughout the interviews and linked producer participants' comments to specific examples of online content.

In these interviews, I was less concerned about my position as researcher negatively impacting on the data by creating a power imbalance. Instead, in the interviews with professional producers, I felt I was in the more junior position. Although this increased my anxiety about 'proving myself' to the interviewees, particularly in terms of understanding their organisation's focus, it did mean that I could ask open introductory questions which elicited responses from producer participants that fore-grounded issues they identified as priorities.

3.11 Interview data analysis

3.11.1 Transcription and data management

Soon after each interview the recordings were transcribed verbatim to produce a typed record for analysis. The first eight recordings were transcribed by me and the remaining recordings were transcribed by a transcription agency, then checked against the tapes and amended where necessary by me. Throughout transcription, I attempted to include indicators of non-verbal communication. Pauses, laughter and gestures, where possible, are recorded in the transcripts in square brackets. Interjections which did not break the flow of the participant's speech are indicated by inclusion within their speech rather than on a separate line. I added inverted commas to indicate the use of words like 'like' and 'share' when they referred to specific actions related to social media sites. As part of the process of checking the transcripts and familiarising myself with the data generated I wrote summaries of the interviews and profiles of each participant. Young adult participants were all given pseudonyms to protect their

anonymity, and producer participants have been given non-gendered signifiers to identify the focus of their organisation. Given the specificity of producer participants' roles, this precaution aims to reduce the potential for deductive disclosure and protect participants' anonymity.

3.11.2 Data analysis: influences and process

A number of approaches to qualitative analysis of interview data have developed in particular epistemological and methodological traditions (Frost et al., 2010). Like much qualitative research, the process of thematic analysis employed in this study is informed by that of Grounded Theory. The principles of inductive coding, the construction of categories and the continuous comparison of codes identified in Grounded Theory are common across a number of methods of thematic analysis (Floersch et al., 2010). However, in this case the ultimate aim of the analysis was not to generate a theory of process and so a more flexible thematic approach was taken.

The analysis procedure I followed was informed by Attride-Stirling's (2001) approach, which involves constructing thematic networks. She describes this process as facilitating systematic thematic analysis. While "thematic analyses seek to unearth the themes salient in a text at different levels [...] thematic networks aim to facilitate the structuring and depiction of these themes" (p.387). The creation of thematic networks, therefore, aims to aid in the process and organisation of the analysis by helping to visually represent how codes cluster together to create sub-themes and themes.

I began the process by reading and re-reading the transcripts in order to identify patterns in meaning across the data set (Braun and Clarke, 2006), and constructed initial networks around four main themes:

- Navigating and assessing health-related content
- Considerations and expectations of engaging with health-related user-generated content
- Critiques of online resources and suggested improvements
- Producers' perspectives on the creation and maintenance of online resources

Each of these main themes consisted of several sub-themes and a number of codes associated with each sub-theme (see Appendix 11 for an example of the initial thematic network for navigating and assessing health-related content). In order to further refine the main themes and sub-themes within these networks, I uploaded the transcripts to NVivo10 and systematically coded each transcript. The codes, sub-themes and over-arching themes were revised as this process progressed, and the first few transcripts re-coded accordingly. Following Braun and Clarke's (2006) recommendation that writing should be an integral part of the entire process of analysis, alongside coding I wrote 'memos', which supplemented the analytical comments I had been making as part of my fieldnotes. These 'memos' and fieldnotes were then collated with summaries of coding and sub-themes to produce summaries of each of the over-arching themes which in turn formed the basis of each of the three findings chapters.

As the data analysis progressed, I noticed some patterns in the young adult participants' accounts around offline support and their engagement with health-related user-generated content. In order to explore this in more detail, and compare across participants' accounts I constructed diagrams based on different dimensions of each participants' account of online experience. For this I drew on the participant profiles I had written after each interview was transcribed, which summarised their accounts (for edited versions see Appendix 5), to compare the range of people's experiences of engagement with social media and create a framework on which to place each participant. This was later refined to illustrate a potential typology of users' social media practices in relation to their perceptions of offline support.

3.12 Summary

This chapter has presented details of the methodological processes of designing and conducting a qualitative study to explore engagement with health-related content online from a range of perspectives. The interpretive approach adopted allowed me to explore young adults' experiences of engaging with content related to their health experiences online and the impact of this in everyday life offline. Furthermore, exploration of online text and interviews with professional producers of online resources produced complementary data, fulfilling the

holistic aims of the study. The following three chapters report on the findings of analysis of the data resultant from this exploration.

4 Young adults' experiences of seeking health-related information online

4.1 Overview of chapter

This chapter provides an overview of the ways in which the 40 young adults that were interviewed discussed their motivations and considerations for accessing online resources and the processes involved in negotiating health-related content. The aim of the chapter is to contribute to the literature on users' interpretations and perceptions of online health information by exploring these issues with a sample of young adults familiar with social media environments and variously engaged in consuming and producing user-generated content. The participants' responses were grounded in their individual experiences of either diabetes or a CMHD such as depression or anxiety, and reflect specific considerations related to these issues as well as broader insights relevant to discussion of online health resources more generally. During the interviews participants discussed the ways that they had learned about their health issues, why they had accessed online content and how their experiences of drawing on online content impacted their experience of either diabetes or a CMHD. By describing the linked processes of locating and assessing health-related online content, this chapter provides broad contextual description and introduces the participants' practices. First, the participants' motives and intentions for accessing online content are discussed and then the various processes of negotiating online content are described. Prior to data collection and analysis some differences had been expected between participants with diabetes and those with experience of CMHDs, and between men and women. Participants' responses were compared throughout analysis, with a focus on similarities and differences between the sub-groups within the sample, by gender and health issue. These are highlighted throughout the chapter.

4.2 Motives and intentions for accessing health-related content

All of the participants had accessed online resources at some point to find information about either diabetes or mental health and generally this was presented as a routine response to illness and a taken-for-granted aspect of

health experiences. Despite this common understanding of information seeking as most often an online activity, diversity emerged in how participants discussed their motives and intentions for accessing health-related content. Sometimes, the activity of 'going online' was constructed as a means of 'fact-finding', with participants discussing accessing professionally-produced content to increase understanding. At other times, it was discussed as a means of accessing other people's experiences. While in most accounts the boundaries between these two activities were clear, in some they were not. Furthermore, some people discussed online information seeking as something that was time and context dependant. Generally, there were few differences in discussions of motives and intentions related to participants' health experiences and there were no notable differences by gender.

4.2.1 Fact-finding

The most commonly mentioned motive for accessing health-related content online was to access information, ranging from basic descriptions of illness to specific treatment related queries. For instance Mia said: "[...] I started to feel, like, 'well, maybe it is depression,' and I did, like, Google it and stuff, like, the usual stuff, and I thought, 'yeah, this must be it'" (Mia, CMHD, 20). Mia positioned Google as central in her account of realising that she might be experiencing depression. She referred to searching online as "the usual stuff", identifying it as a self-evident practice in developing an understanding of her health issue. These types of references to using the internet and online searching were common in most of the young adults' accounts. That their information-seeking was done online was taken as read, as 'obvious' and usual.

This 'fact-finding' approach to online engagement was often associated with a concern around the source of information, for instance, Fran commented:

What I did use [the internet] for was, I started off on one kind of SSRI [Selective Serotonin Re-uptake Inhibitors, commonly prescribed as antidepressants] which was particularly prescribed, kind of, for anxiety, essentially. And I was really nervous about taking them so done a lot of online research into, like, side-effects and research on whether it's effective and all that kind of thing and just little things that they don't

tell you. Like now it's Fluoxetine and the doctors never said to me "Don't drink when you're taking it," like you never drink when you're taking it. You know, and to eat grapefruit, all this kind of thing. So, more the kind of medical stuff and there are forums but they... the ones I've seen tend to be kind of American and filled with emoticons and, like, very much kind of "We're all in this together, guys" you know that way, [...] Sometimes I find that useful but, yeah, mostly I use the internet to kind of find out about research in terms of the drugs and scare myself silly with side-effects (Fran, CMHD, 25).

In this extract, Fran differentiates between "the medical stuff" she encounters online, related to drug efficacy and side-effects, and "forums" with "We're all in this together" messages. In this way, Fran presented factual, medical information in contrast to supportive, experience-based, user-generated content. She suggested that it is the former that she goes online most regularly to find in order to develop her knowledge of treatments. Fran also suggested that these 'facts' were ones she was not made aware of by her doctor and that going online to seek information provided a more in-depth picture of the drug treatments she had been prescribed. Similarly, Poppy described her 'fact-finding' online activity:

I know that if I want some factual advice, [...] you know, if I want to know say the NICE [National Institute for Health and Care Excellence] guidelines, stuff like this, I know where to get them and that's really useful. I'm trying to think what other, oh I've Googled contraception once which was a good job because my doctor was talking rubbish.

Oh really?

Yeah. So I've, so yeah the same, if I know it's factual information and that I can trust a factual website, so if I've used the NHS website or something I've got some faith in, Wikipedia to some extent, I'll do that (Poppy, diabetes, 30).

In her interview Poppy described her search for resources relevant to the advice she was given by health professionals and indeed, seemed to rate 'factual' online resources, such as NICE guidelines and NHS website content, as more

reliable than her doctor's advice. In this way, she emphasised the importance of information and evidence, as accessed online, as opposed to information which has been mediated, interpreted and relayed by another source, such as a health professional. Although not all participants expressed a preference for online resources over health professionals' advice, for all of the young adults, going online was crucial for accessing 'facts'. The internet was described as an essential resource for fact-finding to support their understanding of the health issues which they were experiencing. Furthermore, for some, like Poppy and Fran, the internet was used to access to factual *primary* sources of information removing the need to rely solely on health professionals' advice or interpretations.

Some of the participants described these online 'fact-finding' practices by drawing on discourses around personal responsibility for health issues. Indeed, often discussions about the processes of becoming informed were linked with successful self-management practices. Mhairi discussed her consumption of online information over time, since her initial diagnosis:

I think when I was diagnosed [...] I got the leaflets, and stuff from the nurse and I read through them, but then the internet is such a wealth of information that I just Googled "diabetes" and saw what came up. And, I think I did read—there was so much information it was kind of a bombardment of information, and I felt that the more information I had, the more powerful if you like, or in control I was of my diabetes, and what it was, and how to manage it, and everything else. But, looking back now, although I did read loads, and I just spent evenings looking through things. It was useful, but now I'd be a lot more selective about what I would look up. I think at that point I just looked up anything, and everything. Whereas now I'd be a lot more focused on what was more specific to me. And, I suppose that's why I don't really go on a lot of sites. It's because I found the best ones I suppose, and I've just stuck to them ones (Mhairi, diabetes, 28).

This extract illustrates the importance of online information seeking for some young adults' experience of managing health issues, and regaining an element of

control over their lives and illness management. Mhairi described the experience of going online to find diabetes-related content as a “bombardment of information” suggesting the need to develop a strategy to make sense of the range of competing resources available. The association of “more information” with being “more powerful” and “in control” of “diabetes, and what it was, and how to manage it and everything else”, contributes to the construction of an identity as an active and competent patient. By searching online for information, Mhairi takes advantage of resources to fact-find and build her knowledge to establish expertise in dealing with her diabetes. Mhairi’s comments also construct online information seeking as motivated by needs. She illustrated how, over time, she has taken a more discerning and strategic approach to accessing online resources that is congruent with her (more recent) identity as an ‘informed patient’. This notion, of taking personal responsibility for health issues by becoming informed through online ‘fact-finding’, was evident in a number of accounts, particularly for participants with diabetes.

Discussions of ‘taking control’ through online engagement in relation to mental health issues were less common. However, a related idea was raised in several accounts which featured reflections on engaging with mental health content. Several participants discussed how the process of online information seeking led to the development of a broader interest in mental health generally. For example Debbie commented on what sites she had accessed and how her interest had grown:

I guess like using the government sites, or charity sites about things, researching maybe like therapies. I’m like particularly interested in nutritional stuff, and [...] vitamins that are proven useful, and I try to do like a little bit more like in-depth reading, like trying to actually read the journal articles and everything. Especially because... I’m kind of dorky, and studying it, [...] ‘cause I was debating like what I wanted to study. And then, I realised that [...] I’ve learned so much, I think it’s because of studying like my own health, it made me interested, ‘cause those are like the first newspaper articles I read in the morning. [...] Basically, [...] researching stuff about me online has made me wanna study it more, and

made me like wanna to do my dissertation, and my career about it, and like improving things (Debbie, CMHD, 30).

During her interview, Debbie suggested that as a result of online ‘fact-finding’, her interests had extended beyond the specifics of her own situation to developing a greater understanding of mental health issues more broadly. For a few of the participants with experience of CMHDs, the internet not only served as a site for fact-finding in relation to personal health experience but also as a resource for developing a broader interest, and in some cases the basis for advocacy or awareness-raising activities.

In summary, for all of the young adults interviewed, the activity of going online was described as crucial for accessing ‘facts’. As an essential resource, the internet was cited by participants as a key means of developing their understandings of the complexities of the health issues which they were experiencing. In particular, for some accessing reliable information from trusted sources was a means of honing expertise and acquiring knowledge beyond that imparted by health professionals. Furthermore, accessing online information resources was described by some participants as more than issue-focused searching and instead, a key means of asserting personal responsibility or developing a broader interest in ongoing health issues. There were some differences in how participants with diabetes and those with experience of CMHDs framed their motives and intentions for accessing online resources. More accounts from participants with diabetes featured references to taking responsibility for and control of their illness by accessing online information. Participants with experience of mental health problems more often mentioned online engagement with information as a means of developing a broad interest in mental health, beyond personally relevant issues. Few differences were evident between the men and women in the sample with regards to how ‘fact-finding’ was discussed.

4.2.2 Accessing other people’s accounts

While ‘fact-finding’ was the most dominant explanation of participants’ motives for online activity, some participants discussed using the internet to seek out

accounts from other people with similar experiences. For example Nicola commented:

[...] because the organisations [diabetes charities] aren't, I suppose, they're not the people who are actually dealing with it [diabetes] on a day-to-day basis, so it would be more about getting in touch with somebody that's actually got it and has got the same problems that you've got. [...] I don't know, just the burden of having it, like I don't mind having it, I mean I do mind having it obviously, but I've got used to it, whereas sometimes it is just a drag and like you can't always do the same things as everybody else and like, [...] so yeah [...] I think these [Facebook pages featuring other people discussing their experience] they're good, these kind of pages for just, I suppose, knowing that there are other people that have the same [experience] (Nicola, diabetes, 28).

Some of the participants, as well as searching for professionally produced or evidence informed content online, sought out content that was consistent with their own experience, and indeed, the challenges or “burden” they felt. Similarly, Alistair discussed his experience of accessing other people's accounts online:

When I've been feeling down I've Googled “other people feeling down”, [...] just to see what they're dealing with, not what they're dealing with 'cause I don't want to know their problem, I just like to know that you're not the only person that feels that way. But I wouldn't say I've done active research into the actual biology, for lack of a better word, into why it is.

So when you Googled other people's experiences, how did you find that?

It was, I suppose it was, it wasn't nice to know they were, it's nice to know you're not alone, it's nice to know that people understand, you know, how it can beat you and it's... [...] and knowing and going on Google and stuff like that and seeing other people, I don't know, I suppose it's kinda just knowing there are other people out there that are the same (Alistair, CMHD, 21).

In this extract, Alistair makes a clear distinction between content about people's experiences - "other people feeling down" and professionally produced content, "the actual biology". Despite having been uninterested in the specific circumstances of other people's mental health problems, he sought content that made him feel less isolated and to some extent validated his experience - "it's nice to know you're not alone, it's nice to know that people understand [...] how it [depression/low mood] can beat you." For some of the young adults, therefore, information seeking online was contingent on other users contributing content about their experiences of health and illness. Searching and consumption of such content worked to relieve feelings of isolation and seemed to act as a form of emotional support.

4.2.3 Combining 'fact-finding' and accessing other people's accounts

Although most participants distinguished between 'fact-finding' and accessing other people's accounts as different forms of information seeking, for some these activities were much less distinct. In particular, a few participants (all of whom had diabetes) discussed how the complexities of managing diabetes meant that professionally-produced information and advice was somewhat limited. Instead, for these participants, 'fact-finding' was a matter of drawing on other people's lived experience sometimes in combination with accessing more formal online resources. For instance, when asked about what sources he had drawn on in learning about diabetes, Max commented:

Everything from the internet, as I said.

Really?

The last year or so, I think gaining an understanding of how it all works - doing some background reading, how your body works. Why your body does this, why you're taking certain insulins. [...] I now understood that from going from a sixty forty mixed insulin, to two sets of insulin that were split, and this one's a long acting one, and this one's short... I never really understood why I was taking that one, what the theory is - I just used to take it. [...] I'd just take any dose, it was like, "oh... I'll just dial it up, oh it's somewhere there or thereabouts," and just do it, and I'd take it anytime of the night, you know, until I learned why it was, why I

was doing it, and what the reasons were. I think that's how I built that understanding of what the basal insulin does. And, I've learned about that from people who used the pump [device for administering insulin] (Max, diabetes, 29).

This extract from Max illustrates the diversity of resources some participants drew on during a period of information-seeking online. He describes his motivation as wanting to develop a greater “understanding” of diabetes, and gives details of the different regimes he has been on and how his management had been haphazard, until he “built that understanding”. Max then concluded “I've learned about that from people who used the pump”. His experience of using online resources was not subject to the same distinctions as some other participants, with other people's accounts serving as more than just relieving feelings of isolation. Indeed, accessing other people's experiences was highlighted as an important resource for asserting responsibility for his diabetes and informing changes in self-management practices. For Max, and a small number of the other diabetic participants, the internet was constructed as a more dynamic resource, as a space for active negotiation of a range of complementary resources. By combining the processes of ‘fact-finding’ and accessing other people's experiences online they were able to build usable knowledge for developing self-management practices.

Online information seeking therefore seemed to involve different considerations and motivations dependant on individuals' perceptions of the online environment. ‘Fact-finding’ and accessing other people's experiences were constructed as both separate concepts by some, and intrinsically linked by others. However, conceptions of the process of online information-seeking, as something that contributes to being a responsible, informed individual were apparent throughout accounts, regardless of which health issue participants had experience of or their gender.

4.2.4 Timing and context: critical junctures, ongoing concerns and everyday engagement

During the interviews, as well as discussing their conceptions of information-seeking, the participants emphasised the timing and context of their online

information-seeking. When asked about their experiences of accessing health-related content, many of the participants discussed being motivated to access online content in response to a specific issue, concern or query for which they needed timely information. In some cases information-seeking was presented as a response to a particular crisis or critical juncture, while at other times it was presented as a response to a less urgent but ongoing concern about developing self-management practices.

Across both health issues, participants provided examples of times when information seeking online was done as a matter of urgency in response to a critical issue. Perhaps the most striking instance was described by Joe. He had experienced depression and anxiety since adolescence related to dissatisfaction with his gender identity, and gave an account of how crucial online resources had been for him:

[...] when I was at a really bad point a few years ago [...] the last time I was really badly suicidal and was self-harming and things like that, there was a web page that, when I felt really suicidal and I felt like I was going to actually do it, I would open, I had it as a shortcut on my desktop and I would open it and spend time reading it and the time it took me to read it would quite often let the suicidal feeling subside. [...] I'll show you the one it is 'cause I think, I basically Googled it, well I didn't Google the site originally I just, you know, just typed into Google, you know, "I'm considering suicide, please help" and well, you know, this was one of the first pages that came up and it's so well put and so even handed and non-judgemental that it, I found it very helpful and I did consult it again at times when I felt I needed it (Joe, CMHD, 28).

Joe's account highlights the time-dependant nature of online information-seeking. He stressed this in relation to his state of mind: "when I felt really suicidal and I felt like I was going to actually do it" and "at times when I felt I needed it". Similarly, Penny described her use of online content at a critical juncture:

When I fell pregnant with [daughter] I hadn't had good control, I was in the middle of trying to switch onto a different type of insulin so my sugars

would have been quite high and [...] I wasn't planning to get pregnant so em, the like, the midwife at the beginning she said like, you should maybe think about having a termination, [...] because there could be like heart problems and really serious birth defects [because] at the beginning you're meant to be really careful [...] so after that I was on the internet and things researching what I should do. She'd given me this information, [partner] wasn't here, he was away cos he's always away...

That must have been hard

It was, and I thought, I can't not, you know, I couldn't have a termination, I thought that's terrible, like, I may have done if there had been a lot of problems when I got a scan, but they said everything was fine at 12 weeks and then at 18 weeks you get a scan on the baby's heart and they said that was fine and 20 weeks they said yeah it's fine, so I'm glad I didn't listen to her, so I did research then (Penny, diabetes, 27).

These extracts illustrate how important immediate access to online information was for some of the young adults who had encountered challenging health-related issues. During times of crisis, when offline supportive resources were either unavailable or unhelpful, specific health-related content seems to have provided timely and necessary assistance.

Participants from both groups also provided examples of instances when they had drawn on online resources in less critical circumstances in response to more general concerns about their current health or self-management practices. These queries were often related to day-to-day challenges, such as diet and exercise:

That's something that you know you can use the internet for I suppose, you know diabetes and exercise [...], like I'm not very active but when I have been it does affect your diabetes, and like it's not always instantaneous as well, so sometimes if you go for a run, or if you do something, it can be like either the next day or a few hours later that suddenly your blood sugar might dip for no apparent reason and it's something to do with the fact that you did exercise earlier. That's only happened once to me before and that was the only explanation [...] I

think I probably did use the internet to kind of look up what the links are because you don't always remember to ask doctors about things like that - "oh if I go for a swim what will that do?", [...] so for things like that the internet [is] quite good, you know ways to actually manage "if you go for a swim for 20 minutes what will that do to your body?", that kind of thing [...] I suppose the internet though is one of those things where you're not talking to an actual person, you can look at whatever you like and there's no one thinking you are asking a silly question (Nicola, diabetes, 28).

Like a number of the other participants with diabetes, Nicola described how she drew on online resources in response to a specific concern about her blood sugar level and an ongoing query about diabetes self-management. For Nicola, accessing online content seems to be a particularly convenient means of accessing information without embarrassment, avoiding face-to-face engagement with health professionals but informing her self-management practices. Liz who had been experiencing low mood and anorexia for the past five years also discussed her experience of engaging with online content related to an ongoing concern:

There's a website called Calorie Count which is like basically just a health website, but it's got different forums, and it's got one for, like, for gaining weight, and that's like a really, actually quite helpful. [...] Well, obviously, gaining weight is quite, it's not as straightforward as you kind of think, and there's, like... oh, just things like how... well, "at school, how do you manage to eat this amount of calories?" like, or whatever. "Do you have any ideas for what I can bring to school which..." cos obviously everybody else is going through the same sort of thing, and so they'll be like, "oh, I eat a lot of peanut butter" or whatever, you know, just like quite straightforward questions, but... I think that's helpful, because, yeah, like, as I said I've obviously got loads of people around me, but nobody else is gaining weight, like, and so, like, and that's quite good (Liz, CMHD, 19).

Some participants, like Liz and Nicola, described accessing online content to support ongoing developments to self-management practices, and address less

critical concerns. For most of the participants, therefore, online information, generally, seemed to be drawn on in response to time-sensitive issues in two ways, to inform either immediate decision-making or more ongoing concerns about behaviour or self-management practices.

Some of the participants' discussions of the timing and context of their information seeking, also featured references to the means of accessing health-related information, particularly through mobile phones. For example, Max commented:

And, I can remember the nurse looking up at me, and saying, "You've got protein in your urine." "Right, ok, what's that mean?" I remember walking home, and like checking on my phone [...]. Yeah, checking on my phone you know, "Protein in urine. What's this mean?" "Kidneys." "Right." (Max, diabetes, 29).

Like many of the other participants, immediate, focused online information-seeking is central to Max's account of the ongoing development of his diabetes knowledge. He specifically highlighted the device which allowed him immediate access, "walking home, and like checking on my phone". Many of the young adults constructed information-seeking as a responsive activity, conducted almost entirely online and regularly facilitated by smart phone technologies.

In contrast to the dominant practice of responsive online information-seeking described by most, a small number of participants discussed accessing online information as a more habitual practice, which was embedded in their everyday activities. These were mainly individuals who regularly engaged online, both producing and consuming health-related content. For instance, Eleanor, who contributed to a number of health-related social media websites, discussed her information-seeking practices:

Vitamin C for example, [...] giving 1000 milligrams a day, was one of the things I was reading up on and [...] Wikipedia says it's not founded but there is studies that suggest, but I think well I'll give it a try because if I go on to forums other people have [had] great success with that, I'll give it a try, because it's a couple of pounds for tube of Effervescent [vitamin C supplement], one a day, I'll give it a month or two and then I'll see how

I'm feeling, and then it turned out it was a good thing. [...] Again it's just coming across things online, if you Google, or if you see something someone's posted. [...] A lot of them do come from [professionally-produced sources], but again a lot of it's just random Googling and you come across sort of whatever is there. I think that the best way to keep up with research is to cover all angles, you go through official angles, and then you'll maybe have a wee Google to see or go on to the health bits on [...] news websites to see if there's anything that catches my eye for you know, energy, or people who are struggling for ME, or people who are struggling with depression, if there's anything with that in the headline I'll go into that and have a wee look cos there's studies going on all the time with that sort of thing, there's always a link to something or other (Eleanor, CMHD, 26).

In this extract, Eleanor, as one of the most active users of online resources, explains how her consumption of online content and her self-management practice are closely related. Rather than being motivated to search for relevant content at a critical time, her consumption of online resources has become part of her constant exploration of developments in research and treatment/management options. Keeping up-to-date with new online content, for some participants, was a crucial part of the day-to-day experience of their health issue. Rather than engaging in response to critical or ongoing health concerns as they arose, these participants seemed intent on developing their knowledge and self-management practices as a matter of course.

4.3 Negotiating health-related content online

As well as discussing why and when participants were drawn to use online resources, participants also shared their experiences of negotiating the online environment and commented on the closely linked processes of locating and assessing online content. Again, there were few differences in how participants described these processes which seemed to be related either to the particular health issue they had experience of, or their gender. Rather, practices for negotiating health-related content seemed more connected to differences in everyday online activity.

4.3.1 Locating relevant content

Participants spoke at length about how they located relevant content. Most commonly they commented on the necessity of searching and, in particular, using Google to locate useful online content. As mentioned previously, the term ‘Googling’ was used almost universally as tantamount to information-seeking. In general, all participants discussed employing an uncomplicated approach to searching, as Fiona described when asked to talk through the steps she took to locate information:

So yeah I will go to Google, and I’ll type in my question or type in just generally, I can try it now, like Diabetes, can I do it yeah?² So I say “diabetes”, and [...] more often than not I’d go to the first one...

Yeah, just the top of the page?

Yeah just the top one, go on to it, which I think I’ve already looked at before, and if that doesn’t answer what I’m trying to find, I’ll go to the next one and I’ll keep going until, even if it has a little bit of the answer I want, I’ll go to the next one, and I like it when it’s bullet points, I don’t want to read through things, I want it straight to the point (Fiona, diabetes, 22).

Mia also described her experience of searching for relevant information. She considered:

Like, if I was feeling absolutely desperately unhappy I’d maybe type in “what to do when you’re feeling desperately unhappy”. Like, do literally the most basic thing in the world, and I’d probably read the first, like, I don’t know, few pages, just glance at them (Mia, CMHD, 20).

Like most of the participants, Mia and Fiona seemed to rely on search engines to bring up relevant results and did not mention visiting sites directly by entering the URL. Many participants, like Fiona, described searching for specific key words and combinations of key words, while some others used longer search queries like Mia’s search “What to do when you’re feeling desperately unhappy”.

² At this point, Fiona used the tablet computer to demonstrate by searching for ‘diabetes’ on Google.

Individuals' searching practices, such as the key words or queries they used, impacted the resources they accessed, since most mentioned only viewing the first few links returned by the search engine. Throughout the interviews the importance of searches was stressed and 'Googling' a focused query seems to remain an important part of the young adults' active navigation of online resources, particularly given the time-dependant nature of much information seeking.

Participants' accounts were not solely focused on the process of searching. Navigating a range of online resources for some involved more than just 'Googling'. Their experiences of engaging with health-related resources were not always the result of active searching but also involved informal or incidental navigation of content. Given the rise of social media and the range of dynamic content available online, participants' accounts reflected their familiarity with consuming content through these platforms. A number of participants, across both health issues, discussed how navigating online health-related content was not solely facilitated by search-engines:

[...] it's a bit more informal isn't it or, you know, like if you're on Facebook, you do, [...] you go off on tangents, it's a bit like being online, you just go, you skip from one thing to the other and it goes blah, blah, blah, blah. You might just come across this and just pick up a little bit of it, but it might just catch [your attention], do you know what I mean? You might just kinda think "yeah, well that's quite interesting, I'll read a bit more into it", and then yeah, it might lead onto looking at the website or... (Simon, CMHD, 30).

During his interview, Simon described a more unstructured and unpredictable approach to navigating content. He related his experience of exploring health content to his general experience of Facebook. He described how he "goes off on tangents" and how content "might just catch" his attention and "might lead onto looking at a website". This description of navigating online content is in contrast to discussions of deliberate and targeted searching. Furthermore, implicit in Simon's account is the social aspect of his navigation. Due to the nature of Facebook, the content he consumes is likely to come directly or

indirectly from his online social networks. A number of participants, including Max, mentioned this more explicitly, when asked about whether he ever accessed diabetes research online:

[The administrator of diabetes Facebook group] quite often posts links, yeah, the latest stuff that's going on, and anything from the news.

Yeah, developments, and things, yeah.

Developments, yeah, and that quite often leads me to go and have a look into these things. And, yeah I mean—there's been a couple of articles that have certainly led me in a direction which I've gotten quite excited about these things, and I've done further research, and found out more about a product, or something that's happening (Max, diabetes, 29).

Like Max and Simon, a number of participants described navigating the online environment as a relatively unplanned process of following links and recommendations. This less focused approach was often based on recommendations from social media contacts or wider networks, and was presented as an alternative means of finding and appropriating health-related content. Although some participants discussed utilising both approaches successfully, the less focused approach was more commonly emphasised by those participants who engaged frequently online, as everyday consumers of a range of health-related content.

4.3.2 Assessing: determining credibility and reliability

Despite participants' discussions of accessing online resources as routine, their accounts were permeated with references to concerns about encountering misinformation online. For instance, comments such as “obviously any online activity should be taken wi' a pinch o' salt” (David, diabetes, 29) and “but, again, you don't really want to trust anything over the internet” (Liz, CMHD, 19) were typical asides made during the interviews. The emphasis conveyed through the use of specific language, such as “obviously” and “again”, suggests shared assumptions around conscientious use of the internet for health information. In stating these reservations, participants constructed themselves as responsible consumers of online health information. Several of the participants reinforced

this by suggesting that, when in doubt, they deferred to the expertise of health professionals. For instance, when asked where he finds information online, Ronan (diabetes, 28) responded “I’ll just look everywhere online [...] and then try and make a judgement on it... If I was really concerned or worried I’d just go and speak to a doctor”. Although the participants made broad comments about the unreliability of online information, many went on to describe instances where they found useful information online which they considered to be trustworthy. Indeed, the participants generally described their own online activities as successful and none mentioned that they had appropriated information they later discovered was inaccurate. Rather, they provided examples of a range of assessment strategies which included comparing multiple sources, evaluating the purpose of content and assessing the visual impact of content.

The practice of comparing multiple information sources was mentioned by almost all the participants as an important means of assessing the credibility and reliability of health-related content online. For instance when asked whether she ever looked up mental health research online, Sylvia replied:

Yeah but you know I said like if I see anything on Facebook I’ll go, and have a look at it, like the vitamin D... and, I’m trying to think what else, and like tablets, or exercise. [...] Yeah, I do, if I read anything I tend to go, and have a look elsewhere to see if it’s telling me the truth, or just giving me a snippet, [...] if nothing else I’ve done before it’s like go onto Google, and I’ve had a look to see if the sources that are on Google saying that are quite reputable even if it’s not looking at journals, and actual research. If it’s like... charities [that] are quite—like big charities are quoting it then it’s probably gonna be ok (Sylvia, CMHD, 26).

Sylvia’s response has much in common with other participants’ accounts of negotiating online resources to compare sources and extracts of content. Eleanor also discussed this process, when asked to give an example of a time when she used the internet to access mental health information:

Yeah, well there’s the Cymbalta, right, it was a combined anti-depressant and to help me with my ME, I was told to take it at night, and [...] it had

me up all night and then you're online looking for ways to get to sleep, em, [...] and then I had come across something online about how it was dangerous for you and then you start going into videos about how over so many milligrams is dangerous for you, and I had to stop taking that cos I was taking quite a heavy dosage of that to try and get me to fall over [go to sleep], [...] again with Googling, just Google the information to find out, go to the NHS websites or see if I've got a tablet or something and there's a side-effect I'll Google just the general and see what other websites come up like forums, you know, just random forums with other people posting experiences. And you don't need to post, you can just read what they've been through and you think "Well yeah that's happening to me", that's what helped them (Eleanor, CMHD, 26).

As Eleanor described moving between various sources (watching videos, doing Google searches and checking "random forums") to find information about a particular anti-depressant drug she suggested the range of comparisons she makes as she assesses content. Similarly Anthony discussed comparing a range of diverse sources of content:

Basically with all the information that I see online, it's something that I'd always check up afterwards, everything that popped up on there, somebody says "this is quite a good move", well the first thing I'm going to do is go on Wikipedia, is go to the forum, is go on Google, like PubMed just to see, is that backed up by the information that I can find elsewhere. So all of these things are only ever used as kind of the starting point (Anthony, diabetes, 28).

These accounts reflect the complexity of negotiating health-related content; different sources with different types of information, delivered through different media are brought together by the users as they browsed. Navigating between these diverse resources, and comparing content from them, seemed to be an important part of determining reliability of information for some young adults. As with much health-related online activity, this strategy for navigating seemed linked to day-to-day online practices, with regular movements between social media and more static online resources commonplace in accounts.

As well as describing how they navigated across sources of online content to ensure they appropriated reliable information, participants also reflected on the specific strategies they employed when assessing the reliability and credibility of individual resources. For many, making distinctions about the purpose of content was crucial in determining both reliability of information and relevance to users' own experiences and perspective. For example, when asked about how she determined if the information she encountered online was reliable, Nicola said:

Em, I suppose it depends, like you say, where you get it from, so if it was an official sort-of diabetes type website, then I would assume it is reliable, whereas a Facebook page, I wouldn't necessarily assume it, unless someone, I suppose it depends what you are wanting, what the kind of information you are wanting to get out of it, because obviously it is just people's opinion and they could be just spurting absolute rubbish. Whereas you think a medical background knowledge, like a diabetes, medical, you know doctor or hospital, organisation whatever, I would just think that's more reliable.

Then are there things you'd be more likely to trust, ways of figuring it out?

[...] I suppose it would depend on the actual issue, I think if, if it was like a comment on a Facebook page, and then lots of people had agreed or something like that, if it was a generally, if you did more reading and you found that lots of people had the same opinion or same experience then I would be more inclined to believe it than some random person saying something [...], you just need to use your general sort of common sense I suppose (Nicola, diabetes, 28).

During her interview Nicola highlighted the distinction she makes between professionally produced content - "an official sort-of diabetes type website" - and social media content - "a Facebook page". She suggested that the value of these resources lies in her particular needs at the time, "it depends what you want to get out of it". Across the interviews, while participants often reported that they did not trust social media content as 'fact', they described judging it

by different standards. User-generated content was valued as ‘opinion’ and for some participants ‘crowd-sourcing’ these opinions, as Nicola alluded to, was seen as useful. A small number of participants commented on this more explicitly: “With [user-generated content], if you find a lot of people agreeing with something, if you get a lot of people with diabetes saying “actually yeah, I did this, this really helped” and someone else says “me too” and so on, that helps, cause you’re getting crowd-sourced information” (Anthony, diabetes, 28). Assessing online content, therefore, seemed to depend on the context of individuals’ information needs and the types of resources they were assessing. Social media content was often assessed according to the responses it provoked from the networks of individuals responding to it. Drawing on other people’s experience in this way, by gathering crowd-sourced information, seemed to be as important as accessing more professionally produced content for some.

