Trust, empowerment, and identity online: A qualitative exploration of the use of Internet forums by individuals with long term conditions

A thesis submitted to The University of Manchester for the Degree of Doctor of Philosophy (PhD) in the Faculty of Medical and Human Sciences

2015

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# Table of Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table of Contents</td>
<td>2</td>
</tr>
<tr>
<td>List of Tables</td>
<td>5</td>
</tr>
<tr>
<td>List of Figures</td>
<td>6</td>
</tr>
<tr>
<td>Abstract</td>
<td>7</td>
</tr>
<tr>
<td>Declaration</td>
<td>8</td>
</tr>
<tr>
<td>Copyright Statement</td>
<td>9</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>10</td>
</tr>
<tr>
<td><strong>Chapter One: Perspectives from the Literature</strong></td>
<td>11</td>
</tr>
<tr>
<td>1.0 Overview</td>
<td>11</td>
</tr>
<tr>
<td>1.1 Long Term Conditions and Illness Identity</td>
<td>11</td>
</tr>
<tr>
<td>1.1.1 Self-management of long term conditions</td>
<td>15</td>
</tr>
<tr>
<td>1.1.2 Contested illnesses</td>
<td>18</td>
</tr>
<tr>
<td>1.2 Social Networks and Social Support</td>
<td>20</td>
</tr>
<tr>
<td>1.2.1 Peer support</td>
<td>23</td>
</tr>
<tr>
<td>1.3 Use of the Internet by Individuals with Long Term Conditions</td>
<td>24</td>
</tr>
<tr>
<td>1.3.1 Functions of Internet forums</td>
<td>26</td>
</tr>
<tr>
<td>1.3.2 Identity and empowerment online</td>
<td>27</td>
</tr>
<tr>
<td>1.4 The Digital Divide and Health Inequalities Online</td>
<td>29</td>
</tr>
<tr>
<td>1.5 Role of Online Peer Support</td>
<td>31</td>
</tr>
<tr>
<td>1.5.1 Effects of forum usage</td>
<td>32</td>
</tr>
<tr>
<td>1.5.2 Online and offline discourses</td>
<td>34</td>
</tr>
<tr>
<td>1.6 Assessing Peer Support Online</td>
<td>35</td>
</tr>
<tr>
<td>1.6.1 Experiential information</td>
<td>37</td>
</tr>
<tr>
<td>1.6.2 Forum norms and online performances</td>
<td>38</td>
</tr>
<tr>
<td>1.6.3 Establishing credibility and legitimacy online</td>
<td>40</td>
</tr>
<tr>
<td>1.7 Contested and Uncontested Illnesses Online</td>
<td>41</td>
</tr>
<tr>
<td>1.7.1 ME/CFS</td>
<td>42</td>
</tr>
<tr>
<td>1.7.2 Diabetes</td>
<td>44</td>
</tr>
<tr>
<td>1.8 Rationale for the Present Study</td>
<td>45</td>
</tr>
<tr>
<td>1.9 Research Questions</td>
<td>46</td>
</tr>
<tr>
<td><strong>Chapter Two: Methods and Methodology</strong></td>
<td>48</td>
</tr>
<tr>
<td>2.0 Overview</td>
<td>48</td>
</tr>
<tr>
<td>2.1 Rationale for a Qualitative Research Approach</td>
<td>48</td>
</tr>
<tr>
<td>2.1.1 Reflexivity in qualitative research</td>
<td>50</td>
</tr>
<tr>
<td>2.1.2 Quality and rigour in qualitative research</td>
<td>51</td>
</tr>
<tr>
<td>2.2 Internet Research Methods</td>
<td>53</td>
</tr>
<tr>
<td>2.2.1 Online and offline recruitment</td>
<td>53</td>
</tr>
<tr>
<td>2.2.2 Semi-structured interviews</td>
<td>54</td>
</tr>
<tr>
<td>2.2.3 Vignettes</td>
<td>55</td>
</tr>
<tr>
<td>2.3 Participants</td>
<td>57</td>
</tr>
<tr>
<td>2.3.1 Sample size</td>
<td>57</td>
</tr>
<tr>
<td>2.3.2 Participant demographics</td>
<td>58</td>
</tr>
<tr>
<td>2.4 Recruitment and Sampling</td>
<td>61</td>
</tr>
<tr>
<td>2.4.1 Participants with diabetes: Online and offline recruitment</td>
<td>61</td>
</tr>
<tr>
<td>2.4.2 Participants with ME/CFS: Online and offline recruitment</td>
<td>64</td>
</tr>
</tbody>
</table>
List of Tables

**Table 1.** Methods Used to Assess Quality and Rigour in the Research (Adapted from Elliott et al., 1999) ................................................................................................................................................52
**Table 2.** Gender of Participants ..................................................................................................................58
**Table 3.** Age of Participants .......................................................................................................................59
**Table 4.** Education Level of Participants ....................................................................................................60
**Table 5.** Participants’ Employment Status ..................................................................................................60
**Table 6.** Recruitment Methods for Participants with Diabetes ........................................................................63
**Table 7.** Recruitment Methods for Participants with ME/CFS .................................................................66
List of Figures

Figure 1: Vignette 1 .......................................................................................................................... 135
Abstract

The Internet is increasingly being used as a source of health advice and information by individuals with long term conditions (LTCs). Online forums allow people to interact with others with similar conditions, providing access to a form of social support that is based around the shared experiences of living with and managing an LTC. However, it is not clear how this support is integrated into people’s lives and their use of health services. To date, research in this area has predominately focused on single conditions, and while it has been suggested that Internet forums may be particularly beneficial for those with ‘contested’ LTCs, this has not been adequately explored. This study aims to address this gap by exploring how individuals with contested and uncontested LTCs utilise Internet forums.

This study used qualitative methods, and semi-structured interviews were conducted with 20 participants with ME/CFS and 21 participants with type 1 and 2 diabetes. These conditions were considered to provide an appropriate context in which to explore the use of the Internet and Internet forums for contested and uncontested LTCs. Participants were recruited via a number of online and offline routes, including discussion boards, email lists, newsletters, and face-to-face support groups. Interviews transcripts were analysed using thematic analysis.

The results focused on three overlapping themes that were identified during the analysis; namely (1) the process of developing and maintaining trust on forums, (2) accessing support and empowerment online, and (3) forum users’ presentations of self online. The use of online discussion groups was a complex and nuanced process, and was influenced by a number of individual and illness specific factors. Developing relationships with trusted forum members enabled individuals to give and receive support online, and provided a tool of empowerment. While access to peer support and the lived experiences of others were valued by interviewees, forums also allowed participants to access both experiential and scientific knowledge online, providing both lay and expert perspectives around LTCs. In addition, interviewees were seen to carefully manage how they presented themselves on forums, selecting the information that they shared about themselves in order to develop and maintain a particular online persona.

By drawing on the advice, information, and support shared online, participants were empowered to position themselves as active participants in their own healthcare and to further engage with healthcare professionals. The findings indicate that forums can play a valuable role in aiding and motivating individuals in the daily management of LTCs, and highlight how this support is used to complement formal health services.

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Name: Ellen Brady
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Thesis Title: Trust, empowerment, and identity online: A qualitative exploration of the use of Internet forums by individuals with long term conditions
Date Submitted: 8th of November 2015
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Acknowledgements

I am indebted to everyone who was involved in the research process. Firstly, and most importantly, thank you to all of the participants who generously gave their time and energy and made this research possible. I would like to thank the Medical Research Council for supporting this PhD with a Doctoral Training Grant and for providing me with the opportunity to study at the University of Manchester. I am also grateful to everyone who assisted with the recruitment process, especially the forums, support groups, and charities that were so helpful and encouraging during this time.

Thank you to my wonderful team of supervisors, Dr Caroline Sanders, Dr Julia Segar, and Dr Ivaylo Vassilev, and to Professor Anne Rogers, who was involved in the initial stages of this study. In particular, I am grateful to Caroline and Julia for their invaluable support, guidance, and encouragement – both virtual and face-to-face – over the last few years.

I would also like to thank my fellow PhD students at the University of Manchester, particularly Naomi Wood, Lisa Brunton, and Dr Donna Bramwell, for their help and advice. A special thank you goes to Dr Abigail Methley and Katie Paddock for providing constant support and a listening ear. Thank you to all of my Dublin friends for their advice and encouragement, especially Dr Lauren Kavanagh.

Lastly, thank you to my family: Mary, Peter, and Tess. Their support during this PhD, and throughout all aspects of my life, has been unwavering, and for that, I am extremely grateful.
Chapter One: Perspectives from the Literature

1.0 Overview
Rapid advances in technology and Internet use have led to an increasingly evolving body of research and practice in the area of eHealth. In particular, there has been a wealth of patient-centred systems and services which aim to extend traditional health services by offering personalised support (Swan, 2009). This includes a move towards the integration of technology into formal health services, such as the provision of telehealth and telemedicine (e.g., Cartwright et al., 2013), as well as the growth of informal support systems via online patient communities (e.g., Frost & Massagli, 2008; Johnston, Worrell, Gangi, & Wasko, 2013). This thesis addresses a specific subsection of this informal growth, namely the use of online discussion groups by individuals with long term conditions. Notably, Internet forums provide users with easy access to relevant health information, advice, and support from peers (Coulson, 2005), and allow individuals to control the content and flow of the information that they receive, rather than accessing it through healthcare professionals (Hardey, 1999). Within this context, the nature of Internet forum usage by individuals with contested and uncontested long term conditions will be explored, and aspects of this usage – trust, support, empowerment, privacy, anonymity, and identity – will be examined.

1.1 Long Term Conditions and Illness Identity
A long term condition (LTC) is a chronic condition which may not necessarily cause someone’s death. The UK’s Department of Health defines an LTC as “one that cannot currently be cured but can be controlled with the use of medication and/or other therapies” (Department of Health, 2010, p. 4), and includes diabetes, asthma, arthritis, heart failure, chronic obstructive pulmonary disease, dementia, and a range of disabling neurological conditions as examples of LTCs. LTCs often involve multiple symptoms, are associated with a number of uncertainties, require considerable palliative efforts and supplementary services, tend to interfere with the lives of patients and their family and friends, and are expensive to treat and manage (Strauss et al., 1984).

While there has been considerable progress in the control and treatment of symptoms and effects for some conditions, people are rarely completely cured of LTCs (T. Hogan & Palmer, 2005). In some cases, their lives can become dominated by the control of illness-related complications and responses to crises. It has been suggested that the experience of serious chronic illness represents a continual ‘hovering’ between the states of suffering and
enduring, along with the ongoing process of reformulating the self (Ohman, Söderberg, & Lundman, 2003). Strauss (1981) argued that ‘multiple problems of living’ are associated with chronic illnesses and can impact every aspect of a person’s life. These can include preventing and managing medical emergencies, managing symptoms and treatment regimens, efficiently organising and balancing one’s time, preventing or coping with social isolation, adapting to changes in the trajectory of the disease, and normalising one’s life despite illness.

In addition to the physical effects associated with the development and progression of an LTC, the individual emotional and psychological effects are well documented (Sidell, 1997). Stanton, Revenson, and Tennen (2007) reviewed research surrounding psychological adjustment to chronic diseases and suggested that chronic illnesses require adjustment across multiple life domains, as well as the different stages of an LTC (Bury, 1991). This indicates that dealing with the psychosocial issues associated with an LTC is a complex process. Individuals’ understanding of their condition, the delivery and availability of information, social support, and emotion-focused or problem-focused coping strategies have been identified as having an important role in disease outcome. Ensuring these needs are met in an appropriate health care environment can provide a challenge for physicians (Branch, Lipsky, Nieman, & Lipsky, 1999).

In addition to these needs, the impact of LTCs on individuals’ identities has long since been acknowledged. In particular, criticisms of Parsons’ (1951) construct of the ‘sick role’ (Lawton, Peel, Parry, Araoz, & Douglas, 2005) have led to a shift in the conceptualisation of illness identity by researchers. In this construct, the medical encounter and subsequent medicalisation of a patient’s illness was viewed as pivotal. By virtue of their condition, people entered a state of ‘sanctioned deviance’, where they were exempt from normal social roles, but were obligated to seek help in order to recover. Rather than acting as active participants in their own healthcare, individuals merely had a responsibility to comply with the advice and instruction of their doctors, in line with the medical knowledge and authority inherent in healthcare settings (Parsons, 1951).

It should be noted that this shift in focus occurred alongside a broader movement within sociological and psychological research (Burnham, 2013; Varul, 2010). While historically health care has taken a paternalistic approach, in contemporary medicine, alongside other disciplines, there has been a recent trend toward patient-driven and patient-centred care (Murray & McCrone, 2015). Indeed, it could be argued that the consideration of individuals
as proactive participants in their own healthcare merely reflects a change in research, policy, and discourse to mirror the attitudes and behaviours of patients. This is particularly true for those with chronic illnesses, for whom the notion of ‘recovery’ is radically different to that conceptualised by Parsons (Varul, 2010). Instead, recovery from LTCs can be conceptualised as a process of learning to live with and accept the condition (Brooks, Rogers, Sanders, & Pilgrim, 2015). For these individuals, interactions with healthcare professionals make up a small part of their daily lives and management of their conditions (Kielmann et al., 2010), in contrast with the paternalistic view of doctor-patient relationships put forward by Parsons (1951).

The resulting research has provided a number of useful notions with which to consider the experiences of individuals with LTCs. Notably, the concept of ‘biographical disruption’ (Bury, 1982) challenges a biomedical focus on chronic conditions by examining the impact of illness on personal meaning. Bury (1982) contends that the onset of an LTC represents a disruption to an individual’s personal narrative. While the daily interferences with activities and relationships are acknowledged, the model focuses on how everyday structures and assumptions are undermined by the presence of illness and the social and cultural meanings attributed to this presence. This disturbance in turn affects how individuals construct and preserve their self-identity (Reeve, Lloyd-Williams, Payne, & Dowrick, 2010).

Williams (2000) selects three aspects of the process for discussion. Firstly, there is a disruption to ‘taken-for-granted assumptions’ about the world, notably assumptions around age, pain, and the limitations of our bodies (Bury, 1982). In this way, individuals are forcibly removed from a ‘normal’ trajectory of living to one that is marked by upset, disruption, and uncertainty. In addition, disruptions to ‘explanatory frameworks’ result in questions such as, “Why me? Why now?” leading individuals to search for meaning in the events that have occurred and to attempt to frame their experiences within the context of their existing knowledge (Bury, 1982). Finally, there occurs a ‘mobilisation of resources’. In the face of disruption, individuals are required to evaluate the resources available to them – physical, social, temporal, financial, medical, and cultural (S. Williams, 2000) – and to assess them in light of adversity.

While aspects of Bury’s work have received some criticism (e.g., Larsson & Grassman, 2012; S. Williams, 2000), the notion that chronic conditions impact not just on the physical, emotional, and psychological needs of those with LTCs, but also their individual narratives and self-identity, has had a lasting impact. The ‘work’ undertaken by individuals as a result
of this disruption includes identifying which aspects of their identity have been lost, which remain, and which have been added, in order to create a new identity in response to the situation (Corbin & Strauss, 1987). Additionally, individuals have to come to terms with their new identity and to reorganise their lives and daily activities in line with this identity (Asbring, 2001).

The process of adaption to redefined bodily losses and limits occurs repeatedly over the course of the illness trajectory, as individuals adjust to progressive disruption (Charmaz, 1995). In particular, Charmaz (1983) highlights the ‘loss of self’ experienced by many with chronic illnesses, as the experiences and meanings upon which their identities are built are no longer available to them. She argues that this process can be complex and overlapping, with individuals’ restricted lives resulting in them withdrawing from social activities. This can in turn heighten their sense of a loss of identity due to the absence of opportunities for self-validation through socialising with others (Lawton, 2003).

This is not to suggest, however, that the onset of a chronic condition and the subsequent disruption to identity occurs passively, without any input from the individual. As suggested by Bury (1982), a mobilisation of resources typically results in individual strategies of coping and adaption to living with illness. Lawton (2003) provides a commentary on some of the factors that influence, and in certain cases, mediate the effect of this disruption, such as age and life stage (Sanders, Donovan, & Dieppe, 2002), background and life experiences (Pound, Gompertz, & Ebrahim, 1998), gender (Bendelow, 1993), and relationships (Pinder, 1995). Similarly, Williams (1984) described a process of ‘narrative reconstruction’, whereby those with LTCs attempt to create a sense of coherence and stability via a reconstruction of their experiences “in such a way that illness could be given a sensible place within it” (p. 197). Indeed, Asbring (2001) argues for the concept of illness gains, in which individuals gain new insights as a result of their condition and illness experiences.

Despite this, it is evident that the onset of an LTC is a disruptive event, which affects individuals in multiple domains across the trajectory of their lives (Stanton et al., 2007). Taken in sum, research into the impact and effects of chronic illness indicate that the presence of an LTC can result in an array of patient needs, including medical, social, and psychological needs. Indeed, it suggests that factors outside the medical domain can play a pivotal role in individuals’ adjustment to LTCs. It is these factors that will be the focus of the remainder of this chapter, specifically the role that the Internet and Internet forums can
play in supporting and empowering those with LTCs and facilitating their reconstruction of identity.

1.1.1 Self-management of long term conditions

As mentioned, it can be difficult to meet the multitude of needs of chronically ill individuals within current health care settings. In an attempt to offer an improved method of managing LTCs, in addition to lessening demand on health services (Department of Health, 2005), there has been a recent policy shift in terms of the responsibility taken by individuals for their own health care (Parr, 2002). Accordingly, people are beginning to be encouraged proactively seek out health information, advice, and support about their illness (Murray & McCrone, 2015). As part of this adjustment, emphasis has moved from formal healthcare settings to self-care. The aim of this change is to enable those with LTCs to take control of their health and health care, as set out in policy documents by the UK’s Department of Health and National Health Service (NHS) (e.g., Department of Health, 2001, 2004).

As a result, individuals with LTCs are repositioned from passive recipients of expert care to active consumers who make informed choices and share responsibility for their health care (Kielmann et al., 2010). Though this is not to suggest that this behaviour did not always occur, it does indicate that the sanctioned role and identity of patients within the health system has shifted from a recipient of care within a paternalistic doctor-patient relationship, to actively negotiating and shaping their care. In addition, changes in technology and Internet use over the last few decades have meant that individuals’ sources of health information and advice have increased (Dutton & Blank, 2013). While this will be discussed in detail in later sections, some brief considerations around the notion of active patients will first be outlined.

The involvement of individuals in their own health care has been termed self-management. While there have been a number of different definitions of self-management, with some highlighting the notion of self-management as a group process (e.g., Alderson, Starr, Gow, & Moreland, 1999), Barlow, Wright, Sheasby, Turner, and Hainsworth (2002) draw on the myriad of factors involved in LTCs to describe the process as “the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences, and life style changes inherent in living with a chronic condition” (p. 178). In addition, they suggest that, in order for self-management to be effective, it must include the “ability to monitor one’s condition and to affect the cognitive, behavioural, and emotional responses necessary to
maintain a satisfactory quality of life” (p. 178). This illustrates the different roles involved in the psychological and social management of living with a chronic illness.

In an effort to establish and increase self-management strategies, several interventions have been developed which directly target aspects of individuals’ management of LTCs. Typically, these interventions include three components – medical or behavioural management, role management, and emotional management – in order to address the different aspects of chronic illness self-management (Lorig & Holman, 2003). In addition, Lorig and Holman (2003) highlight five core self-management skills: problem solving, decision making, resource utilisation, forming a patient/health care provider partnership, and taking action. By enabling individuals to develop these skills and apply them to their own lifestyles, condition, and health care, they can make decisions, tailor resources, and engage with healthcare professionals as appropriate.

Newman, Steed, and Mulligan (2004) report that the range of approaches of interventions, from symptom specific management to lifestyle management, along with the diversity of the conditions involved in these interventions make it difficult to draw conclusions about the effectiveness of these interventions. However, one key component of self-management literature is the notion of self-efficacy, or “beliefs in one’s capabilities to organise and execute the courses of actions required to produce given attainments” (Bandura, 1997, p. 3). This individualised approach has been at the core of a number of self-management interventions (e.g., Farrell, Wicks, & Martin, 2004; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). Despite this, there has been increasing recognition of the need to consider the context in which self-management occurs (Koetsenrijter et al., 2014), rather than focusing on individual motivations and behaviour change.

With this in mind, researchers have begun to question the extent to which ‘self’-management occurs (Piette, 2010), considering instead the impact an individual’s external environment – namely, their formal healthcare providers, informal social networks, and physical environment (Gallant, 2003) – has on the degree to which they successfully manage chronic conditions. While the role of clinicians in supporting individuals to self-manage their conditions has been acknowledged (e.g., Coleman & Newton, 2005), the focus has been primarily on the impact that social relationships have on self-management behaviours.
Piette (2010) notes that family and friends can fulfil the role of ‘informal caregivers’, and in doing so, fill the gaps created by healthcare services. This work can consist of assistance with transport, medication, and daily living, along with emotional support. Outside of the help directly related to illness management, social relationships also play a role in the practical and emotional challenges of living with a long-term condition (D. Reeves et al., 2014; Vassilev et al., 2011, 2013). For example, in a review of research in this area, Gallant (2003) reports that higher levels of social support are associated with improved self-management behaviours. In particular, this association is present for conditions such as diabetes, where dietary adjustments make up a large part of self-management regimes.

Though family and friends have been viewed as a key component of the social networks of individuals with chronic conditions (e.g., Gallant, 2003; Gleeson-Kreig, Bernal, & Woolley, 2002; Ofstedal, Bru, & Karlsen, 2011; Piette, 2010; Rosland et al., 2008), increasingly research has included a broader perspective of social networks. This outlook includes voluntary and community groups (Blickem et al., 2013; D. Reeves et al., 2014; Vassilev et al., 2011, 2013), religious or ethnic groups (Vassilev et al., 2011, 2013), and pets (Brooks et al., 2013; Vassilev et al., 2013), as members of social circles. Indeed, it has been suggested that these wider networks play a pivotal role in supporting and maintaining self-management behaviours. Vassilev et al. (2013) report that individuals with LTCSs who engage in networks and communities beyond their immediate family and friends have greater access to health-relevant support, while Reeves et al. (2014) suggest that social involvement in a diverse set of networks impacts positively on self-management and well-being, including a greater maintenance of health behaviours over time.

While this will be discussed in detail at a later point in this chapter, for now, it is important to note that in considering self-management in LTCSs, the impact of an individual’s support networks, including family and friends as well as wider social networks, must not be dismissed. Rather than existing in a vacuum, self-management instead occurs in the context of collective and networked phenomena (D. Reeves et al., 2014). In addition, it is necessary to acknowledge the broader environment in which both these networks and individual self-management are occurring. For example, research suggests that contextual factors, such as people’s life stage or socioeconomic background may impact on their illness perception (Pound et al., 1998). However, Lawton, Peel, Parry, Araoz, and Douglas (2005) caution the importance of examining not just individuals’ everyday lives, but also the settings and locations in which they receive their health care. They argue for the need to take into account how and where individuals with LTCSs interact with health services and develop
their self-management strategies, along with broader economic and policy factors which influence the nature and content of health service delivery.

1.1.2 Contested illnesses
Considering the experiences and needs of chronically ill individuals within current healthcare settings highlights the importance of reflecting on the needs and experiences of those who may be positioned outside the realm of healthcare services. The biographical disruption created by the onset and diagnosis of a chronic condition results in simultaneous disruptions in social relationships and access to material resources (Bury, 1982). By contrast, individuals with illnesses where symptoms are medically unexplained or where a biomedical explanation is not present are often not provided with a diagnosis, resulting in an additional source of disruption or ‘chaos’, when individuals’ experiences are characterised by confusion and uncertainty (Nettleton, Watt, O’Malley, & Duffey, 2005).

Commonly cited examples of these medically unexplained or contested illnesses include fibromyalgia and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), while other researchers include multiple chemical sensitivities and gulf war syndrome in that definition (Swoboda, 2008). As contested illnesses are identified by the absence of biomedical explanation, the diseases are controversial and poorly understood due to the lack of objective data to validate the patient’s subjective complaints, and diagnosis and treatment are often difficult to obtain (Schoofs, Bambini, Ronning, Bielak, & Woehl, 2004). Indeed, they have been described as “illnesses you have to fight to get” (Dumit, 2006, p. 577), acknowledging the struggle that individuals can face to have these conditions diagnosed and subsequently legitimised. In many cases, it is the patients themselves who are instrumental in establishing legitimacy surrounding their conditions. For example, Arksey (1994) describes how individuals with repetitive strain injury (RSI) collectively lobbied healthcare professionals by drawing on both their own lay experiences and medical literature to make a case for the existence of their condition.

In consultations with healthcare professionals such as general practitioners, the legitimacy attributed to a patient’s symptoms can provide an initial context in which health care interactions occur. May et al. (2004) suggest that an incongruence between an individual’s presentations of their symptoms and a doctor’s perceptions of those symptoms can result in frustration for the doctor, leading to consultations becoming difficult and unsatisfying for both participants (Salmon et al., 2007). In addition to typical aspects of chronic illnesses, such as managing symptoms and treatments and coping with changes in the progression of
the disease (Strauss, 1981), individuals with contested illnesses may face difficulties in accessing treatment regimes due to scepticism around the validity and legitimacy of their symptoms (May et al., 2004). Indeed, healthcare professionals can be negative or even dismissive towards patients with unexplained symptoms (Shatock, Williamson, Caldwell, Anderson, & Peters, 2013). As a result, considerations around self-care and self-management represent a different context for individuals with contested illnesses compared to those with biomedically legitimised illnesses.

Notably, individuals experiencing contested chronic conditions can face similar difficulties in their interactions with family and friends. The potentially lengthy struggle for a diagnosis, and therefore, legitimacy, can lead to perceptions amongst acquaintances that the illness is ‘all in their head’ or they are ‘faking it’ (Dumit, 2006; Nettleton, O’Malley, Watt, & Duffey, 2004). Ware (1992) details the dichotomy experienced by individuals with ME/CFS as a result of the lack of understanding of their condition – either they are seen as unnecessarily exaggerating routine complaints or they are viewed as perceiving imaginary symptoms. Similarly, the absence of credible physical evidence of their condition can cause individuals to worry that they will be viewed as mentally ill, with the associated stigma resulting in sufferers distancing themselves from their family and friends. In addition, they may hide their diagnosis and/or symptoms from others, leading to further isolation (Newton, Southall, Raphael, Ashford, & LeMarchand, 2013).

Crucially, the lack of consensus and understanding around contested conditions may impact on individuals’ abilities to develop support networks to assist with self-management behaviours. Nettleton (2006) reported that participants with medically unexplained symptoms appreciated advice from clinicians about how best to manage their symptoms, but that this advice was difficult to obtain. In the case of highly debated illnesses such as ME/CFS, the disparate conceptions of the condition from patients and clinicians can result in consultations becoming a struggle between the two contrasting positions (Banks & Prior, 2001), rather than an opportunity to support individuals to develop self-management strategies (Coleman & Newton, 2005).

This lack of support is not unique to healthcare professionals. Lipson (2001) describes how individuals living with multiple chemical sensitivity typically withdraw from interactions with family and friends due to a lack of support and understanding around the necessary procedures and routines that their condition involves. Equally, studies indicate that people react uncomfortably to the unresolved nature and progression of medically unexplained
symptoms, and offer ‘solutions’ like special diets or alternative therapies (Nettleton, Watt, et al., 2005; Nettleton, 2006). In addition, the debilitating nature of contested illnesses often require sufferers to limit their social interactions, instead focusing their time, energy, and resources on their own well-being (Lipson, 2001; Newton et al., 2013; Ware, 1992). This is reminiscent of Charmaz's (1983) notion of loss of self, where patients’ withdrawal from social activity enhances their feeling of a loss of identity due to a lack of opportunities for self-validation through interactions with others.

Returning to considerations around identity, the chaos associated with the onset of a contested condition can enhance the disruption to one’s personal narrative (Nettleton, Watt, et al., 2005). Individuals are prevented from adopting a state of sanctioned deviance (Parsons, 1951), as the lack of understanding and consensus around their conditions challenges their legitimacy as patients and as representatives of the sick role. The mobilisation of resources referred to by Bury (1982) and Williams' (1984) concept of narrative reconstruction are similarly hindered by these wider contextual factors. As a result, the illness identities of individuals with contested conditions are similarly contested, resulting in them experiencing impediments to traditional sources of support, such as those from healthcare professionals, families, and friends.

While this absence of social support has broader implications, which will be discussed in an upcoming section, it is worth considering these findings in light of research from Vassilev et al. (2013) and Reeves et al. (2014) amongst others. These studies suggest that engaging in diverse sets of networks enable individuals to develop and maintain self-management behaviours. It could be argued that the reduced networks available to individuals with contested illnesses, in addition to the wider controversial contextual factors in which they are receiving their healthcare (Lawton et al., 2005), negatively impact on their ability to manage their condition and to navigate the myriad of factors associated with living with such a condition. As a result, consideration now turns to the nature of support provided via social networks.

1.2 Social Networks and Social Support
Social networks can be defined as “all those people with whom we have ongoing relationships and through which individual people are linked into groups and society” (Cleak & Howe, 2004, p. 21). By contrast, a social support system represents a subset within a person’s social network from which an individual can receive support (Lubben, 1988). Social networks impact on an individual’s self-management in a number of ways,
such as shaping and understanding normalcy and deviance, providing knowledge and narratives relating to chronic illness, and displaying how illness is managed by others (Vassilev et al., 2011). The importance of considering social networks in chronic illness has been highlighted in a number of reviews (e.g., D. Reeves et al., 2014; Sanders & Rogers, 2007; Vassilev et al., 2011, 2013). In particular, Sanders and Rogers (2007) point to the need for a thorough examination of social networks in order to understand how health services can complement, substitute, or enhance individuals’ existing resources in managing an LTC.

In examining social networks, there are many aspects to consider – namely the structure and the content of networks, the number of relationships or ‘ties’ in a network, and the strength of those ties. Stronger ties are those which develop through intimate relationships, such as family and partners (Cleck & Howe, 2004; Cornford & Cornford, 1999), and weaker ties are associated with civil organisations and similar groups (Grannovetter, 1973). While strong ties have been associated with a number of positive benefits, such as emotional aid and companionship (Wellman & Wortley, 1990), weaker ties facilitate the diffusion of influence and information (Grannovetter, 1973). These definitions have received some criticisms, however, as they contain assumptions about the nature of traditional families, and require that relationships such as those with family, kin, friends, neighbours, and colleagues are unambiguously categorised as strong or weak ties (Vassilev et al., 2011). Despite this, research into social networks indicates that chronically ill individuals may receive different aspects of social support depending on the structure and content of their networks.

Social support can be defined as "the exchange of verbal and non-verbal messages conveying emotion, information, or referral, to help reduce one's uncertainty or stress" (Walther & Boyd, 2002, p. 154). Within the social support research literature three categories of social support have been identified; these being emotional support, informational support, and instrumental support (Cohen, 2004). Other researchers (Cutrona & Suhr, 1992; Hirsch, 1980) have described and defined aspects of social support; such as emotional support, including expressions of care and concern, and sympathy towards relieving pain and stress; informational support, consisting of advice, factual input, and feedback to help network members evaluate actions and make decisions; and instrumental support, made up of providing financial or practical assistance for a network member in need, and socialising support, such as providing companionship or verbal reinforcement about one's choices.
Lin (1986) suggests that particular sources of social support can provide certain types of support. For example, expressive or emotional support can be best provided by those with whom an individual has strong ties, while instrumental support can be provided by those to whom an individual has weaker ties and who can link the individual to a broader and more diverse social network. In addition, research indicates that people with LTCs may require different types of social support at different stages of their illness (Ma, 1998). For example, in the diagnostic phase, informational support may play a role in managing the stress associated with the uncertainty and anxiety of this process, while during the treatment phases, instrumental support could aid with any physical effects associated with medication or surgery. Reflecting on these findings indicates that those with LTCs require a number of sources of social support in order to meet their complex and evolving needs.

For individuals with LTCs, family, friends, and healthcare professionals have typically been responsible for providing such support, although at times this has been supplemented by face-to-face support groups (K. Davison, Pennebaker, & Dickerson, 2000). Notably, it has been suggested that the people closest to us may not be able to provide the right level of support to those in distress (Wortman & Lehman, 1985). In these situations individuals may choose to turn to non-intimate relations such as peer support groups (Tardy, 1992). As detailed previously, engaging with non-intimate relations and diverse social networks gives individuals greater access to health-relevant support (Vassilev et al., 2013) and has a positive impact on well-being (D. Reeves et al., 2014).

From the perspective of those with contested chronic illnesses, access to support of this type may be of particular relevance. For many, illnesses of this nature can be very difficult to explain and resolve. In encounters with healthcare professionals, patients can frequently experience a sense of being mistrusted or de-legitimised (Hilbert, 1984; Ware, 1992). Without the validation provided by a diagnosis, individuals are often left without a credible or useful explanation for their illness and symptoms (Cooper, 1997; Lewis, 1995). As a result, they may experience less support from healthcare professionals and friends and family (Stewart & Sullivan, 1982). Notably, in relation to the current topic, experiencing scepticism or a lack of support from doctors can result in individuals seeking advice and support from fellow sufferers through support groups (Stanley, Salmon, & Peters, 2002). Consequently, it is necessary to explore the role of peer support groups and the support available from these groups in more detail.
1.2.1 Peer support

A growing body of research has highlighted the importance of support groups in providing mutual aid and self-help for individuals diagnosed with LTCs (Cline, 1999). Some of the previously documented benefits of support groups include both physical and psychological factors, such as positive changes in symptoms, improved recovery, and better adaptation to diagnosis, as well as enhanced quality of life, improved decision making, and increased survival time (Berger, 1985; Speigel, Bloom, & Yalom, 1981).

While there has been some research examining the benefits of social support for those with LTCs, a number of other groups have also been shown to benefit from group peer support. In particular, there is a wealth of literature around the importance of support groups for people with cancer, including identification with others in a similar situation, which can lead to a sense of belonging and empathy (McGrath, 1999; Payne, Lundberg, Brennan, & Holland, 1997). In a UK-based study, Docherty (2004) reported that groups facilitated coping by providing an understanding of the normal course of the illness, emotional support, and a sense of belonging. It could be suggested that support groups go some way towards addressing the loss of self (Charmaz, 1983) by enabling individuals to draw on the experiences of fellow patients to construct of a new self-narrative in which meaning is given to the illness experience (G. Williams, 1984).

Notably, much of the research in this area appears to suggest that the support gained from participation in peer support groups is separate and distinct from the support provided by family, friends, and healthcare professionals. For example, Ussher, Kirsten, Butow, and Sandoval (2006), through interviews with members of Australian peer support groups, suggested that they offered a unique sense of community, unconditional acceptance, and information, in contrast to the isolation, rejection, and lack of knowledge experienced outside the group. At the same time, the support group was positioned as enabling positive relationships with family and friends due to relieving their burden of care, facilitating increased empowerment and agency, and improving the overall well-being of group attendees.

These findings suggest that relationships founded in support groups are based on a shared experience of cancer, one that cannot be replicated by those who have not had cancer (Coreil, Wilke, & Pintado, 2004; Gray, Fitch, Davis, & Phillips, 1997). The difference in the support within support groups and that received from family and friends indicates that individuals with cancer report feeling isolated in relation to their previous social networks.
following diagnosis, because friends or family are unsure what to do or say (Yaskowich & Stam, 2003) or because they are frightened or helpless in the face of cancer (K. Davison et al., 2000).

While these findings are drawn from research with cancer groups rather than chronically ill individuals, it is possible that these results may be present in other samples. For example, Gordon, Robertson, and Swan (1995) reported that in a support group aimed at new mothers, the attendees welcomed contact with other mothers and claimed that the peer group setting was the only environment in which they felt comfortable expressing their feelings and concerns. Similarly, Bülow (2004) suggests that for those with ME/CFS, reinforcement through sharing can occur when individuals share their stories and experiences with peers. Through comparing and discussing their experiences with others, their symptoms and suffering which may have been previously misunderstood or suspected, can become credible. Considering this, it is likely that the positive impact of group social support will translate to those living with LTCs.

Despite the wealth of research around peer support for individuals with cancer, there has been less of a focus around this form of support for individuals with LTCs. Much of the research has involved a programme with a nominated peer support provider, rather than a group support aspect (e.g., Hughes, Wood, & Smith, 2009; Messmer, Mancuso, Battaglia, Zagami, & Mohr, 2004; Paul, Keogh, D’Eath, & Smith, 2013; Schwartz, Meir, & Lincoln, 1999). However, the most likely explanation for the apparent paucity of research in this area is that attention has shifted from face-to-face peer support to online peer support. It is this rapidly expanding topic that will be covered in the remainder of this review.

1.3 Use of the Internet by Individuals with Long Term Conditions
In examining the relationship between those with LTCs and their health care, it could be suggested that information, and the work involved in seeking, evaluating, and assimilating information, is an important area of study. Information has long been suggested as a key resource for individuals dealing with and comprehending the problems associated with LTCs. Medical sociologists have contended that information about a person’s chronic illness can help their understanding of what is happening with their body, situate their experiences in both the medical and social worlds, lessen their fears and misunderstandings, and in turn promote a sense of personal control and decreased dependence on others (Schneider & Conrad, 1983). In this way, the Internet offers multiple forms of support, such as emotional support and informational support.
Notably, however, the Internet can provide emotional support for individuals with LTCs through access to a network of peers, akin to those found in offline support groups. Hogan and Palmer (2005) suggest that, for those with chronic illnesses, ‘information work’, whereby people purposely seek information in order to fill a gap (Case, 2002), is a necessary component of living. They report that individuals with LTCs experience difficulties finding information relevant to their particular situation, and require a mix of information from people and written sources of both a professional and non-professional nature. This indicates that, for individuals, contact and information exchange with both healthcare professionals and lay people is necessary in order to enhance the self-care and management of their chronic illness.

In this sense, health-related Internet use by individuals is reminiscent of the notion of medical pluralism, whereby individuals draw on more than one medical system in order to address their health concerns (Wade, Chao, Kronenberg, Cushman, & Kalmuss, 2008). Typically, it refers to the use of complementary and alternative or indigenous medicine alongside conventional Western medicine (Hampshire & Owusu, 2013). For example, Rochelle and Marks (2010) described the approach of Chinese migrants in the UK who utilised both traditional Chinese medicine and Western medicine. Despite apparent contradictions in the two approaches, users appeared to take a pragmatic approach, integrating the two systems to draw on what they considered to be their respective strengths. Similarly, those with LTCs draw across formal and informal support networks, along with online networks, using a variety of approaches to seek help and support.

In addition to this, people with LTCs tend to seek help or information from people like themselves, as peers who have the same condition can offer relevant information and support (Veinot, 2009). With the rise in popularity and use of the Internet, individuals are now turning to computer-mediated support groups to gain support from both healthcare professionals and others suffering from the same illness or condition in order to address this need (Coulson, 2005). The most recent statistics from the UK suggests that nearly 70% of British Internet users searched for health information online in 2013, while 33% contributed to an online forum (Dutton & Blank, 2013). In the US, one in four Internet users with a chronic illness goes online to search for others with similar health concerns (Fox, 2011), while for individuals with multiple sclerosis (MS), the Internet is their first source for health information (Marrie, Salter, Tyry, Fox, & Cutter, 2013). This has not gone unnoticed amongst clinicians, with suggestions that the ‘cloud of patient experience’ online may provide valuable insights into care unfiltered by healthcare professionals, researchers,
or academics (Greaves, Ramirez-Cano, Millett, Darzi, & Donaldson, 2013; Shepherd, Sanders, Doyle, & Shaw, 2015).

1.3.1 Functions of Internet forums

In the same way that face-to-face support groups provide members with the opportunity to help each other cope, as outlined in a previous section, where members can talk freely about issues linked to their condition that are bothering them, online forums offer similar opportunities. Online support groups function by enabling individuals to engage in supportive interactions through bulletin boards or forums, chat rooms, and individual email exchanges with others facing similar experiences, challenges, or problems (Coulson, Buchanan, & Aubeeluck, 2007).

The benefits of computer-mediated support groups include the potential to access support 24 hours a day, seven days a week at a time most convenient to the user accessing support. The convenience of use enables individuals to receive support whenever they wish to access it rather than waiting for a scheduled appointment (Elwell, Grogan, & Coulson, 2011). Similarly, geographic and transport barriers become removed as support is available from the home, or a similarly convenient location. This results in issues relating to family or work commitments becoming less problematic, while individuals who have difficulties with mobility, speech, and hearing experience less barriers to involvement (Elwell et al., 2011). In addition, the process of actively writing about one’s feelings and emotions has been shown to be beneficial in terms of emotional well-being (Pennebaker & Beall, 1986; Pennebaker, Colder, & Sharp, 1990), reductions in self-reported symptoms (Broderick, Stone, Smyth, & Kaell, 2004), and improvements in mood (Langens & Schuler, 2007).

Message boards are not subject to space constraints and the number of users that can become involved is often unlimited (Winzelberg, 1997). Forum users can also remain anonymous, as sociodemographic factors such as age, gender, racial or ethnic identity, income, and social status are not visible in an online support group (Finn, 1995). Additionally, this potential anonymity provided by online support groups helps facilitate discussion of stigmatising illnesses or conditions or ‘taboo’ subjects (Ferguson, 1997; Klemm & Nolan, 1998; Sullivan, 2003). In particular, for those with uncommon or geographically rare illnesses, online support groups may provide the only means of communicating with people experiencing similar issues. It has also been suggested that online support groups may offer a particular role for individuals with contested chronic
illnesses, such as fibromyalgia or ME/CFS, due to the lack of agreement surrounding the nature and treatment of the condition (Chen, 2012).

In addition, the benefits of an online group extend beyond its immediate participants. Buchanan and Coulson (2007) noted that the format and structure of forums enable those accessing the group to read messages in sequence and search for specific topics, despite not being involved in the dialogue. Participants in Internet discussion boards viewed the ability to silently ‘lurk’ and not necessarily post messages as a significant advantage of online support groups (A. Broom, 2005). Similarly, Mo and Coulson (2010) compared active posters and lurkers on HIV and AIDS forums, where users categorised as lurkers access discussions but do not post messages to the group. They found that, while lurkers received less social support and useful information than active posters, and were less satisfied with the group, there were no significant differences in self-care, self-efficacy, loneliness, depression, or optimism. This indicates that lurkers and active posters experience similar positive psychosocial benefits from accessing online support groups. Comparable results were found in a Dutch study, where it was concluded that participation in an online support group has the same positive effect on lurkers’ self-reported feelings of empowerment as it had on posters (van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2008). This suggests that online boards can benefit those who are reluctant or unable to participate in groups.

1.3.2 Identity and empowerment online
Alongside the psychological impact of online support groups for people with LTCs, there are a number of sociological aspects to consider. Hardey (1999) suggests that the array of information and advice available on the Internet enables users to develop and redevelop their identity in a way that goes beyond the concept of a patient as a disembodied medicalised case (Parsons, 1951). Due to the ability of Internet users to browse and search online, individuals control the content and flow of the information available to them, rather than receiving information through a health professional. This represents a shift in hierarchy from professionals towards patients (Hardey, 1999), and indicates that the use of online support groups can facilitate the development of a person’s illness identity.

This suggests that the Internet could act as a valuable tool in reconstructing identities (G. Williams, 1984) and repairing the loss the self (Charmaz, 1983) for those with LTCs. Individuals’ identities can be reconstructed from their former narratives into that of an active, empowered patient via interactions with other forum users online (Barker, 2008) and
access to specialised information and advice (Hardey, 1999). While not looking directly at LTCs, Trondsen and Tjora (2014) reported that for adolescents with parents with mental illnesses, communicating via an online forum allowed them to normalise their experiences and to reorient and reconstruct their identity. Accessing a community based on shared experiences enabled the teenagers to adjust their identity and that of their family from ‘abnormal’ or ‘mentally ill’ to ‘less out-of-the-ordinary’. Through this normalisation, participants gained agency and were empowered to take action.

This has been echoed by a number of researchers (e.g., Barker, 2008; Pitts, 2004) who suggest that the autonomous nature of Internet use empowers individuals through a number of strategies. Online discussion groups allow individuals to access a collective pool of information, which can benefit their health. In addition, they can access a network of social support borne from shared experiences. Taken together, these benefits of forum participation facilitate empowerment, which aids individuals in taking a proactive approach to their healthcare decisions (Johnston et al., 2013). In short, online support appears to empower lay individuals to engage with their healthcare, as well as consolidating their position as challengers to the concept of medical dominance (Hardey, 1999).

In reflecting on the potential impact of Internet use on those with LTCs, it is important to emphasise information seeking and sharing online as extending beyond a mere channel of information. Rather, the Internet offers information that users interact with, attaching and detaching meaning in relation to their daily health practices and everyday experiences (Kivits, 2006, 2009). In this way, parallels can again be drawn with medical pluralism, where the individual use of different medical systems is influenced not just by an individual’s assessment of the apparent strengths of the respective systems (Rochelle & Marks, 2010) but also the monetary or other resources that enable them to access each system (Kolling, Winkley, & von Deden, 2010).

Similarly, Green, Bradby, Chan, and Lee (2006) report that, while women of Chinese origin living in the UK were influenced to in the use of healthcare system to a certain extent by their level of acculturation, language barriers affected their use of Western medicine, while financial barriers impeded their use of traditional Chinese medicine. Thus an individual’s ‘hierarchy of resort’, in which a person determines the range and sequences of treatments utilised, is influenced by a number of factors, namely their assessment of the severity of an illness, their appraisal of the effectiveness of treatment options, the affordability and accessibility of different treatments, and their own cultural background and beliefs (Rao,
2006). This suggests that the use of health systems or channels of health information is grounded in everyday experiences as well as the broader social, economical, and political context within which these experiences occur.

Kivits (2009) draws on a mediated health perspective in considering health information seeking online, emphasising the integration between media and health experiences. This view requires an examination of the relationship between individuals and online health information, before any scrutiny of the offline consequences of accessing support and information online. As a result, consideration must be given to broader context in which the use of online forums occurs, both in terms of the everyday use of the Internet and individual health experiences (Kivits, 2006, 2009). It is the first of these contexts that will be referred to in the following section.

1.4 The Digital Divide and Health Inequalities Online

Despite the apparent accessibility of online support for chronically ill individuals, it must be noted that this access is not entirely equally distributed amongst all populations. The ‘digital divide’, whereby an uneven distribution of computer ownership and Internet access mirrors other social divides based on social class, income, education, place of residence, and age (Diviani, van den Putte, Giani, & van Weert, 2015; Dutton & Blank, 2013; Dutton, di Gennaro, & Millwood Hargrave, 2005; Hill, Betts, & Gardner, 2015), results in barriers to accessing health information online among deprived communities (Connolly & Crosby, 2014; Mead, Varnam, Rogers, & Roland, 2003). Inequalities associated with education and income are typically associated with lower use of the Internet, and specifically health information seeking (Cotten & Gupta, 2004; Li, Orrange, Kravitz, & Bell, 2014; Neter & Brainin, 2012).

There are a number of contributing factors influencing this divide (Nagler, Ramanadhan, Minsky, & Viswanath, 2013). Firstly, Internet access is not equally distributed. Though online access has become more and more widespread in recent years, the uptake of high speed connectivity is greater amongst those with higher levels of income and education (Viswanath, 2011). Secondly, socioeconomic status is also associated with Internet use and proficiency, with those of higher socioeconomic status feeling more comfortable using computers and navigating the Internet (Lee, 2009b). Finally, there are discrepancies in levels of eHealth literacy, where individuals with lower incomes have expressed concerns about their ability to distinguish between high and low quality health resources and information online (Knapp, Madden, Wang, Sloyer, & Shenkman, 2011).
health information provided online is often written at a level above the recommended reading levels for the general population (De Oliveira, Jung, McCaffery, McCarthy, & Wolf, 2015; Ricci, Vargas, Chuang, Lin, & Lee, 2015).

In recent years, focus has shifted somewhat to the importance of online literacy as a contributing factor to online health inequalities. For example, Neter and Brainin (2012) suggest that the digital divide extends beyond connectivity, with marked differences in how individuals utilise and interpret the Internet as a source of health information and advice. Respondents who were younger and more educated had greater levels of eHealth literacy, and were in turn better able to use the information that they found online to manage their healthcare, adapt their health behaviours, and communicate with their physicians (Neter & Brainin, 2012). Similarly, Li et al. (2014) reported that with those with high eHealth literacy were more likely to go online after a doctor’s visit, and were more likely to look at higher quality, more specialised sources of information. These US based findings are also borne out within a British context, where individuals with a university education were twice as likely to find information online that improved their health compared to those with no educational qualifications (Dutton & Blank, 2013).

In considering health inequalities online, as Kivits (2009) highlights, it is important to go beyond the depiction of the Internet as a mere source of health information. Rather, it offers information and advice which people interact with, attaching and detaching meaning in relation to their daily health practices. This view is elaborated by Bell (2014) who explored the experiences of women of high and low socioeconomic status in relation to infertility. She describes how interviewees’ utilisation of support and information relating to their condition was shaped by their expectations around healthcare. While the women of high socioeconomic status proactively ‘seek’ information, researching information online in order to negotiate with healthcare professionals, women of low socioeconomic status ‘scan’ for information from readily available sources, such as the television (Bell, 2014). Additionally, individuals of a higher socioeconomic status are more likely to have access to and make use of broad interpersonal networks of communications, including improved communication with healthcare professionals (Lee, 2009a).

Researchers have cautioned that, despite the apparent accessibility of online resources and health information, advancements in this area may predominately benefit individuals and communities who are already catered for amongst existing healthcare systems (Viswanath & Kreuter, 2007). As a result, technological progression and the migration of supports and
services online may serve to deepen inequalities between communities rather than addressing the balance. Conversely, it has been suggested that the Internet may provide a means of disseminating health information to marginalised groups. Brodie et al. (2000) report that once individuals are able to gain access to the Internet at home, its use for health information becomes similar across income, education, race, and age. With this in mind, establishing ways of increasing Internet usage among traditionally disadvantaged communities may provide a method for addressing inequalities associated with health and healthcare provision (Cotten & Gupta, 2004). In particular, there have been suggestions that the increasing availability of mobile devices, alongside appropriate training, may be a useful method of circumventing aspects of the digital divide and providing online health information to underserved populations (Connolly & Crosby, 2014).

For example, the Hearts of Salford project, where older people with coronary heart disease were given a home computer, supported Internet access, and access to an Internet health portal, resulted in high levels of Internet use post study (Lindsay, Smith, Bell, & Bellaby, 2007), confidence with Internet use (Lindsay, Smith, & Bellaby, 2008), and improved health practices (Lindsay, Bellaby, Smith, & Baker, 2008). This suggests that when appropriate advice and support is provided along with access, it can go some way towards addressing the digital divide. Thus while it is necessary to reflect on inequalities in Internet access when considering online support groups, it is possible that if sufficiently supported access is offered, individuals with chronic illnesses in both deprived and non-deprived communities may experience benefits from computer-mediated support groups.

Reflecting on the research cited above, it is necessary to examine the current use of these online social networks and their potential for individuals with LTCs. This is particularly relevant considering the prevalence of support groups online. Research suggests that Internet users, particularly those with chronic illness or disabilities, frequently search online for health information, and the majority of those online have contacted an online group (Shigaki et al., 2008). While online information seeking has not penetrated every population (Connolly & Crosby, 2014; Li et al., 2014), there is evidence in the literature that online resources for chronic illness are accepted, used, and in many cases, of benefit to Internet users (Gustafson et al., 2002; Lindsay et al., 2008).

1.5 Role of Online Peer Support
As detailed, online support groups have grown increasingly popular for conditions such as cancer (Seale, Ziebland, & Charteris-Black, 2006), lupus (Mendelson, 2003), and
addictions (Klaw, Huebsch, & Humphreys, 2000). They offer encouragement, acceptance, and an online companionship to counter some of the social and spatial isolation associated with LTCs. Research suggests that they provide ‘safe spaces’ in which participants can anonymously exchange their hopes, fears, and problems without stigma or censure (Sharf, 1997). Through the participants, the groups provide information on managing the disease, treatment, and effects on daily life. It has been suggested that this also allows them to be a tool of empowerment (van Uden-Kraan et al., 2008). This highlights the need to examine the potential of online support networks for those with LTCs, and indeed the potential problems associated with accessing these networks.

1.5.1 Effects of forum usage
One notable effect of the rise of online support groups for illnesses is the blurring of boundaries between expert and lay people. While this has implications for all LTCs, it is worth particular consideration in the context of contested illnesses. By considering the importance of peer support gained from shared experiences, expertise is no longer the sole province of medical professionals (Barker, 2008). Barker (2008) characterises the process of sharing stories and details of fibromyalgia as patients confirming the existence of their illness as a medical entity. In particular, the wealth of this shared expertise enables individuals to challenge the expertise of individual physicians, many of whom were perceived as failing to recognise and treat their illness. This is particularly relevant considering research that indicates the need for greater incorporation of the experiences of those with chronic conditions into health policy (Yen et al., 2011).

It has also been suggested that the use of the Internet for health advice and information facilitates the development of reflexive health consumers taking responsibility for their health by means of information (Kivits, 2009). Pitts (2004) reports that, for individuals with breast cancer, the Internet plays a significant role in the construction of their identities as consumers rather than sick people. By researching and sharing experiences online, individuals positioned themselves as active participants in their own healthcare. Through their actions, the women informed themselves about available ‘products’ or treatments, and gathered information in order to negotiate with their doctors and to argue for their views to be taken into account (Pitts, 2004).

Additionally, Hadert and Rodham (2008) reported that for users of an arthritis forum, the message board offered them a sense of validation and belonging. In addition, their stories were read and acknowledged by peers who had personal insight into the issues being
discussed. The authors suggested that the forum provided a dual purpose – offering advice, information, and support for those seeking it, while enabling those providing the information to feel that they had a useful purpose in meeting others’ needs. Similar findings have been reported across various conditions, e.g., systemic lupus erythematosus (Mazzoni & Cicognani, 2014). This represents a significant departure from the traditional sick role of the chronically ill patient (Parsons, 1951), as individuals are repositioned from passive recipients of expert care to drawing on their own expertise and mobilising the resources available to them in order to participate in reciprocally supportive relationships.

It is necessary to consider the effect that this repositioning may have on individuals’ existing relationships and sources of support. Armstrong and Powell (2009) report that Internet users with health queries were primarily interested in advice and information that is drawn from the experiences of others, which is not something that can necessarily be provided by a health professional, while Kauw et al. (2015) suggest that forums are used to address the needs of individuals that are unmet by existing supports and services. On a similar note, Loader, Muncer, Burrows, Pleace, and Nettleton (2002) found that a Usenet group for individuals with diabetes was a space where health advice and information could be assessed and assimilated in order to inform lifestyle choices. While the group did not replace medical advice, it instead facilitated discursive learning between peers on a more equal basis than the hierarchy of the doctor-patient relationship. This suggests that the information and support provided in online support groups can complement that offered by medical professionals, rather than providing a challenge, indicating that Internet users take a pluralistic approach in utilising online and offline sources of health information and advice.

Likewise, considering the support provided by an individual’s ‘strong ties’, typically their friends and family, Sanders, Rogers, Gardner, and Kennedy (2011) propose that, for those with chronic illnesses, online forums offer a place to develop relationships and benefit from social support without the difficulties present in offline relationships. For example, participants in this study felt that people who were socially isolated could benefit from the accessibility of online support. In addition, forum users often turned to fellow participants for help in managing the difficulties and tensions they experienced in their relationships offline. Internet users were facilitated to share experiences of irritations and negative interaction within their homes, and the online forum offered a safe place for questioning assumed roles laid out for people by virtue of their pre-existing sick role. Supporting this finding, Ziebland and Wyke (2012) highlight the likelihood of individuals simultaneously
engaging in sets of online and offline relationships and adhering to the distinct social norms of each set of relationships. Taken in sum, these findings indicate that, rather than replacing existing offline social networks, online support groups supplement and often complement traditional support networks.

1.5.2 Online and offline discourses

Looking more specifically at the role of online support, the impact of online participation on offline lives deserves consideration in order to examine the integration between media and health experiences (Kivits, 2009). Though participants in a study of individuals with obesity seeking online support in Australia did not appear to find any long term solutions to improve their health and well-being, the support groups accessed provided a space for individuals to share their experiences and communicate with others (Lewis et al., 2011). Some interviewees reported that this support, which offered an alternative to traditional weight loss websites and dominant discourses of obesity, had a positive impact on their ability to engage in healthy lifestyle behaviours.

Research into the content of online support groups has provided some mixed findings, however. Despite Lewis et al. (2011) reporting that participants in a support group for obesity found an alternative discourse which motivated their healthy behaviours, a number of studies have suggested parallels between offline and online messages. Seale (2005) suggests a level of ‘media convergence’ in online and offline representations of gender and cancer. Online, as with offline, individuals with breast cancer were portrayed as people who prioritise emotional support and managing family relationships, and were offered advice and support in doing so. By contrast, those with prostate cancer were depicted as stoic individuals, uninterested in emotional support and merely requiring medical facts and information. The replication of traditional media images of gender and cancer online appears to indicate that broadly similar messages and depictions of identity can be accessed through online interactions as offline interactions.

Similarly, Rier (2007) reports that, while forums and message boards have the potential to present people with HIV/AIDS with an alternative medium for discussion, the themes and messages discussed mostly replicated offline discourses. Pitts (2004) likewise reports that online discourses of breast cancer often replicate traditional and conventional messages around femininity, and cautions that online breast cancer discourses may compound existing social pressures for women to continually re-invent and improve themselves. Like others (e.g., D. Broom, 2001; Wilkinson, 2001), she questions the usefulness of the
‘restitution narrative’, where individuals are soon restored to their original levels of health and optimism. She argues that the repetition of these messages on the Internet undermines the degree to which empowerment occurs online, suggesting that the view of a patient as a consumer implies that women have “not just a chance but a responsibility to save themselves” (p. 54).

For example, Sandaunet (2008), in an analysis of an online self help group for women with breast cancer, reported that group participants were encouraged to circulate socially desirable stories of their experiences with cancer. Many of the forum users who were interviewed expressed a reluctance to introduce negative topics to the group and to deviate from the norm of social desirability on the forum. She likens this behaviour to that of a ‘hero’ construct, where a responsibility is placed on those with cancer to take on the role of hero within their own lives (Pitts, 2004). The concept of the cancer hero can also be seen to dominate media portrayals of people with cancer (Seale, 2002).

Thus while online support can be put forward as an alternative method of support for individuals with LTCs, some of these findings appear to dispute just how ‘alternative’ a method it offers. Indeed, this viewpoint could be extended from discussion boards to the broader use of the Internet for health information and advice. McTavish, Harris, and Wathen (2011) found that while online searching for health information resulted in immediate access to a range of sources, the array of material offered a broadly biomedical consensus. Alternative discourses and perspectives were only available once searchers went beyond the ‘first page’ of results.

Reflecting on these findings suggests that there is a need to consider whether forums represent a challenge to the professional dominance of the medical model, as suggested by some researchers (Barker, 2008; Hardey, 1999; Pitts, 2004), or whether it supports a model of biomedical authority, as proposed by others (Rier, 2007; Sandaunet, 2008; Seale, 2005). While this is an issue that will be returned to at the end of this chapter, it is first worth reviewing how online support is assessed by participants; in particular, the concepts of ‘legitimacy’ and ‘credibility’, and how these concepts are negotiated and performed online.

1.6 Assessing Peer Support Online

While the use of the Internet in healthcare has been a growing area of study, it has also prompted a number of reactions. Nettleton, Burrows, and O’Malley (2005) suggest that these reactions can be broadly categorised into three responses. Firstly, the use of the
Internet for health information can be viewed in a ‘celebratory’ context, as a readjustment of a power imbalance between patients and health professionals. In this way, the Internet provides empowerment to individuals, while online spaces can offer resistance to dominant medical practices. Secondly, responses can be classified as ‘concerned’, which, they report, is predominately the perspective of the medical profession. This reaction stems from a worry about the quality of health information available online, and views lay people as having insufficient expertise to assess the reliability of information available online.