As part of the process of assessing online content, participants mentioned various specific items they looked out for when evaluating credibility and reliability, such as logos, dot org URLs and coherent ‘about’ pages. However, most commonly they articulated the importance of the general visual impact of websites in their accounts. This could either be in relation to whether or not a page seemed professional or official, or whether it seemed relevant to their perspective and preferences. The two interview extracts below reflect some of the ways these issues were expressed:

I think seeing a website that’s well put together, it... it kind of... not builds trust, but you tend to think “Oh, this looks proper.” It’s like, you know, you’ve got two cars - one with a broken bumper or, you know, scratches on it, same type of car that’s all polished up and nice. You’ll go for the nice one, you know? If they’re the same price. It’s that type of thing, you know? It’s more appealing. You feel more... it’s more like you’re going to have... Yeah, I’ll stay here and have a look at this because it’s well-designed. As long as the interface is really nice. If the interface is crap then it’s going down the toilet (Leon, diabetes, 22).

Do you have preferences about the way things are presented?

Yeah. I don't think this one³ - not a lot of thought has been put into it. I mean, I could make something better on Photoshop. It's a bit - I don't know. Not cheap, but just - it's - yeah. It's got a lot of randomness (Byron, diabetes, 18).

Commonly the importance of websites, including social media sites, appearing "proper" and not "cheap" or "random" was stressed. Perhaps related to the processes of browsing websites discussed earlier, where participants described moving briskly between links and resources, they emphasised that websites must appear well-structured and well-designed to retain their attention. This also seemed to relate to wider online experience and day-to-day engagement with a range of websites. Users who were experienced in accessing up to date and well-designed sites as part of their daily online practices were familiar with the conventions of web design and in particular social media sites. Byron's suggestion that he "could make something better on Photoshop" was consistent with some other users who expressed interest in the ways websites are constructed and how images are presented online.

Similarly, images and language were also assessed in terms of how relevant they seemed to users' own experiences. Mia commented:

I think the most important thing is obviously the homepage, that's where everyone, like, obviously, like, goes on and they decide if they want to go on, so I think the homepage, like, needs to have some sort of interesting picture, without someone putting their head in their hands, because that is what all the homepages have, and like, it's just... that's not uplifting! Like, seeing that is just like, "Oh dear. Great. Like, if you're comparing me to this person, my head isn't in my hands," like it just, I don't know, it just seems like, it puts you off, I think, looking any further into it (Mia, CMHD, 20).

Again, in this extract the immediacy of the assessment process is suggested, Mia commented that if the image on the homepage did not appeal to her, she would not engage "any further into it". However, rather than discussing how professional the site appeared, she focused on how relevant it seemed to her

³Byron was browsing a Facebook page group page set up by an individual user or group of users

experience. Similarly, Mhairi commented on both a blogger she followed and some Facebook sites she had disregarded:

Have you heard of Young, Fun and Type 1? She, it's a blogger named Jen Grieves [...]. So, I was just Googling, and sort of came across it, but I think it's really, really good. [...But] there are pages on Facebook, which when I first was diagnosed when I was typing in [searching Facebook for] diabetes, there's like pages that are "I hate my diabetes", and blah, blah, blah, blah. So, yeah, avoided them, didn't click onto them. So, yeah, I wouldn't go anywhere near them (Mhairi, diabetes, 28).

During her interview Mhairi discussed two different social media sites, describing how she regularly accessed and appreciated the tone and perspective of the blog entitled "Young, Fun and Type 1" but that she dismissed a number of Facebook groups based on the negative tone of their titles, "I hate my diabetes". Similar to a number of the young adults, her experience of assessing resources seemed to be based on initial impressions of the language, tone and overall appearance of content.

Broadly then, the perspectives and preferences of the individuals appeared to impact the ways they assessed the relevance of the content. The processes of evaluation seemed to be, not only embedded in everyday internet use but also in individuals' day-to-day health and self-management practices. Perhaps, since the internet is so diverse young adults are able to seek out those resources that appeal most to their specific perspectives, and indeed, assess these based on initial indicators of quality and relevance such as homepage images and blog titles.

4.4 Discussion

It is perhaps unsurprising that young adults seek health content online as a convenient means of accessing relevant information to support active decision-making related to time and context sensitive health issues. Previous studies have highlighted that the internet provides resources for facilitating individuals' emergence as 'lay experts' or 'informed patients' (Fox et al., 2005, Nettleton et al., 2005, Kivits, 2009). Throughout the accounts of the young adults in this study 'going online' was taken for granted as the primary means of accessing

health-related information. Given near universal accessibility through mobile internet devices, participants reported regularly accessing content at any time without negotiating with health professionals. However, accounts of why they were drawn to online resources varied. For most ‘fact-finding’ was prioritised - in line with conceptions of the ‘informed patient’, while for some, going online was about finding resources which gave accounts of other people’s experiences and served to alleviate feelings of isolation. The latter rationale resonates with findings from both the CMHD and diabetes literature which analysed user-generated content to suggest social media facilitates supportive interactions (Giles and Newbold, 2013, Jones et al., 2013, Ho et al., 2014). These two activities, ‘fact-finding’ and accessing other people’s experiences, however, were not always presented as distinct by participants. Indeed, the growing presence of health content on social media sites was highlighted by those participants who were most active online, as they sought content which they identified as both ‘fact’ and other people’s experiences. For these participants, accessing online resources involved negotiating between professionally-produced, evidence-informed content and user-generated content, and their accounts reflected the combination of ‘fact-finding’ and accessing other people’s experiences which resulted in active peer-support. Furthermore, timeliness remains an important motive for accessing content, and while the majority of participants sought online content in a responsive manner some had developed more habitual practices.

In relation to how users locate relevant content, this study raised a number of issues which relate to recent suggestions about changes in users’ online information seeking practices. Previous work around accessing health information has discussed the role of Google as the primary gatekeeper to relevant information (Mager, 2009, Mager, 2012). Mager (2012) analysed data collected between 2006 and 2007 from 40 interviews with individuals who had been tasked with finding information online about a particular chronic disease that was assigned to them by the researchers. The importance of Google as a gatekeeper to information was emphasised in the findings of this study:

[...] search technologies, and Google in particular, mattered since they played a central role in users’ practices. Rather than passively

transmitting information, they actively mediated and shaped what information users ended up with, and how they interacted with and evaluated bits and pieces of information they found on various websites (p. 15).

This statement seems equally relevant to the current study, with most participants acknowledging the vital role Google plays in their information seeking practices. However, although search engines were the predominant means by which users located information related to their health issue, a number of participants also described more unstructured approaches. These participants reported locating a variety of content related to diabetes or CMHDs through following links or recommendations from social media contacts or wider networks, facilitated through platforms such as Facebook and Twitter. These more unstructured approaches were emphasised in particular by those participants who were not seeking health-related content responsively but as part of everyday consumption. This insight into developments in some individuals' online practices for locating relevant health content, away from dependence on search engines, relates to recent suggestions about online information-seeking practices more generally. Dutton and colleagues' (2013) most recent report from the Oxford Internet Survey indicates that search engine use is falling in the UK. The authors suggest that this decline is perhaps related to users increasingly relying on links and recommendations from within their online social networks, and on preferred social media sites, such as Wikipedia and YouTube, which include their own search functions. As users' practices develop and information-seeking becomes increasingly linked to social media and social networking practices, users encounter a range of influences, from both identifiable online relationships and marketing based on browsing habits. Just as Mager (2009, 2012) emphasised that search engines are not passive technologies, delivering content without filtration or priorities, health-related content located through Facebook and Twitter, as well as other platforms, is similarly not neutral, but impacted by a range of both explicit and tacit influences, including peer networks but also commercial interests. Lupton (2014) argues that commercial organisations are increasingly creating new data economies by commodifying patients' production of content about their

experiences of health and illness. With users employing social media more often as a means of locating and consuming relevant content, the impact of these influences requires further research and indeed, participants' perspectives on these issues could be explored in more detail.

The young adults in this study appeared to have developed a number of ways to rapidly assess health-related content in line with their wider online practices. As discussed, their accounts were permeated with references to reliability and trustworthiness, in line with previous studies of everyday engagement with health information online (Nettleton et al., 2005, Fergie et al., 2012). Further, their accounts of negotiating between resources suggested explicit assessment strategies. This has been noted previously in relation to online health information (Adams et al., 2006), although not fully explored in the context of increasing health-related user-generated content on mainstream social media sites. Indeed, the participants in this study expressed their awareness of the varying types of content available online, be it clinical information or accounts of other people's experience and seemed to judge each by different standards, based on their needs, awareness of content limitations and content relevance. The fast-paced nature of navigating resources seems to result in active judgements being based on initial impressions and heuristic approaches to assessment, similar to those detailed by Metzger et al. (2010). For instance, the strategies reported by the participants for assessing health-related content aligned with Metzger and colleagues' 'consistency' heuristic, based on comparing content to ensure consistent information; 'expectancy violation' heuristic, based on identifying content as context appropriate; and 'endorsement' heuristic, based on recommendations from varied sources. These approaches are further complemented by social media practices, such as the 'like' function which makes endorsement visible, and the standard structure of Facebook and Twitter pages which facilitates assessment of 'expectancy violations'. Indeed, for many of the young adults it seemed the consumption of social media content is largely based on brief assessments based on these heuristic strategies, alongside personal tastes or perspectives, which seem to be related to everyday online consumption of news or entertainment-based content.

Another key finding of the analysis of the young adults' accounts of their experiences of seeking health-related content online is the lack of differences by gender and health issue across the sample. Largely, participants' perceptions and experiences differed not according to the health issue they had experience of or their gender, but rather online health-related practices seem to have developed based on participants' approaches to wider, everyday internet use. This is further explored in Chapter 5.

5 Young adults' perceptions and experiences of engaging with user-generated content about diabetes and mental health

5.1 Overview of chapter

Having discussed the range of ways that the young adults talked about accessing and assessing broader online content in the previous chapter, the focus of this chapter is specifically on engagement with health-related *user-generated content*. The first section of the chapter explores users' engagement with health-related user-generated content on social media sites as a source of support, and presents a typology based on participants' consumption and production of content and their descriptions of offline sources of support. The diversity of participants' online experiences and practices is highlighted, and similarities and differences both across and within groups of participants are discussed in detail. Next, the young adults' considerations of identity and audience on social media sites and their expectations of and practices in social media spaces are discussed. Finally, instances of participants drawing on social media to actively support the development of their self-management practices are highlighted. Throughout this chapter, participants' perceptions and experiences of engagement with health-related user-generated content are highlighted to suggest some of the complexities inherent in using social media to access content related to either diabetes or CMHDs.

5.2 Descriptions of engagement with health-related user-generated content in relation to offline support

Throughout their accounts participants described social media as a central feature of contemporary social life, with many referring to it as the most well-used source of media content by young people. During the interviews they discussed the use of social media in their lives and their perceptions of its potential as a site for supporting self-management. Across the interviews, participants described social media as a relevant and pervasive media channel and discussed its potential as a site for health-related discussion:

[In] this day and age Facebook and Twitter [are] such a big thing in people's lives, that maybe that's [...] the best platform these days, instead of searching through hundreds and hundreds of websites there's one place where you could find things, [I] think it's helpful for people, maybe the younger people because they're being brought up in this Facebook, Twitter, social media world [...] and if you're on Facebook, I'm on Facebook every day, so if you are just searching around [...] if you just go on to the diabetes page, you don't have to 'like' it, but you can get the information maybe (Fiona, diabetes, 22).

I think the way social media's going, everything has a place on social media. I think that nothing can be missed off it, especially an issue like mental health where there is the whole stigma attached to it and I think that organisations and people need to have a presence in the social network... yeah (Leah, CMHD, 26).

Related to this, participants consistently suggested that the inclusion of health-related content on social media sites was inevitable. However, although almost all participants discussed the pervasion of social media, their perspectives on engaging with user-generated content about their health experiences were diverse. Initial analysis of participants' discussions of social media as a resource for health information suggested a relationship between participants' descriptions of their sources of offline support and their level of engagement with health-related user-generated content.

In order to explore this further, I examined participants' accounts of their current online practices in relation to their accounts of offline support. Based on my interpretation of these two dimensions, I positioned each of the participants along two spectrums in relation to each other (see Figure 4). It should be noted that participants' positionings, as represented in Figure 4, relate specifically to their accounts of their engagement with *user-generated* content, from channels such as Facebook, Twitter and YouTube. All of the participants described using professionally produced online content related to their health issue at some stage, but the frequency of, and practices for, engagement with user-generated content varied considerably.

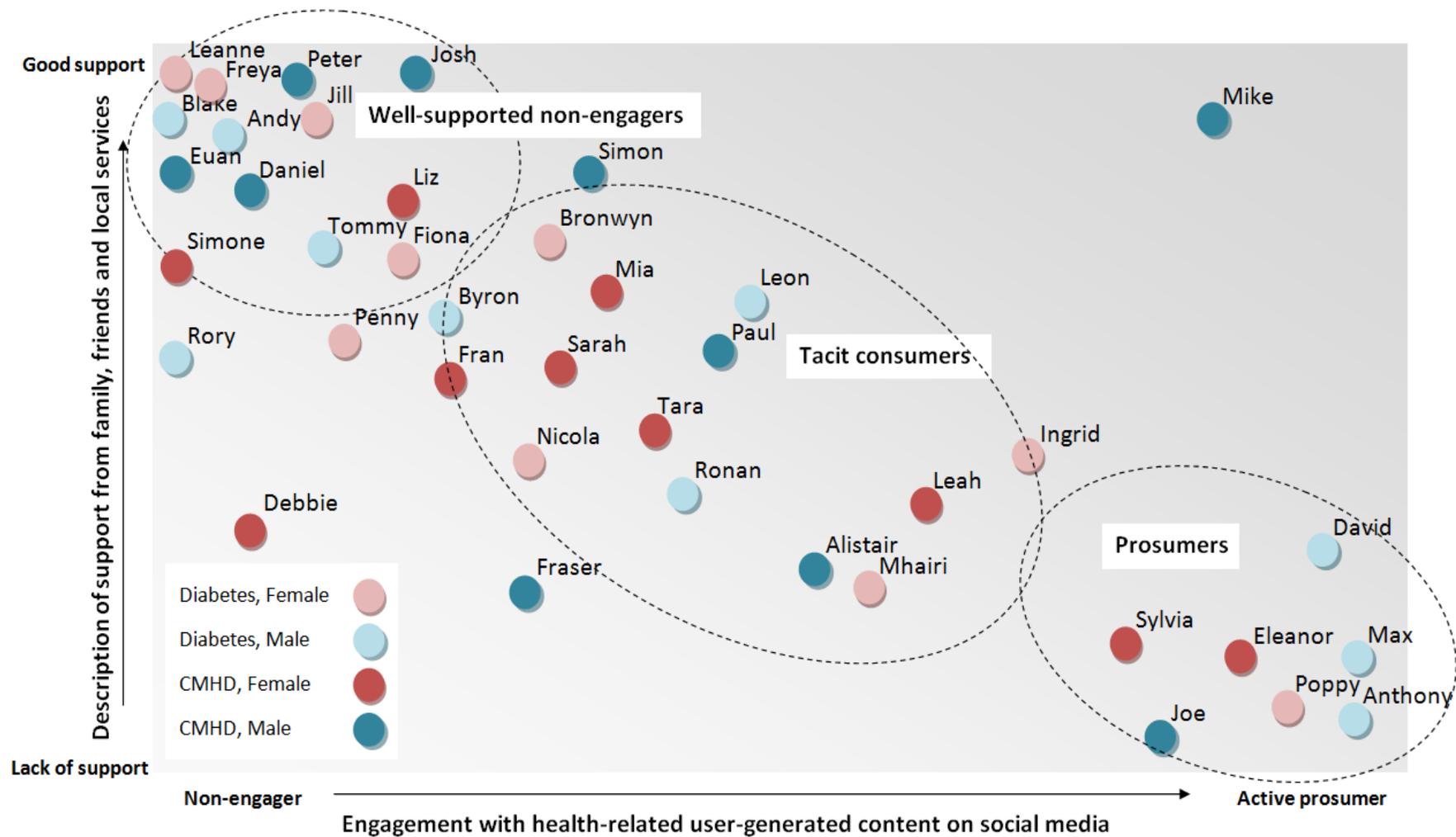


Figure 5: Engagement with diabetes or MH-related user-generated content in relation to descriptions of offline support - the basis of a new typology

Figure 5 illustrates how participants' responses relate to a spectrum of online engagement with health-related user-generated content. Those positioned furthest to the left of the figure represent people who had no experience of engagement with user-generated content, those positioned in the middle represent people who frequently consume user-generated content but rarely generate content, and those positioned to the furthest right represent people involved in frequent production and consumption ('prosumption') of user-generated content. The point at which participants are positioned on Figure 4 (in relation to the y-axis) also indicates how they described the offline resources, such as family, friends and formal health services or charities, they drew on to support their experience of either diabetes or CMHDs. Those situated towards the top reported a high level of support from offline resources whereas those at the bottom reported a low level of support from such resources.

A broad trend, and three main clusters of participants, can be discerned in relation to these two dimensions. Those who described least support in their offline networks seemed to engage most frequently in production and consumption of health-related user-generated content; I refer to these people as 'prosumers'. By contrast, those who described greater offline support seemed to engage less regularly with user-generated content; I refer to this group as the 'well-supported non-engagers'. The third cluster of users, which I refer to as 'tacit consumers', are those participants who described some degree of offline support and consumption of health-related content, but not production. Each of these clusters is described in further detail below, and the similarities between groups and diversity within each group are highlighted. Participants who did not seem to be well described by any of these 'types' of users are also discussed.

5.2.1 'Well-supported non-engagers'

The 'well-supported non-engagers' described high levels of offline support and low levels of engagement with health-related user-generated content and discussed having no desire to access other people's experiences through social media. Several of these participants were diabetic and talked about close relatives who supported them in managing their illness. Leanne and

Freya both talked about their parents who, like them, had personal experience of diabetes. During her interview Leanne reflected on the support she gets from her father:

Something that helps [with managing diabetes] is actually going hill-walking with my dad [...] So when I go hill-walking, one, it's mental focus on hill-walking - you're not even thinking about diabetes; two, it's exercise, which is great, it's brilliant for just... you don't need hardly any insulin which I love. It's like a kind of wee target not to take so much insulin. And, plus, I'm following my dad and whatever he's doing, I can just do and I don't need to worry. Whereas if I was going hill-walking with a friend or someone that didn't really know me, I wouldn't feel safe. But when I'm with him, I'm just like 'oh, it's fine, he knows the score.' [...] Seriously, if... I mean, me and my dad are not... we're not that... we weren't that close but after this we're really close now. And we can talk and we... I mean, we talk about diabetes all the time and it's great because we can be really, really honest. Whereas other people, you maybe say "oh..." you put on a brave face like "oh, it's not too bad." But wi' him I can be like "oh my god, guess what happened to me" blah-blah-blah. Because, like, my mum, for example, would just fret so I don't really tell her. But wi' my dad, I can say "oh, I had a nightmare this morning". So it's really good that he's there (Leanne, diabetes, 23).

Leanne highlighted several times throughout her interview how much she valued support from her dad because of his first-hand experience of diabetes. In particular, she suggested that she can be "really honest" with him since he has a realistic understanding of the challenges of self-management, unlike other members of her family who might be unduly concerned about her. However, Leanne voiced a different view of people with diabetes who discussed their experience online, she commented:

God Almighty!⁴ Yeah, immediately I hate any of this. That's just cringey. [...] I wouldn't go near that one, I wouldn't trust it. It sounds like people are just kind of going on there to moan about stuff. And I think... you feel crap you've got this disease anyway so you don't want to go on Facebook and see it either, so...

Who do you think this appeals to then, if not you?

Probably just people that maybe don't have someone to talk to? Quite needy people, maybe? Yeah, people that maybe just can't express how they actually feel in reality so they maybe go on Facebook to moan. Which is a shame... I don't think these people are bad people, it's just not the place to be doing that, I don't think (Leanne, diabetes, 23).

Leanne's immediate dislike of the Facebook page and her concern that it is a place for people to "moan" suggests her unease with the diabetes-related content contributed by other users. However, she went on to suggest that the producers and consumers of this content are likely to be "just people that maybe don't have someone to talk to". Leanne, like many of the participants who expressed unease with user-generated content, seemed to understand her own experience as well-supported, and not needing to engage with such content for support, whilst acknowledging that this may not be the case for other users.

Other 'well-supported non-engagers' had been diagnosed with diabetes as young children. This too seemed to impact how they viewed supportive content. For instance, Andy reflected on why he did not engage with user-generated content about diabetes:

I think people might be more drawn to using these kind of things if they don't have somebody like I did with Mum and Dad, who sort of really cared for the whole thing, got as much information as they could and em, other people might have different family backgrounds and all these kind of things, they might have to look for it themselves, and that's gonna be difficult for them but I mean having read the guys'

⁴ At this point in the interview Leanne was browsing a Facebook group page I was showing her which was used by individuals to discuss their experiences of diabetes.

[comments] and people they can talk to [the online community] who actually know what they're talking about, [it is] quite comforting for them to have so they probably use that facility quite a lot, eh I know I would if I didn't have the support of Mum and Dad (Andy, diabetes, 22).

Andy's description of his parents as well-informed and initially responsible for "the whole thing" sets him apart from people who "have to look for it themselves". During his interview he discussed having been able to rely on his parents for support and contrasted this with those with less support who might need to search out resources online. Similar remarks were also made by a small number of the participants who had experience of CMHDs and had encountered a high level of offline support. For instance Peter, who talked appreciatively about a mental health professional he was in contact with, commented:

I didn't really look it up [online] like, the ways were just there, [...] after going to see my GP and then [named mental health professional], I didn't really look at any other ways because [she] helped a lot [...] whereas if it was getting worse and [she] wasn't helping, like she was then, I would have [...]. If I was still [...] feeling as bad, and in the same place of mind and [if] I couldn't find anything that was helping, because when I was feeling as bad as I was like, I was looking, I was kind of looking for stuff, and then when I found [named mental health professional], I kind of stopped [looking] because that helped for me. Whereas if it [had not] helped, then I'd still be looking for that, for that open door to kind of make me feel better, in different ways (Peter, CMHD, 22).

In his interview Peter articulated why, for him, finding the support of someone who "helped a lot" meant that looking elsewhere, such as online, was not necessary. However, he recognised that this might not have been the case had circumstances been different.

In summary, for people within the 'well-supported non-engagers' cluster, consistent and reliable offline support seemed to preclude the need for

engagement with health-related user-generated content. Instead, close relatives with lived experience, parents who had developed expertise, or valued health professionals acted as adequate sources of information and support. Perhaps, then, young adults who have established these supportive resources may see little need to explore other people's experiences through social media channels and may be less likely to identify with those who do produce and consume content in these spaces. While this is not problematic, it does pose a challenge for producers of resources in engaging such individuals in dialogue around their health issues through channels such as Facebook and Twitter, since they may not be at ease with consuming or producing health-related content on social media.

5.2.2 'Prosumers'

Unlike the 'well-supported non-engagers' who described coherent, instrumental and emotional support from family, friends or formal services, the individuals characterised as 'prosumers' described a range of experiences to illustrate their low levels of offline support. In some cases, this reflected being diagnosed or first experiencing their health issue as a teenager or young adult, rather than as a younger child, and therefore taking greater responsibility for managing their health issue rather than relying heavily on parental support. For instance Poppy, who was diagnosed with diabetes at the age of 26 after she had established a career as a veterinary surgeon, commented:

I don't know, didn't know about the human side [of diabetes] at all and I probably thought I did. "Oh I'm a vet, I know everything." But the human side and the actual day to day mechanics of treating it was a lot harder and it only dawned on me it was much harder sort of a few months in [a few months after being diagnosed].

Poppy went on to discuss accessing supportive user-generated content online in relation to managing her diabetes whilst pregnant:

Eventually I found the support group on the internet but that was more an emotional thing than finding information. [...] I'm actually a member of a Facebook group [...] and I do, I'm very active on there at

the moment. Again it's only been running about two weeks and I'm sure when a lot of these women have babies it'll fizzle out again. But that's quite nice 'cause it's just very targeted, [...] it's for pregnant women [...] Yeah, so, someone's posted on there this morning. There's conversations going on at the moment about HbA1c and whether it's accurate or not. The three of us sort of said what our levels were, where they seemed to run between and what our average level was and then we looked at our respective HbA1c's and couldn't understand how the three of them added up [...] there's literally a conversation going on all the time on it at the moment (Poppy, diabetes, 30).

Poppy described how she initially expected that her professional expertise would be adequate in developing a successful approach to self-management and dealing with diabetes. However, when she found this was not the case she searched for additional peer support to help manage the "emotional side" and as a forum to discuss specific pregnancy-related issues. Similarly Eleanor began both producing and consuming content when she felt that emotional and instrumental support was less available from family members, friends or formal services. She described how, at 18 years old and first experiencing depression, she lacked support from her family:

There's so much stigma and I think a lot of people are still quite scared, I mean I know when I first got diagnosed my Mum and that didn't really understand it, they thought I was just being, you know 'you're just, snap out of it', you know, 'you're just a nervous wreck' or whatever, it took them so long to kinda realise it was something proper.

She went on to discuss the lack of clear guidance she identified in health professionals' advice and her desire to independently explore a range of online content, including user-generated:

I would say, I mean you go to the doctor for your basics but the main source of information is online I think because I depend on, you know, support groups on Facebook or, you know, [named mental health

forum], things like that because that's where people come. [...] I mean the professionals do do their best to help you where they can but even they're referring you to things online now like '*Living life to the full*', and again other people will say things but I tend to, like my family try and say things, but they've not really been through it, [...] I'd rather find things out on my own and try them on my own, than have someone tell them to me, the doctor I listen to obviously because they're the GPs but again I try to just find things on my own, rather than whatever hearsay (Eleanor, CMHD, 26).

During the interview Eleanor discussed the many ways that she engaged with other people with lived experience of mental health problems online. Regular production and consumption of content on social media were described as her "main source of information", beyond the "basics" provided by health professionals and the input of people who have "not really been through it". Similarly early in Anthony's account, he discussed the different roles of family and professional support and consumption of user-generated content:

To be honest, I tried to keep [my parents] out of it as much as possible because it was already very clear straight from the off that this was going to be about me, I was going to need to deal with this all the way through, so I thought, it just didn't really make sense for them to be too involved with it, I think the only involvement my parents have ever really absolutely had to have in this, was in my first couple of days in hospital, I had my injections administered by a nurse originally, and then my parents did one, and I did one, and I was doing them all pretty much from there on. Obviously they spoke to my parents about diet and well, I suppose, the eating, in retrospect, the advice I think they gave my parents was incorrect but that's kind of another issue [...] that's a separate ongoing debate that's in the NHS at the moment. There's certainly from a lot of the charities and the medical providers, there's an insistence that diet needs to be based around 60 to 70% starchy carbohydrates, whereas, and this is actually from using the internet and communicating with other people, I've learned that

actually most people have a very different experience, in fact that's actually one of the worst possible diets you could probably recommend in the situation (Anthony, diabetes, 28).

Anthony, who was diagnosed with diabetes aged 14, described assuming sole responsibility for self-management of the illness almost immediately and keeping his parents "out of it". Furthermore, although he mentioned the role of health professionals, he concluded by challenging the advice they supplied to his parents based on an understanding developed from "using the internet and communicating with other people". For Anthony, later diagnosis and the development of an independent approach to self-management seem to have prompted him to develop as a 'prosumer' of diabetes-related content.

Unlike the 'well-supported non-engagers', the 'prosumers' described inadequate sources of offline support or a desire to approach their health issues independently and, as a result, they seemed drawn to engage with user-generated content. Their role as health content 'prosumers' seems broadly linked to external factors such as illness trajectory, with their age at diagnosis and current health experience leading them to develop 'prosumption' practices within social media as a means of establishing supportive resources. Although the 'prosumers' all engaged actively in the production of user-generated content, the practices and platforms employed and the types of content generated varied within this cluster. While some, such as Sylvia (CMHD, 26) discussed posting supportive images and emotive content, others, like Anthony (diabetes, 28), were more concerned with contributing to debates around self-management and health policy. These complexities, inherent in users' social media practices, are discussed further in the section on 'Practices and expectations of users in social media spaces'.

Despite diversity amongst the types of content these young adults 'prosumed', accessing other people's lived experience of diabetes or CMHDs through social media seemed to be an important source of technical information or emotional support for them. The 'prosumers' were at ease with the production of content, having engaged actively to create and

contribute to user-generated content about the experience and self-management of their health issue. Online communities therefore seem a particularly important resource for young adults without consistent sources of offline support and prolonged online engagement seems embedded in these young adults' experiences of health and illness.

5.2.3 'Tacit consumers'

The cluster of participants labelled 'tacit consumers' are a diverse group of participants, who shared a propensity for consuming user-generated content about their health issue without contributing any content. Generally, these participants described experiencing *some* offline support from family, friends or local services but explored user-generated content as a means of supplementing these existing offline sources of support. For instance, while browsing a range of Facebook pages related to depression and anxiety, Leah commented:

I like these kind o' wee... like, almost inspirational [Facebook] pages. [...] There might be someone who's sitting in a house by themselves and they've not got any support network and and, like, I love all the wee quotes and things. [...] It's just... it's short and sweet and it makes people smile or it makes people think. Like, I have literally eight hundred of them in my phone because every time I see them on Facebook, I save it. And my friends and I send them to each other. Like, we've got a quote for every season, every problem, and we send them tae each other so I think that's really good. [...] Yeah. It's just that feeling... I mean, I always knew that I wasn't alone, but when you're right down there, you do feel as if 'this is it'. [...] Like, I was just breaking my heart because I felt so low and [...] you know what it's like, when you flick through your news feed or your Twitter and you see something like the wee pictures that I kept seeing or, like, if you see somebody on Twitter, it does just... it kind o'... it kind o' pulls you back a wee bit (Leah, CMHD, 26).

Unlike the 'prosumers' Leah did not use social media to engage directly with groups of other users to discuss her experience of CMHDs. Her engagement

with user-generated content on social media sites seemed to consist largely of consuming visual content featuring inspirational quotes shared by other Facebook users. In particular she discussed drawing on this content to share with her friends - “we’ve got a quote for every season, every problem” and during periods she felt unwell this use of material gleaned from social media “kind o’ pulls you back a wee bit”. Leah relates this engagement to feelings of partial loneliness, “I always knew I wasn’t alone, but when you’re right down there, you do feel as if ‘this is it’”. Similarly, Mhairi described her early experiences of managing diabetes:

I almost felt safe while I was in hospital ‘cause they were kinda telling me what to do, although I was doing it they were kinda telling me what to do. And then, when I did leave hospital I remember having my first meal, which was lasagne, and I was like, “oh my God, what do I do?” Even though I’d done it in hospital it was like, I don’t know, it was just ‘cause you’re back home. So that took a wee while [...] So, that was the biggest one [challenge] I think just trying to get into that routine and, it did feel like such a big thing to do. I suppose ‘cause you’re not used to doing it.

Mhairi associated the hospital and staff with a feeling of safety and described her return home as somewhat unnerving. She went on to discuss the user-generated content she had drawn on to allay this feeling:

I don’t know if you’ve heard of the website ‘Fun, Young, and Type One’ before? It’s fab, it’s a blogger [...] she has done video blogs [...], she’s got a Twitter site and she also write blogs, and it’s about—she’s, I think she’s about 25 or something. But, she writes about diabetes but in terms of her life as well, and it’s all kinda—it’s quite positive the way she puts a slant on it and stuff. So, I was just Googling, and sort of came across it, but I think it’s really, really good. And, I like reading like all her little blogs, and watching her video blog, clicking on her links. So, it’s kinda that peer-support, kinda thing, which is good.

In her account Mhairi identified a specific blogger, of a similar age, as a particularly useful source of user-generated content across a number of social

media platforms. Despite widespread consumption of user-generated content, the cluster of ‘tacit consumers’ differed in the types of content they accessed and the frequency of access. Some participants, like Leah, consumed a specific type of Facebook content (images with quotes), while others, like Mhairi, accessed a range of content from different platforms. Mhairi associated consumption of this content with “that peer support thing”. In this way, Mhairi seems to suggest a desire to understand other people’s experiences of diabetes as a means of supporting her own experience, and consumption of user-generated content as a convenient means of accessing this. However, she concluded that she would never contribute content:

I would read them [sites featuring user-generated content]. I think I would post on it if I knew that what I was saying was definitely a hundred percent accurate. Or, if it was about maybe my experience. But, no, I’ve never posted anything, posted anything on [social media] (Mhairi, diabetes, 28).

Mhairi’s comments seem to suggest that despite her finding relevant information within user-generated content she is not, currently, prepared to contribute to it. This type of comment was typical across the ‘tacit consumer’ participants. Paul (30), who had experience of depression/low mood related to a gambling addiction, talked about his perceptions of contributing user-generated content: “I know it would probably be useful to actually like speak to other kinda like-minded people on something like that [Facebook page]⁵ but it isn’t something that I’ve actually ever done”. In summary, unlike the ‘prosumers’, the ‘tacit consumers’ did not seem at ease with producing content, despite drawing on other people’s accounts of diabetes or CMHDs when they provided relevant or interesting content. The types of content consumed varied considerably, however, the barriers participants identified to contributing content involved complex considerations of the presentation of identity and audience, as well as expectations of typical content and conventions within specific social media platforms. These are discussed in more detail in the following sections.

⁵ Paul was browsing a Facebook group page I had showed him used by people experiencing depression to discuss their experiences.

5.2.4 'Deviant cases' and participants between clusters

While most participants could be characterised as adhering to one of the 'types' described above, the typology does not adequately encapsulate some participants' accounts. The most prominent 'deviant cases' are Mike and Debbie (see Figure 4), who both had experience of CMHDs. Throughout his interview Mike described high levels of offline support, yet also frequent production and consumption of user-generated content about mental health issues. After describing instrumental support from both his mother, based on her experience as a nurse, and his father, who escorted him whenever he left his home, he discussed his online activities:

When you go to a website, like I say, it's the same as reading a blog post, there's limited, well there's virtually no room for discussion you know. [...] On Facebook you have an open forum, and let's face it, it's Facebook, you've got a much wider audience than people trying to look up different websites - everything's there in one place. So many people go on all the time, they're connected on their phones. You know. I think it's good, because people can share, you can meet other people, you can go down see posts by others, meet people, and talk about your experiences. [...]. I mean, I'm a scientist. This isn't my first degree. And I've had arguments with people, and they go, "yeah, well, you're wrong!" I go, "well, you know - I'm just trying to clear up things." [...] I think - the greatest thing I've had is being thanked for my advice. Because people have genuinely - some people are genuinely thankful that you take the time out to help them (Mike, CMHD, 30).