Lastly, and representing a response favoured by the authors themselves, Internet use can be viewed as contingent and embedded, whereby individuals can make reasonable assessments about appropriate information in the context of their own health and illness. This approach highlights how the use of the Internet for health information blends with other strategies to facilitate those seeking help, advice, and support, and thus can provide a complement to the services offered in formal health care settings. Though this view is one that is supported by much of the current literature (e.g., Bell, 2014; Kivits, 2009; Trondsen & Tjora, 2014) and provides an appropriate context in which to explore the use of online peer support by individuals with LTCs, it nonetheless requires further scrutiny. For example, how individuals assess the health information that they encounter online and what factors play a role in this assessment must be considered.

While online peer support may represent a recognition of the expertise of those with LTCs, it is necessary to consider the reliability and accuracy of this expertise, a concern often raised by researchers and healthcare professionals (Middlemass et al., 2012; Nettleton, Burrows, & O'Malley, 2005; Rupert et al., 2014). The level of information provided on forums increases the risks of misinformation and misperceptions being transmitted to a diverse audience. This is something that has been acknowledged by forum users, with members of an online food allergy support group suggesting problems with the trust and accuracy of information received via the forum (Coulson & Knibb, 2007).

Wang, Walther, Pingree, and Hawkins (2008) found that degree of perceived similarity a receiver ascribes to a message source in knowledge, experience, background, and views was crucial in evaluating the information available in online discussion groups, rather than the credibility of the information. This indicates that while online peer support and advice may be beneficial for those with LTCs, there is a risk that misinformation will be accepted due to the nature of transmission. Despite this, Esquivel, Meric-Bernstam, and Bernstam (2006) reported that a tiny minority (less than 0.25%) of messages posted to a breast cancer
mailing list contained statements that were found to be false or misleading. Of the false or misleading statements identified by researchers, the majority were rapidly identified and corrected by mailing list participants, suggesting that online support groups can act as ‘self-policing’, even in the absence of a healthcare professional or forum moderator. Likewise, Armstrong, Koteyko, and Powell (2012) found that no misinformation was shared on a forum for people with diabetes. When a controversial opinion was posted, however, it was soon negated by other forum users, supporting the notion of forums as self-policing.

Similar results have been reported across a range of studies. For example, Sillence and Mo (2014) reported that forums for individuals with prostate cancer provided diverse information and advice, with both a deferral to healthcare professionals and a detailed consideration of individuals’ own health and circumstances. In addition, Giles and Newbold (2011) described a high level of deference to medical expertise on mental health forums, even ones which had an explicitly anti-recovery focus, while van Berkel, Lambooij, and Hegger (2015) report that forum users across a range of conditions were frequently directed to healthcare professionals by other posters. This indicates that forum members appear to situate the advice and information shared online in the context of their knowledge about their health and illness, as proposed by Nettleton, Burrows, and O’Malley (2005).

1.6.1 Experiential information

It has been suggested that exposure to ‘experiential’ information online, e.g., “I can’t tell you what to do but this is the decision I made and why” (Sillence & Mo, 2014, p. 245), is highly valued by individuals and plays a role in determining decisions around treatments (Rozmovits & Ziebland, 2004). Notably, prior research indicates that people draw on others’ experiences as part of their healthcare decision making. They integrate them into their existing evidence base, rather than dismissing existing medical guidance in favour of ‘anecdotes’ (Ziebland & Herxheimer, 2008).

Likewise, people often draw on their own experiences in evaluating advice and information that they encounter online (Sillence, Briggs, Harris, & Fishwick, 2007). In particular, Internet users trust websites that reflected their social identity, and are less inclined to access websites that lacked markers of social identity. This behaviour is seen to be replicated in forum activity, where individuals seek out those ‘in the same boat’, so that they can draw on experiences that match their views and biases (Sillence, 2013). Additionally, forum members typically respond to requests for personal experiences in a
narrative form, providing readers with enough information to assess how applicable the advice is to their own situation (Sillence, 2013).

This is not to say that drawing on narratives in assessing health information online is an unsystematic process, however. In fact, Sillence and Mo (2014) suggest that the public nature of online discussion boards motivates forum users to collect and analyse information in a methodical manner and to present their thoughts in a considered and deliberate way. Posters providing advice tend to do so in line with the limits of their individual experiences and the boundaries set out by the member seeking advice (Sillence, 2010). Sillence and Mo (2014) conclude that the array of narratives on offer in prostate cancer forums provide forum users with an opportunity to consider the various aspects of their condition and its progress and treatment.

In addition, there have been suggestions that with continued participation in a forum, the relevance of the narratives, advice, and information available increases. Individuals can build up a base of knowledge about their condition, comprised of new information as well as experiences that enforce the reliability of the information and add credibility to different sources (Johnston et al., 2013). As individuals become connected to communities, the information provided through these networks becomes more meaningful and accessible to the participant (Johnston et al., 2013).

1.6.2 Forum norms and online performances
Longevity is not the only method of evaluating credible sources online, however. As mentioned, forums are often considered to be self-policing, filtering out misleading or dangerous information. In the Armstrong et al. (2012) study, the community, via its individual members, negotiated and enforced boundaries around what was and was not acceptable to share online. The notion of self-policing forums indicates the presence of certain codes of conduct or ‘norms’ online, which influence how posters interact. Honeycutt (2006) suggests that there are two main types of social norms online – general ‘netiquette’ and forum specific norms. Examples of netiquette include keeping discussions on topic and avoiding the use of bright colours or hard to read fonts, while forum norms are those that relate to specific communities and may vary depending on the purpose of the group or members’ characteristics.

On health-related forums, these norms may relate to certain accepted constructions of the condition under discussion. For example, on a self-harm support forum, members typically
began with a biomedical narrative of their self-harm background and talked openly about their self-harm behaviour, while staying within the ‘rules’ of the site, which forbade graphic or detailed descriptions of self-harm. Posting in this manner led to acceptance and support from the community (Smithson et al., 2011). Similarly, Vayreda and Antaki (2009) explored how new posters on a forum for individuals with bipolar disorder were expected to accept the advice provided by existing members, and to openly commit to a distinctive, biomedical perspective of their illness. Only once this occurred were the community and the site’s resources available to the poster.

This concept of impression management online is by no means unique to health discussion groups. Goffman (1959) described how individuals present their idealised self by drawing on a dramaturgical approach. The ‘front stage’ is where the self is presented according to the specific context, audience, and role that is required. In the example provided by Vayreda and Antaki (2009), the expected idealised self is a compliant forum user who has a biomedical perspective of bipolar disorder, and is presented though a user’s public forum posts. By contrast, ‘back stage’ is where the work is done in order to present the idealised self, often a space where the front stage performance is contradicted.

This concept has been appropriated by a number of scholars for application to the presentation of self online, notably Hogan (2010). Though this work is drawn from social media research, it does have relevance to Internet forums. In this way, individuals with LTCs are not only facilitated in the development of identities, e.g., empowered consumers, but actively perform these identities online. Additionally, individuals may perform a number of identities depending on how they address and submit information online (B. Hogan, 2010). They may exchange private messages with those on the forum that they consider to be friends, while at the same time performing a different identity on a public forum. In this way, a space may be a back stage to another front stage; a forum user may be simultaneously presenting one idealised form of self on the forum, conforming to forum norms and guidelines, while masking a potentially contradictory idealised form of self that they are simultaneously displaying in their private messages.

While this may appear to be a complex process, it has been suggested that forum norms can be ascertained relatively quickly. On an eating disorder recovery forum, new forum members are simultaneously welcomed and confronted with the norms to which they must conform if they are to participate in the forum (Stommel & Koole, 2010). In addition, many forums have moderators, i.e., established forum members who use their posts to teach other
members about appropriate interactions within the community and describe actions using preferred discourses (Mudry & Strong, 2013). On healthcare forums, moderators are often involved in enforcing condition specific norms, for example, ‘modelling’ good self-management (Kennedy, Rogers, Sanders, Gately, & Lee, 2009). Among their roles, moderators may edit posts if they are seen to violate the norms of the forums, such as editing out comments that were seen to glamorise eating disorders (Stommel & Koole, 2010). In this way, it could be suggested that moderators are akin to curators, as described by Hogan (2010), who play a part in filtering, ordering, and managing the information that is presented by forum users.

However, enforcing boundaries is not the sole preserve of forum moderators. As mentioned, forum members were quick to correct what they considered to be misleading or dangerous information (Armstrong et al., 2012; Esquivel et al., 2006). Despite the presence of trained moderators on a self-harm support forum, the participants took on the role of experts, including setting the guidelines around what was and was not permitted on the site. In addition, they reprimanded those whose behaviour fell outside these guidelines (Smithson et al., 2011).

1.6.3 Establishing credibility and legitimacy online
While adhering to forum specific norms may result in users being granted access to support via the forum (Smithson et al., 2011; Stommel & Koole, 2010; Vayreda & Antaki, 2009), obeying forum rules is also a way to establish credibility online. In order to receive direct support and information online, a poster must suggest that their conditions and concerns are legitimate (Galegher, Sproull, & Kiesler, 1998). Legitimacy can be displayed or performed by group membership, e.g., length of time reading/lurking; membership of the condition, e.g., a description of one’s symptoms, medication or interactions with healthcare professionals; or by declaration of a diagnosis (Galegher et al., 1998). Additionally, legitimacy may be displayed more implicitly by including brief but detailed medical information in a user’s profile (Sillence, 2010). Posters who do not display these markers of legitimacy may not receive responses or may not be welcomed into the group (Galegher et al., 1998).

As suggested previously, adhering to norms and presenting oneself in the ‘correct’ manner also influenced members’ legitimacy. On a gambling forum, posters established their legitimacy in meeting the membership category of ‘real addict’ through elaborate descriptions of their situation and behaviour (Mudry & Strong, 2013). Despite this, markers
of legitimacy varied between forums. For example, having a formal diagnosis was a central aspect of users’ identities on online mental health communities. This was somewhat counterintuitive, considering that many of the forums embodied a resistance to the medical establishment (e.g., anti-recovery model) and spoke negatively about interactions with healthcare professionals (Giles & Newbold, 2011). However, it is perhaps further evidence of forums being situated in the context of formalised healthcare settings and participants’ knowledge of health and illness (Nettleton, Burrows, & O’Malley, 2005; Trondsen & Tjora, 2014).

Alluding to this notion, Armstrong et al. (2012) described a diabetes forum as a place where it was acceptable to express slightly unorthodox or ‘deviant’ views, i.e., criticisms of healthcare professionals or admitting to not strictly adhering to prescribed courses of action. However, these views were invariably framed in the context of medical information or knowledge to indicate that, apart from this expressed ‘deviance’, forum members were knowledgeable and authoritative about their condition (Armstrong et al., 2012). In addition, the acknowledgement of these views or actions as unorthodox allowed participants to draw the forum’s attention to the fact that these views may not be acceptable, providing the community with an opportunity to evaluate if the views were suitable for expression within the forum.

This suggests that notions of credibility and legitimacy online are not fixed and can evolve depending on the constitution of a group, as well as external social and cultural factors. As forum members establish legitimacy and authority, they become part of a community. As such, they influence and are influenced by group norms, responding to those who violate those norms (Smithson et al., 2011). In turn, this community develops a clearer definition of legitimacy, constructs the definition of acceptable discourse, and reinforces the authority of individual writers (Galegher et al., 1998). Reflecting on this, it is clear that in order to explore these notions in relation to LTCs, it is necessary to give in depth consideration to the nature of forum usage by specific communities. The communities and conditions selected for inclusion in this thesis are outlined in the following section.

1.7 Contested and Uncontested Illnesses Online
In order to provide an appropriate context in which to explore the use of Internet forums by individuals with LTCs, two particular illness groups were selected for study. It was intended that one condition would serve to highlight some of the experiences of individuals with contested LTCs, while the other condition would represent the experiences of those
with uncontested LTCs. The rationale behind the selection of the two groups, a brief description of each condition, and some relevant research are outlined below.

1.7.1 ME/CFS
As mentioned, it has been suggested that online support groups may offer a particular role for those with contested chronic illnesses, such as fibromyalgia or ME/CFS, due to the lack of agreement surrounding the nature and treatment of the condition (Chen, 2012). In addition, individuals with contested illnesses often experience less support from family, friends, and health professionals as a result of their symptoms (Stanley et al., 2002; Stewart & Sullivan, 1982). Despite this, there had been a limited amount of research conducted into the use of the Internet by individuals with contested conditions. What has received more attention, however, is how the Internet and online discussion boards can empower and politicise a contested community.

For example, Fair (2010) described how individuals affected with the skin condition morgellons, a contested illness which many from the medical community would describe as a psychiatric condition known as delusional parasitosis, used the Internet to mobilise themselves as a patient group. Similarly, the relatively recent controversy over chronic cerebrospinal venous insufficiency (CCSVI) as a purported cure for MS played out predominately online. Despite the lack of support in the medical community for the treatment, individuals with MS took to YouTube to report their successful experiences with the treatment. They situated their experiences in biomedical terms, often drawing on medical explanations, terminology, and tests adapted from clinical practice (Mazanderani, O’Neill, & Powell, 2013).

In an analysis of forum posts around CCSVI, Sudau et al. (2014) reported that the bulk of observations around the treatment were supported by social media links rather than scientific sources. Despite this, they reported that the discussions followed the ups and downs of the scientific debate, rather than promoting dangerous behaviour. As a result, it has been suggested that the Internet allows those with contested conditions to aggregate their experiences online, creating a base of knowledge that others can draw on (Mazanderani et al., 2013). This can in turn be utilised to advocate for policy changes and to prioritise a particular patient-led research agenda.

While this could be viewed as empowered consumers taking an active role in their own health care, from the perspective of the medical community, this empowerment may not
always be viewed in such a positive light, echoing the concerns outlined by Nettleton, Burrows, and O’Malley (2005). Though Fair (2010) categorises the response of clinicians to the online movement of Morgellons as doctor-patient compromise, others have described frustration on the part of clinicians over ‘pester power’ from lay people on behalf of a treatment in which they saw little scientific validity (Mazanderani et al., 2013; Sudau et al., 2014).

This further highlights the value in examining the intersection between online communities and contested illnesses. As mentioned previously, it is likely that individuals experiencing contested chronic conditions may have an extra impetus to go online for advice, information, and support (Chen, 2012), given the lack of understanding and support from family, friends, and healthcare professionals (Nettleton, 2006; Stanley et al., 2002). However, the additional aspect of patient activism online and alternative constructions of credibility and legitimacy online provide a fascinating context in which to explore online and offline sources of support. For example, in contrast with mental health communities online, where, despite the forums’ resistance to the medical establishment, a forum diagnosis was integral to members’ legitimacy (Giles & Newbold, 2011), Copelton and Valle (2009) reported that ‘scientific self-diagnosis’ was promoted and accepted on coeliac support forums. They suggested that use of direct-access stool tests (rather than tests accessed through clinicians) to diagnose coeliac disease provided quasi-scientific evidence that helped individuals to negotiate the dietary modifications necessary to alleviate their symptoms.

Though there has been a limited amount of research in this area, there is one condition that has received considerable media attention. ME/CFS has in recent years been particularly linked to the concept of online patient activism. The condition, which is characterised by fatigue, pain, and impaired cognitive functioning, affects up to 100,000 people per year in the UK (Guise, McVittie, & McKinlay, 2010). Notably, there is no diagnostic test for the condition and symptoms vary considerably between individuals. As a result, those with ME/CFS report a variety of support needs, including the need to gain a diagnosis, respect, and empathy from service providers, as well as information about their condition (Drachler et al., 2009).

From the perspective of those with the condition, of particular importance is the characterisation of ME/CFS as a biomedical rather than a psychological or psychiatric condition (Bayliss et al., 2014; Lian & Nettleton, 2015). It is this campaign which has been
the centre of much online activism, though not without controversy (Smith & Wessely, 2012). Many perceive that money has been channelled into psychosocial ‘cures’ such as cognitive behavioural therapy (CBT) or graded exercise therapy (GET) at the expense of biomedical research (Hawkes, 2011). In addition to the criticisms of the research, research methods, and researchers involved in ME/CFS studies, there have been reports of death threats against researchers or clinicians who are perceived to be in support of a psychological view of the condition (“ME researchers ‘receive death threats from sufferers,’” 2011).

Considering the level of online activism around ME/CFS, alongside the lack of support and understanding of the condition from healthcare professionals (Huibers & Wessely, 2006; Wearden & Chew-Graham, 2006) and family and friends (Drachler et al., 2009; Edwards, Thompson, & Blair, 2007), it is an appropriate condition in which to reflect on the use of the Internet by those with LTCs. While it is not expected that these factors will apply unilaterally across all contested conditions, or even all individuals with ME/CFS, it is likely that this approach will illuminate some aspects of online forum usage. In addition, the politicised nature of Internet use by those with ME/CFS will provide a broader context in which to consider the topic under study.

1.7.2 Diabetes
The World Health Organisation has defined diabetes as “a chronic disease that occurs either when the pancreas does not produce enough insulin, or when the body cannot effectively use the insulin it produces” (WHO, 2015, p. 1). There are two main forms of diabetes; type 1, which is also known as insulin dependent or childhood onset diabetes, and type 2, which is known as non-insulin dependent. Type 1 diabetes is characterised by a lack of insulin production in the pancreas, while type 2 diabetes is caused by inefficient use of insulin in the body, and has been associated with obesity and a sedentary lifestyle (Diabetes UK, 2012).

Diabetes affects more than 5% of the British population (Diabetes UK, 2012) and has been highlighted by the NHS as a key focus of the effort to improve chronic disease management in the UK (Department of Health, 2004). In contrast with ME/CFS, diagnosis involves a simple and routine blood test. In addition, it is one of the long-term conditions included in the UK’s Quality and Outcomes Framework (QOF), whereby clinicians are incentivised to provide evidence-based care to individuals (Chew-Graham et al., 2013).
This is not to suggest that living with diabetes is a simple process, however. There is an increasing stigma associated with the condition, with individuals using terms like “fat, lazy, unhealthy” to describe those with diabetes (Vishwanath, 2014, p. 523). This stigma impacts on people’s self-management of their diabetes, including their monitoring of their blood glucose levels (Ong, Chua, & Ng, 2014). In addition, the progressive and chronic nature of type 2 diabetes means that the necessity for substantial lifestyle changes can place a heavy burden on individuals, their families, and health services (van Puffelen et al., 2014).

Regarding research around diabetes and online peer support, the area has received relatively little attention considering the proliferation of research into diabetes education programmes such as DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) and DAFNE (Dose Adjustment for Normal Eating). However, in line with previous research, it has been suggested that diabetes forums contain broadly accurate health advice and information (Greene, Choudhry, Kilabuk, & Shrank, 2011; Hoffman-Goetz, Donelle, & Thomson, 2009; Loader et al., 2002). In addition, the functions of the discussion groups appeared to replicate those found in other LTCs, with users seeking support, experiential knowledge, and information about medication and condition management, such as diet and weight control (Chen, 2012), and accessing interpersonal and community support along with specialised knowledge from peers (Greene et al., 2011). Similarly, Ravert, Hancock, and Ingersoll (2004) reported that adolescents with type 1 diabetes visit Internet forums for social support, advice, information, and access to shared experiences. This indicates that individuals access diabetes forums in line with other chronic conditions. Given the NHS framework in which this research is occurring and the social stigma associated with diabetes, the condition offers an appropriate context in which to shed further light on the use of the Internet by individuals with LTCs.

### 1.8 Rationale for the Present Study

To summarise, the research outlined in this chapter highlights the need to explore how individuals with LTCs, specifically ME/CFS and diabetes, use the Internet and Internet forums for health information, advice, and support. Within these two communities, how individuals navigate and assess the information that they encounter online will be addressed. Drawing on previous research, the strategies that forum users utilise to determine misinformation online (Armstrong et al., 2012; Coulson & Knibb, 2007; Sillence & Mo, 2014) and to assess other forum members as credible and legitimate information providers (Mudry & Strong, 2013; Smithson et al., 2011) will be examined. In this way, the
present study will attempt to determine how individuals with ME/CFS and diabetes navigate information and establish trust online.

In addition, the nature of forum usage will be explored. It has been suggested that the use of Internet forums by individuals with LTCs is contextually dependent (Gage & Panagakis, 2012) and embedded in one’s knowledge about their health and illness (Nettleton, Burrows, & O'Malley, 2005). With this in mind, the use of forums by those with ME/CFS and diabetes will be examined. In particular, the contexts of these conditions will be addressed in order to explore whether forums represent a challenge to the professional dominance of the medical model, as suggested by some researchers (Barker, 2008; Hardey, 1999; Pitts, 2004), or whether they supports a model of biomedical authority, as proposed by others (Rier, 2007; Sandaunet, 2008; Seale, 2005). Within this, how individuals use the support that they receive online, and whether this support leads to them repositioning themselves as active, empowered participants in their healthcare (Barker, 2008) will be addressed.

Lastly, the concept of forum users’ online identities will be explored. It has been suggested that, alongside facilitating individuals with LTCs to reconstruct and reorient their personal narratives (Charmaz, 1983; Hardey, 1999; Trondsen & Tjora, 2014; G. Williams, 1984), forum members curate their own online identities, engaging in a form of impression management that allows them to present an idealised self online (Goffman, 1959; B. Hogan, 2010). In many cases, these idealised selves are ones that adheres to forum norms and codes of conduct (Stommel & Koole, 2010; Vayreda & Antaki, 2009). In particular, this research will examine how individuals with ME/CFS and diabetes perform their online identities, and will specifically look at whether these performances are linked to forum users’ concepts of health discussion boards as public or private spaces. Additional justification for the study of this topic is provided in Chapter Two in section 2.8.

1.9 Research Questions

Overall, the aim of this study is to explore how individuals with contested and uncontested conditions use Internet forums. In order to address this aim, a qualitative design was used. To this end, three specific research questions were examined:

1. How do individuals with contested and uncontested LTCs, specifically ME/CFS and diabetes, navigate information and establish trust on Internet forums?
2. What is the nature of Internet forum usage by individuals with contested and uncontested LTCs?

3. For individuals with LTCs, how are Internet forums perceived and experienced as public or private spaces and what impact does this have on their online identities?
Chapter Two: Methods and Methodology

2.0 Overview
This chapter will describe the methods and rationale for the present study. The justification for a qualitative approach will be outlined, and some considerations around the nature of qualitative research will be discussed. Next, the procedure for data collection and the recruitment of participants will be described. The use of semi-structured interviews with individuals with contested and uncontested LTCs will be outlined and the inclusion of vignettes in the interview schedules will be highlighted. Finally, the method of analysis and ethical considerations of the study will be presented, as well as some personal reflections on the research process.

2.1 Rationale for a Qualitative Research Approach
In its most basic form, qualitative research is concerned with the quality or qualities of a phenomenon, compared to quantitative research, which is involved with the quantification or measurement of a phenomenon (Langridge, 2004). As a result, qualitative research allows the in-depth exploration of individuals’ experiences via methods such as interviews, focus groups, observation, or document analysis. However, adopting a qualitative approach requires an understanding of the concepts and epistemology that underpin qualitative research, as well as the varied spectrum of approaches that can be termed ‘qualitative methods’ (Hennink, Hutter, & Bailey, 2011). Qualitative research has its roots in interpretivism, which was developed in response to criticisms of the dominance of the positivist paradigm (e.g., Blumer, 1954). Positivism centres on the belief that there is a clear and straightforward relationship between objects, events, and phenomena and our perception and understanding of these circumstances. Consequently, research is assumed to produce objective knowledge, as it is understood that phenomena directly determine our perception of them (Willig, 2008). In other words, positivist research is assumed to be value free and removed from ambiguity or bias (Charmaz, 2006).

By contrast, the interpretive approach holds that, rather than an objective representation, reality is instead socially constructed, and is formed and shaped by various social, historical, and political processes (J. Green & Thorogood, 2004). The interpretivist view acknowledges that what we perceive and experience is never a clear and unbiased reflection of our environment, and must be understood as a specific and individual representation (Willig, 2008). As a result, it seeks to understand the lived experiences of people from their own perspectives, and suggests that there can be multiple perspectives on reality rather than
the notion of a single truth (Hennink et al., 2011). While quantitative research seeks to measure and count topics with the aim of extrapolating these findings to a wider population, qualitative research is not concerned with generalisability. Instead, qualitative research looks at individuals’ experiences through an in-depth process, seeking to understand the context surrounding these experiences (Hennink et al., 2011). It allows an exploration of the lived experiences of individuals, and how they interpret and make sense of their experiences and the world in which they live (Gubrium & Holstein, 1997). Given that the present study explored online relationships and sources of support, and how these networks are understood by individuals with LTCs, this approach was considered to be the most appropriate way of addressing these experiences.

Qualitative research aims to understand, explore, and represent the perspectives of individuals as they “encounter, engage, and live through situations” (Elliott, Fischer, & Rennie, 1999, p. 216). However, the notion of ‘understanding’ within qualitative research is more correctly referred to as “Verstehen” – understanding something in its context (I. Holloway & Biley, 2011, p. 7). This distinction highlights the importance of understanding the perspectives of those under research, rather than understanding within the researcher’s own frame of reference. It could be argued that the notion of Verstehen is particularly important in health research in order to examine the views and experiences of individuals with LTCs. Looking to understand the use of the Internet within individual contexts, alongside broader sociocultural factors, can provide an ‘insider’s perspective’ (Hennink et al., 2011), which may in turn be used to adapt and improve the guidance that individuals receive around Internet use.

While the present study has its roots in a qualitative, interpretivist approach, the influence of pragmatism in the methodological positioning must also be acknowledged. In particular, Seale (1999) argues that subscribing to a specific philosophical view or paradigm risks resulting in an overly restrictive methodological approach. He suggests that drawing on different “arenas of discourse” (p. 446) allows researchers to be flexible yet reflexive in their work. Rather than situating themselves rigidly within a particular epistemological camp, pragmatists hold that it is the research question that should determine the choice of methods (Onwuebuzie & Leech, 2005). This approach is advocated by Pritchard (2012), who recommends that combining qualitative methods should not follow a ‘one size fits all’ approach, but rather should be viewed within the context of the research. In addressing the study’s aims of exploring and understanding the experiences of individuals with LTCs who use the Internet, a qualitative approach was therefore considered to be the most appropriate
methodological choice. Within this approach, however, a pragmatic view was taken. This allowed the examination of interviewees’ lived experiences, alongside the embedded nature of the Internet and technology into individuals’ lives (Kivits, 2006, 2009).

2.1.1 Reflexivity in qualitative research
It is acknowledged that researchers bring their own subjective perspectives to the research process (Hennink et al., 2011). Rather than removing themselves from the research scenario, qualitative researchers are often situated within the study context. While this subjectivity is a pivotal aspect of qualitative research (Elliott et al., 1999), and is not typically problematic, it does require consideration and reflection. This is known as reflexivity, where researchers consciously reflect on their potential influence; namely how their backgrounds, perspectives, positioning, and behaviour shape the research process (Finlay, 2002).

Within this process, there are two occasions when reflexivity may be particularly important. First, the researcher will have an influence on the data created (Hesse-Biber & Leavy, 2006). Within an interview setting, the participant, the interviewer, and the relationship between the two individuals all influence what is discussed and how it is discussed. By being aware of basic distinctions between researcher and participant, such as age, gender, or ethnicity, and taking steps to sensitively address these distinctions and to develop rapport with interviewees, researchers may facilitate more open discussion (Hesse-Biber & Leavy, 2006). Reflexive analysis at this stage allows the researcher to consider how the data collected has been shaped by the methods used and the relationship between the researcher and participant (Finlay, 2002).

In addition, reflexivity during the analysis phase enables researchers to examine their own beliefs and assumptions and to consider the influence that their own perspectives have on how they interpret the views and experiences of participants (Finlay, 2002). Within the social sciences, however, this aspect of reflexivity has received comparatively less attention. Instead, the process is often depicted as a simple one whereby the ‘voices’ of participants are represented, rather than acknowledging the active role that researchers play in determining how to interpret these voices and which extracts to present as evidence of this interpretation (Mauthner & Doucet, 2003).

As a result, an adequate understanding of the phenomenon under study requires a degree of reflexivity of the part of the qualitative researcher (Elliott et al., 1999). Through the course
of the present research, attempts were made to consider the role of the researcher in the research process. In particular, a field diary was used during the course of data collection and analysis in order to facilitate ongoing reflexivity (Chambers, 2004). This is described in section 2.6 where the process of analysis is explained. In addition, section 2.9 discusses the role of the researcher within the present study in more detail.

2.1.2 Quality and rigour in qualitative research

Just as qualitative research is distinguished from a traditional positivist scientific approach, the criteria traditionally used to evaluate the scientific value of quantitative research, such as reliability and validity, are not fully applicable to qualitative research (Golafshani, 2003). Thus it is necessary to consider additional methods of verifying quality and rigour in qualitative research. For example, Leininger (1985) suggests redefining notions of rigour in the absence of statistical verifications, proposing that validity be understood as the development of knowledge and understanding of the nature of the phenomenon under investigation, rather than the degree to which an instrument measures what it is supposed to measure.