Unlike most of the other participants Mike highlighted that an important part of his online activity involved providing mental health advice to other users. His 'prosumption' of mental health content seems to be related to his identity construction - "I mean, I'm a scientist" and his role within social media seems to have developed accordingly - "I'm just trying to clear things up". In this way, Mike's account was different to many of the other participants. Rather than describing seeking personal support through producing and consuming user-generated content, he talked about using social media to share his experience and knowledge specifically to support

other users. Mike's account also differed from many of the other participants in his discussion of diagnosis:

I thought, "oh, I'm having panic attacks." So I started seeing a psychotherapist. I only saw him six times. By that time I felt better, I was fine. And then about seven, eight years ago, [it] started happening to me again. And ever since then it's just got worse and worse and worse. Although they're [health professionals] telling me it's panic attacks, I don't think it is. And [...] now they're starting to come round to the realisation that it might not be psychological. [...] I think it's neurological. Just having bloods done, they've found that I'm hypercalcaemic. [...] That means I've got a very, very low B12 in my blood. Well outside the normal range. And the effects of that, of course, is nerve damage, demyelination, fibroid sclerosis, nerves. Luckily I'm not anaemic with it, because that can be fatal in a couple of years. [...] They call them panic attacks, but they're very strange panic attacks. They're mostly muscular, neurological. I get spasms in my left shoulder, smacks into my head, bruises my head. Sometimes it just locks up rigid. Mum's a nurse, she's a staff nurse, she took my pulse and blood pressure -- perfectly normal. Doesn't strike me as anxiety or even panic, but -- you know. Haven't been able to work at all, a lot of the time I'm dizzy (Mike, CMHD, 30).

Mike's account of his diagnosis and his ongoing dialogue with health professionals about whether his symptoms were psychological or neurological was unlike most others. Generally the participants discussed their experiences in less detailed medical terms and with less emphasis on contesting health professionals' views. Perhaps, this additional concern with challenging his diagnosis, coupled with his more 'advisory' online role, led Mike to 'prosumption' as a means of establishing his authority and actively constructing medical knowledge around both his own experience and mental health more broadly.

Debbie also discussed the complexities of diagnosis, however, in her case this involved both mental health problems and learning disabilities. She too

reported a range of diagnoses and difficult interactions with health professionals, but in contrast to Mike described a lack of support from family, friends and formal services. In particular, Debbie described her parents as “not very supportive” and commented “I have basically no friends, and no social network, [...] just being around people makes me nervous.” When asked about how she had used the internet for mental health information Debbie commented:

Looking up information about it - I don't really like user-generated ones, like when people talk about a topic. [...] Like sometimes there'll be sentences I can associate with. But, then they're not the most accurate, and then people just go on, it's like you have all the answers, lots of smiley faces, and I'll never participate in one of those. I could read things - but like with Facebook I deleted my Facebook account, I never will participate in like posting to an online message board, or anything. I'm like way private about that. Internet, so I guess like using like the government sites, or like charity sites about things, researching maybe like therapies. [...] I tend to like trust the ones that are like—I know are government organisations, or charities more, and like the major charities, because I find even like you know if you're like reading a news article on like BBC, and people will put comments, and the conversation's always devolve into like really ignorant, or prejudice, or criticising comments (Debbie, CMHD, 30).

Debbie's experience is at odds with most of the other participants. While others seemed to access user-generated content as a means of obtaining or supplementing supportive resources, Debbie did not identify this type of content as potentially supportive. She highlighted potential inaccuracies as problematic, as well as the tendency for user-generated content around mental health issues to include “ignorant, or prejudice, or criticising comments”. Perhaps, for Debbie, use of social media is complicated by concerns about engaging with other people given the lack of supportive relationships she seems to have established offline.

There were a number of participants whose accounts resonated to some degree with both the ‘well-supported non-engagers’ and the ‘tacit consumers’, but did not conform completely to the characteristics of either group. Generally these participants described being well-supported and rarely consuming user-generated content, yet they were not averse to engaging with some forms of user-generated content in specific circumstances. For instance Penny, who rarely consumed user-generated content, discussed accessing forum content in response to contentious pregnancy advice she received from a health professional at a time when she lacked alternative sources of support:

You go on forums and things like that and they are quite interesting to see because people [forum users] will be like “no, no”, like not to me, but you saw other people [forum users] in maybe the same situation or similar things, just it’s good to get other people’s views, because I didn’t really have many friends, cos it’s when we lived in England and [partner] was away and spoke to my Mum and that but it was good to see other people speaking about it [...] and what their thoughts and that were on it (Penny, diabetes, 27).

Rather than engaging in production of content to elicit advice, Penny searched existing forum content to find users’ discussions of a situation similar to hers. The temporary absence of her partner and the specific nature of her concerns seem to have prompted her to access advice in a way which she suggested was fairly atypical for her. When asked about accessing user-generated content about more day-to-day aspects of diabetes and self-management she commented “I never looked, I didn’t look for stuff about moving from home or being a student [...], I’d never thought about looking for any information on those things.” Similarly, Byron reflected on the only instance of consumption of user-generated content he recalled:

I got this [injury] on my foot, and I thought that was something, but it turned out it wasn’t, it’s fine. I got really scared. So I was searching that up, and that didn’t help.

Did you look at images?

Yeah, and that's not a good idea. Because that makes you shit yourself. [...] But I suppose the internet... Forums were quite good. [...] I remember just going on the forum to see about that [gestures to foot injury] - and it was just people being, like - "I've had the same type of thing, but it turned out to be nothing" (Byron, diabetes, 18).

Like Penny, a specific concern seemed to prompt Byron to search user-generated content. Thus, where other sources of information or support are inadequate or perhaps (temporarily) unavailable, participants who generally did not engage with health-related user-generated content seemed to seek relevant content where it offered additional or alternative guidance.

More broadly, these instances, and others described by participants illustrate the limitations of conceptualising users as these three groups. Whilst the typology usefully summarises participants' accounts of current online practice with regards to both production and consumption of user-generated content *and* current experiences of offline support, it does not reflect the dynamic nature of either the online environment or people's lives and health experiences. Unforeseen changes in participants' health status, self-management practices or supportive resources are likely to affect their online practices. Similarly, since social media use has increased considerably over the last decade there may be differences in how people draw on user-generated content across generations. Perhaps well-supported young adults diagnosed with diabetes or first experiencing a CMHD in the future might simultaneously draw on offline resources and user-generated content, which would not have been available to some of the participants in this study when first experiencing diabetes or CMHDs. Thus whilst this tentative typology is a useful heuristic device to illustrate the connections between offline support and online engagement within a group, at an individual level it provides a transient snapshot of participants' experiences in relation to these two dimensions.

5.2.5 Similarities and differences in engagement with user-generated content by gender and health issue

Throughout development of the typology, responses from specific groups within the sample were systematically compared. Prior to data collection and analysis some differences had been expected between participants with diabetes and those with experience of CMHDs, and between men and women. However, across these groups, rather than many differences, there were a number of similarities in how online engagement with user-generated content and offline support were discussed.

Both young men and women described user-generated content as a potentially useful way of creating supportive communities with other people who had similar health experiences, even if they personally did not engage in this way. For instance Jill, one of those characterised as a ‘well-supported non-engager’, talked about the potential value of users interacting with each other through social media about their experience of diabetes:

I think it's great for like - the same as it is for everything - everybody has got something a wee bit weird that not everybody has, [you] can find other people that have [that] something too and that's a great support. And you don't have to go to a meeting and be like "I have diabetes, let's talk about it." Nobody wants to do that but sometimes it is nice to know people or be in contact with people that are the same because you do have issues that like - I would have liked to have known somebody that was my age and going through the same kind of problems that I was going through, like your parents bugging you to have another snack before bedtime and all. My dad still says that to me now; I'm 24 and on a different insulin. He's like "Jill do you think you need a snack before you go to bed?" I'm like "No, I don't need a snack!" but he still does it because he's so like trained to do that and he asks me if I've done my insulin and stuff. But it would have been nice to have somebody that was kind of going through those types of things and I think that is a great way to kind of do it without having to go to one of those meetings or whatever (Jill, diabetes, 24).

Similarly, Josh, another of the ‘well-supported non-engagers’ responded to viewing a Facebook group page for people with PTSD for the first time⁶:

I've never really thought about that [Facebook]. [...] there's bound to be someone suffering the same things that I'm suffering from. And I've never really thought about that. [...] I mean, I think this one [Facebook page] is a good one because it's done by people who have suffered or are suffering from PTSD. Just that phrase there [Facebook group cover image], 'don't wait until it breaks you' - I think I waited too long and it broke me. And I should've probably Facebook searched it a long time ago because 23,000 ‘likes’ and there's probably a lot more people out there who suffer from the same kind of feelings I do, so [...] And it just... it kind o' makes me feel better that there's people out there that are [in] the same boat as me (Josh, CMHD, 27).

Thus, across both the male and female participants, user-generated content was described as having the potential to support people’s experiences of both diabetes and CMHDs. Health-related user-generated content was discussed in similar terms by both, as a means of accessing other people’s experiences to support one’s own, with little mention of different needs or expectations according to gender.

Furthermore, the male and female participants, across all the clusters, expressed similar views on what might limit production and consumption of such content. Participants shared concerns about privacy and stigma when discussing online engagement with health-related user-generated content. For instance, Sylvia (CMHD, 26) commented: “Facebook keeps changing its settings. And, one minute you think everything’s private, the next minute you find out it’s all public [...] I wouldn’t want everybody knowing my business”. Similarly, Peter (CMHD, 19) suggested that engaging with mental health-related user-generated content on Facebook “would make me feel that people, people knew what I was looking into, you know, like it’s not really private, Facebook’s never, never really that private.” Across the sample,

⁶ During the interview Josh had been looking at some generic mental health social media sites I showed him. At this point in the interview I suggested searching for a PTSD Facebook group, since this was the mental health issue he identified with. He quickly found one and then scrolled through the group’s page exploring the content.

few differences emerged between how the young men and women expressed these concerns, however, complexities around how these impacted online practices are discussed in further detail below, under the subheading ‘Users’ considerations of identity and audience on social media sites’.

Participants with experience of diabetes and CMHDs were represented across the three main types of users, with no ‘type’ dominated by either health issue. However, by comparing participants’ responses by health issue, slight differences were apparent in the ways they articulated their experiences of engagement with user-generated content. As discussed, many of the most ‘well-supported non-engagers’ were participants with experience of diabetes (Freya, Leanne, Blake and Andy), who described support from close family members. Across the participants with experience of CMHDs, some, such as Peter, also discussed that the high level of offline support they experienced meant they had not explored online resources. However, for some of the other young adults with experience of CMHDs (Euan, Daniel and Simone), the low levels of online engagement they described were not accounted for as solely a consequence of high levels of offline support. Rather, these participants described additional issues that impacted their levels of engagement with health-related content, such as concerns that accessing user-generated content might exacerbate existing anxieties. For example, Simone, who had experienced prolonged periods of stress and anxiety, discussed her apprehensions about accessing any content on social media:

I mean, I'd watch things on YouTube if they were linked [to], from a news website or something, like *The Guardian* or something linked to it. I'd read that, but... the Internet [is] quite a, I don't know, if I were to look on some kind of blog [...] that I hadn't read about on another [website], something that was -- I keep saying that, 'above ground', I don't know what I really mean by that -- but I'd feel like I shouldn't be doing it in some way? (Simone, CMHD, 25).

Simone mentioned the potential of encountering inappropriate or illegitimate content online several times during her interview, and in this instance stressed the importance of only consuming content that was “above ground”

in that it came from a legitimate source. She indicated that these concerns about viewing inappropriate content exacerbated her level of anxiety and therefore adversely impacted her mental health. Similarly, Daniel discussed how using social media to consume or produce health-related content might exacerbate his anxieties about what other people thought of him:

That's part of the reason I would stay away from it [mental health content on social media channels], it's because of those sort of negative... like the fear that people might not react the way you want them to react and it's eh, and you've got more chance, it's almost like eavesdropping on someone talking about you because it's so possible to see other people's conversations and you could almost interpret them as if they were talking about you or whatever. Yeah I couldn't, I couldn't it would drive me insane (Daniel, CMHD, 25).

Although both these participants had engaged with formal mental health services, and acknowledged support they had received from both professionals and family or friends, their decisions not to seek out user-generated mental health content do not seem entirely related to the level of offline support they had experienced. They articulated anxieties around accessing content when discussing what influenced their online practices, rather than suggesting that their support needs had been comprehensively met offline, as appeared to be the case for the most 'well-supported non-engaging' diabetic participants.

A further difference between participants' descriptions of engagement with user-generated content across the two health issues was evident in participants with experience of CMHDs accounts of consumption of user-generated content. Although relatively similar numbers of participants with each health issue are positioned within the 'tacit consumers' cluster and concerns around the impact of publicly contributing content online were articulated by most, those with experience of CMHDs talked explicitly about the negative effect social media use could have on mental health. Sarah, Tara, Simon and Mia all reflected on their tendency to access other people's narratives rather than make any contributions themselves. For instance

Sarah explained why she would never contribute content related to her experience:

I think people are exposing themselves, making themselves vulnerable to people they don't know, and even though that shouldn't matter I know more than anyone that people's opinions, even a stranger in the street, matters, you know and it's like if you put something on and then some idiot thinks it's funny to write a horrible comment underneath that could push you somewhere else or make you... I think, you know, it's taking away from people verbalising how they feel and being able to talk about it (Sarah, CMHD, 22).

For 'tacit consumers' with experience of CMHDs, perhaps consideration of the negative impact contributing mental health-related content might have is an additional concern which inhibits users from becoming *producers* as well as *consumers* of content. This could, perhaps, relate to the young adults' perceptions of stigma associated with mental ill health and reflects broader concerns around the impact of social media practices on people's identity and experience which are discussed more fully in the following sections. However, if mental health charities and organisations wish to facilitate supportive communities via social media, it seems crucial to provide multiple opportunities for users to consume content without explicitly engaging, and indeed, perhaps also to develop ways for these consumers of content to contribute anonymously should they wish to.

5.3 Users' considerations of identity and audience on social media sites

Despite the range of ways participants engaged with health-related user-generated content online, across all three 'types' of users, participants all discussed how considerations of their identity and audience on social media sites impacted their online practices. For many of the participants, 'social media' as a concept was conflated largely with social networking, and primarily with Facebook. During the interviews participants discussed Facebook at length, both broadly as a social phenomenon and in terms of their own experience. Central to their accounts of Facebook use were issues

of identity management. Considerations of identity and audience were particularly evident when discussed in relation to opportunities to contribute to the increasing volume of content related to diabetes and CMHDs on Facebook.

5.3.1 Contributing explicitly health-related content

During the interviews many participants reflected on the undesirability of contributing any health-related content to Facebook, since the site was seen primarily as a space for the conscious construction of a positive identity, and inclusion of diabetes or mental health content could jeopardise this. This conception was articulated in particular by ‘well-supported non-engagers’ and ‘tacit consumers’, who had never contributed content related to their health issue, but also by some ‘prosumers’, who did not use Facebook as a site for the production of health-related content. For instance Fraser, who had never contributed mental-health related content to any social media site and rarely consumed such content, discussed his concerns:

The thing with Facebook is that it, Facebook links into your sort of general, your wider, you know, Facebook profile, and it's [mental health issue] not something you would necessarily want to be public. And if someone's stalking you on Facebook, not stalking, but, you know, someone is looking at your Facebook page and they see that, that's not necessarily something you'll want them to see (Fraser, CMHD, 28).

Fraser's comment “that's not necessarily something you'll want them to see” suggests the active decisions he makes about what personal content is presented to those viewing his profile, and that his current experience of depression is not something he wants made “public” or presented as part of his identity. Similarly, alluding to health issues on Facebook was described variously as “too public” (Alistair, CMHD, 21), “cringey” (Liz, CMHD, 19) or like “shouting it from the rooftops” (Leanne, diabetes, 23). Some participants elaborated on their reluctance to post health-related status updates, their rationale relating directly to concerns about identity:

People would think she's moaning on about it [diabetes] and I don't want to be a moaner, so...

So it's kind of about other people's perceptions as well?

Don't want to be just known as the girl who has diabetes and is always going hypo and things like that (Penny, diabetes, 27).

Many participants, including a number of the 'prosumers', expressed concerns about being perceived as "the girl/boy who has diabetes/mental health issues" or as someone who was always "moaning on" about their illness.

Although most suggested it was better not to post health-related status updates, two participants discussed using Facebook to share their feelings. When asked if she ever posted about diabetes on Facebook, Ingrid responded:

Yeah I have, just moaning about feeling sick and stuff, like I've got my manager on my Facebook as well so I'm very aware of her knowing that I'm not just faking it and taking the piss and stuff so um, I do post how sick I'm feeling or like em, the other day I got all my medications for winter from the chemist and it was a bag like that big so I posted a picture of that, just like 'lol' [laughter] about it and stuff, so I try and like make jokes about it and stuff just so that people are aware and don't just like think I'm being grumpy or something for no reason, so

Yeah and what do you think about the, there's obviously different sort of groups of people who'll see that, so there's your manager but then friends and stuff?

I'm fine with it, I'd rather that everyone knew, instead of like either saying something that would like offend me or something or thinking that I'm being grumpy when I'm just really really sick and I don't want to have to go to everyone all singly and explain everything, so it's easier if I just explain it once on Facebook and then everyone knows (Ingrid, diabetes, 23).

Unlike the other participants, Ingrid discussed using Facebook purposely to announce how she was feeling to all her 'friends', including her manager at work. She did, however, make reference to her audience and their possible responses to her comments, in a way that was similar to the other participants. By sharing her experiences on Facebook she hoped to justify her sickness absence from work to her manager and provide a rationale for her mood to friends.

Joe also used Facebook to contribute explicitly health-related content, although he did refer to the potential undesirability of using the site in this way. In particular, he introduced the term 'vague booking':

You know, I will quite often just sort of tell Facebook that I'm feeling really anxious or I'm feeling really down or I'm just confused and things like that. I try to avoid what they call 'vague booking', which is, you know, posting something really vague sounding so that people'll ask you a question about it.

I've never heard of that before.

It's called 'vague booking', when people say "oh I wish some people would get a life" and things and they're clearly talking, you know, they're usually talking about a specific person who's in their 'friends' list and they want them to see it but they want, but they won't, you know, speak to the person directly like an adult, they do it in a really passive-aggressive way and I hate that. Like I really hate passive-aggressive behaviour 'cause it just makes things worse. But unfortunately a lot of people do it when they feel down or upset so, and a lot of people don't realise that they're doing it. It's a thing that I consciously try and avoid so I try and, I try and be more specific when I, you know, this thing happened and it's made me feel really down or this, you know, I'm doing this thing and it's making me really anxious. So that people don't think I'm looking for attention because the 'vague booking' thing tends to be wanting people to ask you about what's wrong and give you attention (Joe, CMHD, 28).

Joe highlighted the complexity of posting about personal experience of CMHDs on Facebook, since practices such as ‘vague booking’ can negatively impact people’s perceptions of motives for posting. By making rules about what to post and how to express it, “I try and be more specific”, he attempted to avoid appearing “passive aggressive” or like he was “looking for attention”.

While Facebook is often conceived as a site for discussion of the mundane, details of health issues were not always deemed suitable content for status updates due to the potentially negative impact it could have on individuals’ presentations of themselves. For the small number of participants who did use it to share experiences of their health issues as ‘status updates’ they justified the practice, by providing either a practical rationale for posting or suggesting boundaries around how posts are phrased to avoid ‘vague booking’.

5.3.2 ‘Liking’ health-related content

During the interviews participants also discussed other ways of incorporating health-related content into Facebook profiles. While many participants expressed a general reluctance to discuss health issues on Facebook, the act of ‘liking’ Facebook pages related to health issues provoked varied responses. When asked about ‘liking’ a mental health charity page, Simon discussed his considerations:

I probably would actually, yeah, yeah, cause I know that you can, yeah people can see what you ‘like’, so, yeah that’s strange isn’t it ‘cause I would actually, I would like to ‘like’ that page, but...

Would you have any concerns about anonymity and people knowing that or...

Yeah, I probably would, yeah, em... (pause). Yeah, that’s interesting, yeah I don’t know, I would be reluctant to ‘like’ it, yeah (really?) yeah, even though I do like it, I’d be reluctant to, do you know what I mean? It’s strange ‘cause you feel like “oh”, I’d feel a bit vulnerable,

I'd feel like, well you know, that people might be like "oh, why has he 'liked' that?"[...]

I don't have any charity 'likes' and I've never really thought about why not.

That's the same with myself actually, yeah, yeah, yeah, I don't know... it seems more like, Facebook, you just, you kinda promote yourself or, yeah, you promote a version of yourself, that you maybe think people would like to... like to 'like' [laughs] (Simon, CMHD, 30).

For a number of the participants, to 'like' a page was a statement of endorsement and personal association with the subject of the page. For some, like Simon, health charity pages or support group pages were not deemed suitable content for 'liking' since they did not contribute to the purpose of Facebook, to promote the 'right' version of yourself. Further, Simon suggested that these online associations could lead to him feeling "vulnerable" and open to questioning and criticism from the largely undifferentiated network of contacts that make up his Facebook audience. Indeed, the "people" he referred to, his Facebook 'friends', are likely to consist of both close friends and one-time acquaintances.

Similar concerns were voiced by participants with diabetes about the prospect of 'liking' a diabetes charity page:

Yeah, would you ever 'like' pages like that⁷?

No because then everybody would know that... no.

Really?

I wouldn't ever get involved in anything like that. I'd look at it but I wouldn't... because if you 'like' it, all the people you're friends with then are like "Why's she 'liking' that?" But I wouldn't think twice about 'liking' Cancer Research UK or any other, but just because I

⁷ Jill and I were both looking at the Facebook page of a national diabetes charity that I had brought up on the tablet.

know I've got that [diabetes], I don't know, I'm just... no. So no, I wouldn't get involved in that (Jill, diabetes, 24).

In this extract, Jill seems to suggest that her status as a diabetic informs her resolution to never 'like' a page associated with diabetes, despite being happy to 'like' other health charity pages. As with many of the participants, explicit online engagement with social media content related to a health issue she has personal experience of, seems to be restricted by considerations of identity and audience on Facebook. For some young adults, therefore, 'liking' content related to their own health issues, seems to be construed as a means of publicly acknowledging their first-hand experience of specific issues. The act of 'liking' seems to be particularly threatening to the identities these young adults had striven to construct online and therefore this concern took precedence over other, perhaps more altruistic, considerations.

Within the cluster of 'prosumers', some participants also expressed concerns about 'liking' pages on Facebook and the response the action might provoke from Facebook 'friends':

I wouldn't choose to 'like' it⁸ because, of course, it's a great big red flag that's up now on your Facebook and then what actually happens from that is although most of my friends and people I know, know that I have diabetes, there are those who, like friends that I have from primary school that I've not seen for like 15 years or whatever, who might not necessarily know, and then of course that pops up and suddenly you've got to go through conversation again, having to explain everything. I've had to do that so many times in my life, I don't really want to have to do that anymore (Anthony, diabetes, 28).

Despite being one of the most regular producers of content around diabetes and engaging online through a number of social media platforms, Anthony also chose not to 'like' diabetes Facebook pages in order to avoid unwanted questioning from an audience whom he saw as distinct from his online peers

⁸ Anthony was browsing the Facebook page of a national diabetes charity that I had shown him.

with diabetes and his current close friends. His production of content was therefore limited to other social media channels.

Some participants, however, expressed little concern about being seen to 'like' health-related Facebook content. Mike (CMHD, 30) explained "I 'like' some pretty zany stuff. You know. I'm not really one that cares what others think. Not really - I'm not really self-conscious." Others commented that they presumed no one was interested in their 'likes' (Poppy, diabetes, 30 and Alistair, CMHD, 21) or that they 'liked' pages to raise awareness of their health issue (Eleanor, CMHD, 26). Leon, was one of the few individuals who discussed the incorporation of diabetes-related content into his Facebook profile as a means of positively contributing to an identity he had purposefully constructed of himself:

So do you think you would ever 'like' a [diabetes charity page]?

Definitely.

And what do you think about all your friends seeing that you'd 'liked' it and that kind of thing?

Oh, they'd probably just say "Captain Diabetes, it's official" because that's what quite a few of them call me [...] Yeah. "I'm Captain Diabetes, me hearties!" (Leon, diabetes, 22).

In this instance, Leon's apparently playful response is at odds with most other accounts; he portrayed himself as entirely comfortable with his Facebook 'friends' understanding his diabetes as an integral part of his identity. Where others carefully avoided alluding to their health issue on Facebook, he appeared happy to incorporate his experience of diabetes into his identity on Facebook, perhaps as a means of reinforcing aspects of his identity established offline.

Thus, making active decisions about what characteristics to include or privilege whilst presenting 'a version' of themselves online seems to be an over-riding concern for many of the young adults when engaging with health-related content on social media, regardless of their health issue or level of 'prosumption'. Their production of content on Facebook seemed restricted

by considerations around how they presented their identity to the collection of ‘friends’ they conceived of as their ‘audience’. Online interactions, such as the act of ‘liking’ Facebook content that may relate to their health condition, could also be limited by concerns about how other people’s perceptions of them may be impacted by the appearance of this content on their profile. For a small number of participants, however, Facebook offered an opportunity to integrate diabetes into their identity both online and offline.

5.4 Practices and expectations of users in social media spaces

As well as discussing their considerations of identity and audience with regards to engaging with health-related social media content, participants also shared their views on practices and expectations in social media spaces, the ‘rules of engagement’. Daily social media use was common across all participants, and their everyday preferences and practices related to the three main social media platforms, Facebook, Twitter and YouTube, were explored during the interviews. In particular, they reflected on consumption practices, and how their expectations and daily engagement with social media impacted how they viewed health content in these spaces.

5.4.1 Consumption practices in social media spaces

While concerns about identity construction inhibited the practices of some users on Facebook, others actively used social media features (such as the ‘like’ function) to enable them to consume content around either diabetes or mental health in the same way they consumed social or entertainment content.

Although many participants were wary of ‘liking’ health related pages on Facebook, as described above, a small number discussed the practice as a means of content consumption online. For some ‘liking’ was seen primarily as a means of populating Facebook feeds with relevant content. For instance Mhairi explained her engagement with a diabetes charity on Facebook:

I've got [Diabetes Charity] on my Facebook as a kind of like group thing.

Mm hmm. So, you've 'liked' it?

So, I've 'liked' it. I wouldn't go onto it every time I'm on it. I tend to just read the feeds as they pop up [...]

And, what do you think of the type of content that's on that? What's useful?

Probably just hearing others' kind of comments, and stories, and experiences... just reading about like the condition I suppose. There was something recently that came up on my feed about how... I think it was on GMTV or something - somebody was speaking and they didn't—diabetics commented on it, and didn't feel that they made a kind of difference between type one, and type two and I remember seeing it on this page, like they'd almost put like a little explanation. And then they talked about how they're raising money, and things like that - the good things that they're doing. So, that's good to hear about what's new, and what research is out there, and things like that - and, all the different campaigns (Mhairi, diabetes, 28).

By 'liking' Diabetes UK Mhairi had integrated diabetes content into her Facebook news feed. Rather than actively searching for diabetes-related information online as and when required, she received updates alongside content from 'friends'. These updates ranged from information about diabetes in the media, accounts of other people's experiences of diabetes, recent diabetes research and fundraising campaigns. This plethora of content had become part of what she was exposed to daily when she read over her Facebook feeds, without having to search for content or visit the charity page directly. In this way she was able to "hear about what's new", in a way more akin to consuming news media than health information seeking online.

Max also discussed 'liking' diabetes charity pages, as a way of consuming the subsequent news feed updates. As an experienced and active member of a number of diabetes forums, Max's social media preferences were more

discerning, and he was more critical of diabetes content in his Facebook news feed:

I mean what they're doing is good, they're trying to get people signed up [...] to campaigns, and raising money... I mean if this was—if I was friends, or 'liked' this page I mean how often... I don't think I'd want it popping up on my [news feed] all the time. [...] I mean, what day is it? Wednesday. I mean it's not a lot of posts, but you know on Wednesday there was three, and obviously the more people that comment on it, it's gonna pop up again, and again. So, you might... I get annoyed—like on my phone I wanna see what my friends are doing, not what a company that I'd 'liked' seven years, or something have got to try and sell me, or they're doing a poll on this, you know and I'm flicking through all that [...] Yeah. I mean I'm... I'm looking through and nothing that's really on here I'm finding that interesting. I like reading people's blogs, and talking about things that are you know going on with individuals and discussing similar situations... (Max, diabetes, 29).

Max articulated his decision to avoid 'liking' diabetes charity pages in relation to his daily experience and expectations of Facebook as a site for social engagement. He commented "I wanna see what my friends are doing, not what a company [...] have got to try and sell me". In his differentiation Max conflates the diabetes charity content with commercial activities on Facebook and distinguishes this from what he is interested in, "people" and "things that are going on with individuals", and his preference for "talking" and "discussing". Like Max, many of the participants justified their social media practices according to previous experience and expectations of the social media platforms being discussed. Their preferences for the incorporation of health content on Facebook seemed dependant on the specific characteristics of the pages they considered subscribing to and how the resultant content would be presented and integrated into their everyday social media use. Furthermore, both Max's and Mhairi's comments exemplify the processes of 'reflexive' consumption inherent in engaging with health-related user-generated content. As they negotiated the social media

environment, users seem to make an array of decisions around the consumption of health-related content, considering both identity presentation and information consumption simultaneously.

5.4.2 Expectations of content and interaction in social media spaces

Participants also discussed how their expectations of what content was commonplace on social media sites and how they interacted with other users in these spaces impacted how they viewed the health-related user-generated content they encountered. In particular, content on social media platforms which were not already incorporated into everyday online experience was often dismissed. Commonly Twitter was described as a platform that people needed to be familiar with before they could make sense of health-related content hosted there. For instance, Sylvia commented⁹:

I've got Twitter but I haven't quite [...] got to grips with it at all, I'm terrible on it.

What do you think about that sort of thing?

[Sylvia browses the tweets about depression]

I don't like it as much as the other [Facebook] page. [...] I know Tweeting is just quick little things, but, it doesn't... [make sense] like he [Twitter user] had put something, and nobody's commented or 'liked' it, and it's kind of ignored... there's nothing... like more explanation, or conversation or anything coming after it. I don't know if that makes sense, but...

Yeah. Sometimes maybe it's difficult to follow on Twitter?

Yeah. It just—it sounds quite random [...] I know they're all about the same kinda thing. But, they're quite... yeah, no I'm finding that harder to follow. But, I don't know if that's just 'cause I don't get [understand] Twitter (Sylvia, CMHD, 26).

⁹ At this point in the interview Sylvia was browsing the results of a search I had performed within Twitter for the hashtag depression. Previously she has been browsing a Facebook group page for people with experience of depression which I had shown her.

Sylvia's response to seeing discussion on Twitter, her hesitations and lack of clarity around the progress of the discussion ("there's nothing going... like more explanation, or no conversation") is substantiated by her final comment "I don't get Twitter". Her habitual online practices do not include following other Twitter users closely and this makes content hosted there both less accessible and less relevant.

Similarly, participants' consumption of video content on YouTube seemed to be influenced by their conceptions of common subject matter and presentation of content on the site. Paul, who had experienced low mood in connection with his experience of a gambling addiction, described his expectations of a YouTube video:

I'd watch anything on YouTube to be honest, I watch YouTube quite a lot so, yeah I would watch anything. Generally, it would need to kinda catch my attention.

And would something about gambling...?

I mean something, it doesn't necessarily need to be funny, but there's, it kinda needs to catch my attention [...], yeah, it would need to catch my attention if, and also a lot of videos, if it's not kinda caught my attention in the first 10-15 seconds I'll usually just turn it off.

Yeah, totally. So say something like a video blog, would that be likely to be...?

Yeah, I mean, I've never actually, I know there's quite a lot of people on YouTube that have got like their own video blogs but it's not something that I really, that I'm into really watching, it's not for me (Paul, CMHD, 30).

Despite his initial positive response to YouTube content, Paul explained that video blogs, which lack humour and are not instantly engaging, are "not for" him. His perception of YouTube seemed to be as a platform for entertainment and less for support or information. It seems therefore, that across the main social media platforms, participants' daily engagement with the different platforms impacted how they viewed health-related content in

these spaces. Platforms that were little used or understood, or those that had come to be associated with a particular genre of content or purpose, for example entertainment, were less likely to be seen as an appropriate site to seek health-related content.

Participants also related considerations around content production to their expectations of particular social media sites. Their conceptions of the purpose and remit of social media spaces and related audiences were crucial determinants of how participants interacted with health content on social media sites. Many of the participants conceptualised Facebook as a social space and not a space for ‘serious’ or personal health-related discussion. This was often associated with a reluctance to post health-related content. Alistair, who had experienced depression and anxiety periodically since childhood, described what he perceived to be inappropriate Facebook content:

Putting stuff that’s personal on the internet, to me, is weird, [...] it’s just something that I wouldn’t do [...] like there’s a guy who, he lost his mum [...] to cancer this year and he posts about it quite a lot, like on her birthday, saying “oh miss you lots, rest in peace mum, love you”. Like I just find it weird to put stuff that personal on the internet, [...] I don’t think Facebook’s the place for anything like, for serious discussion, for things as important as that, I mean I know, it’s difficult ‘cause you want people to understand what’s going on in your life, that’s what it’s for. But it’s where you draw the line about what you put on it.

Like a kinda public, private...

Yeah. Aye, yeah. It’s like people who [...] post on each other’s wall saying “oh I love you so much, blah, blah, blah, blah” and all kinds of smoochy stuff. Like that shouldn’t be on there (Alistair, CMHD, 21).

Alistair’s account of what is not appropriate content for Facebook echoes the concerns of a number of participants that health-related content is too serious and personal for Facebook. Other social media channels were seen less as wholly social spaces and more appropriate spaces for serious

discussion. Although less common in participants' accounts of using social media, Twitter, in comparison to Facebook, was sometimes presented as a more appropriate site for health-related debate:

[...] this¹⁰ is the sort of thing that I would get quite interested in, cause it's a lot of real time conversations, it's people sharing experiences.

Yeah. And what's better for you about that, than say something like the Facebook?

Facebook's not really a place you have discussions, people will post something and say "great comment" and that's kind of the gist of it [...] there's not really a discussion [...] Also, to be blunt, some of this has a little bit more anonymity for me because, generally, the people who are following on Twitter are not actually personal friends, it's, either organisations, or people I communicate with in general, so that's also quite interesting. [...] But what I think is good, is that they do, they do actually have these kind of debates on Twitter, I've actually tried to engage [diabetes charity] on Twitter a few times before.

And how's that worked out?

That was, well it was interesting because it clarified something for me, cause I did raise a question there, there was a series of programmes on Radio 4, about diabetes, and they were Tweeting on that fairly regularly, so I did ask the question, cause they were talking about research funding, [...] And they did quite a good job of explaining "we only fund UK based projects", which to some extent, was fair enough, I can understand that, and I also did kind of pointedly ask the question that "yeah but diabetes, my version of diabetes isn't really different from what they have in the States or what they have in France, surely we all just want to get past it, overall", I didn't get a response to that,

¹⁰ Anthony was browsing the results of a search I performed on Twitter for the hashtag gbdoc (Great Britain Diabetic Online Community), which is used by Twitter users who contribute to a weekly discussion about various diabetes-related issues.

but I wasn't really expecting one, because I was starting to be a bit confrontational, I know, it's not really, that's not what the PR person running the account wants [...].

And did you feel that Twitter was a good way of opening up that debate or...?

Yes, because also what they were doing, which is really effective, is they were hashtagging everything so there was like a whole sort of stream of people posting on the same tag, and then you also, if I was putting that tag on, when I'm asked the question, it's actually pretty public because everyone else who's sort of following the trail is also seeing that question. Because I also asked a few questions about diet as well, at the end of that week I had another like 30 or 40 followers (**really?**) because people had sort of engaged and I was having other conversations with other people so that was nice to know that I'm sort of not on my own overall with that (Anthony, diabetes, 28).

In his discussion of Twitter, Anthony identified a range of online practices and platform-specific cultures that made Twitter a more appropriate site for him to engage in debate about diabetes online. He suggested that since he perceived his audience to be different (Twitter 'followers' rather than Facebook 'friends'), he could interact with greater anonymity and engage with new users who 'followed' him as a result of a shared interest in diabetes. He also reflected on his interaction with a diabetes charity, recognising his approach could be construed as "confrontational". He suggested that such interactions, creating debate or challenging prevailing advice, were easier to initiate on Twitter, since "Facebook isn't really a place for discussion". Furthermore, Anthony's description of "hashtagging" as a means of engaging with larger networks of people with a common interest in diabetes shows how unique features of particular platforms seemed to impact users' perceptions of online spaces and their opportunities for communication. As a 'prosumer' of online content, focused on developing a critical understanding of many aspects of diabetes, Anthony seems more likely to contribute to challenging

established medical discourse and orthodoxy in a space like Twitter, where he deemed such discussion more appropriate.