Similarly, there has been an increasing use of checklists, such as COREQ, to ensure comprehensive reporting of qualitative studies (Tong, Sainsbury, & Craig, 2007). Some researchers have cited ‘trustworthiness’ as a key element of verification in qualitative research, where the evident capacity of the researcher to conduct research in a transparent and auditable manner is central to the calibre of the findings (e.g., Sandelowski, 1986, 1993). In addition, it has been suggested that elements of verification can be incorporated by procedures such as member checking, where findings are reviewed by participants post data analysis, or peer checking, where experts or colleagues reanalyse the data to ensure that they were interpreted correctly (Guba & Lincoln, 1994). Others have questioned the appropriateness of blanket use of predetermined criteria in evaluating qualitative research, arguing that it is necessary for individual studies to be evaluated on their individual merits (Rolfe, 2006). In addition, it has been argued that that the variability amongst individual participants means that strategies like rigorous member checking can negatively impact the research process (Carlson, 2010). Despite the variation in perspectives amongst researchers, it can be useful to consider some commonly agreed areas of appraisal in evaluating the quality of qualitative research, e.g., the publications of guidelines for qualitative research outlined by Elliott et al. (1999). Table 1 provides a description of these areas and the ways in which each area was addressed in the current research.
<table>
<thead>
<tr>
<th>Guideline</th>
<th>Description</th>
<th>Methods used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owning one’s own perspective</td>
<td>Recognising and disclosing own values, interests, assumptions and roles.</td>
<td>Critical examination of my role as a researcher and how this may have influenced the data collection and analysis.</td>
</tr>
<tr>
<td>Situating the sample</td>
<td>Providing demographic information about participants.</td>
<td>Provision of information on age, ethnicity, gender, level of education, etc. Integration of field notes and personal observations into the analysis process to provide additional information.</td>
</tr>
<tr>
<td>Grounding in examples</td>
<td>Providing examples of the data to illustrate the analytic process.</td>
<td>Provision of a detailed account of the methods used during the study. Use of specific examples and quotes from the data to illustrate the themes reported in the research.</td>
</tr>
<tr>
<td>Providing credibility checks</td>
<td>Verifying findings with other researchers or participants, using multiple perspectives or methods.</td>
<td>Regular and ongoing meetings to discuss analysis process with supervisors. Use of semi-structured interviews and vignettes.</td>
</tr>
<tr>
<td>Coherence</td>
<td>Producing a narrative through coherent and integrated analysis.</td>
<td>Provision of an integrated summary of the findings from the analysis.</td>
</tr>
<tr>
<td>Accomplishing general vs. specific research tasks</td>
<td>Using appropriate methods to address the research question.</td>
<td>Recruitment of individuals from online and offline networks. Use of thematic analysis to describe the themes in the data and provide an examination of the context in which the identified themes are located.</td>
</tr>
<tr>
<td>Resonating with readers</td>
<td>Ensuring that the subject matter and the experiences of participants are adequately represented.</td>
<td>Provision of a detailed description of the sample and findings. Use of appropriate quotes to highlight and ‘bring to life’ the experiences of participants. Production of a vivid and coherent narrative.</td>
</tr>
</tbody>
</table>
2.2 Internet Research Methods

As outlined previously, this study used a qualitative approach. This approach allows an exploration of how the Internet is embedded into individuals’ lives (Nettleton, Burrows, & O’Malley, 2005). Initially, the field of Internet-based research was dominated by computer scientists, and it was not until the early 2000s that social science researchers became interested in the notion of networked communities online (Wellman, 2004). While much of the early work was quantitative in nature, qualitative approaches were quickly established as useful tools in understanding the nature of computer-mediated communication (Hewson, 2014; Markham, 2004). Broadly speaking, qualitative Internet research methods fall into four categories: interviews, focus groups, observational research, and document analysis (Hewson, 2014).

However, as Hine (2011) notes, there are a number of issues associated with relying solely on data derived from the Internet, namely the lack of information about how individuals interpret and utilise the support, advice, and information that they encounter online. Similarly, focusing purely on offline interactions risks excluding pivotal aspects of life in contemporary society (Garcia, Standlee, & Bechkoff, 2009). As a result, the notion of online ethnography, often drawing across a number of methodological approaches, has received much attention. For example, Sade-Beck (2004) utilised online observations, offline interviews, and analysis of online and offline documents in studying Israeli online bereavement support groups.

While the present research is not ethnographic, attempts have been made to explore the views and experiences of individuals with LTCs via semi-structured interviews which discuss their experiences online and offline. In addition, vignettes created from forum data have been incorporated into the interviews in order to integrate Internet-derived data. A description of the methods used in the research and the rationale behind this approach is provided below.

2.2.1 Online and offline recruitment

In order to explore the experiences of those with LTCs, semi-structured qualitative interviews were conducted. Potential participants were recruited through both online and offline sites, such as Internet forums, face-to-face support groups, email lists, and research networks. Those who expressed an interest in taking part were offered the option of face-to-face or phone interviews with the researcher, at their convenience. It was anticipated that each participant would complete one interview of 30-60 minutes, though participants were
offered the option of completing several shorter interviews if required. This approach was primarily taken in order to address the needs of those with ME/CFS, who may experience difficulties completing an interview in one sitting due to fatigue or cognitive difficulties; though it was expected that the option of multiple interviews may also appeal to those with limited time to participate in research.

Drawing on online and offline methods of recruitment had a number of benefits. Recruiting individuals online for participation in offline interviews offered a method of obtaining information about the perspectives of the interviewee alongside their experiences and practices with Internet forums. In addition, this approach also allowed interviewees to act as ‘informants’ on the process of online support for those with LTCs, providing ‘behind the scenes’ information about the operation of online discussion groups (Sade-Beck, 2004). Similarly, sampling from face-to-face support groups allowed those who were not frequent Internet users to share their own experiences, and provided an opportunity for interviewees to discuss the reasons why they did not engage with online support.

Due to the digital divide and inequality of Internet use, recruiting participants via solely online sources limits sampling to those who have adequate Internet access (Goldfarb & Prince, 2008), and users who post personal stories online are likely to display different characteristics to those who do not (Seale, Charteris-Black, MacFarlane, & McPherson, 2010). To ensure that a number of perspectives were considered, where the views and experiences of both users and non-users were collected, recruitment took place both online and offline. In addition, the messages posted on forums (see Appendix D) emphasised that a range of interviewees were sought. This represented an attempt to incorporate lurkers, i.e., those who read but do not contribute to forums, as well as active forum users.

2.2.2 Semi-structured interviews
A key factor of using interviews in social research is recognising that conversations between the researcher and participant do not occur in a vacuum; instead, the situation influences what and how topics are discussed in the interview (Hennink et al., 2011). The notion of ‘storytelling’ within an interview setting, where individuals perform their preferred self as situated within the social interaction between researcher and interviewee, has long since been acknowledged (Riessman, 2002). As a result, there is a need for researchers not only to acknowledge how they are perceived and the impact this perception may have on an interviewee’s narrative, but also their subsequent role in depicting and disseminating this narrative (Mauthner & Doucet, 2003). Despite this, the aim of the
interview is to discover the interviewee’s own framework of meanings, and to avoid imposing the researcher’s frame of reference on the participant’s views, opinions, and experiences (Britten, 1995).

Within qualitative research, there are typically considered to be three types of interviews – structured, unstructured and semi-structured (Bryman, 2004). While structured interviews are strictly defined conversations, where the interviewer determines the precise form and direction of questions, and unstructured interviews follow a very broad guide rather than a strict schedule, and allow interviewees to guide the direction of the conversation (Bryman, 2004), semi-structured interviews fall in the middle of these two extremes. Semi-structured interviews allow participants to discuss their experiences and perspectives, in addition to addressing the topic under study. They typically result in fewer logistical difficulties, and are easier to arrange than other forms of qualitative research (Willig, 2008). Utilising this method also enabled participants to bring their own opinions and ideas into the conversation, which was particularly important given that one of the aims of the research was to consider the views and experiences of both frequent and infrequent Internet users. Rather than using a more prescriptive method of data collection, semi-structured interviews allowed infrequent Internet users, for example, to discuss at length their relationships with family, friends, healthcare professionals, and other offline support networks, while making tangential references to their use of the Internet. While an interview schedule was used throughout the interviews, the phrasing and order of the questions evolved based on the progression of data collection. The interview schedule is available in Appendix E and described in more detail in section 2.5.

2.2.3 Vignettes
In order to utilise both interviews and forum data and to allow for the integration of present and retrospective narratives (Seale et al., 2010), representative forum data were incorporated into the interview schedule with participants in the form of vignettes. The vignettes are available in Appendix E. Typically, vignettes consist of words, images, or other types of stimuli to which participants are asked to react (R. Hughes & Huby, 2002). This allows them to be used as a stimulus to extend discussion of the scenario in question (Bloor & Wood, 2006).

Threads from forums focusing on LTCs were reviewed and purposively sampled in order to compile material that directly addressed the research questions. The chosen vignettes were selected from forums relating to diabetes, ME/CFS, and fibromyalgia, but care was taken to
ensure that the situations described were not condition-specific and were instead generally related to the use of the Internet by those with LTCs. For example, online discussions which centred on the role of forums in users’ lives or the impact of sharing information anonymously online were viewed to be relevant to the study’s aims. Through the compilation of thread data, quotes and scenarios detailed on online forums were accumulated in order to create appropriate vignettes for use during the participant interviews. By adapting existing threads, it was intended that one of the major criticisms of the use of vignettes in research would be addressed; namely, the situations and conversations utilised in the present study would be realistic and would therefore be valid and reliable research tools (Gould, 1996).

As the included vignettes were created predominately from quotes and scenarios outlined online, it was anticipated that this would ensure that the situations depicted were plausible for the participants. The more plausible a situation, the more likely it is that the interviewee will be able to consider themselves in the place of the character (Jenkins, Bloor, Fischer, Berney, & Neale, 2010). As the interviews aimed to explore the nature of online social support, the vignettes related to that topic. Interviewees were presented with vignettes in which characters interact with online social support, and were asked to imagine, drawing on their own experiences, how the characters would behave (Bloor & Wood, 2006). Integrating interviews and vignettes enabled an element of triangulation, whereby more than one methodological approach was enlisted in order to enhance confidence in the findings (Bryman, 2004). While the two approaches resulted in the production of interview transcripts rather than multiple sources of data, as is traditional when using triangulation, the combined techniques facilitated the collection of richer data than could be provided with a singular approach.

The vignettes centred around three scenarios – a forum user who is concerned about the privacy of an open forum; an individual who wants to bring information from the Internet to his GP, but is unsure if this is appropriate; and a poster who describes her experiences with her condition in detail in order to provide support and validation to other forum members. For each vignette, an abbreviated version of the opening post of the thread was included, and adapted responses from two or three forum members followed. The responses from forum members were selected to represent the range of views of posters on the original threads.
Rather than aiming to study individual behaviour, the intention of the vignettes was to explore interpretive processes and experiences (Jenkins et al., 2010). Asking interviewees to comment on a scenario can provide a more sensitive and non-confrontational method of engaging participants on an issue than asking them to directly discuss their experiences (Barter & Renold, 1999). While it was felt that participants may not find the discussion of online support a sensitive issue, it was considered likely that presenting them with vignettes to comment on would enable the consideration of the practice of online social support for individuals with LTCs from a number of perspectives. For example, describing the behaviour of a healthcare professional in relation to online support as a result of a vignette depiction would be contextualised by the conduct of healthcare professionals which the interviewee has previously encountered, by reference to the norms and beliefs that they have previously experienced and observed (Jenkins et al., 2010).

2.3 Participants

Interviews were conducted with a number of individuals with LTCs who represented a number of illnesses and viewpoints. Specifically, participants were recruited from two populations. One sample consisted of interviews with individuals with type 1 and 2 diabetes based in the UK recruited through online and offline recruitment sites. Given that the condition has been highlighted by the NHS as a key focus of the effort to improve chronic disease management in the UK (Department of Health, 2004), it was anticipated that this sample would provide an appropriate context within which to study the role of online support. The other sample consisted of interviews with individuals with ME/CFS who were recruited via online and offline recruitment sites. Given that ME/CFS is a contested illness, with debate and discussion over the symptoms and prevalence (Wearden & Chew-Graham, 2006), many people struggle to receive a diagnosis and real world support from health professionals (Huibers & Wessely, 2006). As a result, individuals can access the Internet to receive information about their condition and to attempt to legitimise it (Chew-Graham, Cahill, Dowrick, Wearden, & Peters, 2008). It was therefore anticipated that examining the online practices of those with ME/CFS would provide an appropriate context in which to study the nature of Internet forum usage by those with contested conditions.

2.3.1 Sample size

As outlined above, individuals from two distinct samples were recruited to take part in a semi-structured interview. Due to ethical reasons, only those over the age of 18 were invited to complete an interview. It was anticipated that all participants would be based in
the UK; however, a small number \((n = 2)\) of British expatriates living outside the UK took part in phone interviews due to their connections with UK-based support groups. For each sample, the initial target number of participants recruited to take part in interviews was 20-25, i.e., approximately 40-50 participants in total. This number is in keeping with the nature of qualitative studies, where the aim is to provide a deep understanding of social phenomenon rather than generalisable findings from a large, representative sample (Silverman, 2011). In addition, the sample size was influenced by an iterative process of analysis throughout the period of data collection, whereby data saturation was approached. While the notion of data saturation has been queried by some researchers (e.g., Mason, 2010), other have suggested that it can be approached in as few as 12 interviews (Guest, Bunce, & Johnson, 2006). This is discussed in more detail in section 2.6.2. In total, 41 interviews were completed, 20 interviews with individuals with ME/CFS and 21 with individuals with diabetes. The interviews ranged in length from 18 minutes to an hour and 48 minutes, with the majority of interviews lasting in excess of 45 minutes.

### 2.3.2 Participant demographics

A short questionnaire was used to collect information on participants (see Appendix E). A number of summary demographic statistics relating to the interviewees are presented below in Tables 2, 3, and 4, while the full demographic statistics are available in Appendix F. All participants described themselves as white, with the vast majority (93%, \(n = 38\)) identifying as White British. The remaining two interviewees selected White Other (5%, \(n = 2\)). One female participant with ME/CFS declined to provide any demographic information; as a result, the figures do not always sum to 41.

<table>
<thead>
<tr>
<th>Gender of Participants</th>
<th>ME/CFS</th>
<th>Type 1 diabetes</th>
<th>Type 2 diabetes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Female</td>
<td>15</td>
<td>7</td>
<td>5</td>
<td>28</td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
<td>12</td>
<td>9</td>
<td>41</td>
</tr>
</tbody>
</table>

Across the two samples, the majority of participants were female (68%, \(n = 28\)), with 75% of interviewees with ME/CFS and 62% of interviewees with diabetes identifying as female. There was a large amount of variation in participants’ ages, with interviewees ranging from
18 to 82 years of ages. The modal age categories were 36-45 years and 56-65 years, with nine interview participants selecting these respective categories.

Table 3

<table>
<thead>
<tr>
<th>Age bracket</th>
<th>ME/CFS</th>
<th>Type 1 diabetes</th>
<th>Type 2 diabetes</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-25</td>
<td>2</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>26-35</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>36-45</td>
<td>5</td>
<td>4</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>46-55</td>
<td>2</td>
<td>0</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>56-65</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>66-75</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>76+</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Total*</td>
<td>19</td>
<td>12</td>
<td>9</td>
<td>40</td>
</tr>
</tbody>
</table>

*Demographic information was not provided by one participant with ME/CFS

Just over half of the 41 interviewees (51%, n = 21) were recruited using online forums. Of the 21 participants recruited online, 15 were individuals with diabetes, while six were individuals with ME/CFS. The remaining 20 participants were recruited using face-to-face support groups (34%, n = 14) and advertisements (15%, n = 6). All interviewees recruited through support groups had received a diagnosis of ME/CFS, while all those recruited through advertisements were diagnosed with type 1 or type 2 diabetes.

Participants were offered the option of completing the interview by phone or in person. The majority of interviewees chose to participate by phone (71%, n = 29). Though there has been some debate about the quality of telephone interviews compared to face-to-face interviews, it has been argued that there is little evidence to support these criticisms (Novick, 2008; Sweet, 2002). It has also been suggested that phone interviews allow respondents to discuss sensitive issues more openly (Mealer & Jones, 2014). In addition, the high uptake of phone interviews by participants in the present study indicates that that it is considered an acceptable method amongst the populations under study. For participants who chose in-person interviews, these predominately took place in participants’ homes, though a small number of interviews took places in coffee shops, pubs, and at the University of Manchester.
As seen in Table 4, the majority of participants (71%, \( n = 29 \)) had completed at least a higher education degree or equivalent. Though similar percentages were found for those with ME/CFS (70%) and diabetes (71%), this is considerably higher than the rate of higher education across the UK. The latest census data suggested that in 2011, just 27% of the population of England and Wales had received a degree or higher (ONS, 2014), indicating that participants in the present study are more educated than the general British population. This is particularly noteworthy considering research outlined in Chapter One which indicates that inequalities associated with education are associated with lower levels of health information seeking online (Dutton & Blank, 2013; Neter & Brainin, 2012). As a result, it is likely that inequalities in the use of the Internet for health information are reflected within this sample of participants, despite the use of online and offline methods of recruitment.

Table 5

<table>
<thead>
<tr>
<th>Employment status</th>
<th>ME/CFS</th>
<th>Diabetes</th>
<th>Total*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to work</td>
<td>9</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>Employed</td>
<td>3</td>
<td>10</td>
<td>13</td>
</tr>
<tr>
<td>Retired</td>
<td>4</td>
<td>8</td>
<td>12</td>
</tr>
<tr>
<td>Out of work</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Student</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Total*</td>
<td>19</td>
<td>21</td>
<td>40</td>
</tr>
</tbody>
</table>

*Demographic information was not provided by one participant with ME/CFS*
Employment status was the most striking difference between the two samples of interviewees, as illustrated in Table 5. While none of the participants with diabetes were unable to work, just under half of those with ME/CFS (45%, n = 9) indicated that their condition prevented them from working. In addition, a number of those with ME/CFS who described themselves as retired (20%, n = 4) later clarified during the course of their interview that they had taken early retirement as a result of their health. By contrast, nearly half of those with diabetes were employed (48%, n = 10), while another large proportion were retired (38%, n = 8) for reasons unrelated to their condition.

2.4 Recruitment and Sampling

Potential participants were recruited from two distinct populations, and as a result, a number of different recruitment and sampling strategies were employed. Broadly speaking, participants from both populations were drawn from a number of online and offline sites. The recruitment process is described below.

2.4.1 Participants with diabetes: Online and offline recruitment

Recruitment for participants with diabetes took place between February and May 2013, and 21 interviews with individuals with type 1 and type 2 diabetes were completed. For the online recruitment phase, a list of suitable forums was compiled using Internet search engines. In addition, searches were made for websites associated with diabetes in order to examine if these websites contained a forum aspect or linked to an online support group. Once potential forums were reviewed, the forums considered most appropriate for the research (i.e., forums on which UK-based users with diabetes appeared to be sufficiently active) were contacted via the appropriate gatekeeper. Samples of the correspondence with websites are located in Appendix D.

Based on an initial search, two forums were identified as potential avenues for recruitment. The first forum was an active UK-based forum with over 1,000 members at the time of recruitment. It was open access, i.e., registration was not required to access and browse the boards, though an account was needed to participate. It catered for individuals with type 1 and type 2 diabetes and included sections for discussions on insulin and diet and weight management as well as general discussion and chat. In order to access the forum, contact was made with the forum administrators via the email address displayed on the forum. This was in line with the guidelines for researchers listed on the website. The initial email included details on the study, along with the researcher’s contact details, and a copy of the information sheet that would be provided to potential participants was attached (see
Appendix A). The researcher requested permission to recruit participants through the website by starting a thread on the topic in an area of the forum dedicated to research requests.

After discussion among the administrators, permission was given for recruitment to take place via the website and a message was posted on the forum inviting users to take part in a semi-structured interview (see Appendix D). Both frequent and infrequent Internet users were invited to take part, in order to include a variety of viewpoints and perspectives. Interested forum members were encouraged to contact the researcher, who provided them with more detailed information on the study (see Appendix A).

If they decided to take part, an interview time was arranged by telephone or in person, at the convenience of the interviewee. Prior to the start of the interview, the researcher explained the study with reference to the information sheet provided to the individual and encouraged them to ask any questions. In particular, participants were reminded of the nature of the study and that the interview was being recorded. If the participant was willing to take part in the interview, written consent was obtained (see Appendix B). In the case of the interview taking place by phone, written consent was posted to the researcher in advance of the interview. If the participant was not willing to take part, no further action was taken. In total, six participants were recruited from this forum.

The second forum was also a UK-based open access forum, which covered similar topics. At the time of recruitment, there were over 10,000 members. The recruitment process for this forum was similar to that previously detailed, though the administrators required proof of ethical approval from the University of Manchester before giving permission for recruitment to take place. Once this was furnished, a message with details on the study was posted on the forum, and an additional nine participants were recruited.

In addition to online recruitment methods, a number of offline recruitment strategies were also utilised. The study was advertised in the magazine of a UK diabetes charity, which has a bi-monthly reach of over 100,000 members. As with the forum messages, the advert contained details on the study and encouraged potential participants to contact the researcher (see Appendix D for a copy of the advert). As a result of this advert, a further five interviews were completed.
A final offline recruitment attempt was made through the University of Manchester research volunteering site, where ongoing research at the university is advertised. As before, the advert provided details of the study and encouraged potential participants to contact the researcher. One participant was recruited using this method. A summary table of recruitment avenues for the 21 participants with diabetes is included below.

Table 6

Recruitment Methods for Participants with Diabetes

<table>
<thead>
<tr>
<th>Method</th>
<th>No. of type 1 participants</th>
<th>No. of type 2 participants</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forum 1</td>
<td>4</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Forum 2</td>
<td>4</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Magazine</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>University</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>12</strong></td>
<td><strong>9</strong></td>
<td><strong>21</strong></td>
</tr>
</tbody>
</table>

Though a number of additional recruitment routes were planned, including accessing research networks for individuals with diabetes and recruiting through face-to-face diabetes support groups, the pace of the recruitment meant that this was not necessary. Interestingly, the two forums provided not just a route for recruitment, but also facilitated discussion of the study. Due to the nature of the medium, the researcher was able to engage with potential participants, and answer any questions about the study in a public forum. In addition, a number of interviewees stated on thread that they had completed an interview and provided positive feedback in order to encourage other forum members to participate (e.g., “I just had my interview with Ellen and she’s a lovely lady – allowed me to talk as much as I wanted and asked some very thought provoking questions”). On one forum in particular, the qualitative nature of the research received a very positive response. When one forum member criticised the use of interviews, and suggested that a survey would be preferable for participants, a number of users responded in defence of the research. One poster expressed scepticism at the forum member’s suggestion that he did not have time to participate in an interview (“What – never? I have arranged to do an interview in the evening”) while another indicated that an interview allowed her to express her own opinions and experiences (“I was able to give my own opinion rather than try and fit my

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1 All quotes taken directly from forums have been adapted in order to protect the anonymity of forum users.
experiences into a set of options designed by someone who obviously had very little idea about diabetes 

2.4.2 Participants with ME/CFS: Online and offline recruitment

While recruitment for participants with ME/CFS followed a similar pattern to those with diabetes in terms of online and offline recruitment, the numbers of avenues of recruitment explored were much greater, with individual routes proving less fruitful than experienced with participants with diabetes. Recruitment took place between October 2012 and June 2013, and 20 interviews with individuals with ME/CFS were completed. As before, for the online recruitment phases, a list of suitable forums was compiled through searches on search engines. In addition, searches were made for websites associated with ME/CFS in order to examine if these websites contained a forum aspect linked to an online support group. Once potential forums were reviewed, the forums considered most appropriate for the research were contacted. A sample of the correspondence with ME/CFS websites is available in Appendix D.

Initially, four forums were selected as potential recruitment routes, though this grew to seven as recruitment continued and additional searches were carried out. Of these forums, six were contacted, while one website was excluded on the basis that the forum was expressly a place for support and that any research activity was banned. Out of the six forums contacted, no responses were received from three websites, one of which was based in the UK and two of which were based in the US, while the remaining three agreed to participate in the research.

The first forum was an open access forum based in the US with over 5,000 members. The forum was contained within a website which covered current issues and research within ME/CFS, and though there was a focus on the US healthcare system, it was felt that there was sufficient discussion on UK-based systems and research to justify its inclusion in the study. Contact was made with the forum administrators by registering on the forum and sending a private message with details on the study and requesting permission to recruit interviewees via the forum. After some discussion with the administrator, including the provision of the information sheet for potential participants and details on the background of the research team, permission was granted to recruit via the forum. Based on this recruitment, three people with ME/CFS completed interviews.
The second forum targeted was affiliated with a UK-based charity for individuals with ME/CFS. In addition to the forum, the website focused on accessing practical support for ME/CFS, such as welfare benefits, and updates on recent news and research. Membership figures for the forum were unavailable and the forum was open access. As before, contact was made with the forum administrators through the website and permission was requested to post on the forum. This was granted on the basis that it was made clear to members that the charity were not involved in the interview process or the research. Following the posting of a message on the forum, three individuals with ME/CFS were recruited to take part in interviews.

Finally, the third forum utilised was a large US-based website aimed at a range of health conditions, including ME/CFS. As the forum actively encouraged research recruitment and contained an allocated section for members to engage in medical and academic research, permission was not sought from forum moderators or administrators before posting on the website. The posting did not receive any responses and no participants were recruited using this route.

In addition to recruitment via online forums, offline recruitment of individuals with ME/CFS also took place. Lists of face-to-face support groups throughout the UK were compiled using information from ME/CFS charities and organisations, and the nominated contact was phoned or emailed. They were provided with information about the research and asked to distribute this information to their members. They were informed that, if desired, the researcher would attend a support group meeting in order to answer questions or discuss the research, and that detailed information sheets could also be posted to the group to be distributed at meetings. An example of the message sent to the groups is presented in Appendix D.

In total, 33 support groups were contacted. 12 groups agreed to facilitate recruitment via their members, with three groups forwarding details about the research to their members, eight groups advertising the research within their newsletters or Facebook pages and three groups allowing the researcher to attend a support group meeting to speak to members and distribute information sheets. Of the remaining 21 groups, one reported that they were no longer active and 20 did not respond. Overall, 14 participants were recruited using offline support groups. In addition, interviews were conducted with three participants recruited through support groups without clarifying through which groups they heard about the study. As before, an additional offline recruitment attempt was made through the University
of Manchester research volunteering site, where ongoing research at the university is advertised, but no ME/CFS participants were recruited. A summary table of the recruitment routes of the 20 individuals with ME/CFS is included below in Table 7.

Table 7

<table>
<thead>
<tr>
<th>Method</th>
<th>Recruitment</th>
<th>No. of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Forum 1</td>
<td>Thread on forum</td>
<td>3</td>
</tr>
<tr>
<td>Forum 2</td>
<td>Thread on forum</td>
<td>3</td>
</tr>
<tr>
<td>Group 1</td>
<td>Attended meeting</td>
<td>1</td>
</tr>
<tr>
<td>Group 2</td>
<td>Newsletter</td>
<td>1</td>
</tr>
<tr>
<td>Group 3</td>
<td>Newsletter</td>
<td>1</td>
</tr>
<tr>
<td>Group 4</td>
<td>Attended meeting, newsletter</td>
<td>1</td>
</tr>
<tr>
<td>Group 5</td>
<td>Attended meeting, newsletter</td>
<td>3</td>
</tr>
<tr>
<td>Group 6</td>
<td>Information forwarded to group</td>
<td>1</td>
</tr>
<tr>
<td>Group 7</td>
<td>Information forwarded to group</td>
<td>1</td>
</tr>
<tr>
<td>Group 8</td>
<td>Information forwarded to group</td>
<td>2</td>
</tr>
<tr>
<td>Group unknown</td>
<td>Unknown</td>
<td>3</td>
</tr>
</tbody>
</table>

As with the online recruitment for those with diabetes, the forums also facilitated discussion of the study, but with a more mixed response. On the first forum, the majority declined to participate, but also expressed their displeasure at the research. Among the areas highlighted for criticism were the perceived lack of medical focus of the research, the time commitment required from participants, and mistrust about the potential agenda of the research. This is in line with previous research, which indicates that the characterisation of ME/CFS as a biomedical rather than psychological or psychiatric condition is a key priority for those with the condition (Hawkes, 2011; Smith & Wessely, 2012). For example, one poster questioned, “Is this type of study the best use of scarce resources for medical research?”, while another forum member added, “It’s easy to imagine your study turning into a nightmare for patients. Are they going to use your study to cut us all off from disability because we can sit up in front of the computer? That’s all I’m saying”. While three interviewees were recruited from the forum, none of them spoke about their participation on the thread.
On the second forum, however, the research received a much more positive response. As with the diabetes forum, a number of posters said that they had completed or intended to complete an interview and encouraged others to participate. In contrast with the previous forum, the value of the research was praised, and the researcher’s ‘interest’ in ME/CFS was welcomed (“Every bit of research that could have an impact on the medical profession is worth using some of our precious energy resources”). It is possible that the contrast in reactions could be attributed to the difference in focus between the forums. The first forum was heavily focused on current ME/CFS research, with numerous threads dedicated to the discussion and critique of research, while the second forum centred on support for those with ME/CFS, with members encouraged to ‘check in’ daily.

2.5 Interview Schedule

In advance of the recruitment for this research, the interview schedule was piloted with an individual who was known to the researcher and had been diagnosed with an LTC. The purpose of this pilot was to assess the interview schedule and vignettes and to highlight any potentially problematic issues with the process of data collection. In addition, the interviewee was encouraged to provide feedback on the process and to offer suggestions for any potential areas of improvement. On the basis of this feedback, small changes were made to the interview schedule and the purpose of the vignettes in relation to the overall study was clarified in further interviews. Interviewees were also encouraged to ask questions about any issues that arose during the course of the interview.

For all participants, a semi-structured interview format was followed using an interview guide. A short demographic questionnaire was also administered in order to collect some basic demographic information on participants, as detailed in the previous section (see Appendix E). The interview schedule was developed to encompass the study’s research questions and was used with participants with diabetes and ME/CFS. The interview schedule is available in Appendix E. However, it should be emphasised that the schedule provided a guide for the interview and did not represent a prescriptive itinerary. Interviewees were given space to express their own opinions and ideas, and, in many cases, their responses shaped the order and structure of the interview (Dyer, 2006).

In addition, participants were encouraged to contribute their own stories and narratives wherever possible. Drawing on recommendations from Chase (1995), interviewees were asked questions that related to their life experiences, in addition to questions that were considered pertinent to the research topic. For example, interviewees were asked to provide
a brief description of their illness history and trajectory. It was anticipated that asking open-ended questions in a broad manner would offer an opportunity for respondents to provide detailed narrative accounts (W. Holloway & Jefferson, 2000). In order to examine the nature of Internet forum usage, this study drew on research on offline support groups from Ussher et al. (2006). As such, the interview schedule from the Ussher et al. (2006) study, where focus groups were conducted with users of face-to-face peer cancer support groups, was drawn upon in the interview schedule for the present study. In particular, questions such as ‘What do you get out of participating in this cancer support group?’ and ‘How does participating in this group interact with your other social support networks?’ were adapted to explore the nature and role of online support for those with LTCs.