A small number of other participants made similar comments about using Twitter as a more 'interest-focused' social media platform. For example, Mhairi (diabetes, 27) commented "Twitter's useful, it's... getting your voice heard, it's like putting your opinions and things, I suppose, in a safe place where everybody's maybe got the same agenda". Perhaps then, active 'prosumers' of health content on social media sites are limited by their perceptions of established practices within particular online spaces and their contributions are dependent on understanding and negotiating these site-specific conventions.

In summary, both consumption and production of health-related user-generated content seems to be impacted by the participants' expectations of particular online spaces and their daily engagement with different social media platforms. Their conceptions of the purpose and remit of social media spaces, and how other users interact in these spaces seem to be crucial determinants of appropriate content production. Therefore, for many of the young adults, even the most active 'prosumers', the social and environmental aspects of the online context seem to impact engagement with user-generated content.

5.5 Drawing on social media for supporting self-management

Although the range of online practices that participants engaged in seemed limited by various considerations of context, identity and audience, some participants provided examples of specific instances in which social media content had been invaluable in informing their self-management practice. Most often this involved consumption of visual content. YouTube, which was less discussed in terms of constraints related to identity presentation or expectations of conventional practices, was identified by some participants, particularly those with diabetes, as a means of 'crowd-sourcing' useful health information.

Byron, who had little experience of engaging with any kind of diabetes-related social media content, shared his views on video-blogs from insulin pump users:

That's¹¹ quite good.

What's different about that kind of thing, what makes it more appealing [than text content]?

They're actually showing it, rather than in writing, so you're actually understanding what's going on. There's no misinterpretation (Byron, diabetes, 18).

In this extract, Byron seems to suggest that the visual aspect of the content offers more useful information than text alone, "you're actually understanding" and "there's no misrepresentation". Indeed, the importance of "showing it", "hearing it" or "seeing it" was mentioned by many of the participants when discussing the place of online video content in their health-related information-seeking activities. For instance, Mhairi talked about another of the bloggers she followed:

[...] she's gonna do a blog, she's gonna do a video blog as well so, we can actually see what it [an insulin pump] looks like, and stuff.

Cool.

So, it'll be interesting, yeah to see.

And, what sort of insights do you think like the video element of that gives you?

Just like what it looks like. 'Cause I've never seen one. Well, I've seen a pump, but not how it attaches, and how you take it off, and clean it, and just like all the practical stuff. Like, I dunno even like things like going swimming, like how does that work? [...] I don't know, even like if you were going on holiday, and you're on the beach, like all these questions (Mhairi, diabetes, 28).

¹¹ Byron was watching a video on YouTube that I had directed him to posted by a user, demonstrating how he used an insulin pump.

These types of responses provide insight into what the impact of readily available images and video content on social media sites might be for those experiencing particular health issues. In terms of diabetes, the practical treatment options, such as insulin pumps, and the embodied experience of using them, seemed to be best appreciated through video content. Further, some participants discussed accessing video content online for reassurance around more basic self-management practices. For example, Max described checking his injection technique using YouTube:

There was something else the other day, and something came up where I thought, when it comes to the simple things, the basics like how to do your injection, these things move on. I'm probably still using the same technique as when I was first given my pen, but have things moved on? Have things changed in some of the science? 'Cause it was always - [...] pinch your stomach, or pinch your leg, and inject into that, and someone saying, "oh no, well I was told to do it a different way..." And, you're like... "oh, am I doing it wrong? Is... is that why certain things are happening." And you go on the latest videos of, "how to take an insulin injection." Of course you've got people out there who for some reason want to show off how to do an injection, or whatever - an insulin injection. And, you feel more at ease for seeing people who still do it in the same way as you do it, and it was posted a month ago (Max, diabetes, 29).

In his account Max described accessing video content to informally establish current best practice for injecting insulin. The dynamic nature of social media, with the date stamp - "it was posted a month ago", made this possible without contacting health professionals. For some diabetics therefore, self-management practices can be developed and revised through the processes of 'visualising disease', facilitated by accessing explicit, relatable video content on YouTube.

For participants with experience of mental health issues, YouTube was discussed less in terms of accessing practical resources for informing self-management. However, a small number of participants did describe specific instances where they had usefully accessed video content related to mental

health. Eleanor, who was very active online and contributed to a range of online support groups on Facebook, commented:

I was on my phone one night and I was just going through the health bit on the apps and it was a binaural beats [tones normally played through headphones which are thought to have a relaxing effect] app and it was to help me sleep, I was really struggling with insomnia and it was supposed to help you sleep and I put it on and it's just a sort of sequence of beats with relaxing music, it's just a bit weird, a bit weird sounding, it didn't really do much but then I was on YouTube every so often I try to go onto YouTube and try to do sort of relaxation, meditation, cos I've got to pace my day and I've got to make sure I relax and that was one of the ones that came up, it was a binaural beats and I gave it a try, didn't really do anything but you know give it a bash and see. Yeah, it's like the hypnosis and everything like that [...] it tends to be music or relaxation studies that I'm on on YouTube (Eleanor, CMHD, 26).

Like the participants with experience of diabetes, Eleanor described searching YouTube with a specific purpose to find a video that might be useful for supporting her self-management practice. This approach to searching YouTube for useful mental health resources, is in contrast with those who identified YouTube as an inappropriate space for health content, perhaps reflecting Eleanor's more active role online, as a 'prosumer' of health content.

One participant, Alistair, used YouTube for another specific genre of content. When asked if he had ever watched a video blog about depression on YouTube, he responded:

I did, yeah. In fact it was one of the most useful ones, can I look for it?¹² One of the most useful ones I found was a guy just pretending, I think he was depressed, I think he had experience of it but it was an ASMR thing.

¹² Alistair searches YouTube for the video he described as useful.

What's ASMR?

God what is it? Auto-sensory meridian... it's meant to be, it's a thing where you get tingles when, from like relaxing triggers. I don't know if you've ever heard of it. I don't know if the ASMR is a genuine scientific thing. [...] It sounds almost like pseudo-science to me but it's kinda like goosebumps but pleasant, it's the sensation people get. And I used to get it when I was younger, I seem to not get it any more. But I just watched the videos 'cause I find them relaxing and a lot of them are really weird 'cause a lot of them are like make-up tutorials and stuff. Like people brushing your face and stuff but just 'cause the sound of the brush, like if you go and get a haircut or something, you know, it feels really relaxing. It is the attention being on you, it is, that's the ASMR part but then I think this¹³ works because the guy's sincere, the guy's likeable, the attention's on you. I don't [know] how much help it gives you other than letting you know you're not alone [...] but it is, I found it useful, you know, 'cause sometimes it's difficult to talk to your friends (Alistair, CMHD, 21).

Alistair's account provides an insight into the consumption of the kind of niche content that has flourished since the proliferation of social media. Searching for supportive content in an exploratory way led him to engage with a variety of novel content and develop his self-management practices in an idiosyncratic way. Alistair's consumption of ASMR video content as a tool for relaxation and support illustrates the inherent diversity of online experiences and the propensity of some people to pursue specialised content they encounter and find useful.

5.6 Discussion

'Users' have been variously characterised in the literature since the emergence of the internet as a source for information. In particular, previous authors have suggested that offline characteristics, such as users' social position and age, determine how they access and appropriate online

¹³ Alistair plays the video, which features a man talking directly to the camera in soft tones about his experience of depression, to illustrate what he has been describing.

content. Some have suggested that online technologies exacerbated existing social inequalities, creating a 'digital divide' (Norris, 2001), while others have characterised young people as 'digital natives' (Tapscott 1998, Prensky 2001), a generation of internet users accustomed to the online environment and its associated technologies. Dutton and colleagues' (2013) report based on the most recent Oxford Internet Survey suggests five cultural groupings of 'users' based on their perceptions of the internet as a source of "enjoyable escape", "instrumental efficiency", "social facilitation" and "problems" (p. 6). Other authors have considered patterns of internet use for health purposes. Nettleton and colleagues (2004) constructed a typology based on relationships to the internet and reflexive practice, to suggest the range of dynamic ways 'users' deal with health information gathered online. This study builds on these previous characterisations of 'users' to explore engagement with health-related user-generated content in young adult men and women with experience of two health conditions. Rather than focus on *internet use generally* the proposed typology explores engagement with *user-generated content specifically* and seeks to explore this in relation to experiences of offline support.

Increasing levels of "prosumption", the production and consumption of online content through social media channels, has meant the volume of health-related user-generated content has increased exponentially. However, the online activities of the young adults who participated in this study were diverse and ranged from regular 'prosumption' of health-related user-generated content to no engagement. Analysis suggested three main types of users: 'prosumers'; 'tacit consumers' and 'well-supported non-engagers'. These categories of users reflect not only engagement with health-related user-generated content but some of the differences in participants' offline experiences of diabetes and CMHDs, particularly their descriptions of offline sources of support related to illness biography and age at diagnosis. Expectations of differences in online engagement by gender and health issue were not supported by the data. People with both diabetes and mental health problems were represented within each of these 'types', and although there were some nuances in how these health issues impacted online

engagement, there were many similarities between participants around issues of support and online engagement. Furthermore, few gender differences emerged in how participants discussed their engagement with user-generated content. Both male and female participants identified opportunities for supportive resources to be established through social media but cited concerns about privacy as limiting their engagement, with little mention of different needs or expectations according to gender. Perhaps, for some young adults, the offline context of their experience of health and illness has greater impact on their online practices, than differences based on gender or specific health issue.

Just as ‘users’ are characterised in the literature, so too are they constructed by producers of online resources as they create and manage online content (Oudshoorn and Somers, 2006). Therefore, when developing online resources to support users’ experiences of health and illness it seems important to understand the variation in young adults’ engagement with user-generated content and the context of potential users’ engagement. Profiling users according to the levels of *offline* support they encounter may be a useful means of understanding their *online* practices. In particular, those who describe having little offline support may be more likely to become active ‘prosumers’ of content. Indeed, by recognising the profile of this most engaged group, producers of online resources can attempt to facilitate the close peer-support, experience sharing or detailed technical discussion that these users may lack from offline sources. However, this relationship between offline support and online engagement could continue to change over time, with the development of both online technologies and users’ practices, and require continued responsive innovation of online resources.

However, for those attempting to use social media in health interventions, understanding many people’s reservations about engaging online seems crucial. Despite the range of participants’ experiences of ‘prosumption’ of health content on social media sites, the activities of consumption and production of content, through sites like Facebook, Twitter and YouTube were very familiar to the young adults. Throughout their accounts of online engagement they conveyed the complex decision-making processes,

particularly around content production, that are embedded in their everyday online practices and reflected on what this meant for engagement with health-related content on social media sites. One issue which was central to most participants' accounts of engagement with health-related user-generated content was the importance of identity and presumed audience online.

The insights from this study suggest that these concerns with identity construction profoundly impact on how users choose to engage with health content online. The notion of identity has been widely discussed in both psychological and sociological literature. In the social-interactionist tradition identity is conceived as the product of interaction in the social world involving constant negotiation of roles, norms and group boundaries rather than a set of intrinsic or innate characteristics (Mead, 1934, Goffman, 1959). Drawing on the work of a range of authors within this tradition Lawler (2014) proposes a broad concept of identity as consisting of two overlapping dimensions: individuals' assignment to particular social categories such as gender, class and ethnicity, but also the more personal reflexive sense that people have of who they are, both of which are produced through social interaction. A number of authors have discussed the construction of identity in relation to health and illness, particularly as challenged by the experience of ill health. Bury (1982) suggests that the result of illness for individuals is not just physical symptoms but 'biographical disruption' or the re-arrangement of their networks, relationships, plans and daily routines. Charmaz (1983) suggests that this can lead to "loss of self". Identity is diminished because individuals are constrained in expressing their responses to illness for fear of negatively impacting other people's perceptions of them.

These conceptions of identity, particularly in relation to health and illness, are all relevant to the current study in which the young adult participants discussed identity construction and health experience on social media sites. In accordance with previous research (e.g. boyd, 2006; Ellison et al., 2006) Facebook was identified as an important space for construction of personal and group identities. Furthermore, the participants' accounts seem aligned with social-interactionist conceptions of identity, with users of social media

sending signals to establish their identities through interaction with other users. Posting status updates on Facebook, Tweeting or 'liking' content are means of performing identities in Goffman's terms, in a way that mirrors offline social interaction. Robinson's (2007) discussion of identity in relation to shifting internet users' practices also highlighted this resonance. She asserts that postmodern notions of identity online (which suggest the recreation and reinvention of the self through role-playing online) are less relevant to contemporary users' practices:

[...] postmodern accounts of cyberselfing do not prove convincing for today's internet users in light of changing trends in the internet user population and its online activities. [...] Like offline self-ing, cyberself-ing is rooted in interaction as understood by Mead (134); the 'I', the 'me' and the 'generalised other' inform each other as the core of the self-ing project (p. 107).

This study provides further empirical evidence for Robinson's assertion, particularly in the context of discussions of health experience on social media sites. The social interactive nature of Facebook and Twitter make these platforms key sites of identity construction which is closely related to offline identities and not re-invented selves. While for some users this environment provides an opportunity for the production of identities linked to their health experience, as experts or advocates, for many users health experiences go undisclosed on social media profiles in a bid to limit negative implications for identity construction.

While many studies point to the use of social media for the communication of key health messages to young people (Schwartz, 2011), and young men in particular (Robinson and Robertson, 2010), it seems important to understand how this context impacts the interpretation and response of the intended users. Explicit concerns about how the audience of one's social media profile, particularly on Facebook, might view references to health issues, meant even the seemingly innocuous act of 'liking' pages was subject to considerations of identity-management.

While the study raised a number of issues, around identity and established online practices, which could be seen as barriers to young adults' online engagement with health content, some participants' accounts highlighted the colonisation of distinct online spaces for supporting self-management. This is in accordance with findings from studies of online content that suggests social media creates supportive environments for users with experience of both diabetes (Greene et al., 2011, Jones et al., 2013, Ho et al., 2014) and CMHDs (Griffiths et al., 2009). In particular, some of the participants in this study utilised social media for the consumption of user-generated video content. Recent research has pointed to the growing importance of considering the visual elements of online engagement with health content. Ziebland and Wyke (2012) suggested that "the Internet is inherently visual and that the ability to post and access images of people dealing with health issues may be another important, albeit rarely explored, feature of health experiences and the Internet" (p. 237). Similarly, Thompson's (2012) exploration of the use of stock images on mental health websites and the messages they convey to online consumers about the nature of mental health concludes, "as old and new media converge, blurring the lines between information dissemination, consumerism and socio-digital participation, research that investigates the impact of visual communication in online environments remains vital" (p. 417). The importance of user-generated video content, as discussed by some participants in relation to their diabetes, suggests visual, diabetes-related content might be a key resource for improving understandings of diabetes and informing self-management practices. Previous research has suggested that the 'body project' for young adults with diabetes consists of the active construction of multiple bodies, attempting to adhere to social norms related to age and context, whilst also actively managing diabetes (Balfe, 2009). Perhaps then, consumption of video content demonstrating other people's embodied experiences of insulin injections and insulin pumps supports this process.

Furthermore, broader use of video content by those with experience of common mental health issues, illustrates the diversity of use of visual online content, in line with Thompson's assertion (2012) that online visual

communication is a key feature of shifting boundaries around health content consumption, production, and online engagement. Perhaps, the specialised use of YouTube to access specific types of content exemplifies Nettleton's (2003, 2004, 2009) ideas around the diffusion of health knowledge through networks and the assimilation of health knowledge with context-specific experience of health and illness. The findings of the study suggest some young adults who engage with social media content about their health issue seem to be seeking specific niche content. This is in line with previous studies which suggest the internet fosters alternative discourses around health and illness, particularly around stigmatised issues (Gavin et al., 2008), contested illness (Barker, 2008) and unorthodox health practices (Kata, 2010). Consumption of non-evidence based mental health content, existing outside of orthodox medical knowledge, illustrates how some people's experiences are profoundly influenced by the proliferation of video content available online for supporting individuals experiencing mental health issues.

This considered access of user-generated YouTube content by some participants, and the established preferences of others to utilise Twitter and forums for health-related discussion, rather than Facebook, highlights a further tension around the use of social media to support young adults with diabetes and CMHDs. Libreri and Graffigna (2012) have commented that few studies explore the differences in the type and tone of content contributed across different social media platforms. The findings of this study confirm the importance of considering these potential differences, but from the users' perspective. Both consumption and production of user-generated content about diabetes and CMHDs seems to be impacted by expectations of particular online spaces and established conventions within them. Conceptions of the purpose and remit of social media spaces, and how other users interact in them, seem to be crucial determinants of appropriate content production for even the most active 'prosumers'. However, as with much online practice, these conventions are likely to alter over time. For those who propose developing social media as a site for intervention, understanding platform specific conventions and concerns and how they develop with time should be prioritised.

The findings of the study have implications for the development of social media resources to support self-management. The importance of established online practices in shaping young adults' uptake of opportunities to engage with health content online was salient in participants' accounts. Individuals' everyday engagement with social media content, the types of content they preferred and their perceptions of the purpose, potential and cultures of particular online spaces seemed to impact how they consumed online health-related content. Even those who both consumed and produced content were careful to adhere to established conventions around what was considered appropriate content and appropriate interaction on the different social media platforms. In addition, participants were critical of those who flouted these conventions, highlighting the kinds of contributions that were considered 'cringey', 'too personal' or 'weird'. Indeed, as health departments and charities attempt to utilise social media platforms to reach specific audiences, it seems important to consider each platform separately. In particular the genres of content a platform hosts, the cultures and practices which have developed in relation to this content and the platform's individual interactive features are key concerns of users as they consume or produce health-related content. Therefore, those communicating about health issues online should also aim to understand and adhere to these conventions and continually examine their evolution.

Users' perceptions and experiences of engaging with health content on social media remains an underexplored area in research. In this study participants with experience of two different health issues were interviewed to explore the complexities of users' perceptions and experiences of engaging with user-generated content around diabetes and CMHDs. The findings highlight the range of considerations common to many young people as they encounter health content on social media, around identity management and integrating health content into everyday online practice. However, differences across the sample of young adults can be discerned in how user-generated content is being used to support their experiences and active self-management, which seem dependent on the offline sources of support. The specificity of the content available online, and the development of niche areas of content,

mean that the resources users draw on for different health issues relate to their precise needs, and therefore vary by issue. Understanding how this issue-specific content develops and how users understand and appropriate the discourses presented within this content are key areas for further research.

6 The challenges of creating and maintaining online health resources: perspectives of producers and ‘users’

6.1 Overview of chapter

The aim of this chapter is to provide a detailed discussion of the challenges that the producers of online resources face in creating and maintaining online content related to either diabetes or CMHDs. The chapter presents data from six interviews with seven individuals (includes one paired interview) who were professional producers of online content (‘producer participants’) and discusses these in relation to comments about the barriers to accessing and using such resources made during the interviews with the young adult participants. The chapter opens with a summary of the producers’ roles and a description of their associated resources. Next, similarities and differences in their approaches to the design, development and purpose of various resources are highlighted. The producer participants’ varied approaches to resource management and the ways they use social media are then explored and, finally, their constructions of users and user-groups are discussed. The producers’ expectations of those who used their resources are then juxtaposed with the young adult participants’ discussions of the shortcomings of health-related online content. First, their perceptions of the limitations of online content to support people’s experiences of health issues are described. This is followed by a discussion of participants’ reflections on the relevance of online content to their own experience, in particular how their conceptions of self and health experiences influenced their assessments of the utility of online resources. Finally, related to both the limitations and issues of relevance cited, the young adult participants’ perspectives on the future development of online content are presented.

6.2 Key characteristics of the producer participants

The ‘producer participants’ were drawn from a range of organisations and had varied experiences of developing online resources related to diabetes or CMHDs. Table 4 (p. 97) provides a summary of the producer participants’

roles within their organisations and the online content they were associated with.

The types of online content discussed during the interviews varied hugely: from text, image and audio content about how to manage low mood and stress; to tailored diabetes content based on users' own test results. While some organisations employed health professionals to develop online content (MH-2 and MH-3), others employed communications specialists (MH-1 and Diabetes-1) or technical IT specialists (Diabetes-2). The Diabetes-3 site was unique in that it was being co-developed by a youth worker (PP-7) and a group of young people and young adults, who were recruited as the target users. These differences in the types of content featured and the roles of those who produced them reflect the diversity of available online resources intended to help to support people in the management of their health. Indeed, the differences in how online content can be conceived were evident throughout producer participants' accounts of the purpose, design and development of resources.

6.3 Purpose, design and development of resources

During the interviews the inception and development of online content was discussed with the producer participants. For some the purpose and development process was strategic, whereas for others the emergence of resources was more iterative.

All of the producer participants discussed the processes involved in developing online content. In relation to this, they made comments on what they saw as the primary purpose of their resource. Perceptions of the purpose of online resources varied; while some identified their online resources as a distinct entity or output, others saw them as a communication tool. Furthermore, some saw the purpose of their online content as being aligned with broader strategic organisational aims and objectives.

PP-6 described the origin and purpose of the Diabetes-2 resource:

[...] it was probably about five years ago we started thinking about "right, we've got this vast [online] information resource [patients' test

results, clinic letters and treatment plans] but it's only the clinicians that can use it just now and we need to start putting a bit more of a focus on what the patient can actually do." And there was a big push at that point as well with the Government self-management strategy, the diabetes action plans and diabetes frameworks about patient self management [...]. We'd had some discussions in the past with patient groups [...] look[ing] at all the information resources that were available in paper format across the country and they reviewed all of that and then picked out the ones that they believed to be the best [...] At the same time [...] we were working on a separate website looking at building interactive resources for diabetes [...]. With these discussions that were ongoing and my sort of relationship with the patient groups at that time, we decided "right, there's two streams going ahead here, both trying to do generally similar things to support patients, let's merge those together, [...] take the content that had been validated by the patients and the content that we'd been building and validating [...] and pull these together and ultimately what came out of the back of that was [our resource]". [...] Yeah so there's two distinct sides to the website as it stands just now. We've got the public pack content which is all the sort of traditional text based leaflets and that kind of stuff, we've got the videos, we've got the people talking about living with the condition, [and] we've got a secure web form on the website. People can put in their name and address details and then we follow them up with the normal process and ultimately people get access to exactly the same information out of there that the clinicians see.

In PP-6's account the Diabetes-2 resource is framed as a collaborative project, resulting in the production of a resource which has "two distinct sides", a repository of text and video content that has been reviewed and approved by patients, and an innovative portal which allows patients direct access to medical information from routine diabetes tests. The producer described this function as "putting a bit more of a focus on what the patient can actually do", positioning the resource as an innovative means for people

with diabetes to further develop their self-management practices. PP-6 also alluded to the aims of the resource as aligned with broader health policy initiatives which prioritise supporting self-management of chronic health problems. The resource, therefore, was presented as a strategic output in itself, providing both text and video content and an innovative portal to support self-management.

The mental health resources, produced for MH-2 and MH-3, were also positioned as self-contained resources, which had both arisen from specific projects to make predominantly text-based materials more accessible. PP-5 remarked that the online mental health resources developed for MH-3 were a programme of “life skills [...], deliver[ed] effectively as a training, teaching resource [...] trying to engage people who wouldn’t necessarily be seeking help through the conventional health service”. Rather than offering an innovative range of resources, PP-5 positioned the online content as another means of delivering content already available elsewhere: “there’s lots of evidence[...] that you can learn CBT skills through books, through reading, through videos, things like this [...] books, classes, resources, online [...] everything is just variants on this one book”. Similarly, PP-2 discussed the online content that had been developed for MH-2:

I have a kinda unofficial role, which is to be more creative, and come up with different ways of getting mental health advice and help out to the larger community [...] There are several websites that we do, [...] the most significant [...] I think initially we probably just transferred a lot of written material online. So, you know, there were already a lot of booklets written. I’ve written a lot over my career about common mental health problems.

For both of these producers of mental health content, the resources were seen as a means of increasing the availability and accessibility of existing offline resources to support people experiencing common mental health problems. Rather than providing innovative content specifically created for the online environment, the content they developed was based on pre-existing text-based resources.

PP-7, the producer of Diabetes-3's resource, was also tasked with the re-development of a text-based resource for the online environment. However, in this instance the associated diabetes resource was focused on a particular target group:

They brought me on board as they realised that they weren't engaging effectively with young people in Scotland regarding managing their condition. They were also concerned with the number of 'do not attends' amongst young people at their regular clinic check-ups. [...] I [said] I can update a resource for young people if you want, however, I'm not a young person. [...] The way I choose to work, the way I prefer to work would be that we get a core of young people [...], and actually see what [...] the information and support that they need is. [...] So they took apart the existing [resource], that big magazine with all the text-heavy content, they cut that to shreds.

The resultant resource was co-developed by PP-7 and the group of young people recruited by Diabetes-3. This resource, with content developed specifically for young people by their peers, aimed to address the organisation's objective to "engage effectively with young people".

While for some producer participants online content was developed as the output of a particular project to widen access to information, for others content was described more as a communication tool. In these cases, although the websites (Diabetes-1 and MH-1) provided some static text and image content they also functioned as the primary point of contact and reference for the associated organisations. For instance, PP-3 and PP-4 (Diabetes-1) described the evolution of their approach:

PP-4: [We] used to rely on sending out printed packs of material if people gave [us] a phone call. And then at what point did the website actually come online?

PP-3: It was online before I got on board, and that was in 2005. But, back then it was very basic with, I think, just one page, and it's sort of evolved since then really as we've expanded slightly beyond our

[original remit] around to education, support, the online community, that sort of thing. So, it's expanded, in a way.

Rather than only discussing the static content of the site PP-3 and PP-4, described their site in terms of how their organisation and roles in supporting people with diabetes had developed. PP-1 also discussed how MH-1 functions through their website in terms of its strategic aims and related communications objectives:

Communications is really a lot of what we do and it's our primary goal. So our first goal is to raise awareness and increase understanding [...] - so we also have a five-year communications strategy- that's where that sits. However, communications is also mainstreamed throughout all the other work that we do. [...] What we do is we have an online presence via our website [...]

For both Diabetes-1 and MH-1, developing online content was less about providing a specific resource and more about maintaining some static content alongside evolving dynamic content which is developed in line with the organisation's broader strategy and remit to raise awareness and communicate regularly with audiences. Therefore, it seemed that while some producer participants were focused on the development of one specific resource, others viewed online content as a means of communication and produced dynamic content as an ongoing task.

6.4 Approaches to online resource management

Following discussion of the inception of online resources, the producer participants provided insights into the ways that content was generated and managed over time. In discussing these issues, differences between those who maintained static websites and those who maintained dynamic websites were highlighted. This distinction relates in particular to conceptions of purpose, with some producer participants conceiving of the online content they developed as a *static resource*, providing a range of textual, image or video content, and others understanding online content as a *dynamic channel of communication*.

6.4.1 Updating content

The differences in approach to resource management across these two types of resources (static and dynamic) were particularly evident in discussions about reviewing and updating content. For some producer participants, particularly those associated with more static resources, issues of resource availability constrained how much new content could be added or existing content updated. For instance, PP-2, the producer of MH-2's resource, commented:

You know I'm kind of conscious of some mental health sites, which you kinda go in it once, and you can't see any great reason for going back onto again. I think there's kind of always something to be found there [...] We don't [review and update content] as much as we should have, and again I think that's one of the—that's probably one of the problems about working in... is that we're really short staffed just now. So, that kinda stuff goes by the wayside, and you know, because the focus then becomes on... make sure that people get phoned back quickly enough, and you know put into therapy quickly enough. What we will have from time to time, is we'll get volunteers, usually psychology graduates looking for some you know further experience to get you know onto the ladder you know, get to you know, to get to an assistant post. And, they'll come, and they'll kinda clean up the websites for us. So they'll—they will actually go through page, after page, see what's out of date, update it for us, and so on. But, do you know I haven't did any substantial work on that website for about... two years now.

Although PP-2 suggested that it was important that the website could be accessed and used several times by individual users, the approach to updating the resource seems to have been somewhat haphazard, constrained by the context of the resources available. PP-2 also implied that while there was some degree of reviewing and “cleaning up” existing content, there was no strategy for developing entirely new content. PP-2 related this to a lack of available resources, however, this approach seems in accordance with the conception of the website as a standalone static online resource.

PP-6's account of updating the Diabetes-2 online content was also consistent with the relatively static nature of the organisation's resource. However, in this case internal resources for reviewing and updating content seemed more readily available:

We do, we've got a diabetes specialist nurse who works with us a day a week, but that's enough to just allow it to sort of tick over, identify new content. We do sort of 18-monthly content reviews. If there's new legislation comes out for example with diabetes and driving, we'll focus on that and make changes and at that point as well. So we do have that resource in place to allow us to make changes pretty quickly. [...] I think a lot of the original content, because it had been identified by patients, they had solely focused on the traditional text based stuff, so that was what we were given as the first raft of information. We have tried to develop more of the video type content ourselves [...] and we've got about five videos on there now, which one of them gives you a 3D graphical tour through the diabetic eye so it describes the various different stages [...] It's all these sorts of things that are on there as videos that we've developed in house, but as I said, there's also other good stuff out there that we've linked into externally. I suppose we would like to have more focus on getting rid of some of the traditional text based stuff and replace it if possible with more video content because it's possibly easier to digest as well.

Again, this response reflects the perspective of a producer participant who conceives of the content produced as a relatively static resource. The time scale for reviewing content seems relatively lengthy - 18 months - and new content seems only to be developed when content becomes outdated, for example "if there's new legislation". However, PP-6 also discussed Diabetes-2's intentions to continue to innovate around how content is presented, replacing text with three-dimensional video content. Similarly PP-5, the producer of MH-3's online content, which was also conceived as a static resource, acknowledged that the content of their website required regular review, but retained largely the same content even after updates had been performed.

For the producer participants who maintained more dynamic resources, such as MH-1, updating was a more integral part of the management of the online resource. PP-1 commented:

We have a weekly production schedule, for want of a better terminology, whereby we ask members of the team... anybody can propose a news story and they put the information into a spreadsheet and then I basically decide whether it's good to go or not and either myself or the Communications Officer, who I manage, then writes up a short news piece based on it and we publish that on a weekly basis. We have what we call 'News Nibs' on there, [...] they're supposed to be short, snappy things [...] and we tend to use them predominantly to inform people about other people's events that are going on, maybe a new piece of research , [...] basically shorter, non-opinion piece type things, basically just imparting information. On a monthly basis we produce an eBulletin [...] and we tend to produce three feature articles in that. [...] One of the main sections on our website that's visited a lot by people are the 'Stories', so one of the other activities we do is 'Story Sharing' so we gather and share people's stories of lived experience.

Unlike the producer participants, involved in maintaining more static resources, regular content development was discussed by PP-1, the producer of MH-1's online content, as related to the key objectives of the organisation. PP-1 described online communication as a key activity of the organisation required to meet the objectives of awareness raising and developing understanding about mental health issues.

Similarly PP-3 and PP-4, the producers of Diabetes-1's dynamic resource, also described daily maintenance and updating of content to ensure the organisation reached as many users as possible in their communications. Since Diabetes-3's resource was early in its development, PP-7 was unable to reflect on experiences of reviewing and updating content.

In summary, the producer participants' approaches to managing online content seemed to be dependent on whether their online resource was

viewed as largely static or dynamic by them and by the organisation they were affiliated with. The extent to which content was updated seemed particularly dependent on broader organisational issues, such as availability of staff resources.

6.4.2 Social media

Producer participants' perspectives on the value and utility of social media were also discussed. Generally these also seemed to relate to their view of resources as either static or dynamic. None of the producer participants described social media channels as their primary means of generating online content. However, some did maintain active accounts. PP-1 described MH-1's use of social media:

I think what happened was, in terms of Twitter, that the Director kind of started using it and started finding it, you know, quite good and quite useful and we'd always thought that it seemed like it would potentially be quite good for us to do it, and it is proving that it is so far. We don't want to get involved with Facebook because the moderation involved in that, we just don't have the capacity. Twitter is good because, you know, you can dip in and out and there's tools like HootSuite where you can schedule up Tweets and things like that. But you can also dip in and out and you can decide whether you're going to Follow up with people and respond to comments and things like this. Facebook just seems like a nightmare, frankly. We've looked at a few of our sort of sister organisations, and the experiences that they've had with it. And we just think it's not for us. For example, one of our sister organisations they do seem to have to spend... not a lot of time necessarily, but blocking people who are posting inappropriate comments, people getting involved in sort of discussions within it that then the moderation just seems to become a real hassle. But also I just think it's quite an inane tool [...] you can post comments on our news stories [on the website] and have exchanges with people that way if you want. [...] And I just don't think Facebook's the future. [...] And I think that there's more growth potential in Twitter, to be honest with

you [...] and, you know, not one person has ever said to us “why aren't you on Facebook?” Not one person has ever asked us that.

Despite MH-1's resource being one of the most dynamic and PP-1 stressing it was informed by their communications strategy, concerns about dealing with high levels of user engagement seemed to have informed the organisation's social media practice. Rather than regularly entering into dialogue with users, PP-1 described preferring to “dip in and out” of interaction and “decide when” interaction was most useful for meeting the organisations' communication objectives. Therefore although MH-1 maintained a social media presence, engaging with users daily was not prioritised.

In contrast, PP-3 and PP-4 (Diabetes-1) discussed how they had integrated social media into the core of their organisation's online activities, specifically so they could regularly engage with users. Unlike MH-1, Diabetes-1's online presence extended to delivering support to individual users:

I think one of the things that we do which some of the other organisations that might have a social media presence around diabetes don't do quite as much of, is the coaching... I mean I can only think of the word coaching for it, which is to say, “Ok we may be people that have never sat down in real life. We may have met on the internet. [...] But, tell me about the conversations you have with your [diabetes health professionals]. What happens when you ask this question?” “Oh, I've never done that.” “Well, ok, what do you think might happen if you did?” “Oh, I don't know, I mean, uh...” I'm like, “Ok, let me just give you a for instance... if I were your healthcare provider and you sat through a 15 minute appointment with me, nodding, I would—might think that you understood everything I said. And, I was actually possibly even boring you, and you might not really have any questions for me. Do you think that's a possibility in the clinic that you attend?” “Well, I don't want them to think I'm daft.” “Well, I don't think they would think you were daft. They might think you were very interested, and they might decide to give you a recommendation of a book to

read, or... they might suggest a resource that they could provide to you in person.”

Throughout the interview PP-3 and PP-4 provided a range of examples of the ways they actively pursued interaction with individual users, on both Facebook and Twitter, to deliver support and advice as representatives of Diabetes-1. The different objectives of MH-1 and Diabetes-1, therefore, seemed to have a considerable impact on how social media were used. While both maintained dynamic websites with additional social media platforms, for MH-1 social media seemed to offer an innovative way of delivering key messages, whereas for Diabetes-1 social media seemed to offer a key opportunity to interact directly with individual users.

Some of the producer participants reported less frequent, and often less considered, use of social media. Generally, these were the producer participants associated with more static resources. PP-5 (MH-3) and PP-6 (Diabetes-2) had established Facebook pages for their respective organisations but were not consistently contributing to them. PP-5 cited concerns around managing users’ comments on social media sites:

As an individual I actually don’t do social media very much at all. For the social media things that are linked in with the sites, that’s really more because it’s a logical thing to do because other people are doing it [...] Because one of the things with these things, you see it in big companies all the time, is things can go unexpectedly wrong with social media because people have absolutely the control to say what they want. And, they can say the positive things they like, or they can say the stuff they don’t like, and that can be fair, or unfair. But, I think it’s still another way of engaging and pointing to the range of things that we [MH-3 as an organisation] are involved with.