In addition, questions were also asked that attempted to examine the unique aspects of online support. There have been suggestions that online support groups and the anonymity associated with sharing and receiving information online allow open discussion of stigmatised conditions or aspects of conditions (Sharf, 1997; Sullivan, 2003) as well as contrasting research which indicates that broadly similar discourses take place online and offline (Pitts, 2004; Rier, 2007; Seale, 2006). Considering this, issues around validation and legitimacy through online support were examined, along with additional topics suggested by the literature.

During the interview, as detailed previously, participants were presented with vignettes. For face-to-face interviews, participants were provided with a copy of the vignettes during the interview, and given a few moments to read through each scenario before responding. For telephone interviews, the vignettes were posted to participants in advance of the scheduled interview, along with the consent form.

Finally, the interview schedule contained some questions that attempted to address the ethical issues involved with collecting data online. The study of online support groups, and particularly the use of content from discussion boards as research data, has been a growing area of study in recent years, in part because the majority of forums for LTCs open-access and are considered to be public spaces and thus have not typically required informed consent from individual forum participants. This topic is discussed in more detail in section 2.8. In order to examine this, interviewees were asked about their views of online support groups as public or private spaces and their concepts of audience, privacy, and ‘safe spaces’ when sharing and receiving information and experiences online.
2.6 Data Analysis

As described in section 2.1.1, conducting qualitative research requires an element of reflexivity on the part of the researcher, in order to consider how an individual’s background, perspectives, positioning, and behaviour shape the process of data collection (Finlay, 2002). However, reflexivity during qualitative analysis has received comparatively less attention (Mauthner & Doucet, 2003). As a result, this section will contain both a description of the methods of analysis used within the present study and a personal reflection on the process.

2.6.1 Initial stages of analysis

All 41 interviews conducted with participants were audio-taped and transcribed. Due to the length of the interviews and the pace of data collection, 34 were transcribed by professional transcriptionists and the remaining seven interviews were transcribed by the researcher. All transcriptions were checked for accuracy against the audio files. In addition, the interview recordings and transcripts were reviewed throughout the data collection process, in order to assess the level of data saturation. Following this, anonymised interview transcripts were imported into a qualitative data analysis computer software package, ATLAS.ti version 7, in order to carry out the analysis. It should be noted that the use of a software package merely provided a tool to organise and review the data during the analysis process, rather than offering an objective method of analysis (Mauthner & Doucet, 1998).

Using an iterative process, each transcript was read through several times, and notes were made using the memo function in ATLAS.ti. These notes predominately related to comments and observations that were made during the data collection process, and often concerned personal communications with participants. For example, Rebecca’s boyfriend had ended their relationship shortly after she was diagnosed with ME/CFS. This had been discussed at length during the support group meeting through which she had been recruited, and she had acknowledged that she was still quite hurt about the break-up. A note describing this and detailing communication between Rebecca and the researcher, as well as comments from Rebecca’s mother, who had also attended the support group meeting, was attached to Rebecca’s transcript. While these memos did not represent an additional form of data, they did help to situate the interview transcripts in a broader context, and provided a reminder of additional communications with participants. As data collection progressed, and additional interviews were conducted and transcribed, the memos were reviewed and updated on an ongoing basis in order to make note of preliminary connections between interviewees, as well as suggestions of initial themes.
In addition, a field diary was kept during the process of data collection and analysis. This fulfilled two main functions – it facilitated an internal dialogue, allowing me to pose questions to myself and to reflect on my own research practices, and provided an early form of analysis, where I noted key themes and commonalities within and across the participant interviews (Chambers, 2004). For example, I recorded my personal thoughts and feelings throughout the recruitment of participants (e.g., 23/10/2012, “I have a few emails to follow up on from people who contacted me through [website] and newsletters. It’s a bit strange to follow up, it feels a bit pushy, but I think that it’s fair enough to double check and see if they’ve just forgotten”), as well as making field notes immediately after each interview (e.g., 22/11/2012, “[Participant] kept checking back in with me about what question I had asked. I think that she was quite concerned with being a ‘good’ interviewee, and wanted to bring things back to the Internet and how she thought it was useful”).

The field diary entries were reviewed in tandem with the interview transcripts, and were incorporated into the transcript notes. In particular, the initial themes that had been noted throughout the interview process provided the basis for an exploratory coding frame, where labels were assigned to portions of the transcripts. This served as a process of ‘data reduction’, whereby the boundaries of analysis are delineated (Namey, Guest, Thairu, & Johnson, 2007). Following this initial coding attempt, the themes and transcripts were reviewed and discussed with my supervisors. Based on these discussions, the broad topics that addressed the research questions underpinning the present study were highlighted and refined. This process is discussed and described in more detail in section 2.6.3.

2.6.2 A note on data saturation
Throughout these initial stages of analysis, a broadly iterative process was followed. Through the field diary and memo function of ATLAS.ti, the data were visited and revisited during data collection and analysis in order to engage with the transcripts and to reflect on their implications for the research questions (Srivastava & Hopwood, 2009). This also facilitated the consideration of data saturation, whereby the collection of new data does not provide any further insights (Guest et al., 2006). However, in addressing the concept of data saturation, it is necessary to acknowledge the debate surrounding this topic (Mason, 2010). For example, Charmaz (2006) suggests that the notion of saturation will vary depending on the researcher, with an inexperienced researcher claiming saturation much sooner than a more experienced one.
Considering the pragmatic approach of the present study, as described in section 2.1, I drew upon the principle of data saturation rather than striving to achieve it. Though the transcripts were reviewed on an ongoing basis in order to examine the topics and themes contained within them and to compare these topics and themes to those identified within other transcripts, this was distinct from the constant comparison method advocated by grounded theorists (Charmaz, 2006). Instead, I aimed to achieve theoretical generalisability, whereby “the data gained from a particular study provide theoretical insights which possess a sufficient degree of generality or universality to allow their projection to other contexts or situations, which are comparable to that of the original study” (Sim, 1998, p. 350). However, on completing 41 interviews and following a review of the interview transcripts and initial coding frame, I was satisfied that collecting additional data would not offer any additional insights.

2.6.3 Process of analysis
Following the initial review of the data, a more systematic approach to data analysis was taken. As mentioned, the broad topics that addressed the research questions were highlighted and refined following discussions with supervisors. These areas provided the basis for the findings that are addressed in Chapters Three, Four, and Five; namely, participants’ experiences of developing and maintaining trust on forums, accessing support and empowerment online, and forum users’ conceptions of privacy and anonymity.

In order to fully explore these topics, a thematic method of analysis was employed, with a view to examining comparisons and contrasts across participants and within cases. Thematic analysis was chosen as it provided a flexible approach to analysing qualitative data. Thematic analysis involves identifying themes in a body of data (Braun & Clarke, 2006). Themes were considered to capture something important about the data, and to represent a level of patterned response or meaning within a data set. This process allows the development of a conceptual scheme which enables the researcher to ask questions of the data (Basit, 2003).

Themes are identified in two ways (Braun & Clarke, 2006); either by noting all the themes that are evident in the body of data, or by approaching the data set with pre-set themes (e.g., from previous research or literature) and finding evidence in the data to support the existence of these themes (Elo & Kyngäs, 2008). The former approach is known as an inductive approach and using thematic analysis in this manner entails identifying particular chunks or instances of data and then grouping them into more general themes that capture
their meaning. A deductive approach consists of an examination of the data using a pre-decided framework, usually garnered from previous research in the area.

Within the present study, a primarily inductive approach was used. As described, an initial review of the data resulted in an attempt at data reduction (Namey et al., 2007), whereby the focus on the analysis was refined to areas that addressed the research questions and the overall aim of the study. For example, on examining the interview transcripts, the topic of ‘before and after’ was identified, whereby participants spoke about the sense of disruption and the drastic change in their lives and lifestyles that stemmed from the onset of their LTC, reminiscent of Bury’s (1982) concept of biographical disruption. While this focus was not carried forward beyond the initial stages of analysis, this is not to suggest that participants’ experiences of this nature were disregarded. Rather, the sense of ‘before and after’ was considered in relation to changes – or the absence of changes – in participants’ use of online support networks, as discussed in Chapter Four. However, this framework resulted from an initial review of the data, rather than a more deductive approach.

This inductive approach was particularly important given the context in which the research was taking place. As described previously, the underpinning epistemological position of the research was pragmatism, which allowed me to be both flexible and reflexive in my work (Seale, 1999). In addition, taking a pragmatic approach enabled me to navigate some of the difficulties associated with interdisciplinary research. Rather than subscribing to a particular theoretical framework associated with psychology, sociology, or another academic discipline, and viewing participants’ accounts within this framework, the analysis was instead predominately data-driven.

Within these broad topics, a coding frame was devised based on the themes identified within the data. Following this, the data were coded according to these themes by identifying complete segments (e.g., sentences or paragraphs) as categories that had been isolated and defined during the course of the research. Initially, these codes were broadly descriptive, and related directly to the content of interviewees’ transcripts, rather than any more subtle nuances within the data. For example, descriptions of interactions, communications, or consultations with GPs were coded as ‘GP’; references to an interviewee’s family were coded as ‘Family’; and so on. As coding continued, categories were frequently broken down into further sub-categories, as the initial coding frame did not sufficiently capture the complexities of the data. I used the memo function of ATLAS.ti to note occurrences where I thought that additional codes might be required. For example,
while many participants described the interactions that they had with other forum members (coded as ‘Forum’), a number also spoke specifically about the interactions that they had with forum moderators. Mid-way through the analysis process, an additional code of ‘Moderator’ was created, as I felt that these interactions were distinct from those that interviewees had with normal posters and required further consideration. Transcripts that had been coded previously were reviewed in order to apply any additional codes.

As the coding progressed, and I grew more confident and familiar with the data, I began to move from more tentative, descriptive codes to ones that addressed the complexities of the data. I found it useful to maintain my initial broad codes (e.g., ‘Family’, GP’, ‘Forum’) and to use these categories to further explore the transcripts. For example, I used the capabilities of ATLAS.ti to isolate the segments of the data coded ‘Forum’ and was able to examine these in more detail. On reviewing the data, I made note of the diversity of interactions on the forums. This led to me creating codes to acknowledge the nuances of interactions online (e.g., ‘Supporting others online’, ‘Negative interactions online’). As before, I reviewed transcripts on an ongoing basis to ensure that any additional codes were applied.

As mentioned, the use of ATLAS.ti offered a tool to organise and review the data during the analysis process, rather than offering an objective method of analysis (Mauthner & Doucet, 1998). While there has been some debate over the use of software for qualitative analysis (e.g., Chapple & Rogers, 1998), I found it to be extremely useful within the context of the present study. In particular, ATLAS.ti enabled me to link codes, transcripts, and memos, which helped me to consider comparisons between cases (Basit, 2003). This was especially valuable in comparing the experiences of participants with diabetes and ME/CFS, as I was interesting in exploring if differences in their use of online support networks were present.

In addition, I found that, rather than fragmenting the transcripts and viewing quotes in isolation, ATLAS.ti instead encouraged me to contextualise the data. For example, during her interview, Lisa commented, “I've got a good family”, which was coded as ‘Family’. By clicking on this quote within ATLAS.ti, I was brought to the specific portion of Lisa’s interview transcript. This allowed me to read through her further comments about her network of friends, as well as the ME/CFS support group that she attended. I could also review the rest of her transcript, as well as reading the memos that I had made based on my field notes and thoughts during coding. As a result, I was able to focus on Lisa’s individual
story and the context in which that story occurred, as well as drawing comparisons between her experiences and those of other participants.

In this way, I attempted to consider the broad narrative of each interviewee’s experiences. Rather than thematically coding transcripts, narrative analysis views the interviews as social products that are produced by people in the context of specific social, historical and cultural locations (Lawler, 2002). It offers a method of examining individuals’ ‘storied lives’ (Riessman, 1993), providing an alternative to fracturing and fragmenting accounts into distinct thematic categories. While I did not follow a procedure of narrative analysis, I was mindful of representing participants’ individual stories and timelines. As a result, I was able to explore certain interviewees’ experiences in more depth, as illustrated in Lisa’s story. Overall, it was intended that, while a predominately thematic approach to analysis was utilised within the present study, acknowledging elements of narrative analysis provided a valuable addition to address the research questions.

2.7 Ethical Considerations

Ethical approval was granted by the University of Manchester research ethics committee in October 2012 (reference: 12232). The approval confirmation letter is available in Appendix C. Ethical considerations were a key focus of this research. In addition to acknowledging and accounting for ethical issues throughout the development of a research plan and application for ethical approval, the ethics of Internet research also represented a focus of the present study. Consequently, ethical issues were explored through the process of data collection, as well as in advance of data collection. Three key ethical topics were considered throughout the duration of the research, namely confidentiality, sensitive issues, and the ethics of online research. These are outlined below.

2.7.1 Confidentiality

An important ethical issue was the protection of participant confidentiality. The interview data were safely stored at all times, in accordance with University of Manchester ethical guidelines, and any potential identifying information was removed from the interview transcripts. As the vignettes used during the interviews have been created from quotes and scenarios contained on forums, they were also anonymised and any identifying information removed or changed to protect the identities of the original posters. The forums approached to participate in the research have remained anonymous, as have interview participants and forum users. Any forum usernames have been removed or changed in the case that it was necessary to refer to them during the analysis and write-up of the research. Participants
were given an anonymised code and pseudonym that was used on the interview recordings, transcripts, and in the PhD thesis. All electronic copies of the interview transcripts and consent forms were stored and encrypted on the username and password protected University of Manchester server and hard copies were kept in a locked cabinet at the university. The transcription of the interviews was carried out either by the researcher or by a professional transcriptionist using encrypted files to transmit interview data.

2.7.2 Sensitive issues
As the research explored the experiences of individuals with LTCs, it was expected that the interview process would involve discussing some sensitive issues. While it was felt that risk to participants was minimal, steps were taken to reduce any negative impact of the process on individuals. If a participant became distressed or upset at any point during the interview, they were asked if they would like to take a break or given the option to stop the interview completely. Participants were reminded that they were under no requirement to take part in the research and it did not affect the services they received in any way.

This was particularly relevant for those with ME/CFS, many of whom expressed concern in advance of data collection about their ability to complete an interview in a single sitting. While all participants completed one single interview, the interviewees who had expressed worries were repeatedly offered the opportunity to take a break and finish the interview at another time. The researcher also used discretion during the course of the interviews and in a small number of cases did not introduce the vignettes due to concerns about overexerting the participants.

Interviewees were informed verbally and in writing of the nature of the research and what was required of them. This was restated in advance of the interview, and participants were reminded that the interview was being recorded. In addition, they were informed that they could stop the interview at any time and could withdraw from the study after completion of the interview and have their data destroyed. Participants were also encouraged to contact the researcher at any stage if they had concerns or questions about the research, or if they wanted to provide additional information about themselves, their condition, or their Internet use.

2.7.3 Ethics of online research
An additional ethical issue, and one that was considered in detail during the course of the research, was the use of online data. The ethics surrounding the study of web-based
interactions is a debatable issue. For example, King (1996) argues that it is unnecessary to receive permission from a virtual community to conduct research based on messages generated in publicly available spaces, as long as certain criteria surrounding privacy are adhered to, for example removing all references to the name and type of the groups. Similarly, Reid (1996) mentions that once participants in a multi-user dungeon (MUD), a type of Internet forum, learnt the nature of her research, they began to “manufacture quotable quotes” (p. 171); leading her to conclude that non-disclosure of her research was not only justified but also essential.

In addition, many researchers make distinctions between degrees of public and private spaces online. Much of the forums used in healthcare research do not require any subscription or registration in order to access the messages, and it has been suggested that members of such forums are thus not likely to view the discussion boards as a ‘private place’ in cyberspace (Eysenbach & Till, 2001). For example, Elwell et al. (2011), in studying forums used by adolescents with cancer, justified the lack of informed consent from forum participants on this basis, saying,

*Ethical issues associated with the present project include the issue of informed consent, as the adolescents who posted messages to the computer-mediated support group are not aware that their messages are being used for research purposes, so thus have not formally consented. However, in the present study an online support group was chosen that did not require subscription or registration in order to access the messages, thus it is argued that messages posted to the computer-mediated social support group are indeed accessible to the public and thus informed consent from the adolescents in this instance is not required.* (Elwell et al., 2011, p. 239)

While this argument is frequently made in the study of online forums (e.g., Coulson, Buchanan, & Aubeeluck, 2007; Rier, 2007; Seale, Ziebland, & Charteris-Black, 2006), it must be considered just how ethically valid it is. The advantages of conducting research with data taken from discussion boards are numerous, not least the convenience of working with a ‘naturally occurring’ qualitative dataset (Silverman, 2011) and a “rich source of qualitative data” (Edward & Robins, 2012, p. 550), which can be obtained without recruitment or informed consent from participants. However, the issue is not as clear-cut as it would seem from some recent papers, which are reviewed in section 2.8.
In order to reflect on this issue in further detail within present study, interviewees were also asked about their views of online support groups as public or private spaces and their concepts of audience, privacy, and ‘safe spaces’ when sharing and receiving information and experiences online. In particular, efforts have been made to address concerns raised by Daker-White, Sanders, Greenfield, Ealing, and Payne (2011), who outline the potential impact of awareness of dissemination on individuals’ participation in online support groups. Through this, the research has attempted to contribute to the growing field of Internet ethics in addition to adhering to the current recommendations.

2.8 Public and Private Spaces Online
Despite the growing focus on online forums in research, and the use of forums as data by researchers, less attention has been paid to the ethical considerations surrounding this research. Some early attempts were made to establish a series of ethical guidelines around the Internet as a source of data, notably the 2002 recommendations from the Association of Internet Researchers (AoIR). These guidelines were updated in 2012 to acknowledge the evolving field of Internet ethics. As the guidelines themselves acknowledge, rather than representing a strict code of behaviour, they merely serve to “emphasise processes for decision-making and questions that can be applied to ever-changing technological contexts” (Markham & Buchanan, 2012, p. 3). While the recommendations cover a number of topics which are beyond the scope of this chapter, of key relevance to the present research is that they highlight the nebulous notion of privacy. In particular, they outline how social, academic, and regulatory distinctions between public and private are not likely to be applicable in the context of the Internet and social media.

With this in mind, it is necessary to give particular to consideration to concepts of public and private spaces within Internet forums, specifically within health-related discussion forums. As the guidelines suggest, this will by no means result in a strictly defined delineation between the two concepts. In addition, consideration of these topics within the context of ME/CFS and diabetes forums may not, and likely will not, extrapolate to the wider population. Factors such as the level of access available, the number of forum users, and individual forum guidelines and norms will all likely play a role in establishing the boundaries between public and private spaces (Eysenbach & Till, 2001). Nevertheless, an exploration of these concepts within the aforementioned groups may provide a useful case study of the notions of ‘public’ and ‘private’ in practice.
Firstly, though, it is necessary to consider what current research exists on these topics. The AoIR recommendations highlight the potential for discrepancies to exist between the *actual* privacy and the *perceived* privacy of online content. For example, despite forum content being publically accessible, and available to anyone with a web connection, it is possible that that the creators of the content may perceive that the information, experiences, and opinions that they share online are being disseminated in a private space. This may have particular resonance for health-related forums, where the topics under discussion may have a particular emotive significance (Daker-White, Sanders, Greenfield, Ealing, & Payne, 2011). As Daker-White et al. (2011) highlight, the knowledge that their words and experience could potentially be shared and disseminated could have an impact on participants’ posting style or even discourage them from posting.

The potential contradictions between notions of public and private are covered at length by boyd and Marwick (2011). In this paper, they describe a scenario where images from teenagers’ Facebook pages were used in an educational lecture on Internet safety by educators and law enforcement officials in the US. Despite students being aware that the information and pictures that they shared on Facebook were public or relatively public, their expectations of privacy included an expectation that their profiles would not be accessed and shared without their prior knowledge and consent. Students reacted angrily, describing the lecture as “a violation of privacy” (p. 6).

boyd and Marwick (2011) argue that rather than representing a contradictory stance, this perception is in line with typically social norms around public engagement. They suggest that expectations of privacy online mirror expectations of privacy offline – just as one would not expect a conversation held in a public restaurant to be overheard and broadcast, despite the knowledge that the conversation *can* be overheard (Sveningsson, 2003). Indeed, early research into computer-mediated communication indicated that individuals often self-disclose very personal information online that they would not be willing to reveal offline, known as the ‘online disinhibition effect’ (e.g., Suler, 2004).

Supporting this notion, other researchers have pointed to apparent discrepancies in Internet users’ perceptions and expectations of privacy. Bassett and O’Riordan (2002) highlight an example where LGBT forum users’ constructions of privacy online, and their expected levels of confidentiality, safety, and freedom, were sharply divergent from both the actual levels of privacy and access and the description of the site and forum provided by the website owners. This indicates that despite signals to the contrary, individuals involved in
online discussion groups may view the spaces that they occupy online as safe spaces, unlikely to be accessed or disseminated by outsiders.

As Hogan (2010) indicates, expectations of privacy online do not necessarily indicate that individuals are sharing information that they wish to remain hidden (B. Hogan, 2010). Rather it suggests that, when information is shared, the people with whom the information has been explicitly shared (i.e., forum users, Facebook friends, members of an email list) are considered to be contextually appropriate for the specific information (Nissenbaum, 2004). This notion of contextual integrity (Nissenbaum, 2004, 2011) holds that conceptions of privacy are shaped by the norms of the contexts in which the information is shared. Instead of utilising a strict public/private dichotomy, Nissenbaum proposes that individuals exist in a plurality of realms, each with different guidelines outlining how to act and interact. Privacy is considered to be violated when norms specific to a particular context are violated, such as norms about what information is appropriate to divulge in a given situation or how it is appropriate for that information to be distributed (Nissenbaum, 2004).

For example, within a healthcare consultation, it is considered appropriate for an individual to share information about his or her physical condition with a doctor. If the doctor were to reciprocate by divulging information about his or her own physical state, however, that would not be seen as appropriate. Similarly, while an individual may expect a doctor to share information about his or her condition with a practice nurse, if required, it is likely that distributing that same information to the doctor’s family and friends would be receive an extremely negative reaction from the patient (Nissenbaum, 2011). Though the information being shared in all cases may be virtually identical, the alterations in context and audience result in privacy norms being violated.

However, as Marwick and boyd (2014) point out, this model presumes that the individual at the centre of the scenario is fully aware of the social context surrounding their disclosure. In order to navigate privacy online, individuals must have the technological expertise to operate their medium of sharing information, and have the knowledge and skills required in order to influence how information flows in an online context and how it is interpreted within that context. Instead, they propose a model of networked privacy, which draws on social media research to argue that information norms are co-constructed by participants and are constantly shifting due to variations in social norms and technological skills amongst individuals. This further highlights the potentially nebulous notions of privacy.
online, and suggests that a blanket approach towards particular media as ‘public spaces’ or ‘private spaces’ may be problematic.

From a research perspective, Hudson and Bruckman (2004) reported that many of the chat rooms they entered as part of their study responded negatively to the presence of researchers. In the majority of cases, the researchers were ‘kicked out’ or banned from participating in the space. Comments from some groups indicated that they viewed the publically-accessible chat rooms as private spaces, and were unwilling to tolerate the use of the content for research purposes. While this is in line with findings from boyd and Marwick (2011) and Bassett and O’Riordan (2002), it does have potential implications for the use of user-generated content and particularly forum content as data. Specifically, it contradicts the assumption that publically accessible spaces online are seen as public spaces by participants (e.g., Elwell et al., 2011; Eysenbach & Till, 2001), and therefore do not require informed consent from users.

While there has been a growing use of forums in research, particularly health research, and to a lesser extent, debate and dialogue around the ethical implications of this practice (e.g., Bradley & Carter, 2012; McKee, 2013; Palys, Columbia, & Atchison, 2012), there has been a dearth of research directly exploring forum participants’ perceptions and expectations of public and private spaces online. To date, there has been just one study addressing forum users’ views. Bond, Ahmed, Hind, Thomas, and Hewitt-Taylor (2013) interviewed users of online diabetes discussion boards. Though the participants were generally supportive of the use of forum data for research purposes, citing the need for the voices of individuals with diabetes to be heard, there were fewer consensuses about the specifics of using the data.

Despite many participants acknowledging that their posts were publically available, and therefore ultimately in the public domain, a number were uncomfortable with their words being used without their consent. In particular, the use of direct quotes was controversial, with interviewees expressing concern that they may be identifiable from the quotes (Bond et al., 2013). While these findings provide some insight into the views and perceptions of forum users, the brief nature of the research offers little clarity around the topic. In particular, it appears that more research is needed into the factors that affect and influence discussion board members’ perceptions of public and private online. As a result, the present study aims to address this gap by exploring these concepts amongst individuals with LTCs.
2.9 The Role of the Researcher

The process of data collection and analysis have been detailed earlier in the chapter, along with the justification for the chosen methodology, but it is important to note that as qualitative research is a reflexive process, researchers are unable to exclude themselves from the cycle of data collection, interpretation, and reporting (I. Holloway & Biley, 2011). Thus it is necessary to explore my own role as a researcher and to consider the impact that I may have had on the research process.

Initial contact was made with interviewees through a number of different online and offline sources. As described earlier, this often facilitated discussion of the research in advance of participants agreeing to take part. This occurred both on forums and at face-to-face ME/CFS support group meetings, which enabled me to answer questions or address concerns that individuals may have had about the study. For example, some participants had questions about the funding sources or potential agenda of the research, while others were concerned about the time commitment required to take part. Many people expressed an interest in the direction of the research and wanted to know more about why I had chosen to study that particular topic.

In advance of the interviews, I reminded participants about confidentiality and anonymity, and that they were free to withdraw from the study at any time. I also took some time to clarify my background and to emphasise that while my PhD was situated within the Faculty of Medical and Human Sciences at the University of Manchester, my previous degrees had been in psychology rather than medicine. I often told participants that they knew more about their illness than I did, and that I would appreciate it if they would explain things to me wherever possible, e.g., if they were referring to a drug or procedure. The purpose of this was twofold; I wanted to ensure that I fully understood what the participants were saying, and I also wanted to give the participants space to frame their experiences in whatever context they felt was most appropriate, without any assumption of prior knowledge (Britten, 1995).

Throughout the interviews, I attempted to continue this process. When a participant asked me if I was aware of a procedure, e.g., the function of an insulin pump or graded exercise therapy, I responded with a neutral phrase, such as, “I know a little bit about it but not too much, would you like to tell me more?” or “I’ve heard about it but I’m not too familiar with it”. At times, I was concerned that interviewees may have been disconcerted by my apparent lack of knowledge; however, on reviewing the interview transcripts, participants...
appear to have welcomed the opportunity to explain technical information in their own terms and to fully reflect on their own experiences and opinions.

Additionally, I tried to use active listening processes during each interview. This was in part aided by my training as a helpline volunteer for Greater Manchester Nightline, a listening and information service for students in the Greater Manchester region. This helped me to identify topics that were important to the participants, and to develop rapport between myself and the interviewee (DiCicco-Bloom & Crabtree, 2006). In addition to reflecting back participants’ experiences (e.g., “It sounds like the last few years have been very difficult for you” or “You mentioned that you found your GP hard to deal with, would you like to tell me a bit more about him?”), I also attempted to stay within an individual’s framework of meaning during the interview (Britten, 1995). For example, though the information sheet referred to the LTC as ME/CFS, on the basis of recommendations from various ME/CFS charities and patient advocacy groups, the terminology used by interviewees themselves varied, with some using ME, some using CFS, and some using ME/CFS. I tried to integrate participants’ own phrasing into the interview, to ensure that the questions reflected their own reality wherever possible.

Throughout the process of data collection, I was aware of how I may have been perceived by participants. This was often addressed explicitly within and in advance of interviews, as many participants perceived that I had an American accent and were curious about my background and my route to the UK and to the University of Manchester. This enabled me to explain that I was Irish and had moved from Ireland to the UK at the start of my PhD. In addition, I attempted to dress relatively formally for face-to-face interviews, usually wearing black trousers and a shirt. I also wore my student card in a University of Manchester lanyard around my neck to display a professional persona. This was particularly important as the majority of these interviews took place in participants’ homes and I wanted to ensure that they felt reassured that they were participating in a credible academic study.

In particular, I was aware of my role as a researcher during recruitment and data collection when speaking to individuals with ME/CFS. As described previously, approaching people to take part in the research was often met with a negative reaction, with some expressing concerns about the potential agenda of the research. While I attempted to dispel concerns and answer questions where possible, I was aware that many of the concerns were directed as much towards me, as the researcher, as they were at the research. In particular, my
background in psychology was frequently met with disapproval by potential participants, with many interpreting this as a sign that the research viewed ME/CFS as a psychological, rather than medical, condition. By contrast, participants with diabetes often welcomed this perceived psychological approach, with one interviewee commenting, “I’m glad that you’re not actually a, well, not glad, but the fact that you’re not medically qualified is not necessarily a downside as far as I’m concerned... I’m a scientist, I take a different view of the medical community” (Robert, type 1 diabetes, 61 – 65). As the study progressed, I found it useful to acknowledge my background, but to emphasise that my previous training and employment had been as a researcher rather than a practitioner. I often drew on my previous research on parenting forums (e.g., Brady & Guerin, 2010) to situate myself as a researcher with an interest in Internet forums, rather than a psychologist with an interest in ME/CFS.

This was a standpoint that I took throughout the duration of the research. Having been located in a psychology department for my BA and MLitt and previously situated my work within psychological theory and practice, I found my initial interactions with the interdisciplinary setting of the Faculty of Medical and Human Sciences at the University of Manchester somewhat jarring. While the methods remained familiar, much of the perspectives, theory, terminology, and style of writing were less customary, and I struggled at times to situate myself as a PhD student and as a researcher. As a result of these experiences with interdisciplinary research, I gravitated towards the concept of Internet-based research rather than aligning myself with a particular discipline. This allowed me to fully embrace a pragmatic approach, as I drew on a range of conceptual insights from different fields rather than applying a singular theoretical framework. While I appreciated the flexibility that this approach provided me with, I was also conscious that the amalgamation of a number of disciplines meant that my research may lack a unifying conceptual basis.