During the interview PP-5 referred to the ubiquity of social media, “other people are doing it”. Indeed, all of the producer participants identified social media as an obvious means of promoting their primary websites. However, also recurrent throughout interviews were the practical concerns about managing these channels, particularly in terms of moderating users’

comments. Most of the producer participants suggested that the level of interaction with users that social media allows can be problematic and that the resources required to manage this interaction are demanding. For PP-2 (MH-2) these concerns, coupled with a lack of resources, prohibited even the establishment of social media channels, despite frequent suggestions within the organisation that Facebook could be a useful tool for promoting the main website. For producer participants, whose organisations produced more static online resources (MH-3, MH-2 and Diabetes-2), social media was used less frequently. Although PP-5 (MH-3) and PP-6 (Diabetes-2) both suggested that it seemed appropriate to maintain social media accounts, the maintenance of Facebook pages and Twitter accounts related to their online resources was minimal. For PP-5 (MH-3) and PP-6 (Diabetes-2) in particular, discussion of social media was limited during the interview. Such resources seemed much less embedded in their organisation's online activity than the social media accounts of those organisations who developed more dynamic resources (MH-1 and Diabetes-1).

Thus, although producer participants seemed to view use of social media as a necessary or expected means of promoting their organisation's resources, adoption and management of social media channels varied considerably. While producer participants within organisations which maintained more dynamic online resources seemed to develop ways of embedding management of social media into their daily activities and objectives, producer participants associated with more static resources employed a piecemeal approach to social media use and seemed to retain significant concerns about the management of interactions with users. Furthermore, social media were not always viewed as an innovative means of connecting with wider audiences. Only Diabetes-1 seemed to use social media to regularly interact directly with new users and seek out opportunities to contribute content to debates and discussions across various social media channels. The other organisations seemed to use social media more as a marketing device, or as a further platform for one-way communication of information, without engagement or interaction with users. As well as the availability of resources, perhaps organisations' use of social media is in part dependent on

the individuals currently employed, and their personal preferences and practices with regards to the different social media platforms.

6.4.3 Evaluating online activity

Linked to the producer participants' approaches to updating content and their social media use, were the strategies they employed for evaluating users' engagement with their organisation's online resource(s). Generally, most of the producer participants mentioned the importance of evaluating and monitoring the use of their online resources, although few had conducted any systematic analysis. PP-1 (MH-1), who was perhaps the most active in this area, commented:

We use Google Analytics and we look at that every month, [...] I produce a report against indicators and my outcomes, my communications outcomes. So I report on things like numbers of visitors, during the previous month, average number of pages visited, where the visitors are from, predominantly they're from the UK, [...] What page did they look at? So we do that and look at number of new versus repeat visitors, average number of pages visited, average stay, time, and that's about it. But like I said, you know, we don't then compare that... I don't think I've ever compared that to the previous month. But, I mean, what we do know is we do know that the day that our eBulletin goes out, there is a massive spike in the number of people that visit the site. Because that is the day that they'll click on a link and all our links are, you know, we shorten our links with Bitly [URL shortening service] and then they, you know, click through to the website. And, you know, so we do as well look at the number of u[nique]... in our email marketing software we can tell, you know, the number of people who opened, the number of unique opens, the number of forwards to a friend, you know, all that kind of stuff. So we also look at that as well. [...] But yeah, but really kind of like digging down into some of this, you know, we just as yet really just not done it. But that was one of the things that we'd always intended to do as part of our strategy because part of our strategy is about constantly looking to improve and refine our communications, and in order to do

that we have to know better what's working and why it's working and stuff.

Despite describing the range of data available for analysis and collation of some data on a monthly basis, PP-1 acknowledged the organisation's limited exploitation of data sources for analysis. Across the interviews the producer participants seemed to suggest that even though data were available, particularly through Google Analytics, they had yet to get to grips with any in-depth analysis. Furthermore, some producer participants seemed unsure about how to then use the results of monitoring and evaluation, PP4 (Diabetes-1) commented:

We haven't used any metrics yet. [...] "oh we've been mentioned on Twitter five hundred times." Ok, is that useful without the context? Was it positive? Was it helpful? Was it thank you? Do we wanna get into the semantic analysis of that? So, I'm kinda like until we have more ways of enquiring, and mining the data I don't really wanna look under the hood too much.

Some other producer participants were less interested in monitoring use and evaluation and relied more on informal feedback. When asked about tracking what pages on their primary website were most popular, PP-2 (MH-2) commented:

I think we can get at that information. I would have to say that's not something I've been all that bothered about. [...] You'll get that [feedback], again it's very anecdotally, so you might see someone you know [...] who will simply say to you, "God I saw that video, it was brilliant, that really was helpful." You will get people emailing because there is a facility to email, so, it's not monitored as often as it probably should be, but people will email often saying nice things. They will often be quite helpful in pointing out there is a mistake on this page so we can rectify it. So, we are getting some kinda feedback from users.

PP-2's response further reflects the range of ways online content is created and maintained, relying mainly on informal feedback.

It seems, therefore, that across the organisations there seemed to be varied approaches to monitoring and evaluating content, with only some gathering data from sources such as Google Analytics, and others relying solely on informal feedback. Furthermore, only PP-6 (Diabetes-2) mentioned a more proactive approach to gathering feedback by describing a facility they had developed for users to rate each page of the Diabetes-2 website in terms of how useful they found it. This type of evaluation is perhaps more in accordance with social media practices which involve users in rating content and was the only example given in the interviews of ongoing and active collation of user feedback.

6.5 Producers' constructions of intended users

6.5.1 Intended users of resources

Across the interviews the producer participants described the intended user groups of their online resources. There were some differences in how they conceived their end users and who their online content was thought to be relevant and useful to. Some of the producer participants identified particular groups they sought to reach. For instance PP-2 (MH-2) commented:

It seemed fairly clear to us that the one group of people we were not all that great at getting at were the under-25s. So, we thought, 'well, they kinda live online, so we have to go to where they are'. So, we'd setup the website. [...] I have a feeling under 25s don't partic—well, you know this is a huge generalisation. But, I think a great many of them actually don't want to see a therapist. I think they want to go about things in a different way, and I think that's more likely to be online, than any other way. So, again we should give people what they want. [...] So, again, a major issue for us, you know because this is largely a deprived area, is stigma about mental health is huge. So, you know the idea about... Well, the idea about going to your GP, and saying, "I think I have a mental health problem", is a very big step for a lot of people to take. And, then, the system I think almost kinda reinforces the stigma, so the GP says, "ok, I'll refer you to 'a mental

health team'. And, 'the mental health team' sends you an appointment," and it's kinda, you're... In one you're putting barriers in the way of people who don't have much motivation, and you're asking them, they've got, right, you've got—"before you see me you've gotta jump over various hurdles," and if you don't have much motivation you're just gonna give up. Whereas if you're sitting at home in front of your computer, which you sit in front of all the time, or your smartphone which you use all the time, the stigma's not there. And, I think when, you know, when you look at something online, and if there's video clips of other people who are saying things that are very akin to the way that you feel, the stigma's probably going to be reduced. You think, "well, that's guy's just the same me, and he looks quite normal..." whereas you kinda come to see a therapist, and it's just you and the therapist, you kinda never get the impression that there's other people out there, who have the same problem.

This account suggests MH-2's website was viewed as a means of reaching young people with mental health issues. PP-2 suggested that online mental health resources were more appropriate for this group because of their online practices - "they kinda live online". In particular, PP-2 commented on the potential of online resources for overcoming barriers related to stigma for people seeking information about mental health issues, and suggested this was particularly useful in deprived communities. Similarly, PP-5 (MH-3), who produced online content for people experiencing depression and anxiety suggested: "[...] I'm particularly interested in the idea of trying to work to engage people who wouldn't necessary be seeking help through the conventional health service. [...] it does include young adults certainly". Both producer participants reflected that the online environment can particularly appeal to young adults and be used to "engage" people who have had less contact with the health service. For PP-2 and PP-5 making resources available online seemed to be about increasing access for groups who might be more comfortable using online technologies rather than traditional face-to-face approaches or published materials. PP-7, the producer of Diabetes-3's online resource, was also responsible for engaging young people. Indeed,

Diabetes-3's content seemed more explicitly targeted at young people as a consequence of user group involvement in the design and development of the website from an early stage. Although not exclusively, young people and young adults seem to be a key concern in the producer participants' accounts of intended users of online resources for both diabetes and CMHDs.

Other producer participants referred to a much broader range of users. PP-1 (MH-1) commented:

The broad audience groups are stakeholder groups, for the website and for the Twitter. I mean, they're very broad - they are people with lived experience of mental ill health and/or recovery; carers; service providers; policy-makers - so that's Government, national and local-; service providers, I hasten to add, are public, private, and third-sector; the user movement and other NGO-sector; academicians and students and researchers. So, you know, that's really, you know, everybody. We're trying to talk to everybody and, certainly, we're trying to talk to everybody in terms of our overall goal of raising awareness and increasing understanding. [...] So we're trying to, you know, be careful because we're trying to appeal to everybody but at the same time we're trying not to be kind of, you know, as a consequence so bland that we don't appeal to anyone. And in our news story, we know to use certain key words and things like this - so 'carers', 'training', you know 'parenting', you know what I mean... There's certain key words that we might use within the headline or the opening paragraph in order to try and pull people in as well. [...] And the other thing is that, the other thing that's important to remember with our work is that you might have one person who's got five different hats. So you might have somebody who's got lived experience, and they're a carer, and they work for the NHS and provide professional services, and they may also be a part-time student. You know, so that's the other thing.

This extract reflects the range of very broad groups that MH-1's online content targeted - "we're trying to talk to everybody". However, PP-1 did

comment that this could lead to the site being too general, even “bland” and discussed the approach they employed to managing this, which involved tagging content with key words. PP-6, the producer of Diabetes-2’s content, also discussed attempting to ensure the content they produced had broad appeal: “We try not to have particular target groups. We just say anybody over the age of 16 will find this of use”. However, PP-6 also mentioned that some level of tailoring might be useful for the youngest user group. PP-3 and PP-4 (Diabetes-1) also discussed the wide-range of people with diabetes who accessed their site:

It’s a challenge to kind of manage all these different varieties of people sometimes. And, I suppose when I get to doing the user profiles for the website I’ve got some composites. I’ve got some buckets that I can sort of think of, ‘yeah. Yeah. I’ve got, you know the parent who just wants the best for their child, and the child’s recently diagnosed’ [...] And, you know finding out whether they feel supported by their team, or whether they’re taking advantage of local resources, or online groups can be the bigger priority. And then, you get down to the uni students, who you know suddenly mum’s not picking up the prescriptions anymore, and they are just like not sure what to do [...], healthcare providers who come to us asking—actually that’s another audience. We very rarely, but occasionally we get enquiries from healthcare providers [...]. And, we’re always very happy to hear from those people, and to put them onto the right information. There’s also been a little bit of an uptake in enquiries from people who’ve had Type 1 for a very long time, they maybe even read it in a newspaper story that was online, or maybe one of their grandchildren sent them a link.

In this extract, PP-3 suggests the range of users the Diabetes-1 resource attracts. However, perhaps as a result of their regular social media and email interactions with these users, PP-3 and PP-4 seemed to have constructed an informal typology as a way of characterising some of their user groups. These included ‘concerned parents’, ‘students’, ‘healthcare providers’ and ‘older people’. Thus, all of the producer participants seemed

concerned with reaching young people and young adults through online resources, even if their resources were targeted more broadly. However, beyond this general concern to reach young people, the producer participants did not articulate detailed understandings of the range and diversity of users' online practices and interaction. The producer participants' conceptions of users did not seem to be based on detailed profiling. Instead, most seemed to prioritise broad appeal over specific targeting. However, since generating interest from young adults remains a general concern, perhaps developing a greater understanding of this diverse group and their online practices should be prioritised.

6.6 The 'trouble' with online resources: young adults' perceptions of the limitations of health-related content

In this section, the young adults' perceptions of professionally produced online resources for diabetes and CMHDs, like those developed by the producer participants included in this study, are discussed and commonalities and differences across the 'producer' and 'user' perspectives are highlighted. As described in Chapter 3, during the interviews with the young adults, participants reviewed a range of resources based on both my suggestions and theirs. However, only in a very few instances did they explore the specific websites developed by the producer participants. Although this limits the direct comparisons that can be made about specific resources, the wide-ranging comments provide key insights around both producers' considerations and users' reservations.

As discussed in Chapters 4 and 5, use of health-related online resources was commonplace amongst participants. All of the young adults had accessed professionally produced content online, many also regularly consumed practical and topical user-generated content, and a number engaged in 'prosumption' of health-related content (see Chapter 5). However, despite participants' reported use of online resources, they noted a number of limitations to the utility of professionally produced online resources for supporting the day-to-day management of their diabetes or CMHDs. In particular, their critiques of resources focused on the basic nature of the

information, the overly-involved engagement required for interactive resources and the tendency for resources to seem patronising or overly-simplistic.

6.6.1 Too basic?

During the interviews participants often commented that some online resources offered relatively basic information that was of little day-to-day help. In particular, they suggested that informative content, such as symptom lists and basic descriptions of self-management practices, were almost useless for people who already had some degree of experience. Participants mentioned this in relation to both health issues:

[...] it's just the same thing you read every single time¹⁴. Like oh symptoms and all that, like, I don't care about the symptoms, I want, like, motivational, [...] stuff that'll make me feel instantly happy. Like, I know that's impossible in some ways, but d'you know what I mean, that's what you want if you're desperately unhappy. If that's what you're typing in, 'what can I do to make myself feel better,' that's what you want, you don't want, 'oh, you're tired,' and all this. You don't want that (Mia, CMHD, 20).

Em... I like the layout¹⁵. I like what's on here. My issue with it is the more, you know, I'm looking at bits and pieces it... it's been done. And, it seems to have been done a few times. It doesn't... I can't spot anything... I can't spot anything new on there that I haven't already seen on the main sites, like [names a popular diabetes website](Max, diabetes, 29).

In their accounts, Mia and Max both suggest that the websites which they were asked to review, which featured general information about depression (in Mia's case) and diabetes (in Max's case), were not appealing to them. For many of the young adults, who already had several years of experience of

¹⁴ At this point in the interview Mia was browsing a professionally produced website focused on depression and low mood, which I had identified and pre-loaded onto the tablet computer.

¹⁵ Max was browsing a professionally produced online resource for young people with Type 1 diabetes, which I had identified previously and pre-loaded onto the tablet computer.

their health condition, reading “the same thing” or something that has “been done” was not useful. Instead, they sought up-to-date, interesting and relevant content that was more appropriate for their stage of illness, level of understanding and current needs. Indeed, Mia’s suggestion that she seeks practical, supportive content rather than tired, familiar information conveys the importance of the relevance and timeliness of content.

Some participants, especially those with diabetes, further reflected on how basic information can appear particularly unappealing to people with several years experience of self-management.

[...] because I feel like I know all this stuff¹⁶. So maybe it’s not even [for a] younger audience, maybe it’s just people that have just been diagnosed but I feel like I’m as experienced as she [young adult featured on the website] is, like well not quite, she says she’s [had diabetes for] 16 years, but I feel like when I’m looking for information it’s for *something*- I don’t need general information, I have all the general information I need. When I’m looking for information it’s something weird like I’m taking another medication and I’m looking to see if there’s a reaction, or something’s happened to me [...] something like that (Jill, diabetes, 24).

Jill’s comment that general information is no longer necessary for an experienced diabetic like her, illustrates how some individuals with chronic health issues take on an “expert” identity to some degree and therefore are unlikely to access online content featuring basic introductory information about their health issue. However, Jill did point out that specific information is useful when “something weird” arises in her daily life and she needs information relevant to an unusual or atypical issue.

Perhaps then, the perceptions of young adults who access online resources to support self-management of their condition are bound up in their identities and experience of that condition. For many it seems that as they gain experience and knowledge, their preferences for online resources become

¹⁶ Jill was watching a professionally produced video blog, on a prominent diabetes charity website, featuring a young woman discussing her experience of Type 1 diabetes.

more specialised and discerning. Indeed, online resources which feature the ‘same old’ information are perhaps at risk of being dismissed or overlooked by most young adults who have some experience of day-to-day self-management. For professional producers of resources, perhaps clear signposting of content that highlights which users the information might be most useful for is key to ensuring users do not dismiss content as ‘too basic’ before having accessed it in detail.

6.6.2 Too involved?

As well as expressing a general preference for less basic online resources, some young adults discussed the limitations of interactive resources, such as online diaries for monitoring things like mood or blood glucose levels. Whilst browsing an online diary for collating information to support diabetes management, Ronan commented:

When I [...] was first diagnosed [I] wrote a food diary and my blood sugars¹⁷, what time I took them, what they were etc. But it just becomes a bit of an inconvenience and [...] it would be one of these things that you should do and it’d be good to do but you just lose interest in doing it (Ronan, diabetes, 28).

Similarly, Fraser, who had experience of depression and low mood, discussed an online stress diary application:

I’ve heard about stuff like this before¹⁸. I’ve never used it myself. Would I use it? Maybe. But you’ve then got the thing of actually getting round to filling it out. I mean, it is useful to, you know, put it in perspective to, you know, show that, you know, maybe you’re not feeling as bad as, all the time as you thought you were, you know, there are periods where you are actually feeling OK. It can be useful, I suppose, but I’ve never got round to it (Fraser, CMHD, 28).

¹⁷ Towards the end of the interview Ronan and I Googled a number of interactive online resources designed to track diet, blood glucose levels and insulin dose over time. He looked at one ‘diary’ in particular which consisted of a basic table with columns to add diet information and blood glucose levels.

¹⁸ At this point in the interview Fraser was browsing an online stress diary which consisted of a basic table to record time and date, stressful event, 1-10 rating with additional comments for analysis of ‘what I did’ and ‘what could I do next time?’.

These types of comments were made by participants with experience of both of the health issues considered in this research. Online resources which required a degree of input from users were acknowledged as being potentially useful and valuable, but participants often expressed some apathy around actively using tools which required this kind of ongoing input.

Furthermore, some participants with experience of CMHDs elaborated that these types of interactive resources, which required ongoing commitment, were particularly difficult to integrate into the experience of mental health issues. For instance Fran commented:

[...] “write down when you next feel stressed.” It's like, I don't know, if you're in your kitchen and you've set fire to your hair at the cooker and the dog's barking, it's all gone a bit tits-up. Would you think pause: “I must write this down for my mood diary.” Do you? No (Fran, CMHD, 25).

Related to this, Mia discussed her attempt to complete a popular online self-help programme based on the principles of Cognitive Behavioural Therapy (CBT).

I definitely think the problem with [the particular online program] is that it was so structured and it was, like, for ages and it went on and on and on, and [...] it was a burden, it was like something that you have to fill in, and it was too long, like, you don't want to take on that much responsibility for something [...]... you want to be able to go back to something and not know that it's gonna go on forever, d'you know what I mean? (Mia, CMHD, 20)

These extracts illustrate some of the ways that online resources, particularly online tools which require some degree of regular input from the user, can be seen as difficult to embed into day-to-day experience of CMHDs. In particular, their accounts suggest that the need to enter information during difficult periods of stress or low mood limits how useful such interactive resources might be for people who are already under stress or lacking motivation.

6.6.3 Too patronising?

When talking about the limitations of online resources, some participants also suggested that resources could be patronising, conveying an overly-simplistic account of the health issues that they themselves were experiencing. This was raised primarily by those participants with experience of common mental health issues; participants with diabetes did not discuss patronising language or concerns about the presentation of their health issue. Perhaps, this is related to the complexity of CMHDs and the difficulties of conveying useful information when personal experiences can be so diverse. For instance, while browsing an online resource for depression and anxiety, Fran commented:

[...] it's a bit reductive¹⁹. It's like, if you're kind of having a crisis, breaking problems down into manageable chunks sounds like, you know... like, I don't know... like, that's what you would say to a child or whatever. It's a wee bit patronising I think. And then it's like "if you print off handout two, you will be fixed." It's like, if it was that easy... do you know? [...] Between the drawings and the self-help thing... and just this kind of ticky-box thing as well, I don't like. Just, again, to me, this looks like something for kids. [...] Like, I can imagine this being done as part of PSE [Personal and Social Education] in a high school. And I don't know that this, like, diagnostic thing of "Do I have social anxiety?" is helpful. Like, people kind of know that for themselves - they don't need to tick boxes. And it's like a *Cosmo* [*Cosmopolitan* magazine] quiz, you know (Fran, CMHD, 25).

Similarly Tara said:

I prefer when it's written as if you know what you're talking about, not as if you're a child and you need to be told. I don't like the kind of condescending tone that comes off in some of them. It has to be, like, "you're an adult and you're going through this but these could maybe help." Not like "you feel depressed and this is why and this is what you

¹⁹ Here, Fran highlighted an online resource she had been recommended by both her GP and her mum. She searched for the resource and then showed me the homepage which featured text about the aim of the resource.

should do.” I don't like that. I like being [...] talked to like I'm an adult (Tara, CMHD, 21).

During the interviews a number of the participants with experience of CMHDs articulated their concerns about the tone and style of some online mental health resources. Descriptions of resources as sometimes “reductive”, “patronising” and “condescending” highlight a further challenge for those who wish to provide information and support through online resources. Both Fran and Tara expressed dislike for resources which they perceived to be addressing users as children and, particularly, resources which appeared to over-simplify the experience of mental health issues. Indeed, online content provided by mental health charities and organisations provoked particularly negative responses from young adults with experience of CMHDs if they appeared, in their tone and language, to underestimate users’ experience or their level of comprehension.

The content of online resources, therefore, did not seem to be universally appreciated by the young adults, and many expressed some qualification. The basic level of information conveyed in some resources, the demanding nature of some interactive resources and the patronising tone perceived in some content (particularly in relation to mental health) were issues identified as limitations of online resources for supporting the experience and management of health conditions.

6.7 Complexities of engagement: relevance of online resources to experiences of health issues

Alongside the range of limitations of online resources raised in participants’ accounts, participants’ reflections on their identity and on the nature of their past health experiences also seemed to impact perceptions and use of online resources. Indeed, throughout the interviews the relevance of content to participants’ own experience and needs was both evidenced and questioned.

6.7.1 Conceptions of diabetes and CMHDs as individualistic issues

During the interviews, participants also discussed their concerns around the relevance of online resources to their specific health issue. Many of the

participants, with either experience of CMHDs or diabetes, described individualised experiences of their condition and they often related this to the perceived usefulness of various online resources. In relation to diabetes, participants generally suggested that diabetes was ‘different’ for everyone. For some this could mean that drawing on other people’s experience was seen to be unproductive: “I just believe that everybody’s different, so [...] if someone blogs about themselves it doesn’t mean that you’ve got to be like that as well, it’s kinda different” (Freya, 19, diabetes). Freya, like many of the participants, opened her contribution with a statement about the diversity of experience of diabetes -“everybody’s different”. She then used this rationale to justify her assertion that others’ views were therefore not relevant to her experience. However, this argument was in contrast to how some other young adults discussed the individual nature of their experience:

I think [the forum is] better²⁰, a better way of going, because you’re getting so many different voices and so many different experiences. To me, that’s really important because it’s a very individualised condition, everybody has their own different form of diabetes to some extent. And it’s quite hard to actually pin down information specifically from Google searches unless you know exactly what you’re looking for, I mean, one example for this has been, the people on the [online discussion] boards I frequent, sort of dig around on PubMed and on all the different kinds of articles that are there. Now most of the information there is beyond me, I’ve got a basic grounding in science but it’s not in-depth, but they are very good at sort of picking out kind of the key points and mentioning a few terms, that gives me something that I can then talk about and work with (Anthony, diabetes, 28).

Like Freya, Anthony identified diabetes as “a very individualised condition”. However, rather than suggest this made sharing experiences and information unhelpful, he explained that this was why he considered forums, with multiple members contributing to detailed discussions, to be valuable

²⁰ Anthony was browsing a newly developed website containing lots of static information about diabetes but with embedded social media links, to allow for sharing of content on sites like Facebook and Twitter.

resources. His preference for online resources seemed built on the same premise as Freya's aversion to them.

Many of the participants with experience of CMHDs also described their experience as individual and unique and, similarly, this was often related to the limitations of online resources. For instance Simone commented:

So I think [...] I think that my experiences are unique, really [...] Like I know or I don't think I'm... I mean unique in the sense that they're not, it's [mental health issue] not worthy to be classed as this or that. So whenever I've been to a psychologist I never think I should be there, as though I'm not bad enough to be there or something, in a way. So if someone were to say [online], "Oh, well, I had this experience," and I think, "Well, you haven't really, because we're different." Does that make sense? (Simone, CMHD, 25).

In her response, Simone prioritises the "unique" nature of her experience, and suggests that other people cannot easily relate to her experience because of inherent differences. She alludes, in particular, to the fluid nature of the diagnosis of various CMHDs in her statement that it "can't be classed as this or that", setting herself apart from other people's diagnoses. However, Eleanor, who draws heavily on online resources to support her experience, relayed her differences and similarities to others in another way:

[...] The girls in the group sometimes post pictures of all the supplements they've had to go and buy and say "This is what we're on". Some people will say "What is that one, what does that do?" We'll say "Well this does this" and "Here's a wee link, go and have a read up on it and see what you think" because it does take a wee while to find what works for you and if you can say to people, well you go on and say "I've really found that taking 1000 milligrams of Vitamin C" for example "a day has really helped my mood" and there are people who say "Well it made me feel ill, there's research for this and that" but if someone comes across it and they might want to try it [...]. Personal experience - through my trial and error might help someone else's trial and error (Eleanor, CMHD, 26).

Eleanor's acknowledgment of individual differences, finding "what works for you", was discussed in relation to the broad range of individual experience available online. Her perspective was more similar to Anthony's, in that both suggested access to the diversity of people's personal experiences was one of the key merits of online resources which included other users' perspectives.

These contributions illustrate the link between how people understand their own experience and how they respond to online resources. It seems that while there was some degree of consistency in how both diabetes and CMHDs were framed as primarily individualised issues and with each person's experience of them conceived of as unique, there was diversity in how this uniqueness was seen to impact the perceived relevance of online resources. Across participants' accounts, some suggested this made online content invaluable, while others deemed it irrelevant.

6.7.2 Generic and targeted resources

This tension between conceptions of health issues as individualised and unique, and the perceived relevance of online resources relates to another theme in the participants' accounts, on the complexities of online engagement. For some of the young adults, constructions of their identity, as well as their experience of their health condition, often seemed at odds with the way that some online resources were presented. Both generic online resources and online resources targeted at specific population groups were discussed by the participants.

In particular, some of the participants with experience of CMHDs considered resources to be too generic or not specialised enough for helping to deal with complex health issues. For example, Daniel, who had been experiencing depression for the past year, said:

[...] Obviously, everybody's experience is their own and no one has the exact same, everyone sort of deals with it and experiences it quite differently, eh em, if you go to someone like specialised in treatment, then you know that, they can sort of cater that to you once they've found out a bit about you, [...] So it just, yeah, I suppose it's good in

that sense, eh, I don't really, yeah I wouldn't, yeah, never normally use anything like this [online depression website] I don't think.

What puts you off something like that?

[...] I mean, I think, if [a mental health professional] told me to maybe use it I'd, like if I was coming away from like a therapy session or whatever, like "You should try that out", I'd maybe use it but be incredibly cynical throughout. I dunno I've just never found myself that convinced with that sort of stuff. I don't know I just, yeah like I dunno I, part of my problem is I almost see myself as this completely unique and un, like, problem that only someone that focuses completely on me could help, I don't know why it's maybe a bit of like of an ego or something, I, I

No, no I understand, so is there a link between what you are experiencing and how this [online resource] could help?

Yeah, I mean I guess that's exactly it, it's just because it's aimed at everybody, trying to help, but then it's kind of missing everybody at the same time, or that's kind of how I would see it, because it's missing me (Daniel, CMHD, 25).

In this extract, Daniel conveys the disjuncture he perceives between his experience and the specific online resources we discussed in the interview. He contrasts the health professional who is "specialised in treatment" and can "cater" to his individual circumstances with an online resource "aimed at everybody [...] but then [...] missing everybody at the same time". Indeed, the potential of online resources seems to be dismissed because they do not align with his conceptions of the complexity of CMHDs or how they could be treated. Similarly, Alistair, when asked to discuss his reasons for disliking a mental health support website, commented:

I don't know, I feel like a lot of the messages are maybe generic about "Learn to relax!" and, you know, "Try to be positive!" and "Get some sleep, exercise, eat well", all the things you're meant to do and you're like "Well I know this and I tried this but, you know, I'm still gonnae

feel down”. I don’t expect to go on a website, do a course and go like “Oh well that’s me resolved all my issues, smashing” but yeah, it was just maybe a bit simple but I’m probably quite cynical as a person. I’m probably quite a miser-, a miserable sod (Alistair, CMHD, 21).

In his interview Alistair discussed the “generic” advice he had encountered on some mental health websites, suggesting much of the content left him feeling frustrated and cynical about the potential of such resources. Many of the participants with experience of CMHDs alluded to similar concerns. Indeed, resources offering general advice to a broad range of users were often perceived as at odds with the participants’ sense of self, their experience of CMHDs and their perceived needs. However, none of the diabetic participants talked in this way about professionally produced online content about diabetes.

All participants discussed how some health-related online content appeared to be targeted at specific population groups, such as young adults. For a small number of participants, this was viewed relatively simplistically. For instance Ingrid described who she thought would use a particular diabetes site focused on young adults - “the youth one [with] the pictures of teens, early twenties will get you wanting to read it if you are that group” (Ingrid, diabetes, 23). This type of conclusion was voiced by a number of the participants when discussing user groups broadly. However, when discussion turned to whether they *personally* felt they were the target of some sites, participants were generally more critical. For many, the features of sites which they thought were directed at a particular target user group were discussed in unenthusiastic terms:

I don’t like the design, it’s a bit too *Hollyoaks*, but I’m older. [...] So, I’m a different era. I think probably—it actually, it looks like a publication for a university course. I don’t really like it. But, I’m quite hypercritical of everything.

Yeah. What are the things in particular that... sort of resonate with *Hollyoaks* or student-type...?

Just the—holistically it just appears like there's three students here. And, it's like the magazines you see at university for courses, and prospectuses. It just looks a bit, I don't know - wanky, to be honest (Rory, diabetes, 30).

When Bronwyn reviewed a similar site, her response also reflected a negative perception of sites which were explicitly intended for young adults:

It looks a little bit like a government publication, [for] youth [...] d'you know when like they do like stop smoking campaigns, "We're trying to relate to you," and stop drinking campaigns (Bronwyn, diabetes, 28).

Other derogatory comments included that online resources were in danger of appearing like school revision sites (Peter, CMHD, 19) and Fran concluded her critique of one depression site, which was particularly targeted to young adults, by saying "I don't know if young people would go near [that site] with a barge pole though" (Fran, CMHD, 25). It seems therefore that for some young adults, explicitly 'youth'-focused sites, characterised by their design and the tone of the information presented, prompted some participants to question if resources were indeed relevant to them.

In summary, many of the young adults described apprehensions about using online resources on the basis of their relevance to their own experience of their health condition to date. Rather than prioritising the reliability and trustworthiness of content, participants expressed more concerns with broader issues around the relevance of online resources to their personal experience of diabetes or CMHDs. The young adults conveyed a perceived tension between the unique, individualised and personal nature of their experience, on the one hand, and the relevance of generic resources, on the other. Furthermore, efforts to target resources at users of their age were often criticised. In particular, young adults with experience of CMHDs, seemed particularly ill at ease with many of the available resources. For them, the generic format and tone of sites was at odds with their experience and needs.

6.8 Suggestions and innovations: perspectives on developing resources

Despite concerns about the relevance of resources, most participants suggested that across the breadth of online resources available, they would be able to find some that suited their personal preferences and resonated with their personal experience. However, two main themes emerged from the analysis of the interviews in relation to how resources could be improved; indeed, these related to the previously discussed limitations of resources. The young adults seemed to suggest first that more tailored, personalised resources could be useful and, secondly, that resources should be updated more often to meet the ongoing needs of those with experience of chronic health issues.

6.8.1 Tailored/personalised resources

In relation to participants' perceptions of the disjuncture between the individualised nature of health issues and general online resources, many suggested innovations in online content that included highly tailored, personalised content. Despite the criticism that health-related resources could be 'too involved', some participants suggested that resources which utilised content or data generated by individual users could be useful and innovative. For instance Sylvia suggested:

[...] linking into the future, like the app thing. [...] I think it'd be amazing if you had something [...], like you put in a bit about your exercise [...] and what you've eaten, and stuff, and maybe mood. And then, if you put that in for a few days, and then you suddenly put in your mood's crap, if it could tell you. Like, "Look at what you've been doing...!" or suggest to eat more fruit, and veg, or this, or that. I think that would be quite a good [...] Yeah, but it would kind of like your own little... diagnostic little thing that could say to you like, "Course you're gonna be in a crap mood you've not been out for a walk, and had fresh air..." or, "You've just eaten crap all week," or you've done this, or you've done that, that would be really good (Sylvia, CMHD, 26).

Sylvia, like some of the other participants, suggested that she would find personalised feedback from “your own little” tool very useful. Such comments contradict those made about resources being ‘too involved’, perhaps highlighting a tension between what young adults envisage as useful and how they integrate online health resources into their everyday lives. However, others extended the idea of personalised feedback, to suggest that real-time interactions with other users and health professionals facilitated through online social media could provide useful support. For instance Tara suggested:

[...] people put themselves forward as, like, an unofficial counsellor and what you would do is [...] you'd email them and tell them about your issues and they'd email back with, like, their experiences and how they coped with it. And I just thought that was a nice idea because of... obviously with [face-to-face] counselling, you're actually waiting quite a long time sometimes, and it's nice just to have a little bit of interaction to help you while you're waiting. I liked that idea (Tara, CMHD, 21).

These types of suggestions, involving “a bit of interaction” with other people, rather than generic resources, were common and coalesce with concerns raised about the generic nature of some resources for CMHDs. Indeed, some participants welcomed opportunities for more personalised support which recognises the complexity of their health issue and personal experiences of it. However, this is perhaps in contradiction to other participants’ comments about complex interactive resources demanding too much time and interaction.

Bronwyn also commented on the opportunity to obtain personalised information and support online:

[...] I always thought it would be really useful - and it might be there - if you could check your blood sugar and upload it and get advice [...], because [...] when you're actually in work, to take time out to go to the doctor within that very like tight 9-5 time frame, it can be quite difficult (Bronwyn, diabetes, 28).

Similarly, Max said:

I'd love to be able to [...] look at records and things, because sometimes when you're at the—you can be at your GP's, and the GP can't know everything. And, they come back with, "Well, these are your test results," and maybe they'll just focus on the bit they wanna know about, and "That's alright, that's alright, that's alright." Well, that one might be alright, but it could be better. And, you get people who will post sort of, "Well my blood tests done today, and my HbA1c was this, my cholesterol levels were this, this, this, this." But, by the time I get home I've completely forgot about everything apart from the HbA1c usually (Max, diabetes, 29).

The opportunity to obtain personalised feedback on blood glucose levels, from an interactive online resource, was also looked on positively by many of the participants with diabetes. Similarly, for many, discussion of the opportunity to access routine diabetes test results in order to inform self-management, as mentioned by Max, was common. Broadly, these kinds of responses suggest the importance for many young people of using online resources to prolong or extend contact with health professionals, or with the type of information they provide, beyond consultations. These opportunities for accessing personalised support online seem to relate directly to the limitations of basic information, and the lack of direct relevance of resources to experience, articulated by many participants.

6.8.2 Updating resources

Related to dissatisfaction with basic and general information-providing resources many participants also suggested that constantly updating content was an important aspect of online resources. Technological developments, new research findings, alternative approaches and treatments were seen as newsworthy and relevant content for consumption by those with long-term experience of health issues. Indeed, when asked about innovation in online resources many suggested that providers of resources adopt and adapt social media practices. For instance Anthony discussed the value of social media in comparison to other more passive, informative sites:

[...] I think, because it's such an individualised condition, I mean one thing I will say is, the design for [Diabetes website] looks really good, and this is a great starting point, but I think because it's essentially a static site, the information that's on there is only going to ever help you once, whereas a forum, you're going to have that over and over again. And the same with Twitter as well, I mean forums are really good for asking specific questions cause obviously everybody sees the question, it's there for a certain length of time, so you get quite a pool of [answers], where as Twitter's very sort of quick and rapid, but it's also very good for kind of raising awareness of things very quickly (Anthony, 28, diabetes).

In his interview Anthony commented on the limitations of static sites and emphasises the point in this extract, “the information that's on there is only going to ever help you once”. He continued, however, by identifying the alternative opportunities of forums and Twitter for “asking specific questions” and “raising awareness”. The contrast between these functions is perhaps timeliness; for many participants social media offered more instant access to timely, specific or personal information. Furthermore, for those with long-term experience of their health issue, social media is perceived as delivering more novel content, around which discussions can form. As with general social media use, consumption of this content was fraught with much less contention than ‘prosumption’, which requires users publicly engaging with health-related content.

Similarly across both health issues, the young adults discussed a number of specific potential innovations that drew on social media practices, to create up-to-date resources. For instance Euan suggested one means of drawing existing mental health resources together:

What about [...] like a list where people can go to that maybe even has a rating by health professionals like the things you get on food in the supermarket where it's got the tick if it's healthy. It might have that for the websites, [...], a bit like Trip Advisor or something. There might be like a user rating and a professional rating (Euan, 28, CMHD).

Similarly, Ronan suggested an innovation based on social media features:

[...] I'd rather there was a diabetes website or Facebook thing that just said like facts, like 'Freestyle have released this new blood sugar meter and this is what it does' or something. [...] Diabetes technology feed, it's a great idea, if that doesn't exist I'm gonna start it. Like a diabetes technology app (Ronan, 28, diabetes).

Euan's reference to Trip Advisor and Ronan's to a "Facebook thing" are typical examples of the ways participants associated innovative resources with integrating established social media features and functions, such as user-ratings or news feeds. Across the interviews participants often discussed the potential for integrating social media into health resources as a means of creating constantly-evolving and up-to-date resources.

6.9 Discussion

The producer participants who were interviewed came from a range of backgrounds and brought a diversity of experience of producing online content. Their accounts provided insights into what informs the development and management of online resources for diabetes and CMHDs. Specifically, their perceptions of the status of the online content they produced, as either a stand-alone, static resource or a dynamic communications channel, seemed to impact how their resources were developed and managed. However, despite apparent differences in how the resources were managed, the levels of interaction the participant producers encouraged, through primary websites and additional social media platforms, was generally minimal. This seems at odds with the range of literature promoting social media use as central to new interventions and health promotion for both diabetes (Shaw and Johnson, 2011, Yu et al., 2012, Toma et al., 2014) and CMHDs (Norman and Yip, 2012, O'Mara, 2012, Schmidt and Wykes, 2012), particularly with young people (O'Dea and Campbell, 2011). However, it is consistent with Thackery and colleagues' (2012) study of social media use amongst US public health departments, which suggests that such tools continue to be viewed as a one-way tool for information dissemination, rather than prolonged engagement with users.

Discussions of interactivity in media studies have defined the various different forms of interaction websites can facilitate for users. These include both user-to-user (interpersonal interactions between individual users) and user-to-‘document’ (interactions with content and the producers of the content) (McMillan, 2002). The producer participants interviewed in this study seemed mostly to give accounts of facilitating user-to-document interaction, primarily with content, rather than producers of content. The impact of this was that accounts suggested websites were more ‘monologic’ than ‘dialogic’, with user interaction restricted to browsing and not content creation. While for many of the young adult participants interviewed, this type of interaction was adequate, some participants sought increased personalised interaction or peer-support, which was not prioritised by most producer participants.

Previous research on how patient organisations develop websites has suggested that users are largely absent from the design and development processes (Oudshoorn and Somers, 2006). Similarly, Livingstone’s (2007) study of teenager’s interpretations of supportive websites created by public sector organisations suggests that producers can often fail to facilitate productive relationships with intended users. This study echoed these findings, with most of the producer participants’ accounts featuring little discussion of potential users’ involvement in the processes of creating and managing online resources. Oudshoorn and Somers’ (2006) suggestion that design and development informed primarily by producers’ own perceptions and experiences risks excluding “the perspectives and needs of people with differing demographic characteristics from the designer” (p. 670) is perhaps also relevant here. Indeed, this study suggests an extension of this claim, that producers also seem to base their decisions on interaction and social media use on personal perceptions of these environments, and do not account for the diversity of users’ online practices.

The existing literature around health and online resources has historically drawn attention to concerns of information reliability and some of these concerns have been restated in relation to social media content (Adams, 2010b, Kata, 2010). However, although participants’ accounts were

permeated with allusions to the risk of misinformation as detailed in Chapter 4, this was not an issue that was prioritised by participants. Rather they expressed concerns about the irrelevance of online resources to their own experience of their health condition to date. The young adults in this study conveyed a perceived tension between the unique, individualised and personal nature of their health experiences, on the one hand, and generic resources, on the other, particularly in relation to CMHDs. The producer participants, however, did not raise this issue as a challenge in creating and maintaining online resources. This dissonance further highlights the tendency discussed by Oudshoorn and Somers (2006) for producers of websites to develop them in ways that are not entirely aligned with prospective users' preferences.

Another way of understanding the disjuncture between the perspectives of users of online resources and their producers is proposed by Mager (2009), who suggests that website producers and website users differ in their epistemological stance in relation to online information, with producers conceptualising single websites as coherent packages of information and users conceiving of websites as one in a number of sources to be navigated through issue-focused searches for information. This concept of differences in issue-focused and information-focused epistemologies resonates with the findings of this study. The young adult participants' preferences for more advanced, specific content, and more personalised content suggests their 'issue-focused' approach, whereas most producer participants seemed to conform to a more information-focused view of online content with some exceptions. The producer participants from Diabetes-1 seemed to have developed an understanding of the issue-focused approach of their users and responded to it through use of social media, by actively searching for diabetes-related Facebook and Twitter interactions that they could usefully contribute to. Similarly, Diabetes-2's development of a resource which links to information stored by health professionals further exemplifies the potential to meet users' requirements. Practical issues obviously limit the extent to which personalised feedback can be supplied and direct communication established with all users by all organisation and resources.

However these cases highlight that where resources are available, it is possible to align producers' resources with users' needs.

While all of the producer participants seemed concerned with reaching young people and young adults through online resources, many identified their resource as targeted more broadly. Beyond a general concern to reach young people the producer participants did not articulate detailed understandings of the range and diversity of users' online practices and interaction. None of the producer participants made reference to the differing levels of online interaction users engaged in through social media or the potential of social media and user-generated content to fulfil particular peer-support needs. The typology discussed in Chapter 5 prioritises both these dimensions in characterising how young adults engage with health-related user-generated content. Perhaps, producers might effectively employ such typologies in order to create and manage resources which appeal to a range of users based on online practices rather than explicit demographic information. Perhaps since few differences in the young adult participants' online practices seemed related to the particular health condition they had experience of it might also be useful to investigate if such typologies are generalisable to other long-term health issues experienced by young adults.

Related to increased consideration of differences in users' practices by producers of online resources is consideration of differences across users' health experiences. The interviews with young adults suggested that while resources developed with a specific and narrow purpose are useful when first encountered and for those with least lived experience of particular health conditions, dynamic resources are perhaps most suited to maintaining users' broad interests with prolonged use. For users encountering online resources this distinction is perhaps less clear, since many of the young adult participants in this study discussed becoming frustrated with content that they perceived to be 'too basic'. Given the heuristic approaches to assessing online content described by Metzger and colleagues (2010), and reiterated in this study in relation to health content, perhaps visible signposting of who, in particular, content is primarily intended for, in terms of experience, could encourage users to revisit sites they might previously have dismissed.

The suggestions of the young adult participants around the potential opportunities for developing online resources seem related to some of the limitations and issues of relevance they discussed. Their concern for more personalised resources resonates with their constructions of diabetes and CMHDs as individual and highly personal issues, which were evident throughout the interviews. Furthermore, the young adults' comments suggest the importance of social media sites, as interactive and dynamic resources, to their conceptions of the possibilities for developing online resources. In particular, calls for constantly updated news content and features to collate users' ratings suggest the embedded nature of social media in young adults' understandings of innovative health communication. In particular users proposed that social media features such as user 'ratings' should be embedded in resources as a means of helping users to assess their quality and relevance. These social media features have also been identified in previous research as useful hallmarks to signify trustworthiness of general health information (Fergie et al., 2012). These suggestions are at odds with producer participants' accounts of minimal interaction with users through social media platforms. Perhaps, where appropriate, producers could attempt to adopt more social media features both as a means of evaluating content, and engaging with users, whilst also providing users with useful indicators to aid their assessment of the relevance of online content. However, as suggested in the interviews with producer participants, any social media activity by health organisations is likely to be dependent on whether such activity aligns with the communication strategy and practices of the organisation, and the availability of resources to manage social media.

7 Discussion and conclusion

7.1 Overview of chapter

This chapter builds on the discussion sections of each of the findings chapters to provide a summary and over-arching discussion of the findings in relation to existing literature and the study research questions. In this chapter consideration is also given to the strengths and limitations of the study related to both the methods used and the substantive contribution of the research. Finally the chapter, and thesis, is concluded with some suggestions for future research and some potential implications of the study findings for professional producers of online content and social media intervention development.

7.2 Overarching discussion of findings

7.2.1 What are young adults' perceptions and experiences of engaging with health-related content on the internet and through social media technologies?

This study explored young adults' perceptions and experiences of engaging with content related to their experiences of either diabetes or CMHDs, with a particular focus on their perspectives on navigating health content on social media platforms. By exploring individuals' accounts, this study has provided insights into the range of ways that social media can impact the processes and practices of online information seeking. In particular, participants' accounts suggested that social media practices can inform how health-related content is accessed, assessed, consumed and appropriated.

Consistent with previous research, accessing health-related content was discussed generally by the participants as a timely and responsive means of information seeking (Kivits, 2009), primarily mediated by search engines such as Google (Mager, 2009, Mager, 2012). However, the findings of this study also suggest that social media provide an alternative means for some individuals to engage with health-related content. This is in accordance with previous research which has suggested that patients with chronic health

conditions are some of the most avid consumers of user-generated health content, using social media platforms to access accounts of health experiences and interact with other users (Fox and Jones, 2011). As discussed in Chapter 4, recent survey data has suggested a decrease in search engine use amongst internet users, which could be linked to an increase in the use of social media as a means of locating content (Dutton et al., 2013). Although most participants in this study discussed relying primarily on search engines to locate content relevant to diabetes and CMHDs, some of the young adults' accounts reflected a shift towards accessing health content through social media platforms. Rather than proactively seeking content, these participants discussed browsing content as it appeared on their social media feeds alongside content based on other interests or recommendations within their social networks. For some individuals consumption of diabetes and CMHD-related content was part of everyday online practice. Indeed, just as "everyday routines surrounding the use of the internet constitute and shape individuals' information seeking" (Kivits, 2009: 685), it seems that social media practices can lead to individuals integrating health content consumption into their everyday experiences of diabetes and CMHDs. Furthermore, given the relatively small number of differences in participants' accounts that seemed to be related to which health condition they had experience of, it may be that individuals experiencing other long-term health conditions might also be increasingly incorporating health content consumption into their everyday online activities.

As well as social media offering alternative opportunities for users to consume health-related content, social media also seems to impact users' assessments of content. Similar to Nettleton and colleagues' (2005) exploration of accounts of online health information seeking, the participants in the current study generally described their approach to appropriating online resources as aligned with dominant biomedical conceptions of reliable information. Broadly, participants reported that they prioritised professionally produced content and that they made judgements based on a range of criteria. These strategies for assessment seem based largely on initial impressions and heuristic approaches consistent with previous research

on online information seeking generally (Metzger et al., 2010). In line with Kivits' (2009) contention that everyday online practices shape information seeking, many participants also discussed using social media features, such as 'likes' and images as indicators of the quality of social media content. These findings suggest the importance of social media to some young adults' experiences of engaging with health-related content online. Social media practices based on everyday internet use provide a template for accessing, assessing, consuming and appropriating health-related content.

The "re-ordering" of boundaries precipitated by social media technologies (Beer and Burrows, 2007) and the emergence of "e-scaped" medicine (Nettleton, 2004) are broad concepts which suggest the impact of internet and social media technologies on the context and experience of health and illness. The findings of this study highlight some of ways in which social media use for health purposes exemplifies the concept of 'e-scaped' medicine:

Medical knowledge is no longer exclusive to the medical school and the medical text; it has 'escaped' into the networks of contemporary infospaces where it can be accessed, assessed and reappropriated (Nettleton and Burrows, 2003, p. 179).

Some participants' accounts reflected how boundaries between 'lay' and professional content are re-drawn or made permeable through social media use. Participants cited many examples of how engagement between individuals, groups of individuals, organisations or health professionals is made possible through social media. For example, they described sharing evidence-informed clinical guidelines on forums; comparing treatments and self-management strategies with groups of other users on Facebook; and accessing user-generated video content demonstrating self-management techniques, therapies and treatments. These sources of content generated or featured on social media sites are subject to rating features which provide indicators of popularity, relevance and usefulness. Participants in this study discussed actively and effortlessly negotiating between both evidence-based, professionally-produced content and user-generated content. For some,

social media offered an opportunity to explore issues in more detail, drawing on accounts of other people's experience, or developing self-management strategies drawing directly on niche content that is brought together on specific social media sites and within specialist online communities. While some have cautioned that the phenomenon of social media exacerbates issues of reliability of online health information (Adams, 2010b), this study suggests individuals negotiate health content in accordance with everyday social media practices, and appreciate opportunities to appropriate and engage with specific health knowledge from varied sources.

Social media, therefore, seem to impact across users' processes and practices for engaging with health content, amongst young adults at least. Technologies like Facebook, Twitter and YouTube offer opportunities to consume and assess content which users deem relevant and useful. As users and organisations continue to colonise these, and other social media platforms, opportunities are perhaps set to develop further. In particular, accessing niche content through social media platforms seems important for users with long-term health issues who seek very specific information or maintain interests beyond evidence-based information and dominant biomedical perspectives.

7.2.2 How are the internet and social media technologies used by young adults in self-management of health issues?

As well as providing insights around the impact of social media on health information-seeking online, the study explored how social media are used by young adults in their self-management of diabetes and CMHDs. In particular, the study explored to what extent, and how, the sample of young adults negotiated social media as a site for peer-support and sharing health experiences.

Previous research has highlighted that electronic support groups (ESGs) provide important opportunities for individuals to congregate and communicate around shared experiences of health conditions (Conrad and Stults, 2010). Many studies of these ESGs highlight positive outcomes for users including peer-support (Broom, 2005a, Fox et al., 2005, Bar-Lev, 2008,

Barker, 2008) and the development of new health knowledge (Fox et al., 2005, Barker, 2008). More recently, studies have explored supportive communities for young people with chronic disease formed on social media sites, with similar positive outcomes (Nordqvist et al., 2009, Ekberg et al., 2010). For example, one study suggests Facebook communities foster peer-support for diabetes (Greene et al., 2011), while another suggests the positive impact blogging can have on people experiencing depression, as a means of self-therapy (Tan, 2008). In relation to this, there are increasing calls for the development of social media interventions to support people's experience of both diabetes (Shaw and Johnson, 2011, Toma et al., 2014) and CMHDs (O'Dea and Campbell, 2011, Schmidt and Wykes, 2012). To date, however, few studies fully illustrate the complexities of this environment as a site for facilitating peer-support around health experiences or engaging individuals in health interventions. Through exploration of young adults' accounts of their perceptions and experiences of engaging with social media content about diabetes and CMHDs, a number of related issues were highlighted.

Firstly, the typology suggested in Chapter 5 describing the range of participants' engagement with user-generated content (well-supported non-engagers, tacit consumers, and prosumers), highlights that offline experiences are perhaps related to people's online and social media practices, at least for these health conditions. In particular, those who experienced good offline support for their diabetes or CMHDs discussed little engagement in social media activity for health purposes. Furthermore, those who experienced some offline support generally expressed unwillingness to explicitly engage on social media about health issues, although they did report tacit consumption of content. Only a small group, generally those who reported little access to offline support, engaged in regular activity on social media sites to produce content explicitly related to their experience of either diabetes or a CMHD. This variety in participants' engagement with user-generated content seemed based on the wider context of their health experience, including their access to support from family, friends and health services. Although reducing the complexity of people's health experiences

and engagement with social media to three broad groups, the typology suggested in this study highlights how social media health resources fit within the broader context of people's offline health experiences. Supportive resources, for individuals experiencing and managing diabetes and CMHDs day-to-day, are drawn from a range of contexts and social media is not prioritised by many. However, for those who do draw on user-generated content, this resource seems to provide valuable peer-support.

Secondly, participants identified a number of barriers to accessing and engaging with health-related content on social media sites related to concerns about the presentation of their identity online. As explored in the discussion section of Chapter Five the notion of identity has been widely discussed in sociological literature and in relation to experiences of health and illness. Identity has also been explored in literature on users' practices online (Robinson, 2007) and their use of social media sites (e.g. boyd, 2006; Ellison et al., 2006). The findings of this study provide further empirical insights around how the construction of identity online impacts on how users choose to engage with health content online. Explicit concerns about how the audience(s) of users' social media profiles, particularly on Facebook, might view references to health issues, meant even the seemingly innocuous act of 'liking' health charity pages was subject to considerations of identity-management. This was consistent across the sample of participants, with few differences between men and women or between those with experience of diabetes and CMHDs.

Given both CMHDs and chronic diseases, such as diabetes, are associated with stigma, this rejection of explicit online engagement could be seen as an instance of managing "spoiled identity" in Goffman's (1963) terms. Goffman presented dual concepts of stigma: 'discredited stigma', in which the individual assumes their difference is already known or visible to others, and 'discreditable stigma', in which the individual assumes their difference is neither known to, nor perceived, by others. 'Discredited stigma' is associated with greater stigma management and 'discreditable stigma' with greater information management. The enactment of these two concepts is less simple online, where identity and difference can be obscured.

Furthermore, on social media sites, such as Facebook and Twitter, users present themselves to a diverse audience of ‘friends’ and ‘followers’, which is largely undifferentiated and could include close friends, acquaintances and colleagues, as well as people users have met and engaged with solely online. The findings of this study suggest that young adults with experience of CMHDs or diabetes seem to engage in regular information management, actively choosing not to explicitly produce or consume content related to their health condition, particularly on Facebook. This is at odds with the growing calls in the literature to relocate health promotion and health interventions to social media sites, which largely present such sites as unproblematic environments for engaging users in discussions about both diabetes and CMHDs. However, the findings do align with recent research by Egan and colleagues’ (2013), whose focus group study explored people’s perceptions of mental health-related status updates on Facebook. Their findings suggested that such content was viewed in many ways, ranging from a sympathetic view of mental health status updates as calls for help to a more negative view of such updates as attention-seeking. Perhaps then, health content related to ongoing health experiences, particularly CMHDs and diabetes which are not necessarily discernible to an outside observer, is seen by some young adults as undesirable and therefore requires information management to mitigate negative responses.

The findings of this study also highlight how the specific social media platform can impact users’ expectations and consumption of health-related content. The differing considerations for production and consumption of content on Twitter, Facebook and YouTube were marked and varied across participants’ accounts. For many of the participants in this study, their information-management strategy was absolute; they discussed never contributing content related to their health issue online. However, others took a more nuanced approach, accounting for different levels of engagement related to the different audiences and conventions of each social media site and profile. These more nuanced approaches are consistent with Libreri and Graffigna’s (2012) recommendation to consider “Web 2.0 not as a whole and unique context” but as “different contexts with different technical

and social aspects” (p. 132). Indeed, the findings suggest that participants’ online practices, based on their established wider social media practices, and perceptions of platform-specific conventions, vary across different social media platforms. As such, information-management related to concerns about compromising identity presentation also varies. For some young adults explicit engagement with content related to either diabetes or CMHDs may be entirely plausible in one social media context but highly unlikely in another.

7.2.3 Lack of differences by gender and health condition

Throughout the development of the study and in subsequent analysis, attention was consistently paid to differences and similarities across the sample by gender and health condition. Analysis suggested more similarities than differences between the accounts of the men and women, and between those with experience of CMHDs and diabetes.

Within the literature on social media and CMHDs/diabetes, gender differences in patterns of use or online practices were not discussed. However, in the broader literature, a number of papers have highlighted the potential of using social media as a means of engaging young men, in particular with health information and promotion for a range of health issues (Robinson and Robertson, 2010, Tyler and Williams, 2014). Tyler and William’s study highlights the potential of online environments for providing an “anonymous and comfortable environment for these men to speak about their health concerns, gain support and ask questions about symptoms that may be unavailable to them in face-to-face situations” (p. 468). Some researchers have also suggested that the online environment suits young men’s preferences to seek out information independently and acts as space where engagement with health discourse is acceptable (Robinson and Robertson, 2010). In the current study, it was evident that health-related online resources do facilitate engagement with health information and support for some young men; however, this was not the case for all of the young men, or indeed all of the young women. The concerns which participants suggested limited engagement with user-generated content, in relation to identity construction and consideration of audience, were consistent across the sample, voiced by both male and female participants.

Indeed, accessing health-related content online seemed more related to participants' experiences of offline support, their current online practices, and their perceptions of the limitations of online resources, issues which varied across participants' accounts.

These factors also seemed to have a greater influence on participants' perceptions of online health resources, and their engagement with them, than the particular health issue they had experience of. One of the few comparative studies exploring differences in online engagement across health conditions suggests that although there are differences in the types of issues discussed online, key common themes were apparent across health conditions related to people and relationships, and emotional and temporal aspects of illness (Chen, 2012). This study suggests that online resources, regardless of health condition, are drawn upon in relation to the offline context of people's health experiences and indeed, processes and practices for engaging with online content are more similar than different across diabetes and CMHDs. These findings may also therefore be relevant across other long-term health issues.

7.2.4 How are online resources and young adult users conceived by professional producers of online content and potential users?

The current study's findings also contribute to understandings of how professional producers of health-related content, and potential users of it, conceive online resources and users of them. In particular the findings highlighted where professional producers' online resources are not wholly aligned with users' conceptions of useful content. Few studies have explored participants' perceptions of a range of content related to their experience of either diabetes or CMHDs, including both professionally-produced and user-generated content. This is perhaps related to the disjuncture suggested by Mager (2009) between users' issue-focused and producers' information-focused epistemologies in relation to website construction. Indeed, it seems that much research has also followed the information-focused approach, in that it attempts to understand online resources singularly and not in the context of users' wider health experiences and online practices. Many of the tentative recommendations discussed in this chapter and in Chapter 6 relate

to users' general concerns about resources being at odds with their perspectives on, and experiences of, their health issues, rather than specific preferences around the appearance of online resources.

Previous research has suggested that producers of online resources should aim to include users in the design and development of online resources (Oudshoorn and Somers, 2006). This study suggests further that producers should aim to understand users' conceptions of health, illness and the role of online resources in the development of online resources. Indeed, participants in this study prioritised concerns around the relevance of online resources to their personal experience of diabetes or CMHDs rather than issues specific to the design and development of particular websites. Their accounts suggested a tension between the unique, individualised and personal nature of their experience, on the one hand, and the relevance of generic resources, on the other. Their suggestions for improvement generally involved developing tailored and interactive features of resources to increase saliency. While involving users in the design and development processes would be one means of attempting this, engagement between producers and those they conceive as potential users could exclude a range of unanticipated groups. Although involving users in the development of online resources could help to align content with some users' preferences, perhaps continued dialogue between organisations and those they seek as users of the online resources they produce would resolve these wider issues. Feedback from day-to-day users, facilitated through social media, could allow for this ongoing engagement. However, given the identity-related concerns of many of the young adult participants in this study, anonymous means of contributing feedback and conveying their perspectives on online resources would need to be offered.

Perhaps related to the generic nature of online health resources, the producer participants' accounts suggest that exploiting the interactive and dynamic elements of social media was not the primary focus of their online activities. Oudshoorn and Somers (2006) also found that interactive technologies were difficult to integrate into websites created for the purpose of patient support, but some patient organisations viewed these technologies

as a means of extending their activities and engagement with patients. This is in line with Thackeray and colleagues (2012) study of the use of social media by public health departments in the United States, which reported widespread creation of social media accounts by public health departments but that activity was limited to one-way information dissemination. This approach seems at odds with the users' preferences reported in this study, many of whom welcomed the involvement of health professionals in social media interactions about both diabetes and CMHDs, and suggested their presence would provide a valuable supportive resource. Vennik and colleagues' (2014) study of 'lay' to health professional online communities, otherwise known as patient-to-doctor or P2D communities, produced similar findings. They highlighted the different knowledges produced by other users as compared with health professionals in these communities and suggested the combination of these two resources is advantageous for both users, who gain informal professional advice, and health professionals, who are afforded an opportunity to develop their understanding of lived experience. Similarly participants in this study stressed a key area for resource development lay in increasing opportunities for users to engage informally with health-professionals. Perhaps then organisations can further develop their reach and relevance online by engaging in new ways through social media.

7.2.5 Implications for professional producers of online resources

The findings of this study have a number of potential implications for professional producers of online health resources. In particular these are focused on exploiting the potential of social media to engage with users.

As highlighted in Chapter 4, consuming content was most commonly discussed as a result of active searching for information facilitated by Google; however, a number of participants also described alternative approaches to content consumption, resultant from social media practices. This context perhaps requires further consideration by producers of online information related to both diabetes and CMHDs. Whereas users cited hallmarks of quality, such as URLs and logos, as key indicators of reliable information on largely static websites, characteristics of social media content which users discussed assessing were related to social media features such as 'likes' and 'shares'.

For producers of online resources ensuring content generates interest requires understanding of viral marketing techniques which maximise exposure. This could involve focusing attention on developing campaigns which precipitate new users to engage with organisations in developing new social media practices. Users could be encouraged to share content such as 'selfies', other images or videos under specific hashtags. For instance, the diabetes patient group #gbdoc encourages users to share images of their latest blood glucose test result in a game they host on Twitter called blood glucose bingo. Activities like these could generate widespread engagement which then legitimises other content shared by the organisation.

The findings of this study also suggest that some users are employing social media to access networks of users and content about their shared health experiences. Rather than continuing to develop standalone resources, professional producers of content could attempt to utilise these existing and developing networks of peer-support. Continued exploration of online content developed by users and groups of users could help health organisations to develop social media content in line with users' practices. Similarly, rather than confining social media activity to spaces created by professional producers, inhabiting spaces created by users could also offer producers of content greater opportunities to engage new users by contributing to debates and discussions in user-administered spaces.

Across the accounts of young adults' online practices, the importance of the offline context to their engagement with user-generated content was highlighted. Professional producers of online resources might more effectively employ typologies in order to create and manage resources which appeal to a range of users. These could be based on users' online practices and offline experiences rather than general assumptions based on demographic information. Although some details, such as age, might still remain relevant, this study suggests the availability of offline support resources impacts users' practices. For organisations developing supportive online resources and social media content related to diabetes or CMHDs it seems important to recognise the profile of the most engaged group - 'prosumers'. These individuals may be lacking supportive resources offline

and therefore producers should attempt to facilitate the close peer-support, experience sharing and detailed technical discussion that these users seem to seek.

The current study also highlighted how user-generated visual and video content is used by some young adults as a key source of information to inform specific self-management practices. However, the specificity of this content makes it difficult for organisations to pre-empt users' needs. Perhaps increasing the range and diversity of video content shared by professional producers could prove valuable to users. Rather than professional producers creating or commissioning video blog content, perhaps organisations could begin to make links with active users who already frequently contribute such content, and have an independent social media following. Video content, produced by these users, could then be endorsed by organisations rather than produced by them, although this would require careful ethical consideration. This content could then be 'shared' through the organisations' social media channels, offering users greater exposure. By taking this approach users would be central to the process of content development and a range of users' perspectives on health issues and self-management could be portrayed. However, it is likely that organisations would still be required to invest resources (potentially health professionals) in monitoring and approving content to ensure that visual demonstrations are consistent with 'best' practice guidelines.

7.2.6 Implications for health intervention development

Increasing calls for health interventions to be facilitated entirely or partially on social media are likely to prompt the development of a range of interventions which utilise mainstream social media platforms or employ bespoke social media technologies to reach young adults. This study has some potential implications for those aiming to develop such interventions.

The findings of the current study suggest that it is important that health content delivered online does not conflict with the everyday identity work that constitutes a large portion of many young adults' engagement with social media platforms such as Facebook and Twitter. Overt acknowledgement or

engagement with health-related content seems to be undesirable to some young adults. Interventions aiming to reach a wide range of individuals, beyond those who actively engage with health-related content on social media already, should therefore avoid delivery solely through Facebook. However, where social media allows a level of anonymity, users may be more likely to consistently contribute to health-related content.

Another finding with implications for intervention development is the importance of considering the platform specific conventions of different social media. Previous research has noted the importance of considering each social media platform as a different online context (Libreri and Graffigna, 2012). It seems that for many young adults the genres of content a particular social media platform hosts, and the cultures and practices which have developed on it, are key concerns in the consumption or production of health-related content. Therefore, those communicating about health issues online, as a means of intervention, should aim to understand and adhere to platform-specific conventions aligned with users' online practices.

Finally, the findings suggest the importance of considering visual content as a means of communicating about health issues in health interventions which use social media facilities. Consumption of user-generated images and videos related to health issues seems to be a key means for some users to access important insights into other people's experiences of health and illness, and can inform the development of self-management practices. By utilising facilities to disseminate images and videos, or encourage peer sharing of such content, perhaps health interventions could facilitate the process of "visualising disease" described by Ziebland and Wyke (2012), which seems to be an important consequence of accessing health-related online content.

7.3 Strengths and limitations of the study

The study has provided a range of insights into young adults' processes and practices of engaging with content related to diabetes and CMHDs online, and attempted to explore this phenomenon from a range of perspectives. Although the study has some key strengths, there are a number of limitations.

With regards to the sample, as described in Chapter 3, the participants included no young adults from ethnic minorities, and most of the young adults were employed or in full-time education. Therefore, there could be a number of groups to whom these findings are not relevant, including different cultural groups, who might have different expectations of health services, and young people (aged under 18) and older adults (aged over 30), who might have different experiences of online engagement. Furthermore, although online access was not a pre-requisite for inclusion in the study, all participants had daily access to online technologies. All had internet access at home and most had smartphones. Therefore, the findings from this study cannot usefully contribute to ongoing debates about 'digital divides' based on socioeconomic status and their impact on information-seeking practices.

More broadly, during the course of this study I became increasingly aware of the problematic nature of defining the boundaries of research which explores online issues. Previous authors have commented that while online research should attempt to address both online and offline perspectives, often the limits of this are difficult to define to create a do-able and insightful project (Hine, 2009). Throughout developing and conducting this study I found it difficult to define boundaries around relevant literature, the scope of the research questions and the perspectives to include in the research. In particular, the study was informed by Beneito-Montagut's (2011) call for research which takes a multi-faceted approach to understanding how online phenomena feature in everyday life. However, it does not fully align with this holistic approach. Although the preliminary phase of the study (analysis of Facebook pages for diabetes and CMHDs) was designed to explore the data existing online, this phase was inevitably limited in the insights it provided around the breadth of health content available.

Further, initial scoping of potential social media data and ongoing exploration of various social media platforms over the course of the project exposed me to the diverse and wide-ranging data available, including image, video and textual content. However, my analysis was limited to extracts of text content and did not include consideration of the elements of formatted text; animation; video clips; music and graphic design that make online content a

unique genre of communication with many constitutive parts (Bergmann and Meier, 2004). Including some of this varied data in an innovative and systematic analysis could have enriched the findings of the study. Perhaps greater insights could have been generated by supplementing the accounts of users with analysis of the visual properties of social media data, which were also identified as important by participants. Furthermore, the preliminary analysis was too specific to relate to the experiences of the young adult interview participants, given they had developed varied online practices, including a number who rejected both Facebook as an appropriate site for health content and user-generated content as an informative resource.

A further limitation relates to the dynamic nature of online practices. Participants' reflections on specific social media sites and how they engage in these spaces in relation to health content were grounded in their day to day experiences. However, these experiences are likely to develop, often very rapidly, with changes in preferences and technologies. The findings from this study can usefully provide some insights into the development of communication technologies generally, but should Facebook, Twitter and YouTube be supplanted by other platforms, or their functions be transformed (e.g. the increasingly overt commercialisation of Facebook) some of the findings from this study could become redundant. Indeed, this relates to some of the limitations of conducting one-off interviews with participants. Perhaps longitudinal interviews with participants could have generated useful data about changes in online practices over time, as well as exploring how changing experiences of diabetes and CMHDs impacted information needs and experience of online information seeking.

A key strength of the study was its timeliness. Despite initial concerns about changes in users' practices and the landscape of social media over the past three years, the study does offer a number of contemporary insights. During the course of the study a number of issues related to diabetes and CMHDs rose to prominence on social media, which typified the dynamic nature of health-related content currently available to users. In particular, related to diabetes, the posting of a photo of the winner of a beauty pageant in the US, Sierra Sandison, with her insulin pump clearly visible, prompted the global

use of the hashtag #showmeyourpump accompanied by users posting images of themselves with their insulin pumps. The 'top' images returned by a Twitter search for the hashtag (conducted 9th September 2014) are included in Appendix 12 (example of social media content). These images include photographs of pumps posted by individual users with diabetes; an image posted by a commercial organisation, a photograph posted by a fundraising group for JDRF (Juvenile Diabetes Research Foundation), a photograph posted by a journalist with a large number of followers and a re-post of the original photograph of Sandison, also known as 'Miss Idaho', which started the trend. However, during the interviews with participants with diabetes, although we discussed sharing pictures and content about diabetes across different social media platforms, it would have been useful to know more about their responses to specific high profile trends such as #showmeyourpump. This highlights the challenge of understanding the impact of contemporary social media content given the speed at which trends emerge.

Conducting 40 interviews with young adults successfully generated a large volume of rich data. A further strength of the study is the integration of social media content into the process of data collection. Accessing examples of social media content, suggested by either the participant or me, enriched the interview discussion by grounding participants' comments in specific contexts. Exploring a range of content allowed participants to compare different types of content (including text, images and videos), different platforms and different social media practices without detailed questioning. It also prompted many of the participants to contrast the qualities of what they perceived to be useful and useless content, generally without prompting. Some of this interaction with social media content is captured in the footnotes presented throughout the findings chapters.

Similarly, the six interviews conducted with professional producers of content provided useful insights which highlighted the breadth of even a small number of organisations' approaches to health content management. These interviews also provided data which complemented the accounts of the young adult participants, allowing for comparison across key issues. In particular,

this highlighted the divergence of views over the production and consumption of content through social media.

7.4 Future research directions

This study has raised a number of issues that require further research. Given the lack of differences between the perspectives of young adults with experience of CMHDs and those with diabetes, similar issues could be researched across individuals with a range of other long term health issues. Another issue that warrants further investigation is online engagement with healthy lifestyle content and users' perceptions and experiences of the 'prosumption' of content related to positive health behaviours such as physical activity. Exploration of users' constructions of identity, and the relationship between online content production and offline practice, in this case could further contribute to our understandings of the impact of social media on people's health.