Partly as a result of these issues, I frequently met with my supervisors throughout the data collection and analysis process to discuss the interviews and transcripts. In these meetings, we discussed emergent themes and issues, much of which fed into the analysis and the dissemination of the findings in their present form. A key concern of the research was looking at underlying issues which occurred both within individual cases and across the dataset of participants, and this was considered in detail during supervisory meetings. As mentioned previously, acknowledging my own reflexivity involves not just a consideration of my impact on the research process, but also my role in depicting and disseminating the
narratives presented by participants (Mauthner & Doucet, 2003). Thus, while it is likely that many of the findings of the research have been influenced by my own perceptions and experiences, I believe that the results presented offer a valid and sincere representation of events.

2.10 Summary
In this chapter, the methodological approach that underlines the current research has been described, the methods for data collection and analysis have been reviewed and critiqued, and some of the key ethical issues inherent in the research and how these have been addressed have been discussed. In the next three chapters, the results obtained from the data collection and analysis will be presented.
3.0 Overview

In examining the use of Internet forums by individuals with LTCs, it is necessary to acknowledge the backdrop against which this usage is occurring. As described in Chapter One, there has been a shift in both policy and practice where individuals with LTCs are repositioned from passive recipients of expert care to active consumers who make informed choices and share responsibility for their health care (Department of Health, 2001, 2004, 2010; Kielmann et al., 2010). In addition, the notion of trust and its influence on health care systems requires attention (Gille, Smith, & Mays, 2015). Timmermans and Oh (2010) argue that, over the course of the twentieth century, trust in healthcare professionals deteriorated. It has been suggested that the power inequity between patients and healthcare providers means that this trust is fragile (Delmar, 2012) and easily damaged by external factors such as medical scandals (Timmermans & Oh, 2010).

Alongside the shift in perceptions and health care policy towards patient centred care (Murray & McCrone, 2015), health-seeking behaviour has also altered. Individuals actively search for information about illnesses and treatments online, and seek advice and support via Internet-based communities (K. Davison et al., 2000; Timmermans & Oh, 2010). However, it is important to note that the use of the Internet for health information and advice does not indicate a rejection of medical care and a breakdown of trust but instead suggests an attempt to access up-to-date information (Henwood, Wyatt, Hart, & Smith, 2003). In addition, Henwood et al. (2003) and Lupton (1997), amongst others, highlight that individuals vary in their use of and trust in online sources of health information. Fotaki (2014) suggests that these variations are shaped by various systemic and interpersonal factors.

In particular, for complex or emergency situations, patients are likely to place high levels of trust in healthcare professionals, and may devolve decision making to those within the health care system (Fotaki et al., 2006; Meyer & Ward, 2013). By contrast, for LTCs, individuals are frequently armed with increased levels of information, along with their experiential knowledge. While trust in health care systems is not disregarded in chronic conditions, it is instead conditional and negotiated between patient and professional (Fotaki, 2014). As a result, trust is a complex and nuanced process, which requires further consideration (Gille et al., 2015). This is particularly true within the context of contested conditions, as different perspectives around the aetiology and treatment of ME/CFS can
lead to conflict between patients and clinicians (Banks & Prior, 2001; Smith & Wessely, 2012).

Within this chapter, how trust is negotiated online will be addressed, and interviewees’ experiences of navigating the Internet for health information and advice will be explored. In particular, participants’ experiences of building trust online will be reviewed. While this will include the strategies that participants utilise for appraising and evaluating websites and information providers online, the focus will be on how forum users assess their peers as credible sources of information. By communicating online with others, forum members can build relationships and determine whether or not to trust fellow posters. In this way, trust is negotiated between peers, rather than the hierarchy of the doctor-patient relationship, where information was paternalistically passed from professional to patient (Loader et al., 2002). Within this framework of trust and collaborative knowledge, mutually supportive relationships can be established, as will be described in Chapter Four.

3.1 Bridging the Gaps: Motivations for Information Seeking Online

Within the present study, the Internet was embedded into interviewees’ everyday lives as a source for health information and advice, resulting in a dynamic use of online support. While the support and empowerment aspects to forum usage are discussed in Chapter Four, this chapter will consider the use of the Internet and Internet forums for health information. As highlighted in previous chapters, access to health information online can serve as a tool of empowerment. Rather than receiving information via healthcare professionals, the ability of Internet users to browse and search online means that individuals can mediate the content and flow of the information that they access (Hardey, 1999).

A number of interviewees described their particular rationale for looking for health information or advice online. The findings suggest that searching for health information online represented an attempt to supplement rather than replace traditional sources of support. In other words, participants were searching online to add to the information that they had previously received from healthcare professionals, to assess whether or not issues were suitable to discuss with healthcare professionals, or to address queries that they did not think fell under the remit of healthcare professionals.

For example, a pivotal reason for individuals searching online was to assess if the symptoms that they were experiencing were related or unrelated to their chronic condition. This was particularly prevalent for those with ME/CFS, considering the spectrum of
experiences that fell under the umbrella term of ME/CFS. As a result, individuals were accustomed to experiencing fluctuations in health and the emergence and re-emergence of different aspects of their condition. Interviewees reported going online to assess whether or not what they were currently experiencing was as a result of ME/CFS or another condition or illness, “If there is something and I’m not sure if it’s the ME or not, I might Google it... So I will look things up to make sure that the ME isn’t masking something else that I could do something about” (Joan, ME/CFS, 56 – 60), and to establish if they needed to take further action by consulting a doctor or healthcare professional, “I will check it out to see if it’s a common symptom and if anything can be done about it. If something can be done then I’ll go to the doctor, but if it’s no there’s nothing they can do about it then I won’t bother him with it” (Elizabeth, ME/CFS, 56 – 60).

In addition, participants also went online to look for information about the particular symptoms of their condition. Again, this was particularly evident for those with ME/CFS, due to variation in symptoms among individuals. For example, Susan described how she broke down her diagnosis into the various symptoms she was experiencing. By exploring her individual symptoms, she was able to attempt to address each of these symptoms in order to manage her condition and increase her quality of life. As before, these online consultations fed into face-to-face consultations with healthcare professionals and helped shape the direction of individuals’ health care.

So then I would start thinking about each of my individual symptoms and thinking, well, how would I go about curing myself? So I started to research the, em, the, like, the brain symptoms that I was getting, the brain fog, I couldn’t put words together. So I started finding out more about that, so it came then that vitamin B12 was an issue. So I did a bit more research on vitamin B12 and I found that I was blood group A, which often has a problem with vitamin B12, and also, having a low thyroid, all connected with B12. So using that information, I went back to my doctor and said, right, can we check my B12? So that was the way I was doing it, I wasn’t looking at ME as ME, I was looking at each individual little bit of it, and thinking, how do I break this down. (Susan, ME/CFS, no age given)

Participants were often clear in the distinction between their use of the Internet to search and browse for health advice and information, rather than to attempt to single-handedly treat their condition without any input from professionals. As described, interviewees used online forums and websites in order to explore the symptoms that they were experiencing
and to assess themselves for indications which suggested that they needed to seek further medical attention. This was emphasised by Lesley, who described how she used the Internet to make minor adjustments to the management of her type 2 diabetes, “If it's only a minor adjustment, you'd think, well, yeah, I'll try that, I'll have... I'll eat my breakfast at such a time, for example”, but for anything major or for more serious concerns, she would consult her GP, “If I had serious concerns about my diabetes, I would still go to my GP. That would have to be my first port of call rather than asking for that kind of advice on any type of forum” (Lesley, type 2 diabetes, 56 – 60).

As illustrated by Lesley’s quote, participants’ assessment of their condition influenced their choice of information provider on a case-by-case basis, rather than an overarching hierarchy of sources. For minor issues, she first opted to go online, while for more serious concerns, she would contact her GP. For other interviewees, such as Susan, the Internet and formal healthcare systems were utilised simultaneously. This allowed her to pragmatically integrate the two resources by drawing on their respective strengths, rather than rejecting one system in favour of another. This is in line with previous research, which indicates that an individual’s use of and trust in health care systems will adapt depending on their circumstances (Fotaki, 2014; Gage & Panagakis, 2012). Gage and Panagakis (2012) argue that in an acute medical situation, an individual’s fear and anxiety may outweigh their desire to seek information online. They suggest that the prioritisation of online sources is highly contextually dependent, resulting in individuals seeking health information online for some health experiences but not for others.

While this is noteworthy in and of itself, it does raise questions around what the perceived strengths of the Internet as a source of health information are. Notably, it highlights the need for an understanding of how those with LTCs assess and evaluate the information that they encounter online. In particular, how individuals decide what information sources to trust, and how credibility and legitimacy are established, particularly on Internet forums. It is this topic that will be explored in the remainder of this chapter.

### 3.2 Identifying Credible Sources of Information Online

In examining how forum users establish trust online, it is first necessary to look at how they assess information sources, such as websites. This is distinct from how participants assess and evaluate other forum members, which is the focus of section 3.3 onwards. Participants described the various strategies that they used in order to assess information sources that they encountered online. By and large, interviewees relied on what they perceived to be
official or reputable websites as a first port of call in accessing health information online, supporting the notion that, despite searching online for health information, individuals defer to the medical community (Giles & Newbold, 2011; Nettleton, Burrows, & O'Malley, 2005; Sillence & Mo, 2014). For example, NHS websites such as NHS Choices and the now defunct NHS Direct were referenced by participants with ME/CFS and participants with diabetes; “There’s usually, you can usually tell when you go on the website if they’re affiliated with the NHS or some of the local authorities and things like that” (Karen, ME/CFS, 41 – 45), “Well in terms of NHS Choices, if that has the information then I would probably quite trust that” (Jessica, type 1 diabetes, 18 – 25).

In addition, charities affiliated with conditions were usually seen as trustworthy and were therefore credible sources of information. This was particularly true for those with ME/CFS, many of whom felt that the lack of understanding and consensus around the condition amongst the medical profession extended to official sources of information. As a result, some expressed a preference for perceived reputable charities associated with ME/CFS, as illustrated by Rebecca. Though she valued the broader perspective of ME/CFS charities compared to what she perceived as the more blinkered approach of the NHS, she was still conscious of selecting charities that were official and had received “recognition” from external sources.

“I’d rather look at something that’s got quite a lot of recognition behind it; so obviously with the charity stuff quite a lot of people will go there to look for stuff. I would rather do that than go on the NHS website because they can be quite, this is what it is and nothing else can happen.” (Rebecca, ME/CFS, 18 – 25)

Despite this, many people expressed a degree of scepticism about information about ME/CFS online. For example, Michael, who was involved in his local support group, spoke about his experiences of recommending websites to the people who contacted the support group for advice and information. As a result, Michael’s assessment of health-related websites online was influenced by previous demonstrations of credibility. He was cautious to only recommend sources that had been endorsed by “reputable websites that we have used before and found to be sound”, and described a number of charities that he had had contact with in the past. He tended to look for information via the websites of these charities, as he felt confident in their ability to recommend sources of advice or information, “If they are being endorsed by those sorts of organisations I feel reasonably
confident that the information or the websites or whatever that they suggest would be worthwhile following up” (Michael, ME/CFS, 66 – 70).

This was echoed by Sharon, who similarly utilised “the two main charity websites”, which she reported that she would “mostly trust”, along with a series of NHS supported websites. However, she avoided other ME/CFS charity websites as “they seem to be quite skewed”. She felt that the lack of understanding around ME/CFS led to charities or websites being focused around a particular agenda, namely an approach which supported biomedical constructions of the condition, which mean that they were less reliable and informative. Equally, the lack of clarity meant that particular individuals were able to promote their own agenda or approach. The activism agenda of certain ME/CFS websites and individuals online is discussed in more detail in Chapter Four.

They’re skewed in an anti-establishment, anti-psychological way, we need more sort of biological research, we need more, and then there are sort of some which have a more particular or are based on more particular individuals’ thinking. There’s a GP called [name] who has, well, she had a website, I think there have been some complications, and some of her stuff on sleep was quite useful, but again, she’s got views that other people would see as controversial. (Sharon, ME/CFS, 51 – 55)

While official websites and sources of information were highlighted as trusted by interviewees, many also reported that they valued ‘alternative’ sources of information that they saw as having a respected underlying theoretical approach. This often related to traditional Chinese medicine, which was viewed in particular by those with ME/CFS as a credible alternative to western medicines. This was in part due to the perceived longevity of these practices, as illustrated by Nicole, “I understand the NHS has to be fact based, but I still understand that Chinese medicine, to me, it must have something that they do because it’s worked for so long and for so many people” (Nicole, ME/CFS, 26 – 30). Similarly, James described how he read about traditional Chinese medicine online and valued the philosophy and spirituality that he saw in that approach. Though he had since disengaged from the practice, describing it as “nonsense”, he was attracted to its underlying philosophical principles, which legitimised the approach for him, and were in line with his martial arts background. For James, the familiarity of these underlying principles and his personal experiences with those approaches provided a sufficient evidence base for him to trust the information provided from these sources.
And one of the first things that I tried was acupuncture and traditional Chinese medicine. So within about three weeks of taking whatever concoction I was being given in traditional Chinese medicine, the reason that I went for that was basically apparently in China they don't have ME/CFS, I've since found out they just call it something else, it's the same thing. But I went along with this nonsense. I think probably I was swayed as well by the fact that I've been involved in martial arts since I was in my teens and there's a certain amount of philosophy and spirituality that goes with that, that it just felt the right thing to do, so I went with it. (James, ME/CFS, 51 – 55)

In addition to participants relying on reputable or official websites in order to assess health information online, interviewees also spoke about the need to triangulate information and advice online with other sources. As Lesley described it, it was important to recognise that the Internet was just “one tool” rather than “the be-all and end-all”, and those with LTCs needed to consider other options rather than relying solely on online information, “The Internet, it's not sort of, it is extremely useful in your life and everything but there are other things as well to make up the whole picture. It's only one thing to help you” (Lesley, type 2 diabetes, 56 – 60). The diversity of the information available online appeared to encourage individuals to be sceptical about the information that was presented to them, and to cross reference this information against a number of different sources (Hardey, 2001).

Participants mentioned a number of sources that they used to assess information they read online, including cross-referencing different websites, accessing peer reviewed articles and academic textbooks, and consulting healthcare professionals. Like James, who used his familiarity with martial arts to assess the information he encountered online, many interviewees drew on their individual backgrounds in order to locate and evaluate information that was relevant to their condition. This was illustrated by Ian, who had a degree in pharmacology and described how this influenced his reaction when his consultant prescribed him Gliclazide to help control his type 2 diabetes. Though he went online for advice and information about the drug, he also utilised a number of additional sources, including speaking to his pharmacist and consulting pharmaceutical reference books. He drew on these varying sources in order to triangulate the information that he encountered both online and offline, and to establish whether or not to trust this information.

If it’s something that has come up on the forum before, I’ll look over that and then maybe take it a bit further on the forum. At the same time in parallel I’ll be looking at, should we say the textbook level of stuff and speaking to GPs, things like that. I tend to
work at a lot of different levels. Like, classic example, when they moved me onto Gliclazide. I came back home with a prescription for the Gliclazide, step one was to go and speak to my pharmacist and say, what have you heard on this here? Then I was on BNF [British National Formulary] here going on all the stuff on Gliclazide, doing research on Gliclazide. At the same time I’m on the forum going, the consultant’s just said you should go on Gliclazide, here’s my history bang, bang, bang, you can see my history from me thingy-me [user profile], what’s your thoughts, problems, things to watch out for? You see, I’m hitting it at a lot of parallel things. (Ian, type 2 diabetes, 46 – 50)

While many participants valued the information that they encountered online, they reported that it was not the only source of information that they utilised. As June described it, it was important not to place too much emphasis on online information and to instead use it as a signpost to direct future research and interactions with healthcare professionals, “You’re not always taking things at face value. I mean, if somebody mentioned a new drug, I would look it up, I wouldn’t just go, oh yes, I’m gonna go and ask for that ’cos you said so” (June, type 1 diabetes, 66 – 70). This was echoed by Ian, who was clear that he would not take direct action as a result of online advice, “If there’s someone coming on there and saying, oh, say, Doctor Susan is terrible. I wouldn’t go, oh, I’m going to cut my Doctor Susan off completely. I’ll use it as a pointer to do further research” (Ian, type 2 diabetes, 46 – 50). Instead, participants drew on a number of strategies to navigate and critically assess the information and information sources that they encountered online, namely utilising official sources, examining the information in relation to their previous experiences, and cross-referencing with other resources. This enabled them to learn more about their condition and the resources available to them, and to use this information to engage with health care services.

3.3 Birds of a Feather: Collective Identity and Individual Markers of Trust
In establishing trust on Internet discussion boards, the relationship between forum members was pivotal. In particular, participants valued receiving information from forum members who they felt had a similar perspective to themselves. This is in line with previous research which indicates that the degree of perceived similarity a receiver ascribes to a message source in knowledge, experience, background, and views is crucial in evaluating the information available in online discussion groups, rather than the credibility of the information (Wang et al., 2008). In addition, Internet users are more likely to assess user-generated information as credible and indicate that they are going to act on this information
when they perceive the user to be similar to themselves (Flanagin, Hocevar, & Samahito, 2013).

This is illustrated by James, who described how the people that he gravitated towards on a forum for individuals with ME/CFS were those who had similar values to him. While he found the forum to be a useful venue for keeping up to date with research and developments around ME/CFS, he felt that a number of members were overly concerned with challenging what they perceived to be a psychological rather than biomedical approach in ME/CFS research. In doing so, James felt that much of the forum was “a very aggressive place”, populated by “keyboard warriors”, “people that wouldn't say boo to a goose in real life but because they're hiding in their own house they feel that they can say anything they want”. By contrast, the people with whom he had developed a friendship took a more pragmatic approach, and were content to dismiss, rather than challenge, research that they felt promoted a perceived psychological agenda, “They know that they're not suffering from any kind of depression or mental illness or whatever and therefore it really doesn't matter what study you do and what link you show”.

As a result of this shared perspective, James grew to respect certain members of the forum and place value on their opinions. Similar to “real life” processes of friendship, he had built up individual support networks with certain members based on their shared perspectives. This enabled him to access not just informational but also emotional support through these networks.

You hear people that you're in accord with, they appear to hold the same world view, the same opinions, the same approaches, the same respect, so you're drawn to those people. And then generally how it'll start is you'll defend them or you'll find them defending you, and then quite often, certainly for the sort of relationships I've built up on that site you'll end up emailing each other separately to the mail in support and building another network, they'll put you in touch with somebody else and what not, and that's how it's worked for me. (James, ME/CFS, 51 – 55)

This was echoed by Laura, who described how forum members’ backgrounds were crucial in evaluating the advice and information that they were presenting, and assessing how it applied to her own health care. As she participated in a lot of sport, many of her queries about her type 1 diabetes related to the impact of exercise on diabetes and insulin dosage. Consequently, she was more likely to trust the advice of someone who she felt led a
similarly active lifestyle, “The person that gave me this advice [in relation to fast acting carbohydrates], I knew they were an athlete anyway and had a lot of exercise with diabetes, so I would take that advice and use it”. Equally, forum members who had similar physical needs to her were valued over those who were required to take different approaches in their diabetes management, “If somebody you know is very, for example, very short, petite on a very low dosage of insulin throughout the day... I’m quite sporty so I’m, sort of, chunky but not overweight, you know, what would work for that person wouldn’t probably work for me”. Accessing information of this nature allowed her to take a more personalised approach to her own health care than could be provided within a formal healthcare setting (Keeling, Khan, & Newholm, 2013).

Like James, this evaluation of individuals’ backgrounds took place on an ongoing basis, and was built up over time. Laura described how she was often aware of people’s individual situations through off-topic conversations. This enabled her to create a complete picture of other forum members and compare and contrast it to her own situation if and when required.

_People do talk about things other than diabetes on the forum and you get to know people’s scenarios because they’ll quite happily say, you know, oh, I’m doing my third marathon next week or, oh, I’ve never done exercise before, I’m about to start it or, oh, I’ve just given birth or, you know, so you get to build up a picture of somebody by what details they’re happy to share with you._ (Laura, type 1 diabetes, 31 – 35)

The relationships between forum members and interviewees were also frequently referenced in relation to assessing members as credible information sources. As described, these relationships developed over time and through a number of interactions. While members who had been actively participating in forums over a number of years were valued, it was clear that it was not just their length of service that was a defining characteristic in evaluating these members. Consistently providing sensible and trustworthy advice, as well as adhering to forum norms, led to members becoming valued and trusted within a forum. In addition, developing a relationship with forum users over time allowed participants to build up a sense of their character and personality, as described previously.

_You get to know the people and whether they’re talking sense or not and certain people within a forum become respected so you’re more likely to take the word of somebody who’s respected than somebody who walked in ten minutes ago, and you think to_
yourself, well, where do they come from with that advice, you know. (June, type 1 diabetes, 66 – 70)

You form relationships so over time you know who you can trust to make sensible recommendations and those who are a bit fruit batty. It’s life, you get people who know everything and you will get weirdos on the Internet, that’s the way of the world, but you’ve got to use good judgement to understand their advice. (Simon, type 1 diabetes, 26 – 40)

In addition to the relationships between forum members playing a pivotal role in posters being assessed as credible sources of information, the general outlook or attitudes of forum users were also important. Again, this is in line with previous research which indicates that people tend to seek out those ‘in the same boat’ as themselves online in order to draw on experiences that match their views and biases (Sillence, 2013). In addition, it suggests that ‘value homophily’ plays a role in establishing trust on online forms, where users gravitate towards those with similar attitudes, beliefs and behaviours (Centola & van de Rijt, 2014; McPherson, Smith-Lovin, & Cook, 2001).

For example, many interviewees valued the supportive nature of online forums, and valued the information that they received from posters that they perceived to be motivational and supportive, “He is always really supportive and encouraging. I think he has some of his own battles with diabetes, but he’s willing to share them, and if anybody’s in trouble, he’s always supportive” (Elaine, type 2 diabetes, 61 – 65). In addition, participants often selected websites and forums that they felt were in line with their general approach towards their condition. Lesley had spent a year monitoring or lurking on the diabetes forum that she used to ensure that they were likely to be sufficiently supportive of her low carbohydrate approach to her diabetes. For her, the supportive nature of the forum was pivotal in her assessment of its members as a credible source of health advice and information.

I’ve found on our forum they’re not there to advise you or make a diagnosis, they’re there to say, we suggest, why don’t you go to your doctor, or this happened to me and this is what I did, do you know what I mean, that’s the kind of support that I’ve found very helpful, and I still do. (Lesley, type 2 diabetes, 56 – 60)
Similarly, forum members who were not supportive were seen as less valuable or credible information providers. This was illustrated by Louise, who described how posters who were overly judgemental in their approach to diabetes management tended to hold other forum users to unrealistic standards, and therefore could not offer useful advice. By contrast, she felt it was important to acknowledge that individuals with diabetes live “in the real world”, and to offer advice and information on this basis.

But also people can be very judgemental and you see it especially if I, you see it a lot with diabetes and food. So I post a problem about, oh, I had pizza for tea last night and my blood sugars are really high, has anyone got any tips? And you'll have somebody coming back going, well, that's ridiculous, you should never have eaten pizza, it's your own fault. (Louise, type 1 diabetes, 31 – 35)

This was echoed by Nicole, who reported that she did not trust individuals who had a very narrow minded perspective, as she felt that their views were too biased to be of use to her. She avoided forum members who she thought held definitive views about ME/CFS and its treatment, and were therefore unwilling to consider other opinions, “You have people who are very definite, so someone will come on and go, oh, I'm new, I'm poorly, and people will go, don't go to the NHS, they're rubbish” (Nicole, ME/CFS, 26 – 30).

Though participants reported that they did not trust forum members who had an overly narrow outlook, as illustrated by Nicole’s quote, those who had an appropriately broad perspective were valued. For example, Louise described how she sought out people “who don't tell me they absolutely know the answer” rather than those who felt that there was only one solution to a particular problem. She appreciated posters who were able to place their advice in context and suggest it as a potential solution, rather than putting it forward as a definitive answer, “What you're saying is founded in logic and commonsense and I can see why you're saying it, you're not advocating it as a solution to world peace, you're putting it across as a point of view, yeah, I trust you” (Louise, type 1 diabetes, 31 – 35).

Posters who appeared to be too open to alternative views, by contrast, were also not seen as credible sources of information. For Edward, this was a major problem in evaluating information relating to ME/CFS online. Due to “problems with misinformation amongst CFS patients”, individuals had developed a mistrust of traditional sources of information and support, which in turn led to them becoming overly trusting of alternative sources of advice.
[They] feel they can no longer trust their doctor, so they can, sort of, be too open to alternative views and so, like, it can, sort of, you know, I think, often people have a real desire to be able to trust someone and if you lose an ability to trust those who, you know, sort of, socially you’d normally be thought of as being able to, that can lead to being more credulous in other ways. (Edward, 26 – 30, ME/CFS)

This resulted in ME/CFS forums being populated with both individuals who had utilised and trusted these alternative services and those who were providing said services. While interviewees felt that they were generally able to assess whether or not people were sharing information for commercial reasons, they did not consider them to be a credible source of information as a result, “Somebody is trying to flog their own particular treatment or book or whatever else, and they do the rounds of the different chat rooms trying to flog their services. It’s another mechanism for people to try and exploit you, basically” (Stephen, ME/CFS, 56 – 60).

Logic and commonsense were valued in forum discussions, as highlighted in section 3.4 below. Alongside this, forum members who could successfully communicate and share ideas in a clear and concise manner were seen as credible sources of information, as they were perceived to be “talking sense”. As a result, people who could share their advice and information were considered to be authoritative forum users, “She is absolutely amazing. She has a way with words she can explain things... So she can explain this in such a way that even a child could understand it, she just has that knack” (June, type 1 diabetes, 66 – 70). However, it should be acknowledged that placing a value on aspects of presentation online could be interpreted as an implicit judgement based on perceptions about social status according to class or education. This indicates that forums seem to mirror societal inequality, and supports previous research which suggests that educated individuals are more likely to find information online that improves their health (Dutton & Blank, 2013). The implication of this will be discussed in more detail in Chapter Six.

Finally, despite the value placed on shared experiences, participants were also interested in interacting with forum users who presented them with experiences that differed from their own. For example, Mark described how reading about the experiences of individuals with type 2 diabetes offered him some useful insights into his own experiences with type 1 diabetes. Though their situations were different, the particular challenges presented to those with type 2 diabetes and the strategies they used to overcome these barriers informed how he managed his own condition.
One of the interesting things for me early in my forum experience was getting to understand the other one, you know, I knew quite a bit about type 1 but virtually nothing about type 2. And, suddenly there were all these type 2s sharing their experiences, sharing their strategies and the ways they have to approach the world and food and all of that sort of stuff. And, those approaches actually informed the way I thought about my own, because they’ve only got in some cases diet and exercise to control their levels with. I’ve got, you know, these fancy insulins I can squirt in which help me out, but if you haven’t got that then what do you do. And so, that was a very interesting experience for me. (Mark, type 1 diabetes, 41 – 45)

3.4 Gaining Credibility Points: Constructing a Knowledgeable Identity Online

In order to receive support online, a poster must suggest that their condition and concerns are legitimate (Galegher et al., 1998). Building on this, the present study indicated that there were a number of additional ways that forum members could establish their credibility as both patients and information providers. Participants described the criteria that were accepted as evidence of a poster’s authority online.

As alluded to previously, many interviewees valued markers of legitimacy which mirrored traditional societal divides. In particular, having a background in research or a high level of education meant that an individual’s advice or information was typically considered to be trustworthy, “If it comes across as reasonable and educational, you know, you kind of trust in it, rather than someone who types ‘lyk dis’, you know” (Jessica, type 1 diabetes, 18 – 25). This was emphasised by Jennifer, who described how she assessed people to see if they were “scientific” in considering information in relation to ME/CFS. While she typically relied on websites put together by healthcare professionals rather than information provided by peers, she was conscious of the need to evaluate them on the basis of their education or research profile. For Jennifer, external markers of legitimacy, such as qualifications or links with a university, played a key role in establishing trust in an individual, along with the use of rigorous scientific methodology.

Doctors, like real, really good solid people that I could trust and not just people that call themselves doctors. But people that I could sort of check out their background and see you know what, you know, how well qualified is this person, are they connected to a university, that kind of thing, and, em, if they are run by a doctor, then sort of I try and work out what, what their sort of general approach and methodology would be and what their sort of general theory and hypotheses would be. (Jennifer, ME/CFS, 36 – 40)
While education played a role in evaluating a forum member, as illustrated by Jessica’s quote, by and large, formal qualifications were not explicitly required in order for an individual to become established as a credible source of advice and information. Instead, forum users could gain the trust of others by providing information about their condition. For many interviewees, a diagnosis of their condition confirmed by a healthcare professional was important, as opposed to a self-diagnosis. While this may seem counterintuitive, particularly considering the ambivalent relationship between individuals with ME/CFS and the medical profession, this echoes similar research around online mental health communities which embody a resistance to the medical community (Giles & Newbold, 2011). This suggests that, even within communities which aim to challenge accepted medical discourse, external markers of legitimacy are still valued.

For example, Nicole spoke about her frustration on reading advice and information from a fellow ‘patient’ with ME/CFS online over a series of months, only to learn later on that the forum member had not received a diagnosis, despite repeated contact with medical professionals. She was concerned that people who had not received a diagnosis may have ulterior motives for wanting a diagnosis for ME/CFS, such as disability benefits, and that doctors were picking up on these motivations. As a result of this experience, she was inclined to place more value on forum users who had received a diagnosis, and was more likely to trust their advice.

*On [name of forum], you have to say whether you’re a sufferer, whether you’ve self-diagnosed, whether your GP has, so you have an idea of some people who, you know, you can see where they are and how long they’ve been suffering from, as to whether or not they, like, whether or not to take their advice, to kind of see where they’re coming from.* (Nicole, ME/CFS, 26 – 30)

On a similar note, the length of time since diagnosis was also seen as evidence of a forum member’s credibility as a source of advice and information online. This was particularly true for those with diabetes, as the length of time was indicative of more experience with the condition, “*Some of them are really helpful and I’ve tried some things that they’ve suggested because I think from what they’ve told me, they have had more experience. So I’m going on the fact that they have had longer experience, longer time*” (Emma, type 1 diabetes, 41 – 45), but also seen as an signal of good self-management and a healthy lifestyle, “*And there are lots of people on the forum who have had it for sort of like 20*
years and they still haven’t got any of these terrible things, so that’s good” (Patricia, type 2 diabetes, 66 – 70).

Following on from this, having experience of a particular procedure or treatment meant that an individual was likely to be viewed as a trusted source of information by forum members. For example, Patricia described her experiences of seeking advice in advance of her first retinal screening after her diagnosis with type 2 diabetes. When she spoke to her local surgery, she received reassurance, but not a very detailed response, “I asked the people at the surgery and they just said, oh, it’s absolutely routine, you just go to the hospital, they’ll put some drops in your eyes, take some pictures and that’s it”. By contrast, forum users who had experienced the procedure were able to provide her with answers to her specific questions, “I thought, OK, I’d like to know a bit more about this, you know, can I drive, that kind of thing, and I found the forum people were very helpful”. Though she received a range of responses and some diverging opinions, she considered the responses from those who had experienced the procedure to be the most credible sources of information. In addition, the ‘lived experiences’ of these forum members meant that their views were valued over traditional medical source of information.

Forum members’ opinions and perspectives were not just accepted uncritically, however. In particular, interviewees trusted those who shared detailed information about their experiences, as this meant that these experiences could be assessed and evaluated in relation to other people’s conditions and lifestyles. This was illustrated by Ian, who described how knowing about forum members’ backgrounds, such as their condition, length of time since diagnosis, and typical blood sugar control, influenced his evaluation of their experiences and the extent to which he was likely to consider them in relation to his own healthcare. This information allowed him to consider a person’s ‘normal’ blood sugar levels, and to evaluate them in relation to his own version of normal. He used this detailed information to assess how credible these individuals were as information providers and to determine if he would utilise their experiences to improve how he managed his own diabetes.

As long as you know what the levels of experience are, that’s an important thing. If I’m speaking to say Miss X on another end of the Internet and she’s saying x, y and z. I’m weighing up, oh, yes, she’s a type 1, she’s been a type 1 for 14 years, she’s got such and such a problem, you know, what her problems are. So you can weigh up, is it a problem that is going to be affecting me as a type 2? The more information to flesh it out, the
more you can look at how similar they are. Like the old friend, with your blood sugar level that, I’m a one for the very tight control. If I go out and do my blood now and suppose I was setting at 4.5, now for me, that’s great, but for someone that is very fragile in their diabetes and they’re a type 1 if they’ve gone down to four point something that can be too, way too low for them. As long as you know what they normally are, you can go, well, there’s a difference of what she should be on. So I don’t need to worry that I’m running too low compared to her. (Ian, type 2 diabetes, 46 – 50)

Similarly, individuals who reported successful outcomes with particular procedures were viewed as authoritative information providers. In other words, forum members who had tried something that ‘worked’ and provided evidence of this effectiveness were considered credible providers of advice. For example, Lesley bought a number of books which described strategies for the management of type 2 diabetes as other people on the forum had reported that they had had success with them. Crucially for her, these successes were measured in “black and white”, meaning that there were quantifiable indications that these strategies were effective, “They’d got better results on their blood sugars, they’d got better annual blood checks, they’d reduced the medication, and they’d lost weight. So you link that up and think, well, that must be some sort of credible information because it has worked for some people” (Lesley, type 2 diabetes, 56 – 60). These biomedical markers provided forum members with a means of assessing their peers.

In addition, participants reported that they valued advice and information from forum members who had previously suggested something that had been successful or helpful for them. Interviewees referred to trusting those who provided advice that they had successfully utilised, “You do value everyone’s opinion and advice but others are probably more valuable to you than others because they might have suggested something that works for you. And obviously with that, then you gain a natural trust from someone from that” (Daniel, type 1 diabetes, 26 – 30), and giving them ‘credibility points’, “Every now and again you need to systematically test your background insulin to make sure it’s right... the people that suggested that to me kind of got credibility points” (Mark, type 1 diabetes, 41 – 45).

For those who had been diagnosed for a number of years, they were able to draw on their own experiences with their condition to evaluate the information presented. As Anne explained, this allowed individuals to assess the forum members presenting the information on the basis of their own experiences, which in turn led to an assessment of the members
themselves. She described how her initial foray into Internet forums resulted in her encountering a number of posters who she considered to be credible sources of information by comparing their advice and information to her own knowledge base.

And then I found this forum, a website and forum, called [name]. And I looked at this forum and I started reading what some of the queries and answers were, and three people on that forum seemed to be giving very good advice, things that I knew to be true, medically speaking, and as a diabetic, I could say, ‘Well yes, that does work’, and, ‘Yes, that does happen’, and, ‘Yes, they are right saying that’ because that is what happens. (Anne, type 1 diabetes, 61 – 65)

Additionally, participants also drew on the experiences of other forum members in assessing the information provided by an individual poster. Mark referred to the “feed of information” and “pool of collective experience” that forums provided, allowing members to assess the information that they were receiving against the benchmark of other information and experiences that had been shared on the forum. Comparing responses to the responses from other members enabled posters to assess the information across a spectrum of knowledge, rather than regarding it in isolation. Forum members could therefore access a group consensus within a single medium, which allowed them to easily distinguish which sources of advice and information were credible. This in turn allowed them to select information which they could apply to their own lifestyle in order to improve their health and condition management.

And, sometimes when you start a thread of course more than one person replies, and you can, rather like when you’re trying to work out what, em, eh, printer to buy, you look at the reviews that users have posted and some will chime as being a bit dodgy, some will chime as having a ring of authenticity. And, if four or five people are saying a similar thing then you think, well, OK, that’s an interesting idea, but the sharp end is you might give it a go. (Mark, type 1 diabetes, 41 – 45)

As a result of this group consensus, forums appeared to be somewhat self-policing. Forum members were able to draw on various pieces of evidence to establish themselves as credible sources of health advice and information. As suggested by Metzger et al. (2010), the posters established a ‘bottom-up’ assessment, where the quality of information could be assessed and constructed via the online community. By sharing experiences online, posters were able to evaluate information in line with their own experiences and knowledge base,
as well as drawing on the collective knowledge on the forum. This enabled them to dispute and filter out negative, not applicable, or dangerous information.

In addition, users were frequently reminded that forum members were not medical professionals, and that they should seek professional advice if required, “I mean, we always end up with, of course, they can’t give medical advice, you should, you know, if you want to do this, go and discuss it with your doctor sort of thing” (June, type 1 diabetes, 66 – 70). This meant that the information presented on forums was typically framed in the context of ‘experiential’ information rather than directive medical advice, and often involved a deferral to healthcare professionals (Sillence & Mo, 2014).

However, it should be noted that much of the evaluation processes described in this section have particular relevance for those with diabetes, due to the nature of their condition. For example, the continuous self-management required in relation to diet or insulin use, and the biomedical markers associated with this usage, cannot be replicated with ME/CFS. While individuals with diabetes were typically required to seek advice and information online on an ongoing basis and to utilise it into their day-to-day lives, the lack of consensus around the treatment for ME/CFS meant that the same procedures did not apply. In addition, the absence of biomedical markers of progress such as weight loss, stabilisation of blood sugar levels, and reductions in medication meant that forum users with ME/CFS were often unable to draw on the same evidence base to assess the credibility of information provided on online forums.

3.5 Establishing Evidence-Based Lay Knowledge

While most interviewees described the strategies that they used to assess the information that they encountered online, a number of participants also expressed concerns about the reliability and accuracy of information accessible on the Internet. For example, Stephen felt that the range of information available on the Internet meant that those with LTCs were likely to be exposed to potentially dangerous misinformation, “The trouble with the Internet is that its openness is also one of its greatest dangers, because any idiot can write whatever they like and it purports to be truth, and it isn’t necessarily the case” (Stephen, ME/CFS, 56 – 60).

This was particularly pertinent for those with ME/CFS, many of whom reported that they had encountered misinformation online. As described in previous sections, much of this built upon the lack of information and clarity around the condition and was targeted at
potentially vulnerable individuals who were unable to access support through traditional sources. This was illustrated by Karen, who described how she had encountered many websites after her diagnosis which touted cures for ME/CFS, usually for commercial gain. She was concerned that these purported cures could not only negatively affect individuals financially and physically, but could also instil them with a false sense of hope and optimism.

*When I was researching ME when I first got diagnosed and stuff there were a lot of websites saying that they could cure it and obviously I knew myself that there’s no cure, I’d already, I know there’s no cure as such and I just thought that, well, they were asking for money, giving false hope and things and that could, perhaps if you invested money and time into something that wasn’t going to work anyway you’re going to make yourself, you know, it would do harm it affects you emotionally, financially and probably physically, and mentally as well.* (Karen, ME/CFS, 41 – 45)

Though many participants expressed concern about the veracity of information online, their concerns predominately centred on the possibility that individuals other than themselves may be susceptible to the transmission of misinformation. As mentioned in Chapter Two, the majority of interviewees were educated to degree level or higher. This was frequently mentioned in relation to participants assessing information online, and many interviewees drew on their own education or employment background in order to evaluate the information that they encountered on the Internet, “I do have a few years of my working background working in evidence-based medicine, so I know how to read a study report and understand its shortcomings and its benefits and read it properly” (Julie, type 2 diabetes, 46 – 50).

There was a perception among interviewees that they themselves had the educational background, “Because having done a BA, you know, I’m perfectly good at researching online, you know, I do a lot of research and I find what I need to find and use it appropriately” (Carol, ME/CFS, 66 – 70), research skills, “I use my own scientific background, to determine what I’m reading is accurate, which perhaps puts me in a different situation from people who haven’t a long lasting scientific background” (William, type 2 diabetes, 76 +), or personal knowledge, “I like to think I’ve got the knowledge to be able to figure out what’s the good advice, what’s the bad advice, what’s going to work for me, what’s not” (Daniel, type 1 diabetes, 26 – 30), to discern good information from bad information online, but that others may not be able to do so quite so easily. This suggests
that while individuals were aware of potential risks about health misinformation online, they believed that their own ability to appraise and evaluate information overrode these risks.

However, it is necessary to contextualise this finding within the existing literature. For example, it could also be argued that individuals’ beliefs in their ability to identify misinformation online are merely the result of false levels of confidence. In an exploratory study of the use of online communities to treat insomnia, many individuals reported that they would be able to distinguish between accurate and inaccurate information online, while healthcare professionals expressed doubts (Middlemass et al., 2012). In addition, as discussed previously, the educational background of participants was likely to have influenced their use of Internet forums. Highly educated individuals have higher levels of online literacy and are more likely to find information online that improves their health (Dutton & Blank, 2013; Neter & Brainin, 2012). It could be suggested that this usage results in a form of self-fulfilling prophecy. Illustrating this, Hocevar, Flanagin, and Metzger (2014) report that as individuals acquire social media self-efficacy, they judge information from social media to be more trustworthy in comparison to offline sources. In other words, Internet users who consider themselves capable of using social media are more likely to encounter information online that they consider to be trustworthy. As a result, the self-reported abilities of forum users to identify misleading or dangerous information online are shaped by factors such as education, socioeconomic class, or social capital (Bell, 2014), and cannot be taken as a straightforward assessment or recommendation of the quality of information available on health-related forums.

This was echoed by Louise, who spoke about how she had participated in the present study due to a lack of information and guidance around the assessment of information online. She felt that many individuals were disregarding the Internet as a source of support and advice due to concerns about misinformation, and consequently were not receiving the potential benefits of the medium. In particular, she highlighted the potential role of healthcare professionals in supporting individuals to use the Internet and Internet forums for health information and advice.

"I don’t think enough people are getting the benefit from them [forums], and I think there is a lot of work we need to do around helping healthcare professionals understand the potential benefits, and equally helping users to understand the potential risks and how to mitigate those. So how do you work out what advice you take from the forum? How do
you identify when this is legitimate stuff and when it's rubbish? So I think there's work on both sides to be done there. And one of the reasons I was really interested in supporting this project is there's very little out there about, are these things beneficial or harmful? What difference do they make? And I think having that kind of data is really useful in getting more benefit out of them. (Louise, type 1 diabetes, 31 – 35)

3.6 Conclusion
This chapter has described how individuals with LTCs build and establish trust online. Within Internet forums, it is clear that trust is negotiated between forum members, with posters gravitating towards those who had similar backgrounds, perspectives, and attitudes as themselves. By sharing experiences online, participants were able to evaluate information in line with their own experiences and knowledge base, as well as drawing on the collective knowledge on the forum, and were able to dispute and filter out overly pessimistic, not applicable, or dangerous information. In addition, there were a number of external markers of credibility that interviewees sought, such as links to professional organisations, a high level of education, and a confirmed diagnosis from a healthcare professional.

Within this framework of trust and collaborative knowledge, mutually supportive relationships can be established. These relationships are a key focus of the next chapter, as the value of sharing experiences online will be explored. The processes through which forum users draw on the lay and expert perspectives available online in order to position themselves as empowered patients, not just engaged with formal healthcare systems but also actively self-managing their LTC in their daily lives, will be described. In addition, some of the topics addressed within this chapter, such as the role of activism on Internet forums, will be examined in more detail.
Chapter Four: Support and Empowerment Online

4.0 Overview
In this chapter, the support that forum users give and receive online will be outlined. In particular, how individuals draw on the support and shared experiences of other forum members in order to empower themselves and position themselves as active participants in their own health care will be detailed. Hardey (1999) suggests that the array of information and advice available on the Internet enables users to develop and redevelop their identity in a way that goes beyond the concept of a patient as a disembodied medicalised case (Parsons, 1951). By participating in forums and providing advice, information, and support to others, it will be argued that interviewees were able to further empower themselves as caregivers rather than just passive recipients of expert care. In this way, online support groups can facilitate the development of an individual’s illness identity and restore a loss of self (Barker, 2008; Charmaz, 1983; Trondsen & Tjora, 2014).

In addition to accessing support and shared experiences online, interviewees also sought out current research and medical practice. In this way, participants’ frame of reference expanded beyond the experiential knowledge of their peers, and encompassed medical knowledge. The process through which this occurred will be described, and it will be suggested that individuals drew on both ‘lay’ and ‘expert’ perspectives online in order to engage with healthcare professionals. In this way, forum users were able to utilise both experiential and scientific knowledge, and could situate themselves as a form of lay expert (Arksey, 1994; Whelan, 2007).

Finally, interviewees’ negative experiences with the Internet and online discussion groups will be discussed. As alluded to in Chapter Three, the role of activism in forums will be explored, and it will be suggested that ‘being ill’ and having a collective illness identity is central to the existence of certain ME/CFS forums. The barriers to the use of forums by individuals with LTCs will be described, and the importance of considering health inequalities online and the role of the digital divide will be highlighted.

4.1 Accessing Support and Shared Experiences Online
One pivotal aspect of participants’ use of Internet forums was accessing support online. This support manifested itself in a number of ways, and interviewees often found the mere act of being online and participating in online discussions supportive, outside of direct expressions or acts of support. In addition, a number of interviewees spoke about looking
for health information online as an act of empowerment, something that supported them in their interactions with healthcare professionals and allowed them to negotiate with the medical profession (Hardey, 1999). In this way, individuals armed themselves with information and were better able to have informed conversations and make decisions about their own healthcare and self-management (Johnston et al., 2013). For example, Susan spoke about how looking for information online had enabled her to gather a wealth of information about ME/CFS, to the point where she perceived that her knowledge was greater than that of her GP. While this information was useful when it came to negotiating her own healthcare, it was also important for her self-esteem and sense of self-worth.

Yeah, it’s helped me, it’s helped to develop my knowledge to the point that I know sometimes when I do talk to my GP, he looks at me as if to say, you know more than I do. So yes, it has strongly helped, and to give me the knowledge, to actually, and especially when you’re feeling as weak and as low as this illness makes you. It actually does give, give you the, a little bit say of self-esteem almost, because you’ve got self-knowledge, you valued yourself enough to do the research. (Susan, ME/CFS, no age given)

In this way, Susan was able to adjust her relationship with her GP from a paternalistic doctor-patient relationship to one in which she was a more equal and active participant. Similarly, Julie reported that using the Internet for health information and advice had a positive impact on her confidence and her ability to actively engage with healthcare professionals. Rather than just passively receiving care, she felt that the information and support she had gained allowed her to participate in shared decision making and take an active role in managing her condition.

Since using the forum and finding out what I have and what works for other people and what works for me I now feel much more confident. I’ve just recently moved so I’ve changed doctors. I haven’t had my diabetes checked with this doctor yet, but I feel quite confident in going in and saying right, OK, these are the tests that I’ve done, I will have had my next three months, the HbA1c that looks back over your control over the previous three months, and I’ll then be able to have a discussion about whether to reduce or maybe come off the metformin, and I feel confident that I’ll be able to have a sensible conversation and that I will understand what I’m being told. (Julie, type 2 diabetes, 46 – 50)
In addition to the support gained by merely being online, interviewees also spoke about the specific benefits associated with receiving support online. From a practical perspective, participants often highlighted the accessibility and availability of online support in comparison to support from health professionals, “I always go to the forum first, always because I know I can get hold of them. I know that if I type a question in within about half an hour somebody will have posted, if not more than one person, will have posted some advice” (Laura, type 1 diabetes, 31 – 35). The Internet also allowed individuals to access advice, opinions, and information from a wide range of people with varied background and experiences, “Well I guess it's just the width of the members. It's not just one or two isolated people, it's a very wide width, not sure width is the right, breadth, a wide range of people's experiences and knowledge” (Alan, type 1 diabetes, 66 – 70).

Crucially, this access was not hindered by participants’ own limitations, geographical or otherwise. This allowed individuals to readily have access to others with similar experiences, something that they may not encounter in their day-to-day lives, “Type 1 diabetes, it’s a bit like hens’ teeth, you don’t generally tend to know another person... the chances of somebody being in your social circle who has got it, is really very, very small” (Claire, type 1 diabetes, 41 – 45), or due to accessibility or mobility issues, “I think sometimes when you are, you know, exhausted and tired, I think having a laptop there and knowing someone’s on the end of it kind of sitting, there’s some support there is massive” (Helen, ME/CFS, 36 – 40).

As described in the previous chapter, a form of ‘value homophily’ occurred on the forums, where forum users were drawn towards those with similar views and perspectives (Centola & van de Rijt, 2014; McPherson et al., 2001; Sillence, 2013). Having access to others with similar experiences allowed participants to communicate with people who had a shared understanding about certain issues. For example, Karen explained how using the Internet meant that she could contact other people who shared her definition of “tired”, unlike family who she felt were unable to understand that her ME/CFS meant that her definition had altered.

It’s really difficult to explain to my family, I’d say to them, I’m tired or I’m having a bad day, I’m tired today and they’d say, yeah, I’m tired too. Then it’s like, well, their idea of tired and mine is two different things whereas if I say on the Internet, oh, I’m tired and someone says, yeah, you know, at least I can say it, it’s off my chest and perhaps get people saying, yeah, because they understand, especially in forums where people are
suffering it’s like, you know, you have that crossover symptoms and everything. So you’ve got that almost compatibility really in that you’re all suffering something similar. (Karen, ME/CFS, 41 – 45)

This allowed individuals access to a form of emotional support by venting to people with similar experiences and attitudes, unlike their family and friends, who may worry or overreact, “And if I said that, to say, my mum, she’d be mortified... Whereas other people can see the funny side of it. You can’t really have that kind of gallows humour with somebody who doesn’t get it” (Claire, type 1 diabetes, 41 – 45). The mention of ‘gallows humour’ is particularly notable, as it has been suggested that using humour and jokes online can be viewed as a form of emotional support (Gooden & Winefield, 2007). This allowed forum members to discuss aspects of their condition in a light-hearted manner, without having to explain the humour to someone who is not a member of the community. As a result of these types of communications, online communities often represented a place where individuals with LTCs could feel ‘normal’, rather than distinct or “the odd one out” (Daniel, type 1 diabetes, 26 – 30) amongst their family and friends (Trondsen & Tjora, 2014). Interviewees took solace in the knowledge that they were not alone in their experiences and that others were going through similar struggles, “Sometimes there is some sort of comfort just knowing that there’s other people out there going through it” (Daniel, type 1 diabetes, 26 – 30).

In addition, among some participants, the Internet was seen to not just offer social support but essential, lifesaving help. Gemma described how using a forum provided her with vital support which she was unable to access anywhere else, “I was in a very bad place and, like, in all honesty, and my husband knows this, I didn’t know if I would see the year out, at that point, and it just made things better to be able to talk about it with other people, so in my eyes, a good, the support that I get from the online forum is so, I get so much more from that, than from, like, medical help that I’ve been offered” (Gemma, type 2 diabetes, 31 – 35). This was echoed by Jennifer, who reported that the Internet provided her with access to support and services, as well as a way of engaging with the world that she would not be able to do otherwise, “If it wasn’t for the Internet, I’m convinced I’d be dead now because I’d have just sort of knocked it on the head and committed suicide. Because I just wouldn’t have been able to do anything else, so, you know, and that, I could state that as a fact, I’m just, I’m convinced that would be the case” (Jennifer, ME/CFS, 36 – 40). As a result, the Internet and online forums allowed participants to access the shared experiences of others and to draw on aspects of emotional and informational support in order to position
themselves as empowered, active participants in their own health care. This process of empowerment is described in more detail in section 4.2 below.

4.2 The Internet as a Tool of Empowerment
This sense of shared experiences also meant that forums provided participants with information that they could not access via their healthcare professionals, notably the experiences of people who were similarly engaged in living with and managing an LTC. This allowed them access to a form of ‘patient knowledge’, where individuals translated medical knowledge into practical courses of action (Pols, 2013, 2014). This was particularly true for individuals with diabetes, as they had to contend with their condition day-to-day in a way that those with ME/CFS did not. This meant that they were receiving information from people who were facing similar challenges and issues on a daily basis, as opposed to healthcare professionals, who were seen as somewhat removed from their care. In many cases, this meant that information gleaned online was seen as more realistic and therefore more valuable than that received from doctors and other medics, “Somehow there’s an authenticity with comparing notes with other people who are fighting the same battle that, as skilled as they are, medical practitioners find it difficult to communicate. If they’re not coming from that shared experience, it can be quite a challenge” (Mark, type 1 diabetes, 41 – 45).

Crucially, this allowed participants to question forum members about their lived experiences with their condition. This was illustrated by Gemma, who described going to the doctor a few months after falling off a horse and injuring herself in a number of ways. While she was sure that her ongoing problems were related to these injuries rather than her type 2 diabetes, she felt that her doctor was unable to look past her diagnosis and consider other options. As a result, she looked for others who had experienced the ‘feeling’ of neuropathy, as opposed to the qualifications of the doctor, who was just aware of the classification. Seeking support online allowed her to access the form of experiential information that she required (Silence & Mo, 2014), as well as providing her access to a community where she was seen as an individual rather than a condition (Laing, Keeling, & Newholm, 2011).

I went to go and see him, because I know that diabetics worry about their feet and instead of listening to the bit where I said, a massive horse stood on my foot, he ignored that and just went straight to, well, it could be your blood glucose, and, like, unless diabetes causes a horse to stand on your foot, it’s not diabetes. So in that way, I have a
bit of a problem with my GP, in that I’ve got this label now which is diabetic and I feel like I’m only ever going to be, have something diabetic considered about me and not anything else, so in that case, like, I asked this week what neuropathy felt like, because they’re, the people on the forum have neuropathy, they know what it feels like, whereas, the doctor doesn’t know, he doesn’t know the feeling, he just knows that it’s classified, if you know what I mean. (Gemma, type 2 diabetes, 31 – 35)

In addition, there were suggestions that forums allowed individuals to develop a frame of reference within which to consider their interactions with healthcare professionals. Crucially, the Internet and online support often represented an attempt by participants to bridge the gap between services offered by medics and their own day-to-day experiences, rather than to replace these services. As a result, interviewees regularly went online to assess their own experiences in relation to the experiences of others in order to consider whether or not they needed to attend or reengage with health services. Drawing again on the use of humour on the forums, Anne explained this in relation to metformin, a drug used in the treatment of type 2 diabetes, or “metfartin”, as it was known on the discussion board she frequented, due to its side effect of “gastric disturbances”. Participants often accessed the Internet in order to assess whether these side effects were normal and expected or whether they necessitated a return trip to their GP, “Sometimes people aren’t sure whether they ought to be going, they’ve got this thing, this query, and they’re not sure whether they ought to be going to the doctor’s and asking or whether it’s just something that happens and will go away” (Anne, type 1 diabetes, 61 – 65). In this way, forum members used online communities to validate and understand their experiences in the context of other users’ experiences (Keeling et al., 2013).

As discussed in the previous chapter, the use of Internet forums by individuals with LTCs appeared to be contextually dependent, with interviewees utilising online sources for routine queries rather than acute situations (Fotaki, 2014; Gage & Panagakis, 2012), and with a frequent deferral to the expertise of the medical community (Sillence & Mo, 2014). For example, participants were often seen to share ‘tips and tricks’ with other forum members, i.e., suggestions that were intended to support individuals to self-manage their conditions. Typically, these were drawn from their own experiences of their conditions, and related to minor inconveniences rather than major medical issues.

Illustrating this, Louise described how she had altered her night-time routine as a result of advice that she received on a diabetes forum. While she used to keep a bottle of Lucozade
by her bed in order to prevent her blood sugar becoming low during the night, she found that the size of the bottle meant that she would invariably drink too much, “The problem with that is that Lucozade comes in big bottles and the temptation is to drink a lot of it and then your blood sugar ends up too high.” Based on the experiences of others, she began to use small boxes of juice that were usually marketed at children, “They're just the right size to treat a low blood sugar in the middle of the night. So you can't take too much of it, and also they last for ages and you're not left with an open box.” As she had not conceptualised her use of Lucozade as problematic, it was not something that she sought help or advice on. However, interacting with other peers online provided her with practical knowledge about her condition which she was able to utilise in her daily – and nightly – practices (Pols, 2013, 2014).

I've been using them now for a good few years, but I picked that up on an Internet forum that someone else was using it. It sounds really stupid, but there was nowhere else to get that information and I would never have asked for that information because I didn't know I needed it. It was just someone saying, oh, I do this and it works well. I thought, actually, that's brilliant, why didn't I think of that? (Louise, type 1 diabetes, 31 – 35)

Interestingly, along with providing practical advice and support, accessing shared experiences online also often provided participants with motivation. For individuals who were trying to lose weight or to focus on a particular food plan, such as a low carbohydrate diet, forums provided a location for users to support each other. Forum members shared advice, experiences, and information in order to motivate each other towards healthy behaviours. Participants were able to access non-judgemental, personalised advice and support that was tailored towards their individual lifestyle and preferences, as demonstrated by Lesley.

And then everybody's supportive on the thread, you can go on that thread and say, I've had a bad day, I've had a bad week, you know, or I can't get into it, can anybody offer any help, you know. And we support one another and say, keep going, don't give up, you know, that kind of thing. And the live chat is good for that because you can actually break down somebody's menu and say, well, where are you sticking, what point of the day are you having difficulty with, what food group are you having difficulty with, let's find an alternative that's low carbohydrate, or diabetic friendly, shall I put it, which is also suitable for you as an individual. (Lesley, type 2 diabetes, 56 – 60)
Many interviewees spoke about the impact that positive role models had on how they managed their conditions, indicating that accessing support online leads to change in health behaviours. Indeed, it has been suggested that accessing support from one’s network is associated with higher levels of motivation and engagement in health promoting behaviours (McKinley & Wright, 2014; Ng, Ntoumanis, & Thøgersen-Ntoumani, 2014). Mark described how the Internet allowed him access to people who would cheerlead him along and support him through negative moments, thereby supporting him towards positive self-management strategies, “You just need people who are now in a good place who were in a bad place going, yes I absolutely get it, I know where you are and it’s wretched but in a few months’ time, hopefully you will have come out of the other side” (Mark, type 1 diabetes, 41 – 45). For him, having access to these role models was pivotal to his control of his condition, which contrasted with his experiences with his doctor, who was not able to provide him with that constant, on-going support, “It’s like a two year intensive course of how to manage it based on not just somebody who sees me for 30 minutes every 12 months, but people who are living with it 24 hours a day like I am” (Mark, type 1 diabetes, 41 – 45).

This was echoed by Simon, who found that online support provided him with not just positive role models, but also realistic role models. Though he had accessed forums before he began participating in them, he had been reluctant to get involved as he felt they were inhabited by “perfect” patients, something he could not relate to. Once he found a forum that fit with his own approach to diabetes management, however, he was able to engage and receive support. In contrast with Gemma’s experiences of visiting her GP, where she felt that she was pre-judged due to her condition, Simon was able to access support and advice without being evaluated on his control of his diabetes.

So, I’d dip into that and then I’d dip straight back out again because that wasn’t who I was. But then, I dipped in again and I found another forum called [name] and it was filled with more people like me, who understand that it’s hard to control, and understand that perfection isn’t easy or achievable for some but is achievable for others. And, there was an acceptance of everyone has, can achieve different things, but there’s no judgement, judgement is the key word, that how well you do isn’t judged. (Simon, type 1 diabetes, 36 – 40)

Just as Mark acknowledged that online support offered him a service that could not be provided by his doctor, similarly Gemma felt that forums provided her with positive role
models that she could not access among her family and friends, despite the fact that her parents had also been diagnosed with diabetes. She highlighted her father as an example of someone who she felt was not successfully managing his condition. By contrast, accessing online discussion groups allowed her to engage with people who were making what she perceived to be healthy lifestyle choices. This provided her with both guidance in managing her own diabetes, and optimism and motivation that she would be able to do so successfully.