In accordance with Liberi and Graffigna (2012), the findings of this study also suggest that more research is required which pays attention to the differences across different social media platforms and environments. The careful consideration of platform-specific conventions, highlighted in this study, suggests research could usefully explore these differences both online and offline, in the content produced in different social media contexts but also users' perceptions and experiences of engaging with it. This study also highlighted a number of concerns from users around the use of Facebook as a space for 'prosumption' of content related to both diabetes and CMHDs. Further research exploring whether these concerns are consistent across other health issues would contribute to understandings of social media as a context for engagement with health content, in the context of broader concerns about the identities which people seek to create in social media spaces. In particular, this is a crucial issue for consideration in studies which propose the development of interventions utilising Facebook, even if only as a tool for promotion and recruitment. The current study suggested differences in how participants viewed Twitter, Facebook and YouTube as sites to seek information and facilitate peer-support; for some young adults explicit engagement with content related to either diabetes or CMHDs may be

entirely plausible in one social media context but highly unlikely in another. Further research could explore whether this is also evident online, by systematic analysis of existing online data related to single or multiple health issues.

Following Mager's (2009, 2012) assertion that search engines shape people's consumption of health-related content, perhaps further research could aim to understand how health content and health networks made visible through Facebook and Twitter, as well as other platforms, are not neutral, but subject to influences ranging from peer networks to commercial interests. This study suggested social media are used by some people to consume health content, less responsively but more regularly, as an embedded part of their social media practices. Lupton (2014) argues that commercial organisations are increasingly creating new data economies by commodifying patients' production of content about their experiences of health and illness. Such influences require further research, perhaps employing the principles of social network analysis to map the range of factors which impact the emergence of health-related content and how it is framed.

Furthermore, the findings of the study suggest some young adults, who engage with social media content about their health issue, seem to be seeking specific, tailored and niche content. This is in line with previous studies which suggest the internet fosters alternative discourses around health and illness, particularly around stigmatised issues (Gavin et al., 2008), contested illness (Barker, 2008) and unorthodox health practices (Kata, 2010). The availability of such content online offers an opportunity for these users to address concerns which are less commonplace on professionally produced online resources. Perhaps further research of these spaces, where alternative perspectives and less evidence-based content proliferates, could usefully inform the development of professionally produced resources which are sensitive to alternative perspectives on diabetes and CMHDs. Further research could also aim to identify the emergence of problematic understandings and potential opportunities for intervention.

7.5 Conclusion

The potential opportunities for utilising social media as a means of delivering health promotion, information and interventions are well-noted. However, research to date has not fully explored the complexities of this environment as a site for engagement with health-related content. This study suggests that amongst young adults there is inherent diversity in online practices related to their health issues, ranging from limited appropriation of professionally-produced content to regular ‘prosumption’ of content. Furthermore, the findings of this study highlight the complexity of identity management for young adults accessing health content on social media sites, and the undesirability for many of incorporating health content into online identity. Given the dynamic nature of online communication technologies, in general, and social media, in particular, identity seems a key issue for continued exploration in research on engagement with health information online. As social media technologies have developed, previously anonymous online profiles and practices have increasingly become aligned with offline identity and offline social networks. Engagement with health information online therefore involves continued reconsideration of boundaries around privacy and disclosure in relation to health and illness. This study, conducted when the mainstream social media platforms of Facebook, Twitter and YouTube are used as everyday communication tools by the majority of young adults in the UK, provides a point of comparison for exploration of future online communication technologies and practices, particularly in relation to the construction of identity online.

However, key opportunities are discussed where social media facilitates peer-support and offers alternative and niche informative resources. Through exploring young adults’ perceptions and experiences of engaging with diabetes and CMHD related content some issues have been raised which could inform how organisations and charities with an interest in these issues develop online resources.

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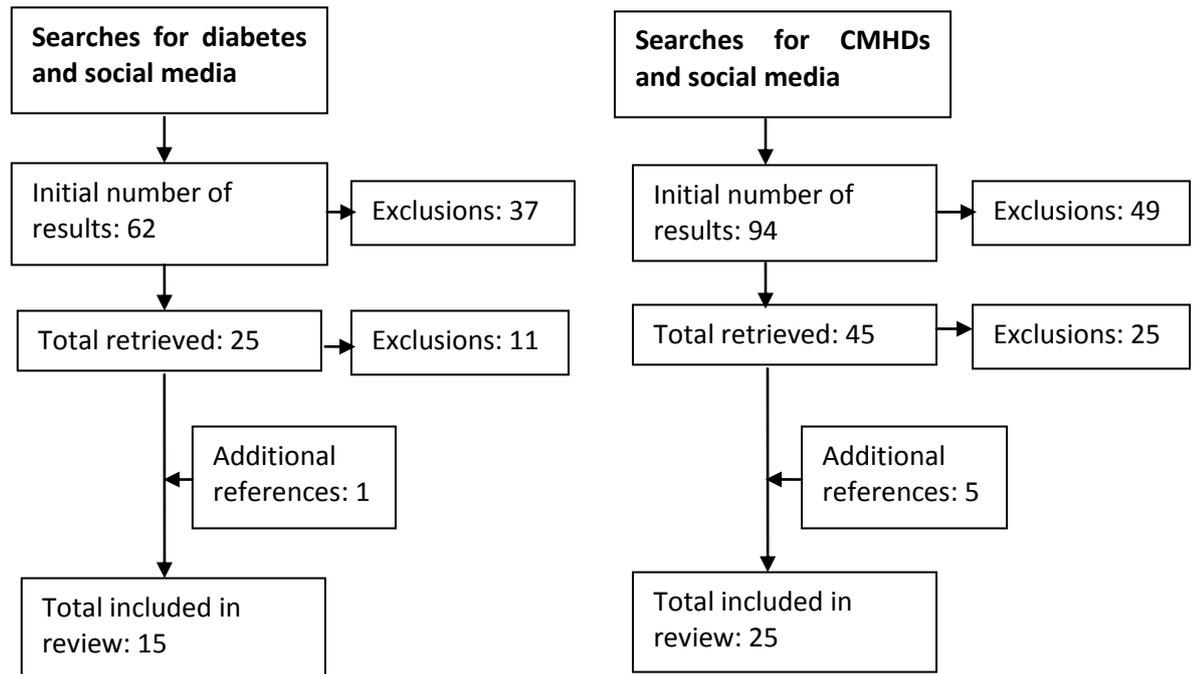
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Appendix 1 – Search process



Appendix 2 – Scoping review of online resources

How well represented are diabetes, mental health, HPV immunisation and epilepsy:

- In professionally produced content? By both large and small organisations?
- On social media sites hosted by charities and organisations?
- On social media sites hosted by individuals users and groups of users?

| Diabetes | | |
|--|--|---|
| Examples of professionally produced UK websites and social media sites | Examples of Facebook groups | Selected other social media activity |
| <p>Diabetes UK</p> <ul style="list-style-type: none"> • Active and well-used Facebook page, 67.2k likes • Twitter accounts (National and Regional), national with 91.2k followers • Active YouTube channel, 2.9k subscribers and 1.6m views <p>JDRF</p> <ul style="list-style-type: none"> • Active UK based Facebook page, 14.2k likes • International Twitter account, 36.1k followers • Active YouTube channel, 1.4k subscribers and 243k views <p>Diabetes.co.uk</p> <ul style="list-style-type: none"> • Active forums and chat facilities • Active and well-used Facebook page, 124.6k likes • Twitter profile, 11.1k followers • Active YouTube channel, with 964 subscribers and 1.3m views <p>Hedgie pricks diabetes</p> <ul style="list-style-type: none"> • Active Facebook page, 542 likes • Twitter account, 1.5k followers • Inactive YouTube channel, 1 subscriber and 102 views <p>DAFNE (Dose Adjustment for Normal Eating)</p> <ul style="list-style-type: none"> • Active Facebook page, 352 likes • Twitter account, 702 followers <p>Diabetes Research & Wellness Foundation</p> <ul style="list-style-type: none"> • Active Facebook page, 376 likes • Twitter account, 919 followers • Inactive You Tube channel, 4 subscribers and 696 views | <p>“Diabetes - the patient experience” - international page, 11.4k likes</p> <p>“Ninjabetics” - UK based page, founded by diabetes blogger, 758 likes</p> <p>“Circle D” - UK based page, 310 likes</p> <p>“Diabetes” - international page 60,969 likes</p> <p>Many US based groups</p> | <p>Weekly Twitter chat: #gbdoc</p> <p>“Young, fun and type 1” UK based blog</p> <p>“Shoot up or put up” UK based blog</p> <p>“tudiabetes.org” International diabetes community forums (created by US based Diabetes Hands Foundation</p> <p>“diabetessupport.co.uk” UK based diabetes community forum (supported by Diabetes UK)</p> <p>“DAFNE online” UK based community forum managed and used by DAFNE graduates (supported by DAFNE).</p> |

| Mental health | | |
|--|--|---|
| Examples of professionally produced UK websites and social media sites | Examples of Facebook groups | Selected other social media activity |
| <p>Mind</p> <ul style="list-style-type: none"> Active Facebook page, 109k likes Twitter account, 110k followers Active YouTube channel, 1.4k subscribers and 786.3k views <p>Scottish association for mental health (Samh)</p> <ul style="list-style-type: none"> Active Facebook page, 4.9k likes Twitter account, 110k followers Active YouTube channel with 56 subscribers and 45.4k views <p>SANE</p> <ul style="list-style-type: none"> Active Facebook page, 9.7k likes Twitter account, 33.6k followers Active YouTube channel with 162 subscribers and 145.3k views <p>The Mental Elf</p> <ul style="list-style-type: none"> Active Facebook page, 2.9k likes Twitter account, 19k followers <p>Mental Health Foundation</p> <ul style="list-style-type: none"> Active Facebook page, 63.3k likes Twitter account, 36.6k followers Inactive YouTube channel, 200 subscribers and 41.8k views | <p>“Depression and anxiety support group” - UK based page founded by individual user, 6.9k likes</p> <p>“Anxiety & I” - UK based page founded by individual user, 54k likes</p> <p>“Depression” - international page founded by individual user, 32.2k likes</p> <p>Many closed support groups for specific CMHDs, such as PTSD, stress.</p> | <p>“Time to change” - UK based page featuring many blogs</p> <p>“purplepersuasion” - UK based blog, 428.3k hits</p> <p>@teaandtalking- UK based lived experience Twitter microblog, 5.1k followers</p> <p>“nomorepanic” website with many well-used forum threads about different facets of panic, anxiety, phobias and obsessive compulsive disorders.</p> |

| HPV immunisation | | |
|--|---|--|
| Examples of professionally produced UK websites and social media sites | Examples of Facebook groups | Selected other social media activity |
| <p>Arm against cervical cancer</p> <ul style="list-style-type: none"> Inactive Facebook page, 526 likes | <p>Some US based HPV community pages, inactive.</p> | <p>Many YouTube videos about HPV vaccine, presenting conflicting information about vaccine safety.</p> |

| Epilepsy | | |
|---|--|--|
| Examples of professionally produced UK websites and social media sites | Examples of Facebook groups | Selected other social media activity |
| <p>Epilepsy action</p> <ul style="list-style-type: none"> • Active Facebook page, 39.8k likes • Twitter account, 13.6k followers • Active YouTube channel, 142 subscribers, 102,452 views <p>Epilepsy society</p> <ul style="list-style-type: none"> • Active Facebook page, 7.7k likes • Twitter account, 7.9k followers • Active YouTube channel, 548 subscribers, 205,386 views <p>Epilepsy Scotland</p> <ul style="list-style-type: none"> • Active Facebook page, 4k likes • Twitter account, 5.2k followers • Inactive YouTube channel, 47 subscribers, 21,228 views <p>Young epilepsy</p> <ul style="list-style-type: none"> • Active Facebook page, 6.7k likes • Twitter account, 4.6k followers • Active YouTube channel, 69 subscribers, 28,104 views | <p>“Epilepsy support” page founded by an individual user, 1.6k likes</p> <p>“Epilepsy Scottish Highlands” page, founded by group of users, 544 likes</p> | <p>“Epilepsy sucks” - forum and social media set up by parents of children with epilepsy, 2.8k Facebook likes</p> <p>“UKepilepsy”- Blog series coordinated by one user (founder of site), with additional social media channels.</p> |

Appendix 3 – Pilot young adult interview schedule

Introductory questions

Can you tell me a bit about yourself?

Can you tell me a bit about your experiences of living with [diabetes/mental ill health]?

Day-to-day, how does your [diabetes/mental health issues] affect your life? Probe on supportive resources - people/health professionals etc.

Information seeking

Can you tell me a bit about how you have found out about [diabetes/mental health issues]?

What are the main sources and people that have helped you find out about [diabetes/mental health issues]?

Can you tell me about any online resources you have looked at?

Perceptions of specific social media sites

[Using the tablet computer] Can you tell me what you think about these sites?

- Facebook page of diabetes/CMHD charity
- Facebook community or group page set up by users for diabetes/CMHD
- Twitter stream for specific hashtag related to diabetes/CMHD
- YouTube video blog posted by a user about their lived experience of diabetes/CMHD

Have you seen this site before?

What do you think about the information on the site?

What do you like and dislike about this site?

Users' perspectives on resources development

So thinking about the sorts of resources we've looked at - do any of them they appeal to you?

Do you think you and people like you would be the target group for those sorts of sites?

Are there any [diabetes/mental health] websites that you feel have been really relevant to you?

Are there any particular times when you have felt alienated by a particular [diabetes/mental health] website?

So we've talked about the kinds of websites and resources that are available, can you think of any gaps or resources that are needed?

Perceptions and experiences of accessing [diabetes/mental health-related] content on the internet and on social media

What do you think about using social media websites for finding out about [diabetes/mental health issues]?

- For finding relevant information on [diabetes/mental health]?
- What about for communicating or connecting with other people?

How reliable do you think information you find on the internet is?

- How do you decide what is and isn't reliable?
- What sources would you say are the 'most' and 'least' reliable?
- What would make you trust something on a social media site?
- Are there any particular signs of something not being trustworthy?

Have you used the internet to help you find out about [diabetes/mental health issues]?

Can you describe what attracted you to use the internet in the first place? OR why you have not been attracted to the internet?

Can you tell me a bit about how you interpret and use the content from the sites you visited? So talk, me through how you would go about it...

Offline impact

How do you think the things you read on the internet fits with what you hear from other people or read in different places about [diabetes/mental health]?

Can you tell me about how you act on things you find out from the internet?

How do you go about incorporating or using things you find online into everyday life?

Are there different ways that you would use things you'd found out from different sources?

Social media and self-management

Do you ever get ideas online about things you might do to help with [diabetes/mental ill health] on day-to-day basis?

Are there any particular resources you use and find helpful?

[Using the tablet to explore various online resources] what do you think of these kinds of things?

- Interactive resources (tests, quizzes, apps to track blood sugar/mood)
- Forum content giving advice about self-management
- Access to health records, test results etc.

Can you think of any things that might be helpful for you to access online or on your phone?

Do you think social media is a good place for these kind of support/self-management resources?

Are there any problems with these sorts of things being available through social media?

What do you think about finding out about other people's experiences of [diabetes/mental ill health] for helping to manage your own experience?

Conclusion

Is there anything that we have not covered that you think is important or you would like to talk about in relation to health and the internet?

Do you have any ideas for how [diabetes/mental health] might feature on the internet in the future?

Appendix 4 - Young adult information sheet

Health Online: Exploring engagement with online resources for diabetes and common mental health issues



Information about the study (Plain Language Statement)

My name is Gillian Fergie and I am a PhD student from the MRC/CSO Social and Public Health Sciences Unit and the University of Glasgow.

I would like to invite you to take part in a research study. The information on this sheet gives you some details about why the research is being done and what it will involve. If you are interested in taking part, please read through the information and feel free to discuss it with others if you wish. If there is anything that is not clear or if you would like more information please do not hesitate to contact me (see contact details below).

What is the research about?

This research study aims to develop an understanding of what young adults, aged between 18 and 30, who identify as having either Type 1 or Type 2 diabetes or a common mental health issue (such as depression, anxiety or stress) think about health information on the internet and what experiences people have had exploring these issues online.

Who can take part?

If you are between 18 and 30, and have experience of either diabetes or a common mental health issue, we would really like to hear what you think and your experiences of accessing online resources. Taking part is entirely voluntary, it is your decision.

What will I have to do?

Take part in a one-to-one interview. This will involve:

1. Looking at some websites on a laptop and talking about what you think of them.
2. Telling me about your thoughts and experiences of seeking information about diabetes or common mental health issues on the internet

There are no right or wrong answers – I just want to hear what you think. If you do not want to answer any particular questions you do not have to.

If you take part, your contributions will be anonymous (no one will be able to identify you in anything written about the project) and they will be used in a research articles, presentations and a PhD thesis about engaging with health issues online. The fact that you have taken part in the research will be kept confidential. The discussion we have will be recorded and then written out in full, the recording and text files will be stored on a password protected computer. These files will not be linked in any way to your name or details.

The study has been given ethical approval by the University of Glasgow College of Social Science Research Ethics Committee and is funded by the Medical Research Council.

The interview will last between one and two hours and take place at a time and place convenient for you. You can withdraw at any stage without giving a reason. You will be given a £25 high street voucher for your time.

What should I do if I would like to take part?

Read this information sheet. If you are happy to take part, please get in touch using the contact details below. Then we will arrange a day and time for our discussion.

What do I do if I have any more questions?

You can ask me...

Email: g.fergie@sphsu.mrc.ac.uk Phone: 0141 357 3949 and ask for Gillian

You can also speak to my supervisor, Dr. Shona Hilton. Email: s.hilton@sphsu.mrc.ac.uk Phone: 0141 357 7537

If you have any concerns regarding the conduct of the research project that they can contact the College of Social Sciences Ethics Officer by contacting Dr. Valentina Bold at valentina.bold@glasgow.ac.uk

Appendix 5 – Young adult participant profiles

In alphabetical order by pseudonym:

Alistair (21, Glasgow, university education, in full-time higher education)

Alistair's experience of CMHDs started when he was in high school and suffered panic attacks related to the weather, he reflected that he was probably depressed for a period of time at school. Last year his mother passed away and since then he has been dealing with "shock and depression". Alistair also discussed that recently he had been suffering from health anxieties - seeing his GP almost every week, however, he reflected that this was probably related to his mother's death. He came into contact with mental health professionals during school, teaching him relaxation techniques to deal with panic attacks. More recently, he has spoken to his GP about anxiety and recently been referred for CBT. Alistair described using the internet to access a range of mental health resources; reading a bit about other people's experiences online and seeking professionally produced content from mental health organisations. Alistair also described how he managed his mental health by regularly accessing ASMR (autonomous sensory meridian response) videos on YouTube as a means of relaxing. He finds many informative health resources too generic and not personal enough, however he expressed concerns about Facebook and Twitter being inappropriate places for mental health content.

Andy (22, Edinburgh, secondary school education, employed as a professional golfer)

Andy was diagnosed with Type 1 diabetes when he was six years old. He lives with his parents. His parents, particularly his mum, were responsible for the management of his diabetes until he was about 11, between the age of 11 and 14 he gradually took more responsibility for self-management. He moved onto Basal Bolus, when he was nine. Andy has a very active lifestyle, playing both golf and curling professionally - balancing this level of physical activity with diabetes is the biggest challenge he identified in terms of self-management. In terms of his online experience, he has not drawn on online resources extensively. However, he has accessed information about other people's experiences of sport/exercise and diabetes self-management. He expressed concern about contributing content online, particularly advice, because he has no medical training. He stressed that even though he does not use online resources he might have more, if he had not had the support of his parents throughout his experience.

Anthony (28, London, university education, employed as a PR manager)

Anthony was diagnosed with Type 1 diabetes at the age of 14. Immediately he took responsibility for management and his parents were not heavily involved. He describes his initial approach to self-management as

uninformed and his move to Basal Bolus regime a few years later as a turning point in developing an understanding of the relationship between food and insulin. He discusses diabetes as an over-riding concern in his life, which affects everything, but does his utmost to minimise the effect it has on his decision-making and lifestyle. Anthony has been using forums for a number of years to generate and contribute to discussions about diabetes innovations and ways of managing diabetes. He follows blogs and posts on Twitter, trying to engage both other users and organisations with debate and discussion regularly. He discussed wanting to challenge high level decisions about research funding and certain dietary advice through online channels with knowledge he had built up through discussions on forums. He described the more emotional support groups as pointless and associates them with middle-aged American women. He also described Facebook as a place less for diabetes discussion and more for socialising. This is one online space where his diabetes is not to the fore.

Blake (27, Aberdeen, secondary school education, employed as a warehouse operative)

Blake was diagnosed with Type 1 diabetes when he was 17 months old. He suggested that this early diagnosis gives him a different perspective from most diabetics since he “never knew anything else”. He did not describe many problems with control although he did suggest that the most difficult period for managing his diabetes was his late teens/early 20s when he was getting drunk more often. Blake said that he might Google terms used by health professionals if he did not understand it but other than that finds no use for online resources. He said he did not trust other people to be providing reliable information and would prefer to speak to professionals. He found the social media sites, Facebook and Twitter, difficult to interpret and did not see any content that he thought was interesting or useful - potentially related to him not using the sites generally.

Bronwyn (28, Glasgow, university education, employed as a paralegal)

Bronwyn was diagnosed with Type 1 diabetes when she was a child, and received lots of support from her Mum, who was a nurse, and the health professionals she grew up with. Throughout her adolescence she maintained good management practices and this continued at University; however she attended check-ups less often. She had experienced some diabetes-related complications with her eyesight. Now, she continues to be well-supported in her diabetes, since her partner and her friends all have a fairly good understanding of it. In terms of online resources, Bronwyn finds the more sentimental social media content useless and “cringeworthy”. She prefers more factual, medical content. In the past though, especially during the period when she was going for treatment of her eye problems, she used online forums to access other people’s experiences of the surgery she was to undergo. She suggests that her age means she doesn’t use the internet as

much as some people might - growing up with diabetes pre-internet means it isn't a default place for her to access information.

Byron (18, Edinburgh, university education, in full-time higher education)

Byron was diagnosed with Type 1 Diabetes when he was 12 years old. Since diagnosis he has struggled to manage his diabetes efficiently and effectively. In particular, Byron mentioned how little he tests his blood sugar and that he can't seem to maintain best practice. He changed his regime to Basal Bolus and he said that this has increased his flexibility. Apart from recently developing a good relationship with his DSN (diabetic specialist nurse), Byron said that he dislikes encounters with health professionals, who generally reprimand him for his poor control. Byron expressed concern about searching for information online, particularly around "scary" long-term complications such as erectile dysfunction. However, he made reference to searching for information about acute issues, such as an injury on his foot. Related to his struggle to stay motivated to maintain good control Byron suggested that technologies that make him accountable to someone/something else might be useful for self-management. With regards to social media sites, Byron made a distinction between helpful opinion based chat content, such as Twitter content discussing self-management practices, and frivolous "cringey" support content, such as emotional and supportive Facebook groups.

Daniel (25, Glasgow, secondary school education, employed as a chef)

Daniel has been experiencing depression for the last year. He discussed a fear of death, anger management issues and stress at work, as well as a "lack of direction" in his life as symptoms of the depression he experiences. He did not describe support from his family, but has confided in a number of friends about his experience. Daniel suggested it was particularly valuable to talk to those of his friends who have had similar experiences, and that this made him feel much better. He has also attended a number of talking therapy sessions, a course of CBT and a more generic counselling session. Initially he found the CBT very valuable, however he has since become more sceptical about it. Daniel explained that he does not see how online resources relate to his experience and therefore does not access them independently. He described himself as fairly private, and although he said that he is not ashamed to admit he has depression, he would never use social media as a channel to discuss mental health issues.

David (29, East Kilbride, secondary school education, employed as an engineer)

David was diagnosed with Type 1 diabetes when he was 15 years old, and moved out of his family home a year later. He was always responsible for managing his diabetes, but generally took two injections daily and rarely

tested his blood glucose. David described a change in his attitude and approach to diabetes, at around age 25, from apathetic to conscientious and concerned. Despite this, David is currently experiencing eye complications which he attributed to poor management in his early years. Since diagnosis his regime has changed several times, now he has an insulin pump which he is particularly pleased about. In order to initiate the change in David's self-management practices he undertook a period of searching online to develop his understanding of diabetes. Later, after going on the DAFNE (Dose Adjustment for Normal eating) course, he accessed the DAFNE forum and then became active on a number of forums, where he appreciated the insights from other people around day-to-day management. He also learned about the pump there and discussed it with other users before getting one himself. He is also a member of a number of Facebook groups related to diabetes. David's online activities seem central to his experience of diabetes.

Debbie (30, Glasgow, university education, in full-time higher education)

Debbie has experienced a range of mental health issues and learning difficulties since childhood. She gets particularly anxious in social situations and finds her university work difficult to manage. Debbie described difficulties maintaining relationships with family and friends. She has a partner, who has similar experience of mental health issues. Debbie uses the internet extensively to explore mental health content, particularly new research, self-management resources and guidelines around symptoms, diagnoses and drug treatments. However, she is less comfortable with social media content around mental health issues, due to privacy issues.

Eleanor (26, Paisley, university education, out of work due to ill-health (ME))

Eleanor has been experiencing depression and anxiety since she was around 18 years old. Since then she has tried various types of counselling and has been prescribed different anti-depressant drug treatments. Earlier in the year she was diagnosed with ME, which she suggests is also connected to her experience of depression. Since first experiences she has not had a great deal of support from her family, although she now has a supportive partner. Throughout her experience seeking out online resources has been a major source of information and support for Eleanor. She is a member of a number of Facebook support groups for people experiencing Depression, as well as ME. She also actively moderates the 'Look OK, Feel Crap' forum hosted by Action on Depression and she portrays her commitment to de-stigmatising mental health issues through actively following and supporting charities online.

Euan (28, Glasgow, university education, employed as a primary school teacher)

Euan suffered from periods of anxiety and stress over the past five years. His main anxieties have been around health issues, he thought he had a heart problem, which caused him to constantly rub his chest giving him a large bruise. Discussion with the GP identified the issues, and allayed his anxieties about his heart health. Euan also discussed having panic attacks related to stress a few years ago, during a period of time when he was in debt and his father had cancer. Euan lives with his fiancée and seeks support from her and his family for stress and anxiety issues, preferring face-to-face contact generally to online interaction. Euan said he has not used online resources at all in the past for information or support about anxiety and stress. His fiancée has tried to support him with information she found online, but he was never very interested. Euan responded negatively to the social media sites we reviewed in the interview, saying they were not the kind of thing he would find helpful. He found various bits of content on them cheesy and likened his response to his response to social media generally.

Fiona (22, Edinburgh, university education, in full-time higher education)

Fiona was diagnosed as pre-Type 2 diabetic two years ago and has been on Metformin (drug treatment) ever since. She has also been attempting to change her lifestyle in order to minimise the risk of developing diabetes. When she was living at home her Mum supported her to follow a low GI diet which was successful, however since moving to Edinburgh for university she has found making changes more difficult. Both her diet and her activity levels are more varied now, making self-management strategies more difficult to implement successfully. At diagnosis Fiona searched online to get informed about diabetes, and periodically she still uses online resources to check facts and monitor her symptoms. She also has attempted to use drinking apps, such as “Intellidrink”, to monitor her alcohol consumption. However, although she said she liked the idea she had not considered using social media for support. She discussed feeling anxious about ‘liking’ pages due to stigma and expressed concern that people would judge her.

Fran (25, Glasgow, university education, in full-time higher education)

Fran first experienced a period of anxiety and low mood at school. She visited a GP and attended a course of CBT sessions, however, she found these difficult to engage with and described her recovery from this period as more related to proactive self-management based around exercise. However, recently she has encountered similar mental health problems and rather than attend counselling she has opted to undertake a course of drug treatment. Although Fran mentioned support from her mum, she seemed to reject her suggestions and general perspective. In terms of using online resources, Fran has accessed a range of content but has drawn on very little to support her own experience. She is sceptical about the use of generic online mental health programmes such as MoodGym and MoodJuice. In particular, she dislikes patronising languages and resources which oversimplify both the issues and recovery from them. However, she has accessed user-generated

content about drug treatments that she found useful. Fran talks about specialist blogs and online journalists she is interested in but is uneasy about the social media resources which feature emotional content.

Fraser (28, Oban, university education, employed as a science technician)

Fraser has struggled with depression at various points in his life - contemplating suicide at some points. Initially he struggled to cope with low mood at university and he has had similar problems coping after relationship breakdowns. He has never sought out professional advice but has looked online for information - both to support good mental health and less positively for suicide information. Fraser has not used social media to find mental health information or support generally. He expressed concerns about identifying with charity pages through 'liking' in case people start asking questions about his mental health. His preference is for helpful, professionally produced resources, which are easy to find and dislikes the conflation of charity fund-raising information with resources for people encountering mental health issues. He expressed scepticism about the usefulness of the more interactive self-management resources.

Freya (19, Glasgow, university education, in full-time higher education)

Freya was diagnosed with Type 1 diabetes when she was 10 years old. After some initial issues with testing her blood sugars using the prick test, she began to manage her diabetes and moved onto a Basal Bolus regime when she went to secondary school. Freya doesn't describe too many difficult management issues but when she first began to drink alcohol she had a bad hypo on a night out with friends and has since decided to be more open with those around her about diabetes. Freya described particularly good support from her dad who also has Type 1 diabetes. When she encounters an issue, he is her first point of contact. She has used the internet to get information, mainly from professionally produced websites. Throughout the interview, Freya seemed particularly dismissive of social media resources for diabetes, and was very resistant to drawing on other people's experiences. She also said she would never share her own experience or identify with diabetes online. She did, however, express some interest in more practical online resources and has the latest iPhone blood sugar meter technology, although this was a gift from her dad.

Ingrid (23, Glasgow, college education, employed as a retail assistant)

Ingrid was diagnosed with Type 2 diabetes two years ago. Since then she has been treated with Metformin (drug treatment), which didn't work, and then daily injections of Victoza (not insulin). She has been having difficulty with the side-effects of this medication, particularly nausea and has had to have time off work. Ingrid described using the internet to find treatment related information and has drawn on content from drug company websites. She was

directed to a number of websites by health professionals. She describes herself as someone who Googles everything. Ingrid has also discussed her health issue on social media, particularly Facebook, talking about the side-effects of her treatment, to prove to others she is unwell and using it as a forum to 'vent'. Although Ingrid is familiar with Facebook groups for sharing experience of Type 2 diabetes she doesn't subscribe to any to avoid that content appearing regularly on her feeds.

Jill (24, Glasgow, university education, in full-time higher education)

Jill was diagnosed with Type 1 diabetes 12 years ago. Before diagnosis, her parents thought she might have an eating disorder. She has had a number of serious hypos and been hospitalised various times related to excessive alcohol consumption. She described her diabetes as something that doesn't really concern her, although she did describe how she incorporates self-management strategies into daily life. She is on a Basal Bolus regime and practises carb-counting. She used to have a needle phobia and had an auto-injector until she was 19, but now uses an insulin pen and no longer has a needle phobia. Her mum is a doctor and a diabetes specialist so she has always drawn on her for information and support, although she suggested that her experience over the last 12 years has made her an expert. She described herself as being too experienced to need or want to use online resources, and found much of the user-generated content about mundane realities of diabetes boring and overly-analytical.

Joe (28, Dundee, university education, seeking employment)

Joe talked about a variety of mental health issues, which have had an impact on him since he was a teenager - he mentioned Aspergers syndrome and depression as well as issues related to gender. He described some of the symptoms of these as "bad brain days" and not being able to maintain relationships with people. As a result of these long term mental health issues he has not been able to maintain employment. Joe's experience of mental health professionals and therapies has been varied, with some not suiting him at all. He is now seeing a therapist who he likes, and has helped him work through issues around his gender. He presented himself as coming to terms with these issues and moving forward. Joe is very active online, he discussed preferring online to face-to-face communication because he can take time over it. He is a member of lots of Facebook support groups and contributes to discussions about mental health issues generally and those specifically relevant to him. He also follows blogs and actively follows people who tweet about mental health on Twitter. He mentioned some more negative aspects of social media as a place for mental health support, discussing blocking previous Facebook friends and in-fighting within support groups.

Josh (27, Kinloss, secondary school education, employed in the military)

Josh has suffered from PTSD since an accident at work killed his friend. He described the accident in detail and discussed his role in the events - he blames himself. Since then he has had flashbacks and suffered from insomnia. Josh also said he finds it more difficult to keep his anger and frustration under control since the accident. He referred to a number of difficult times: getting drunk, crying and “nervous breakdowns”. He lives with his wife, who is supportive, and talks regularly to his family and other military friends who understand PTSD. Josh received therapies and treatments from the mental health team associated with his regiment, in these sessions he has talked through his problems, as well as trying hypnosis and EMDR (psychotherapy - Eye Movement Desensitization and Reprocessing). He described the health professionals he has been working with as “outstanding”. Josh said that the first thing he does when he encounters any health issue is Google it, however his use of the internet with regards to his mental health has not been consistent. He has used some sites recommended by his doctor for self-management. He also found some less trustworthy, alarming information about PTSD which he checked with his doctor. Before the interview he had not looked at sources of other people’s experiences online but reacted very positively to the social media sites we browsed. Phrases and insights often appealed to him and were useful for him in expressing his experience to me.

Leah (26, Motherwell, university education, employed as a primary school teacher)

Leah suffered from a number of physical health issues that meant she spent a prolonged period off work. On return to work her mental health deteriorated. She ascribed this to her work situation and the stress of dealing with challenging professional issues, including work-place bullying, daily. She was diagnosed with post-viral fatigue and spent more time off work during which she suffered from low mood. Her living arrangements have recently changed with the ending of a long-term relationship. She moved from her own house back to her childhood home with her Mum. Her mum has suffered severe depression throughout her life. Leah talked about the impact of her mother’s depression on her childhood, describing herself as having an early awareness of low periods and mood issues and a need to develop strategies to mitigate her Mum’s symptoms. Leah did not identify herself as a heavy user of online resources, but she described various different sources of online information and support she drew on whilst dealing with her stress and low mood. She discussed using and sharing inspirational picture quotes through social media and saving them on her phone to exchange with friends. Leah also said she followed various celebrities (e.g. Marian Keyes) who discuss their mental health issues on blogs and Twitter, and has drawn on their experience to inform her strategies for self-management.

Leanne (23, Edinburgh, university education, employed as a retail assistant)

Leanne was diagnosed with Type 1 Diabetes in October 2011, 18 months before the interview. She had some awareness and experience of diabetes because her stepfather was diagnosed ten years ago. She was overwhelmed at first and anxious about going out and about after diagnosis but now reflects that she was over-cautious. Her dad has an insulin pump and because she saw how much he liked it she got one in December. She described it as “the best thing ever”, and has enjoyed the flexibility and better control it gives her. She described her healthcare team as “excellent” and has been supported by them in various ways (texts, emails), she has also been on a DAFNE/pump course. Leanne discussed her relationship with her dad as strengthened by their shared experience of diabetes. Leanne initially said she thought the social media pages about diabetes seemed like a positive outlet - she appreciated the variety of content and thought they were important for awareness raising and fundraising. However, she described herself as very private and says she would be reluctant to post any kind of public comment on any site. Leanne also expressed dislike at users “moaning” about issues and suggested some of the sites seem to encourage that type of discussion, related to this she would find it hard to trust other users’ contributions. She also described other people as having too many opinions and expressed her preference for more professionally produced content. Leanne is enthusiastic about technological diabetes developments including mobile apps.

Leon (22, Paisley, college education, employed as a sales assistant)

Leon was diagnosed with Type 1 diabetes two years ago, after a difficult period of undiagnosed symptoms. He has had some complications and nerve damage related to diabetes. He said that diabetes shouldn’t be something that affects your life and that he does not let it affect him. He described using online resources to learn about the physiology of diabetes but has a fairly rigid self-management routine and has not used the internet to explore other approaches for managing diabetes. Leon has not made any social connections online related to his diabetes, although he responded positively to the social media sites we browsed. He did say that some of the users of the site might be dwelling on their health issue rather than getting on with their lives and that overly negative or pessimistic posts were not helpful.

Liz (19, Inverness, secondary school education, employed in a restaurant and soon to embark on full-time higher education)

Liz developed anorexia when she was around 14. When she was 15 she was hospitalised and for a number of months afterwards received some talking therapy, involving her family, at a mental health service for young people. She described a period after this time when she felt better but recently she has developed more health problems related to eating. She has made some use of the internet as a resource for mental health content, describing it as the most prominent information source for her. However, Liz expressed concerns about posting on social media generally so would never share

anything about her mental health online. She made interesting comments about the types of users that resources appeal to, suggesting young people generally don't like different resources and information that those aimed at adults.

Max (29, Wolverhampton, university education, employed as a product designer)

Max was diagnosed with Type 1 diabetes when he was eight years old. He said his diabetes was not a big concern during his teenage years, generally his management of it was chaotic, particularly during periods of transition e.g. university life, moving house and splitting up from partners. His control improved when he moved onto Basal Bolus and began carb-counting, however, tests a year and a half ago indicated some diabetes-related changes in his kidney function. Max has sought information, support and advice online, particularly through forums, and he suggested that his perceptions of diabetes and self-management changed considerably at this point. Gaining support and advice through the forum, he perfected his control and now offers other people support online, recently being awarded the accolade 'Hero' of the Diabetes Support Forum. He has concerns about 'liking' diabetes related content and contributing to diabetes groups on Facebook because he sees it as a place for his established offline friends not his online diabetes friends. Max expressed his preferences about various types of content and social media. He dismissed image/quote posts and supportive sites containing them as 'worse than my Dad's girlfriend'. He also raised the idea of video content being primarily important for things like seeing pumps or injection techniques, rather than hearing people's stories, which he preferred to skim-read.

Mia (20, Inverness, secondary school education, employed in a restaurant and soon to enter full-time higher education)

A complex and chaotic family life in Mia's late teens led her to stop attending school and at the same time she began experiencing anxiety and stress. She suffered from panic attacks and after a short while, a traumatic incident led to her attempting suicide. After the resolution of a number of the difficult issues affecting her family life Mia expected that she would feel better, however she continued to experience depression and anxiety. Throughout her experience of mental health issues Mia encountered a number of different therapies. She took part in family therapy with her Mum when she was 14, but then did not attend any other therapy until she was 18, at which point she had some CBT and a course of person-centred therapy. She was also prescribed anti-depressant drug treatment. Mia used Google to gather information to develop her understanding of her experience. She has also used some online resources, such as MoodGym but found them over-involved. She is very critical of a range of online resources, saying they often do not feature the most useful content or appeal to young people.

Mhairi (28, St. Andrews, university education, employed as a social worker)

Mhairi was diagnosed with Type 1 Diabetes 14 months ago, and has been conscientiously learning about it ever since, describing herself as a ‘control freak’ and saying ‘I like to know what my body’s doing and stuff like that. So, the more information I have, and the more little gadgets and things, the kinda better’. She is on a Basal Bolus regime and practises carb-counting. At first she was intimidated by being responsible for her insulin dose and disliked pricking her finger to test her blood sugar. Since then, Mhairi has had very few problems incorporating diabetes management into her daily life, and even mentioned that discussing it with the young people she works with has often been a positive way to re-dress the inherent power imbalance she encounters as a social worker working with vulnerable young people. Mhairi’s experience of engaging online has been mainly limited to passively reading and consuming other people’s user-generated content. She particularly feels an affinity with young female diabetes bloggers and follows them across various social media.

Mike (30, London, university education, in full-time higher education)

Mike has been suffering from panic attacks for a number of years, he is unsure of the cause and although he associates it with anxiety he is not wholly convinced that it is a mental health issue rather than a neurological or physiological issue. He has tried a number of individual and group talking therapies and has had some drug treatment. He described the main impacts on his life as being unable to work and unable to be alone. Despite this he said he remains upbeat and tries to inform himself as much as possible about these issues, as well as mental and general health issues more broadly. Mike discussed using forums to exchange experiences with other people. He is interested in how other people deal with things and seems to enjoy mostly giving advice. He has some complaints about the way some sites are run and the behaviour of other users. He thinks Facebook is a good place for mental health content but enjoys places where he can interact and discuss issues at length. He likes to contribute his perspective and inhabits spaces where this is possible - ie he is less likely to read blogs. He has some experience of using YouTube type videos for self-management. He suggested that any technology that requires long-term commitment is unhelpful - he became bored of using one specific online app and suggests other people would too.

Nicola (29, Glasgow, university education, employed as a primary school teacher)

Nicola was diagnosed with Type 1 diabetes when she was 17 and at school. She got support from her family and health professionals, who gave her information. Her management in her late teens and early twenties was poor - she reflected in the interview that she just “didn’t care”. She continued like this until one health professional discussed the long-term health impacts of Type 1 diabetes and impressed upon her the importance of good control. Nicola’s use of online resources has been relatively inconsistent. She has

used online information regularly to support decision-making about acute issues such as managing diabetes when she was ill, and also managing diabetes and weight loss. However, she has never consumed or contributed social media content about diabetes or accessed information about other peoples' experiences online. She expressed concerns about liking charities like DiabetesUK online, because of what people might think, but is also open to exploring more online resources in the future. During the interview Nicola almost shifted perspective about social media and diabetes content, she went from saying she wouldn't like the DiabetesUK Facebook page to actively suggesting reasons for using it.

Paul (30, Glasgow, university education, employed as a recruitment consultant)

Paul has been experiencing mood swings and anxiety, related to a gambling addiction for a number of years. He related the initiation of these issues to the breakdown of a long term relationship when he was 21. He has discussed these issues with his GP and with a range of gambling counsellors. For a short period he received a course of anti-depressants. He described his current mental health as much better but says he has yet to fully resolve the issues. In terms of engaging online, Paul has not drawn on many resources consistently. However, he has looked at a number of online gambling forums and engaged with an online counsellor who recommended further resources to him. He expressed concerns about linking any kind of mainstream social media to mental health resources and discussed many of the challenges of engaging with online resources, particularly issues around bullying and trolls. Paul also talked about sites like YouTube being primarily for entertainment purposes and mental health content seeming inappropriate in that environment.

Penny (27, Leuchars, university education, currently a part-time health care assistant and caring part-time for two children under five)

Penny was first diagnosed with Type 1 diabetes when she was an infant, so has lived with the disease for as long as she can remember. Her reflections on childhood included all the ways she felt different, and was treated differently, to other children as a result of diabetes. Her parents were particularly strict with her diet growing up. At around 12 years old she took responsibility for managing her diabetes. However, when she was a student she struggled to maintain good control and in particular found it difficult to drink alcohol socially. She describes good support from both her family and partner throughout her experiences, although she described some anxiety about being often alone with her children. Penny has used the internet, fairly infrequently, to get information, from both official provider sites and some user-generated content. In particular, she used the internet heavily when she was pregnant to support her management of diabetes throughout. Penny highlighted that this was due to the lack of people around her at the time, since she was living in England, away from her family and partner.

Peter (19, Galashiels, school education, employed as a retail assistant)

Peter has been experiencing periods of low mood for the past year, related to various family and relationship issues, including the breakdown of his parents' relationship. After a period of time trying to "put a brave face on" he contacted his GP and was referred for counselling through a local young people's mental health charity. He described appreciating the opportunity to talk to someone about his issues and feels like this has been both appropriate and helpful, particularly in comparison to some of his peers who are experiencing similar issues and use drug treatments. Peter has not used online mental health resources at all, he described himself as being cautious of misinformation and therefore avoiding online resources. When navigating online mental health content he pointed to the importance of endorsement as a marker of quality and reliability of content. He also expressed appreciation of the social media resources but disliked the lack of privacy associated with them, and said he was wary of putting anything on Facebook about his mental health.

Poppy (30, Sheffield, university education, employed as a vet)

Poppy was diagnosed with Type 1 diabetes when she was 26 years old, after experiencing symptoms and administering a test herself at work. At first she found self-management challenging, and has always erred on the 'low' side. During pregnancy, Poppy regularly experienced hypos, which caused a number of problems at her various jobs. Following the first pregnancy, and discussions with health professionals about her consistent hypos, Poppy went on the DAFNE course and was also fitted with an insulin pump. She found the DAFNE course particularly useful for informing her drinking practices. At first she found the pump difficult and disliked how it made her feel about her body, however now she has got used to it and thinks her control has improved as a result. At first Poppy expected that the medical knowledge she has as a vet would translate into good self-management practices. However, she went on to talk about realising she knew very little about the "human side" and the "day-to-day mechanics". She then discovered forums and Facebook groups and has found these outlets useful ways of getting emotional support and discussing the day-to-day details of managing diabetes. In particular, she contributes regularly to a Facebook group for pregnant women with diabetes, where they discuss health professionals advice and grey areas in best practice. Poppy has also accessed a range of resources online, including NICE guidelines but discussed her frustration at the lack of research evidence available to her to inform her decision-making.

Ronan (28, Glasgow, university education, employed as an engineer)

Ronan was diagnosed with Type 1 diabetes in 2004. He has had a few bad hypos but described diabetes as having minimal impacts on his life. His contact with healthcare professionals is affected by his belief that if you

report truthfully about your control you could be at risk of losing your driving license. Ronan raised some minor concerns about his HbA1c and his control overall but has not sought support from health professionals for this. Ronan described actively seeking information online about diabetes and accessed a number of websites, many of which he now gets daily/weekly emails from. He has also liked a number of social media pages about diabetes, and while he likes to have information about awareness-raising and diabetes technology in his feeds, he dislikes lots of informal discussion and light-hearted posts. Ronan also reflected that it is difficult to maintain use of many (online and offline) helpful resources. His preference is for usable information that he can act on.

Rory (30, Glasgow, university education, in full-time post-graduate education)

Employment status: Student and tutor

Rory was diagnosed with Type 1 diabetes when he was 12 years old and missed a number of months of schooling. After initial diagnosis he took time to get used to getting regular injections and missed further school. He has also changed regime a number of times since diagnosis, but described Basal Bolus as “best yet”, since it provides him with much greater freedom. Despite this enthusiasm, he talks about diabetes as a big challenge, disliking the idea that he relies on insulin to survive. He described the health professionals he has had contact with positively. Rory discussed using online resources to develop his understanding of diabetes and browsed some online forums to access other people’s experiences of particular issues. However, he talked about being uneasy about the idea of sharing any information about his health online, and disliked Facebook sites related to diabetes. One resource he was particularly impressed by was My Diabetes My Way due to the access it gives to a range of test results. He suggested this could be really valuable for developing good self-management practice.

Sarah (22, Glasgow, university education, currently out of work due to ill health)

Sarah has been experiencing depression, anorexia and anxiety since she was 15. For a prolonged period she was very secretive about these issues but a few years ago she was approached by friends and then talked to a GP and her family about it. She has sought support from various places, and talked most positively about a support group she recently joined, which she described as having a transformative impact on her experience. Sarah has general concerns about information reliability online and about the security and privacy of information on social media. She has used social media, particularly Facebook, to express herself during periods of low mood. She described this as making her “vulnerable” and is concerned, in general, about how people with depression use social media. However, more recently she has joined the Facebook page of the support group she is a member of, and

“doesn’t care” if people can see that. She suggested that in such cases social media can be a good form of awareness-raising.

Simon (30, Glasgow, university education, self-employed furniture designer/maker)

Nine months ago Simon’s relationship with his girlfriend of eight years broke down, he was then homeless for a short period and went through a particularly difficult time. He described himself as always having had difficulties with anxiety and social situations, and notices patterns of negative behaviours related to drinking and his moods. He sought help through a GP and received counselling from an alcohol counsellor, although he isn’t sure if that helped a great deal. He was prescribed Citalopram for a period, and is now gradually stopping taking it. Simon discussed feeling much better about his life and mental health recently. He described his work and work-life balance in very positive terms. Simon has not actively sought very much mental-health related information online, nor has he come across any mental-health content through social media. He is cautious about liking mental health related pages. He did go through a stage of posting about his state of mind on Facebook which he now describes as silly and says it left him vulnerable. From time to time he mentions his mental health on Twitter, mainly in a humorous and oblique way. He is generally positive about the presence of mental health organisations and groups on social media but does not identify with them in many ways - as either relevant or useful.

Simone (25, Glasgow, university education, employed as a classroom assistant)

Simone has been experiencing issues around OCD and anxiety since she was 15 years old. She did not access any mental health services until she was at university, where she saw a counsellor and was then referred to a clinical psychologist. She has tried both CBT and alternative therapies such as ‘tapping’. Her contact with health professionals has not always been positive and in some cases she has felt frustrated by the lack of support available. However, she talked about the most useful support coming from family members and close friends who talk through her anxieties with her. In terms of the internet, Simone discussed using Google “for the wrong reasons”, searching out content which added to her health anxieties. She is particularly anxious about accessing inappropriate or illegal content and would only ever follow recognisable links or those recommended by a reputable source, e.g. BBC, The Guardian. Simone also expressed some anxieties about social media, saying she does not have Facebook because of “paranoia”. She also said that she wouldn’t ever want to write anything about her feelings online in case anyone could see it and had concerns about privacy and identity.

Sylvia (26, Inverness, university education, employed as a mental health support worker)

Sylvia has been experiencing mental health problems since she was a teenager, mainly depression/low mood. She discussed an abusive relationship and family illness as related to these issues. She has not had particularly good experiences with GPs and health care professionals generally, nor were teachers able to support her when she sought help at school. She has had a much better experience with private counselling more recently - her counsellor takes a person-centred approach and Sylvia said she responds well to her needs. Through work, Sylvia has had varied exposures to mental health therapies and approaches. Sylvia has used various different online resources, and spent time searching online for relevant information and support, especially related to her identity as a young mother. She has a preference for more professionally produced and supportive content, disliking isolated user comments giving advice. She said that she wouldn't share any personal insights about her mental health on social media but she appreciates positive affirmation posts - especially images and quotes. She also follows links and recommendations from other people around mental health content.

Tommy (28, Glasgow, secondary school education, employed as a banking assistant)

Tommy was diagnosed with Type 1 diabetes when he was around nine years old. Since diagnosis he has always taken responsibility for managing his diabetes, although he reflects that for the first few years his approach wasn't ideal. His mum in particular was very supportive and he developed good relationships with his DSNs. Around five years ago, he went on the DAFNE course which he credits with having transformed his understanding of diabetes and his self-management practices. His control has been relatively consistent since, although he has had one or two difficult hypos. Before the DAFNE course Tommy said he rarely accessed online resources, however, after doing DAFNE he had accessed a number of sites, including the forum for DAFNE graduates. Content about the carb content of various alcoholic drinks particularly interested Tommy, since this was one of the issues he finds more challenging to manage. Although he has contributed one post about a particularly bad hypo to his Facebook page, generally he doesn't access or contribute diabetes related content on social media. He expressed particular dislike for emotional content on Facebook pages, saying he "hates that".

Tara (21, Glasgow, university education, in full-time higher education)

Tara experienced some mental health issues when she was much younger in relation to feeling unsafe in her home. Reflecting on her mental health since childhood, she suggested she has probably been depressed since she was 13 and only now is she realising it. She talked about self-harming between the ages of 14 and 16 and her relapse this year. Tara had a panic attack at work recently and it was this that prompted her to seek help more formally. Since

then she has had some appointments with her GP and also went to see a counsellor at the university, but describes it as 'early days' in terms of treatment. Tara has used some online resources but her support and information seeking online have been fairly limited. Although she appreciates some aspects of both supportive and informative sites, she is sceptical about the help other people can provide. She also has preferences about types of content posted on social media - she favours resources over information and fundraising items. She also dislikes patronising content.

Appendix 6 – Final young adult interview schedule

Introductory questions

It would be really nice if we could start with you telling me a bit about yourself. So things like:

- What your job is?
- Maybe a little bit about where you live?
- Who you live with?

I'd be really interested to hear about your experiences of living with [diabetes/mental ill health].

- It would be good if you could tell me a bit about when you first started experiencing [symptoms of diabetes/mental ill health]?
 - What made you first think you had diabetes?/ When did you first get concerned about how you were feeling emotionally?
 - What happened next?
 - What sort of healthcare have you received? Can you tell me about management/treatments?
- Day-to-day, how does your [diabetes/mental health issues] affect your life?
 - What impact does it have on things like:
 - your work
 - social life
 - relationships
 - on how you feel emotionally / physically?
 - How do you cope with these challenges?
 - Probe on supportive resources

So one thing that really interests me is how people find out and learn about health issues:

- Can you tell me a bit about how you have found out about [diabetes/mental health issues]?
- What are the main sources and people that have helped you find out about [diabetes/mental health issues]?
 - Are these sources and people the same places that you would normally find out about other health issues?
 - Healthy lifestyle information - diet, exercise?
 - Acute issues - having a cold?

Perceptions of specific social media sites

So if you don't mind - I thought that now we could look at some examples of different types of websites:

| Bookmarked examples of social media websites | |
|---|---|
| Diabetes | CMHI |
| Professionally produced social media site | |
| Diabetes UK Facebook page | Mind Facebook page |
| User-generated social media site | |
| Diabetes - the patient experience Facebook community page | Depression Facebook community page |
| Twitter content | |
| #diabetes feed | #depression feed |
| Video content | |
| User-generated experience of diabetes blog on YouTube | User-generated experience of depression blog on Youtube |
| Professionally produced website, with embedded social media links | |
| Type 1 diabetes site aimed at young people | Depression and low mood site aimed at young people |

- Have you seen this site before?
 - Have you come across other sites like this before?
 - Do you visit this site or other ones like it regularly?
 - What makes the site useful or relevant for you personally?
- What do you think about this site?
- What do you think about the information on the site?
 - Would you trust it?
 - What would make you trust the site?
 - What would make you question its trustworthiness?
- What do you like about this site?
- What do you dislike?

Reminders of prompts for each social media platform

Facebook - users' contributions, anonymity, likes etc

YouTube - video element, blogging, suggested videos, searching etc

Twitter - hashtags, abbreviations, people to follow, celebrities with issue

Users' perspectives on resources development

- How reliable do you think information you find on the internet is?
 - How do you decide what is and isn't reliable?
 - What sources would you say are the 'most' and 'least' reliable?
 - What would make you trust something on a social media site?
 - Are there any particular signs of something not being trustworthy?
- So thinking about the sorts of resources we've looked at - do any of them they appeal to you?
 - Do you think you and people like you would be the target group for those sorts of sites?
 - If not, who do you feel like those online resources are aimed at?
 - Can you describe the type of person, or types of people you think they are aimed at?
- What are the features of websites or social media sites that make them seem targeted at particular groups?
 - Prompts: Design features? Language and tone of textual content? Images, videos, fonts
 - What features do you think makes [diabetes/mental health] sites targeted to young adults?
- Are there any [diabetes/mental health] websites that you feel have been really relevant to you?
- Are there any particular times when you have felt alienated by a particular [diabetes/mental health] website?
- So we've talked about the kinds of websites and resources that are available, can you think of any gaps or resources that are needed?
 - For everyone who has [diabetes/CMHD]?
 - For you personally?

So now moving on to you personally:

- Have you used the internet to help you find out about [diabetes/mental health issues]?
 - If yes - I'd be really interested to hear about how you used the internet as a resource.
 - Can you describe what attracted you to use the internet in the first place?
 - Have you used the internet differently at different stages of your life/illness?
 - It would be great if you could tell me a bit about the different sorts of sites you have visited?
 - For each - can you tell me a bit about how you interpret and use the content from this kind of site?
 - If no - I'd be really interested to hear about why you don't find the internet useful as a resource.

- Do you use or visit social media sites for anything to do with your health?
 - Can you tell me why you do/don't find it a useful place to find information or communicate about [diabetes/mental ill health] for you?
- How do you think the things you read on the internet fits with what you hear from other people or read in different places about [diabetes/mental health]?
 - So for instance, family, friends or health professionals?
 - Complements, duplicates or contradicts other sources?
 - [If no distinction made between websites and social media - probe on the differences]
- Can you tell me about how you act on things you find out from the internet?
 - How do you go about incorporating or using things you find online into everyday life?
 - Are there different ways that you would use things you found out from different sources?
 - A news article on a website?
 - Another user's advice?

And thinking about other people:

- What do you think draws other people to using social media for their [diabetes/mental ill health]?
 - Do you know other people who use social media for their health, can you describe how you think they use to me ?
 - What sort of things do they post? [prompt on different kinds of media as well as content of posts, e.g. images, videos, comments]
 - What do you think they get out of it?

Research

- Do you ever come across research about [diabetes/mental health] online?
 - If yes - Can you tell me a bit about what you have found before?
 - Where would you go to find research evidence?
 - If no - Would new research about [diabetes/mental health] be something you are interested in? If not - why?

Social media and self-management

- Do you ever get ideas online about things you might do to help with [diabetes/mental ill health] on day-to-day basis?
 - Are there any particular resources you use and find helpful?
 - SHOW EXAMPLES - what do you think of this site?

| Bookmarked examples of interactive online resources | |
|--|--|
| Diabetes | CMHI |
| Forum | |
| Netdoctor thread about infection and diabetes | Nomorepanic thread entitled "tips on low mood" |
| Interactive quiz | |
| Boots (webmd) carb quiz | Mindfulness stress test |
| "Tracker/diary" resources | |
| Blood sugar online tracker app | Stress diary tool, mindfulness app |
| Access to personalised information | |
| My diabetes, my way site which provides user access to test results | n/a |

- Can you think of any things that might be helpful for you to access online or on your phone?

- Do you think social media is a good place for these kind of support/self-management resources?
- Are there any problems with these sorts of things being available through social media?
- What do you think about finding out about other people's experiences of [diabetes/mental ill health] for helping to manage your own experience?

Conclusion

- Thanks very much, that's all my questions really, is there anything that we have not covered that you think is important or you would like to talk about in relation to health and the internet?
- Do you have any ideas for how [diabetes/mental health] might feature on the internet in the future?

Appendix 7 – Young adult consent form

Health Online: Exploring engagement with online resources for diabetes and common mental health issues



Consent form

If you would like to take part in the study and have read the information sheet, please tick each statement and sign at the bottom of the form.

| | |
|--|--|
| I confirm that I have read and understand the information about the study (plain language statement). I have had the opportunity to think about the information and ask questions. | |
| I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. | |
| I understand that what I say may be used in future reports, articles or presentations by the researcher. | |
| I understand that my name will not appear in any reports, articles or presentations. | |
| I understand that the information I give will be recorded and stored securely. | |
| I agree to take part in the above study. | |
| I understand and agree that the information from my interview may be made available to other bona fide researchers in the future for further research, but that this would be overseen by the MRC and be in accordance with their strict rules of confidentiality. | |

Name of Participant Signature Date

Researcher Signature Date

Appendix 8 – Producer participant information sheet

Health Online: Exploring engagement with online resources for diabetes and common mental health issues



Information about the study (Plain Language Statement)

My name is Gillian Fergie and I am a PhD student from the MRC/CSO Social and Public Health Sciences Unit and the University of Glasgow.

I would like to invite you to take part in a research study. The information on this sheet gives you some details about why the research is being done and what it will involve. If you are interested in taking part, please read through the information and feel free to discuss it with others if you wish. If there is anything that is not clear or if you would like more information please do not hesitate to contact me (see contact details below).

What is the research about?

This research study aims to develop an understanding of the multiple ways that people access diabetes and mental health resources online and how social media can be used for health information and communication. In particular we are interested in the ways organisations facilitate user-generated content online and how they develop and maintain an online presence. The findings from these interviews will be compared with insights from individuals who have experience of diabetes or a common mental health issue around their perceptions and experiences of exploring online health resources.

Your participation

We would really like to hear from the people who develop online communication and social media strategies for health-related organisations. If this is part of your job, we would like to hear about your views and experiences. If more than one person takes responsibility for this you can be interviewed together or separately. Taking part is entirely voluntary.

What will I have to do?

Take part in a one to two hour interview at a place and time convenient to you. During the interview we will discuss your thoughts and experiences of developing and promoting online health resources; your views on online health communication and user-generated content and the reliability of health information online.

If you take part, you can choose whether or not your contributions will be anonymous and to what degree. You can agree to be named and your contributions to be attributed to you; or agree to your organisation being named but your name replaced by a pseudonym during analysis and in presenting the data; or neither your organisation nor your name being used during analysis or in the presentation of the data. Should you choose the final option your contributions will be anonymous (no one will be able to identify you in anything written about the project). In any case, comments will be used in a research articles, presentations and a PhD thesis about engaging with health issues online. The fact that you have taken part in the research will be kept confidential by the researcher. The discussions we have will be recorded and then written out in full, the recording and text files will be stored on a password protected computer. These documents will not be linked in any way to your name or details.

The study has been given ethical approval by the University of Glasgow College of Social Science Research Ethics Committee and is funded by the Medical Research Council.

You can refuse to answer any questions and you can withdraw from the interview at any stage without giving a reason.

What should I do if I would like to take part?

Read this information sheet. If you are happy to take part, please get in touch using the contact details below. Then we will arrange a day and time for our discussion.

What do I do if I have any more questions?

You can ask me... Email: g.fergie@sphsu.mrc.ac.uk Phone: 0141 357 3949 and ask for Gillian

You can also speak to my supervisor, Shona Hilton. Email: s.hilton@sphsu.mrc.ac.uk Phone: 0141 357 7537

If you have any concerns regarding the conduct of the research project that they can contact the College of Social Sciences Ethics Officer by contacting Dr. Valentina Bold at valentina.bold@glasgow.ac.uk

Appendix 9 – Producer participant consent form

Health Online: Exploring engagement with online resources for diabetes and common mental health issues



University of Glasgow | College of Social Sciences

Consent form

If you would like to take part in the study and have read the information sheet, please tick the applicable statements and sign at the bottom of the form.

All of these statements should be ticked if you are willing to participate:

| | |
|--|--|
| I confirm that I have read and understand the information sheet for the study. I have had the opportunity to think about the information and ask questions. | |
| I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. | |
| I understand that what I say may be used in future reports, articles or presentations by the researcher. | |
| I understand that the information I give will be recorded and stored securely. | |
| I understand and agree that the information from my interview may be made available to other bona fide researchers in the future for further research, but that this would be overseen by the MRC and be in accordance with their strict rules of confidentiality. | |

Please tick one of these statements to indicate how far your contributions can be attributed to you:

| | |
|--|--|
| I understand that my name and the name of the organisation I work for will appear in any reports, articles or presentations. | |
| I understand that my name will not appear in any reports, articles or presentations and the name of the organisation I work for will appear. | |
| I understand that both my name and the name of the organisation I work for will not appear in any reports, articles or presentations. | |

Please tick this final statement:

| | |
|--|--|
| I agree to take part in the above study. | |
|--|--|

Name of Participant Signature Date

Researcher Signature Date

Appendix 10 – Producer participant interview schedule

Introduction, talk over the aims of the research and the issues mentioned in the information sheet.

Find out how long they have worked in the role. Some of the questions refer to the development of resources, if this is not relevant to the participant, edit questions.

I have looked at some of your organisation's online resources:

- Highlight two examples of pages, one social media and one more informative page.

I am really interested in both of these types of resources and the differences in the ways they are created and managed.

If it's useful for you we can use the tablet to have a look at areas of the website, or some of the social media sites your organisation has.

Introduction

Could we start with you telling me a bit about your role/job within [Organisation name]?

- In particular I'm really interested in your responsibilities with regards to the websites, social media sites and online presence of the organisation.

So firstly I'd just like to talk a bit about the ways your organisation is active online and how you manage that presence currently?

- What are the different ways the organisation maintains an online presence?
 - Can you tell me a bit about the website?
- How do you use social media currently?
 - Which platforms do you find most useful for reaching young people?
 - Do different social media reach different audiences for the organisation?
 - For examples, what sort of audience does Twitter have as opposed to Facebook?
- Can you describe the intentions of the organisation in creating the website and social media sites?
 - Were there specific aims and objectives?
 - Are there differences in your intentions for the organisation's website and the social media sites?
- Are there particular ways that you keep track of the main site and its visitors?
 - Do you collect data around visits to the site?
 - Do you know which areas of the site are visited most?
 - Do you have any info about 'lurkers' on social media - people who read posts from other users but do not contribute?
- How often do you update the main site?
 - Are there any specific ways that the site or the content is reviewed?
- How do you manage the different social media?
 - How do you decide what the organisation posts and where?
 - How do you keep track of users' posts and comments?
 - Do you have specific ways of responding to posts?
 - Do you have a particular approach to challenging posts?
- As technologies develop and more people access things on their mobile phone, are there any implications for your website and social media?
 - Do you have any apps under development?

Moving on to thinking a bit more about the design and development of the sites, and the users of the site.

- Can you tell me about the design of your website and how the look and feel of the site and subsequent social media were developed?
 - Pictures, photos, logos, fonts?
 - Are you able to tell me a bit about how it has developed? Has there been any major changes over time?
- When you were developing the site did you have specific users in mind? [If you didn't develop the site, at present do you think the site is aimed at specific users?]
 - Are there different groups of users the site is aimed at?
 - Is there a more specific target user group that the site is most geared towards?
 - Has there been any trade offs in making the website generally accessible as well as more useful to specific groups?
- Have you tailored the site to specific user groups? If so in what ways?
- Are there any particular ways you try to make the content of the site accessible to a variety of users?
 - Is the wording and language used a consideration?
- Is there any resources, research or data that you find useful for informing the design and content of sites?
 - Can you give me any examples of things you might have used?
- Has there been any feedback from users on the main site or the social media sites?
 - Do you every seek any feedback from users?
- Has the growth in social media over the last few years informed any changes in the way you manage the organisations online presence?

I'd like to ask you a little bit about communication and engagement, so about the organisation's communication generally and then some more specific things about communicating with users.

- How does online communication, the website and the various social media, fit into the organisations' overall communication or campaigns policy/strategy?
- Has a particular social media strategy been developed?
 - How did the different social media come to be used?
 - Are there specific considerations for each different social media platform?
 - Has the way each platform been used changed over time?
 - Since people's preferences for social media seem to change regularly, how do you keep up with changes in users' practices?
- What are the advantages to the organisation of using social media?
- What are the disadvantages to the organisation of using social media?
- How do users' engage with the organisation on the website and on the social media sites?
 - Are there differences between the more passive resources and the interactive ones in terms of how users' can interact?
 - Is there a regular dialogue/interaction between groups of users and the organisation?
 - How widely across the organisation are users' feedback and comments discussed?
 - Are there spaces for users to chat with other users?
 - How much do representatives from the organisation get involved in users' discussions?

- Do you see yourselves as providing particular resources for users through social media?
 - Support?
 - Information provision?
- When posting about (CMHD/diabetes) how do you frame it?
 - Are there specific rules around how to discuss it? (e.g. language to use)
- Do you have a particular approach to discussing health professionals and the NHS?
- Do you have a particular way of discussing users' experiences?
- Are the transient social media posts from the organisation different to the content on static websites?
 - What differences are there in the language and tone of posts?
- How do you incorporate different types of information?
 - Is research evidence every included?
 - How do you balance personal experience content with evidence informed content?

I'd just like to ask you a little bit about practical resources for [diabetes/mental ill health], things that can be provided online to help people manage their own health:

- What do you think about individuals using online resources to support self-management?
- Do you think there are any particular barriers to people using online resources for this?
- And conversely what do you think are the things which motivate and promote people to use online resources?
- Are social media sites useful for disseminating self-management resources?

And lastly I'd like to ask you a few things about innovations and opportunities for engaging people online with [diabetes/mental health related] content

- Do you foresee any new ways that users may be able to engage online with health resources - either other users or information?
- I wondered how you felt about mobile technologies and how they can be incorporated into resource provision alongside social media?
- Some of the young adults that I have been talking to have mentioned some ideas for integrating social media into online resources
 - Use of 'storify' technologies for collating tweets?
 - Collating online information resources with comments facilities-creating and accessing databases of resources and information?
 - Rating facilities attached to resources?
- Do you have any thoughts on how these may be useful or problematic?

Appendix 11 – Example of thematic network: ‘Navigating and assessing online content’



Appendix 12 – Example of social media content

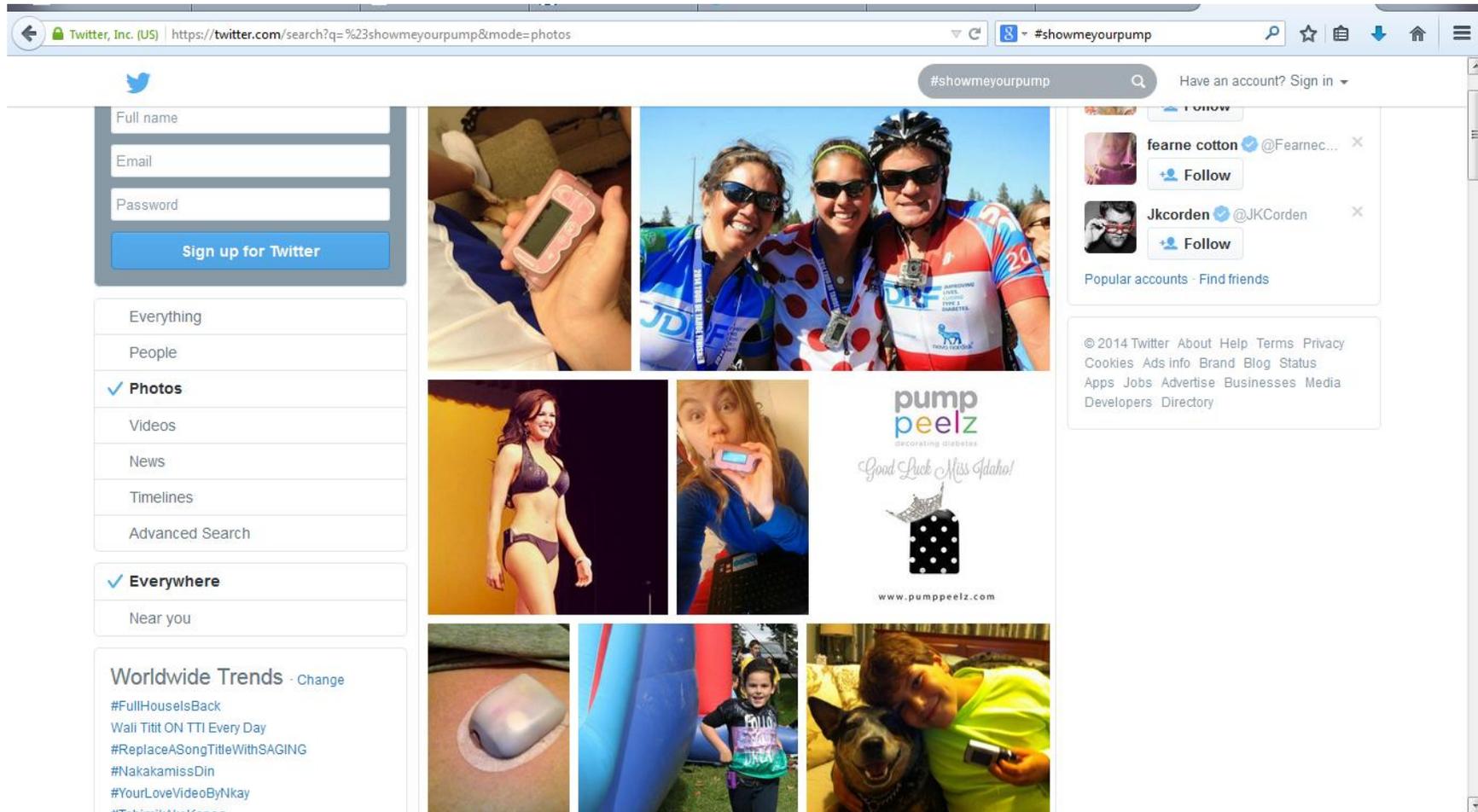


Figure 6: Twitter image search for #showmeyourpump, 22nd September 2014