These are people who have all got diabetes, they’ve all had to live with it for however many years and they’re all actively trying to manage it as best they can, instead of just ignoring, well, not ignoring it, but just I don’t want to be the person that just goes to the doctors, gets my medicine and comes back in six months, and my sugar level has gone high and I’m put on another set of medicine, which I know a lot of people do, I mean, my dad is one of those examples. I’m interested in actively managing it and I need to do as much as I can to reduce my risk of complications, because I want to live another 30 years, at least, so I feel that the people that are on the forum that I use all the time, also have the same outlook, and they try lots of different things and they tell you what does and what doesn’t work for them and it’s all ideas for me to try. (Gemma, type 2 diabetes, 31 – 35)

In addition, accessing support online also empowered interviewees to engage not just with their own conditions but also with health care systems. Laing et al. (2011) suggest that participating in a forum allows individuals to develop a strong sense of ownership over their condition, which in turn leads to them becoming more actively engaged with healthcare professionals. Within the present study, this was illustrated by Margaret, who described the difficulties that she had encountered in receiving appropriate treatment for her diabetes. Though she had initially been diagnosed with type 2 diabetes, she had experienced a number of difficulties with the medications that she had been prescribed, including regular hypoglycaemic episodes and very high blood sugar levels. This had prompted suggestions from posters on the forum that she used that she had LADA (latent autoimmune diabetes of adults) or “type 1.5” due to her unsuccessful cycle of medications. This in turn led to her pushing for a prescribed course of multiple daily injections, which successfully lowered her blood glucose levels. Though her doctor was initially reluctant to acquiesce, Margaret was able to make a case for her preferred choice of medication, thereby placing herself as an active participant in her own health care.
Throughout this experience, she engaged in a process of negotiation and renegotiation, making multiple visits to her GP, while simultaneously consulting the forum, the manufactures of the medication and NICE guidelines. Though Margaret attributed her success in this “battle” to the support and encouragement from the forum, “Now if it hadn’t have been for the forum, I wouldn’t really have known how, what, where to go ahead with a situation like that” (Margaret, type 2 diabetes, 66 – 70), it is clear from her account that she was more than a passive recipient of support. Instead, she engaged with and built on the support, information, and advice provided online, using it to explore and research the different options available to her. This allowed her to take an active approach to her healthcare decisions (Johnston et al., 2013). However, her frequent engagement with her doctor indicates that her online activity did not signal a rejection of the medical profession (Henwood et al., 2003). Instead, Margaret used the Internet as a tool of empowerment, drawing on her own knowledge about her health and illness to complement and engage with the services offered in formal health care settings (Kivits, 2006; Nettleton, Burrows, & O’Malley, 2005).

4.3 The Value of Reciprocal Support Online

In addition to receiving support online, the reciprocal nature of forums and other forms of online communication meant that participants were able to provide support as well as receive it. It has been suggested that online discussion groups can fulfil a dual purpose: providing information to those who need it, as well as allowing those offering advice, information and support to others to feel that they play a positive and useful role (Hadert & Rodham, 2008; P. Reeves, 2000). Within the present study, for many interviewees, this was a key aspect of their use of the Internet and it allowed them to extend beyond their role as a patient, and situate themselves as a caregiver as well as receiver.

A pivotal reason for interacting with others online was to offer emotional support. For example, Emily described this as a crucial aspect of her use of Tumblr, a microblogging platform, where she frequently contacted others with ME/CFS to offer herself as someone to talk to. She was conscious that though individuals might not always take her up on her offer, making contact with others to provide support was often viewed as supportive in and of itself.

*If someone’s having, it looks like they’re having a really bad day, sometimes if I’ve communicated with them a bit through Tumblr before, I’ll quite often message them and say, I really hope you’re OK and if you want to chat, you know, I’m here, I know what*
you’re going through, and sometimes people do take me up on that offer, and sometimes, it’s just a bad day and I’ll be alright tomorrow but I really appreciate you messaging me. (Emily, ME/CFS, 18 – 25)

Similarly, Margaret provided emotional support to others online. While she described herself as answering questions and providing advice to other posters, she was conscious that responding to forum members in a timely manner could offer them reassurance and relief.

I tend to use the computer first thing in the morning, so I go on and pick up on the questions that may have been asked over the previous night, or first thing in the morning, which is where you usually get people who have woken up in the middle of the night and get anxious about something. And then you can jump in and give them support and what advice you can. (Margaret, type 2 diabetes, 66 – 70)

In addition to emotional support, others were interested in sharing practical and informational support. Louise, who was an active participant on forums and a blogger about her diabetes, spoke about her own experiences looking for help and information when she started to use an insulin pump. She found that much of the information available was from a US perspective and was not necessarily applicable to the UK healthcare system, which prompted her to share her own experiences and provide answers to people’s questions, “I’d found it hard to get the information I needed so I wanted to make it easier for other people... So as somebody who was already using this equipment and seeing benefits from it, I went on there to answer those questions” (Louise, type 1 diabetes, 31 – 35).

Likewise, Margaret had sought advice and information from a forum in advance of a holiday abroad shortly after her diagnosis in relation to transporting insulin through security and on the airplane. On her return, she went back to the forum to update everyone about her experiences and to share information that she had garnered while she was away. For example, the aircraft that she had travelled on had a sharps container, for the safe disposal of needles, which she thought may be of interest to other forum members. As described previously, this provided a form of patient knowledge, where forum users drew on their lived experiences and medical knowledge to practical courses of action (Pols, 2013, 2014).
So, afterwards, I was able to feed that back into the forum for other people to say, it really is no trouble, you’re not asked all these nasty questions... So I put that information on the forum as well, because I thought, well, that might help people to know, some people take little boxes around. (Margaret, type 2 diabetes, 66 – 70)

Occasionally, participants reported sharing their own experiences and opinions in order to steer people in a particular direction. For example, Nicole felt a particular purported treatment for ME/CFS which involved working with a therapist was a “clever marketing tool for CBT”, and posted on the subject if it arose on the forum, “I’ll put on it, I personally think that’s CBT and you can get that on the NHS and you can get it for free, so why pay for it if you can get it” (Nicole, ME/CFS, 26 – 30). In this instance, Nicole was attempting to provide support by warning others away from a course of action that she felt could be disadvantageous.

This was not always consistent among participants, however, and some interviewees mentioned how they would avoid directing or advising people so as to not appear negative or controlling. As described in Chapter Three, the generally supportive nature of online discussion groups was valued by many interviews, and many were conscious of the need to adhere to the supportive norm of the forum (Mudry & Strong, 2013; Stommel & Koole, 2010). This meant that forum users considered their online communications in light of this norm, and took care to ensure that the online persona that they were presenting was one that was sufficiently supportive. For example, Lesley had experienced damage to her eye due to diabetic retinopathy, which had prompted her to take greater control of her diabetes. As a result, she found it difficult to strike a balance between offering support and advice to forum members and attempting to persuade them to regulate their own control.

I see some people and, you know, they’ll spend months saying, oh, I will get down to it, I’ll sort myself out, and all that, they go on, and on, and on, and I’m dying to say to them please do something because you could end up like me, you know. But I can't do that, or sort of like if I did say what I wanted, to be so honest it would scare them. And you can't do that because it's up to that individual, isn't it, if they don't really want to know the full truth about diabetes and what it can do to you very quickly, very quickly, then I can't, you know, you can't do anything. (Lesley, type 2 diabetes, 56 – 60)

Other interviewees also reported that they attempted to ensure that they provided support to others online, with a focus on positive and motivating interactions between forum
members. Anne described similar experiences to Lesley in discussing her role as a moderator on a forum for individuals with diabetes. She described the difficult balance between support and criticism, when the criticism would be intended to support and motivate other forum members into a healthier lifestyle. This is in line with previous research, which suggests that moderators may be involved in enforcing condition-specific norms, such as modelling good self-management (Kennedy et al., 2009). Despite this conflict, the forum norm of supportiveness prevailed, with the focus on supporting and aiding participants rather than guiding them towards a particular course of action, “So you do have to be kind of careful like that and obviously when we want to criticise people, we don’t do. But I don’t think, there are also times where you really want to yell at people, ‘You are not listening!’ And you can’t, you can’t say that” (Anne, type 1 diabetes, 61 – 65).

Similarly, in responding to one of the vignettes, Sharon spoke about how she would be reluctant to disagree with or criticise another forum member, even if she had concerns about how they had interpreted or self-diagnosed their medical symptoms, “Even if I disagreed with how somebody had interpreted their symptoms, I wouldn’t ever put anything sort of negative because I kind of think, well, it’s not my business, and they’re not people I know, and you know, it’s not my place” (Sharon, ME/CFS, 51 – 55). This attitude extended across forums to blogs, with Simon commenting that negative attitudes online were not helpful, and he preferred to provide support to others by focusing on more positive or humorous aspects of his condition, “If I drag myself down and think how shit it is all the time then I don’t see the benefit, and conversely if I’m writing about how rubbish it is, how is that benefitting the reader” (Simon, type 1 diabetes, 36 – 40). As a result, participants were conscious of the need to censor the information that they shared online in order to present a supportive agenda. The concept of online personas and self-censorship is discussed in more detail in Chapter Five.

While many participants provided support to others online, there were suggestions that they themselves benefited from the provision of support. Some interviewees reported experiencing a sense of personal achievement from providing support, suggesting that reciprocal support can be a key aspect of forum use (Hadert & Rodham, 2008; P. Reeves, 2000). Susan described how she got “a sense of achievement” from blogging about her experience with ME/CFS, while Joan’s experiences with irritable bowel syndrome meant that she was able to offer dietary advice to individuals with ME/CFS, which she liked, as she enjoyed “being able to help people”. For June, responding to people’s questions and queries online meant that her own knowledge base about her diabetes had expanded, “I
have learnt an awful lot because if somebody asks a question and I don’t know the answer to it, I’ll go and research it so I can give them an answer. And I think that does sort of help me” (June, type 1 diabetes, 66 – 70). This indicates that patient empowerment online can extend beyond an individual’s engagement with their own condition. By interacting with peers and providing them with support, forum users were able to mobilise their existing capabilities on behalf of others. As illustrated, providing support to others online often allowed forum members to engage in a reciprocally supportive relationship, in contrast with the concept of patients as passive recipients of expert care.

4.4 Accessing Medical Knowledge Online

The previous sections have detailed the value of shared experiences and peer support online. As described, Internet forums allow individuals with LTCs to access mutually supportive relationships online, which in turn empower them to become actively engaged in their own healthcare. In particular, the transmission of patient knowledge online was described (Pols, 2013, 2014), whereby individuals drew on their lived experiences with a condition to translate medical knowledge into practical courses of action. However, there is another factor to interviewees’ experiences online that must be explored, and that is the role of ‘science’ and formal medical knowledge. As alluded to in Margaret’s story in section 4.2, forum users often drew on existing research and practice, such as the NICE guidelines. In this way, participants’ frames of reference expanded beyond the experiential knowledge of their peers, and encompassed existing medical knowledge.

One form that this process took was participants using the Internet and Internet forums to address their specific information needs that were not met by traditional service providers (Josefsson, 2005). In this way interviewees used online resources to bridge the gaps left by healthcare professionals, indicating that, as highlighted previously, the support and information provided in online support groups can complement rather than challenge that offered by medical professionals (Loader et al., 2002). In particular, interviewees reported using the Internet to investigate ‘leads’ that they had picked up on from different online and offline sources. For example, Nicole described how a therapist on her care team mentioned aromatherapy to her, which led her to look online for more information. For Nicole, her Internet searches focused on areas that were supplementary to those that would be covered by her team of healthcare professionals, such as herbal or alternative treatments.

So I used, it was what I would call silly questions, like, what about pain management, any sort of herbal, anything that the doctor can’t recommend. So like, for example, the
therapist I saw yesterday as part of my pacing, she said, I can’t tell you to do this, however, you might want to try aromatherapy for your wheat bags. So it’s that kind of thing I look on the Internet for. (Nicole, ME/CFS, 26 – 30)

Along with the use of the Internet to complement traditional sources of healthcare, many participants spoke about using the Internet for dietary advice, something that they were unable to access in great detail from their GP, for example. This was common across many interviewees, but was particularly true for individuals with type 2 diabetes, many of whom criticised the lack of support they received in the wake for their diagnosis. The Internet provided them with a way to address this lack of information by allowing them access to a wealth of dietary information, recipes, and advice from others with diabetes. As illustrated by Lesley’s quote, accessing this advice via the Internet provided a more personalised approach to health care than could be provided within a formal health care setting (Keeling et al., 2013).

There’s lots, using the Internet, there is lots of information on particularly for using low carbohydrates on the amount of carbohydrates in food. There’s some fantastic websites out there which give you recipes, and menus, and pictures, and they're tried and tested by people who are either low carbs or are all diabetic, and they've been doing it for years. (Lesley, type 2 diabetes, 56 – 60)

In addition, accessing information online allowed participants to consider information in detail and in their own time, rather than waiting for a scheduled appointment (Elwell et al., 2011). This was particularly helpful considering that interviewees did not always have immediate access to healthcare professionals. This was the case for Daniel, who described how he began to use the Internet in relation to his diabetes in response to a delay in getting an appointment with his local practice, “I’m a bit impatient so I thought, right, I want to get this sorted and I want to get it sorted now and if it’s not sorted by five o’clock, I’m not going to be happy” (Daniel, type 1 diabetes, 26 – 30).

For Edward, being able to look things up online in his own time allowed him to sift through information in detail, and look at things more critically than he would be able to through other sources of information. The Internet enabled him to check sources and verify information as it was presented to him. As described in Chapter Three, participants used a number of strategies to evaluate the information that was presented to them online. The diversity of the information available online appeared to encourage individuals to be
sceptical about the information that was presented to them, and to cross reference this information against a number of different sources (Hardey, 2001). This was particularly important for Edward, as he felt that a lot of the information available about ME/CFS, both online and offline, was misleading.

*I feel that one of the useful examples is that, basically, a clear record of what was said and the, sort of, precision there and it allows people to, kind of, pick apart what was said in a, sort of, more careful manner, whereas, I think, with conversation, it’s, like, I think, particularly with CFS where there’s so little really clear evidence, there’s just so much it would be so easy for people to say something that was misleading accidentally, or not really clear and there’d be, sort of, just much harder to, sort of, check it out, what they mean, or how well the evidence supports that.* (Edward, ME/CFS, 26 – 30)

Going online enabled participants to research information and treatments that were available internationally and that they and their healthcare team may not have had access to within the NHS. By accessing information of this nature, individuals have the opportunity to put new demands on health care providers and institutions and thus challenge traditional knowledge domains (Hardey, 1999). For example, Louise described how she had encountered insulin pumps online through reading information from the US, and was able to integrate that into the management of her condition on the basis of her research. She saw the Internet as a method of keeping up-to-date with diabetes research and practice, which enabled her to enhance her own care based on new developments. As a result, Louise’s research online enabled her to actively engage in her own health care, and to improve how she managed her diabetes.

*I used and still use the Internet to find out the latest information about diabetes care around the world and how that might apply to me, so the latest research, the latest technology. So I use an insulin pump to control my diabetes which for me works a lot better than traditional injections... So I found out about that from the Internet, from the States about six years ago and took it to my care team and said, 'Actually, this is what I want.' And ever since then I've had really very good diabetes control and that's very much down to having the right equipment to do the job.* (Louise, type 1 diabetes, 31 – 35)

As Louise’s story illustrates, interviewees often used the information that they accessed online to adjust the care that they received from medical professionals, and were
empowered to take an active approach to healthcare decisions (Johnston et al., 2013). Similarly, Michelle described how she read about anti-depressants online and felt that as the potential side effects were very similar to the symptoms of ME/CFS, she was reluctant to take them. On presenting this information to her doctor, he agreed with her, and decided not to prescribe her anti-depressants, “I didn’t want to be wondering if something I had was from ME, or from the anti depressant, so I decided not to take them. The GP actually agreed with me, I was right, so I didn’t, I have no medicine” (Michelle, ME/CFS, 41 – 45).

However, as described previously, the use of the Internet for health information and advice did not signal a dismissal of the services of healthcare professionals. Instead, accessing online forums allowed participants to explore alternative ideas and directions which enabled them to extend their information seeking beyond the parameters set by the NHS (Laing et al., 2011). For example, Emily described how she actively searched online for information on medications prescribed to her by her GP, and in particular their side effects. She used this research to make an informed choice on whether or not to take the prescribed medication, rather than to come up with suggestions of medication which she would then present to her doctor, “I don’t think I’d ever, like, come up with a drug I’d want to take, it would only ever be something the doctor has said, try this, and then I’d go and research that” (Emily, ME/CFS, 18 – 25). The Internet allowed her to engage with healthcare professionals, providing a peer-sourced system that complemented the supports and services offered by the medical profession.

4.5 Integrating Lay and Expert Perspectives
As discussed previously, accessing the shared experiences of peers online allowed individuals access to experiential knowledge. However, this knowledge is typically embedded within formal health care systems (Nettleton, Burrows, & O'Malley, 2005) and frequently involved a deferral to healthcare professionals (Sillence & Mo, 2014). As a result, forum users drew on both ‘lay’ and ‘expert’ perspectives in order to engage themselves in their own health care, and attempt to influence the progression and recognition of their condition (Arksey, 1994). Within the present study, this occurred in two ways. Interviewees accessed academic papers online and used the Internet to connect with researchers, healthcare professionals and other noted figures. These processes are described below.

In addition to interviewees accessing information and support online, a number of participants also used the Internet to read and discuss academic papers. As highlighted in
Chapter Two, over 70% of interviewees were educated to degree level or higher, indicating that the participants in the present study had considerably higher levels of education than the general British population. Many interviewees drew on their academic backgrounds in order to locate information that was relevant to their condition. For Edward, academic papers were one of the key aspects of his online activity. While he valued reading about the experiences of others with ME/CFS online, he preferred to use the Internet to access articles that had been published in peer reviewed journals, which he used to “try and get a better understanding as to how likely it is that I’m going to recover, or if there’s anything in particular I can do to aid that, or anything like that” (Edward, ME/CFS, 26 – 30). He accessed these papers through friends in academia, as well as using open access journals and occasionally contacting researchers to request a copy of a paper.

Similarly, Ian regularly accessed research papers online, which he used to signpost his reading into different areas, “I can go into, look into it, research back and go back, back and go, oh yeah, that study looks good but, yeah. Or, I can see where they’re going with it but they haven’t managed to put any papers out on that, can I find anything round it and read round it?” (Ian, type 2 diabetes, 46 – 50). The peer review process allowed him to have confidence in these findings, but he recognised that his background in academia meant that he found traditional research accessible in a way that others might not, “Of course I’m lucky in that I’ve got enough background knowledge to take a learned paper and sift out where to go from there”. This enabled him to interpret research and direct his reading into different areas to find research that may be directly applicable to his own condition.

The Internet was also a place to disseminate and discuss research. Forum members often emailed each other copies of research papers, as well as discussing research and its implications online. While previous research indicating that individuals with a university education were twice as likely to find information that improved their health compared to those with no educational qualifications (Dutton & Blank, 2013), this was echoed in the present study by interviewees. Many participants acknowledged the role that their educational background played in supporting them to navigate the Internet and Internet forums as a source for health information and advice, “[It depends on] what background and education you’ve got really. I don’t mean that in a snobby way but I... I know how to sift through, and I know myself and my body” (Lesley, type 2 diabetes, 56 – 60). However, the nature of online discussion groups meant that individuals could share both their own experiences with their condition and the information sources that they accessed.
In some cases, this allowed participants access to interpretations of research findings and to consider how they could be directly applicable to themselves. This was particularly noteworthy for individuals with ME/CFS, for whom the direction of ongoing research was of interest. As discussed in Chapter One, from the perspectives of individuals with ME/CFS, a key priority is the characterisation of ME/CFS as a biomedical rather than a psychological or psychiatric condition (Hawkes, 2011; Smith & Wessely, 2012). This was illustrated by David, who described the sense of empowerment that he experienced from hearing about active biomedical research through online forums, “And that’s all I’m interested in really, the way forward, and basically the British establishment, along with the international biomedical researchers that are coming together, and just to keep your eye on it, to see out there, which is also for me very empowering, the threads that go on, the discussions that go on” (David, ME/CFS, 66 – 70).

Interestingly, however, the forums provided David with not just an awareness of ongoing studies, but also interpretations and critique of existing research. While Ian’s background in research and academia meant that he could not just access peer reviewed papers but also interpret these findings in relation to his own condition, David did not have this level of knowledge. By utilising Internet forums, he could draw on the knowledge of others and access their lay interpretations and critiques of research, “There are people on there that their condition has affected that are academics, so you can actually put on and say can somebody please put that into simple terms, and you can have a good chat and a laugh and so on” (David, ME/CFS, 66 – 70).

In this way, David was able to directly access the research that was relevant and of interest to him, rather than receiving this information via a gatekeeper from the medical profession. This allowed him to situate his experiences in biomedical terms (Mazanderani et al., 2013), and provided him with the ability to draw on both lay and expert forms of knowledge in order to confirm the existence of his condition as a biomedical entity (Barker, 2008). Similar to the collective pool of shared experiences described in Chapter Three, forums allowed individuals to share and access scientific knowledge online. In this way, forum users were able to utilise both experiential and scientific knowledge, and could situate themselves as a form of lay expert (Arksey, 1994; Whelan, 2007).

Interestingly, the Internet and Internet forums did not just provide access to the experiences and perspectives of those with LTCs, but also those of ‘experts’ and healthcare professionals. This was particularly true for individuals with ME/CFS, supporting Arksey's
(1994) suggestion that alliances with technical experts are crucial in seeking recognition and legitimacy of a condition. For Jennifer, the mere existence of websites dedicated to ME/CFS made her feel supported and less alone. In particular, she valued the efforts of researchers and healthcare professionals whom she viewed as taking an interest and an advocacy role for those with ME/CFS. She saw this online activity as validation of her condition as a biomedical entity, providing her with a sense of support that could not be achieved through interactions with peers.

* I think it’s so supporting when like, say, you go to sites that are run by doctors that are sort of specifically geared towards ME or health in general, like helping people, and it’s just so supportive to sort of think that you’re making contact with people that care and they’re trying to, like passionate about the fact that you are suffering and that they could help that and so that is just incredibly supportive.* (Jennifer, ME/CFS, 36 – 40)

For other interviewees, this awareness of researchers and healthcare professionals was taken one step further, translating into contact between lay people and experts. For example, James had struck up a relationship with a major figure in the field of ME/CFS research. He had begun by emailing the researcher on the encouragement of a forum in order to “challenge” him about some of his claims, which were perceived as being damaging to the ME/CFS community, “And I did what was being encouraged at the time, challenged this guy, here's his web address, and I was astounded, I did it from work and I thought I'll be one in hundreds and it'll get ignored” (James, ME/CFS, 51 – 55). To his surprise, the researcher emailed back, and they began an email correspondence, discussing developments in ME/CFS research along with other issues.

* And I think he probably picked up on mine because it was incredibly polite in what I said, and I wasn't just going to say you're going to die and I'm going to get your kids, as I quite believe some people have said. And we got into correspondence and I started to see his point of view as I always do, I try and understand the other point of view, and I would ask sensible questions.* (James, ME/CFS, 51 – 55)

While it has been argued that online communities privilege lay knowledge and perspectives over the expert knowledge of health professionals (Burrows, Nettleton, Pleace, Loader, & Muncer, 2000), the present study suggests that that the input and perspectives of those from the medical profession were also valued. In the case of those with ME/CFS, this contact provided individuals with a sense of legitimacy and appeared to validate not just the
existence of their condition, but its existence as a biomedical rather than a psychological condition. In addition, participants were able to draw on medical terms and frameworks to collaborate with professionals and situate themselves as active participants in the construction of medical knowledge, as described by Arksey (1994) and others.

Finally, the Internet also allowed individuals to be participants in research of their choosing. This was particularly important for Louise, who valued the ability to participate in research without the research having to pass through the gatekeepers of her healthcare professionals. Recruitment through online forums, as was the case in the present study, was something that she viewed as empowering, as it positioned her as an active, informed individual, rather than a passive recipient of expert care.

*Because I often feel, I mean, because if I hadn't seen your stuff online, the chances are you'd have had to have approached a set of GPs or a hospital clinic. So the only way to get at me is through my healthcare team, and actually I'm a grown-up, I'd like to deal with you direct. I'd like to choose which researchers, I want to see what's out there and take the pick of, oh, actually, I'd like to help that. So I think it's quite empowering for patients because we get more accessibility to what's happening.* (Louise, type 1 diabetes, 31 – 35)

### 4.6 Conflict Online: The Role of Illness Identities

In addition to the positive experiences and support that people received online, there were also a large number of reports of negative experiences online. These fell into a range of categories, some of which were condition specific, and some of which concerned wider issues online. For example, across both groups of participants, interviewees expressed concerns about the validity of information online, a concern that is typically shared by those in the medical profession (Middlemass et al., 2012; Nettleton, Burrows, & O'Malley, 2005). Illustrating the nuanced approach that forum users took to developing trust online, as discussed in Chapter Three, Stephen raised concerns about how to distinguish between reputable and not reputable information online, “*The difficulty is you don’t really know what a reputable medical resource is on the Internet. There’s so many out there, there’s so many sources of information*” (Stephen, ME/CFS, 56 – 60). Similarly, William explained that he did not use the Internet to look for advice from others with diabetes, preferring instead to rely on information from healthcare professionals, “*They’re far more reliable, because you’re dealing with professional people. I mean, why expect somebody who’s not a*
 professional to give you professional advice? And you can see that immediately you start reading one of these things [forums] on the Internet” (William, type 2 diabetes, 76 +).

Like William, others reported that they preferred to utilise other support networks rather than accessing online support. For Janet, the variation in people’s illness experiences meant that she did not gain anything from sharing experiences with others, “Everybody's different, and you can't just put everybody together and say, right, yeah, they've got that, they've got that, and they've got that, because the symptoms can be different but people are different and how they deal with it is different” (Janet, ME/CFS, 61 – 65). Likewise, Carol reported that she did not access online support, as she did not feel that she needed any of the support that it could provide, “I think possibly because I've had it for such a long time, I haven't really got any questions now, you know, it's sort of, it's OK to chat but I don't really have questions to ask now, I've been at it for so long” (Carol, ME/CFS, 66 – 70).

For others, the information contained online and on Internet forums was overly negative and pessimistic. This was particularly true for individuals with ME/CFS, many of whom felt that the outlook of many Internet sites did not provide them with the sense of optimism that they needed. This is in line with research by Lian and Nettleton (2014) who note that narratives presented on ME/CFS websites are overwhelmingly negative. For example, Rebecca spoke about how, when she needed to see light at the end of the tunnel shortly after her diagnosis, the Internet seemed to suggest that there was no light, “Also there are quite a lot of websites that are very negative; you want to see a way out of it, not thinking, oh, it’s awful, you’re never going to get there” (Rebecca, ME/CFS, 18 – 25).

This was echoed by Emily, who had been very active in ME/CFS communities online in the years following her diagnosis, but had consciously decided to step back from the Internet in order to focus on her health and the more positive things in her life, like a new relationship. For her, participating in online communities such as Tumblr prevented her from focusing on these aspects of her life and kept ME/CFS as a primary part of her identity.

I think that quite a lot of people online have ME as their primary identity, as much as they don’t want to, but they keep doing it, and they stay in the communities and they stay in that world. They don’t want it to be their primary identity, but then they do nothing to stop it being their primary identity, it sort of defines their lives and it’s easy to forget there’s other parts. (Emily, ME/CFS, 18 – 25)
This focus on ‘being ill’ and the subsequent link to negativity of ME/CFS websites, particularly forums, was also mentioned by a number of other interviewees. While Emily described negative effects associated with “wallowing”, Sharon felt that the negative interactions on ME/CFS forums were associated with frustration, something that she did not associate with other aspects of the Internet. This suggests that the focus of these forums is on activism rather support, and involves individuals attempting to mobilise themselves as a patient group in order to establish ME/CFS as a legitimate condition (Fair, 2010).

It seems to be a particular feature of sort of the ME chronic fatigue community, that there are a lot of people with very strong opinions and obviously hugely frustrated by their sort of illness and lack of treatment, but there’s a level of nastiness and vitriol that I’ve not encountered with anything else and which takes me aback a lot, so those sort of wider forums like that, I haven’t found supportive, I’ve found that to be a really negative thing, so mostly I avoid them. (Sharon, ME/CFS, 51 – 55)

On a similar note, James spoke about negativity and conflict that he had experienced on ME/CFS forums. Though he was a relatively active participant on forums, unlike Sharon, and found them useful in terms of accessing and analysing information that he could not access offline, he had also experienced a number of negative interactions. In particular, he highlighted his first introduction to a particular forum, where he posted questions on a topic that he was currently researching and was under discussion on the forum. In response, forum users aggressively questioned the legitimacy of his diagnosis of ME/CFS, “The first thing that I got back was responses that suggested I’d been living on Mars, really quite offensive and how can you possibly have this illness... And I would get challenged, how long have you had it? You’ve got to have your illness credentials sorted out before you venture in this part of the web” (James, ME/CFS, 51 – 55). This suggests that ‘being ill’ and a collective illness identity may be central to the existence of ME/CFS sites online (Barker, 2002). While this has been shown to be a central tenet of participation in certain communities (e.g., Koski, 2014), the results of the present study suggest that it is not something that is of interest or palatable to all individuals with ME/CFS. This also contrasts with the supportive nature of diabetes forums described in section 4.1.

This is not to suggest that discussion groups used by individuals with diabetes were without conflict, however. Many of the interviewees with diabetes spoke about how they had accessed and perused a number of forums before selecting one to participate and post on. For example, Simon explained how he had initially resisted participating in forums because
he perceived them as being populated by an unrealistic ideal of ‘perfect patients’, “I’d delved into forums before and as is often the way with some forums, they’re inhabited by people who have perfect, their perfect life and their tag line at the bottom is their HbA1c, their average glucose score” (Simon, type 1 diabetes, 36 – 40).

Similarly, Daniel described leaving a forum due to conflict between individuals with type 1 and type 2 diabetes. As with James’s description earlier, much of this conflict related to forum users’ illness identity, with individuals with type 2 diabetes seen as less ‘serious’ and therefore less ‘ill’ than those with type 1 diabetes.

And it seems to be that type 1 diabetics and type 2 diabetics don’t seem to be able to get on, so it’s absolutely pathetic. And I think it’s something to do with type 1 diabetics have a problem with type 2 diabetics because you haven’t got the same problems, yours isn’t as serious as ours, why are you on here sort of thing? And then the type 2 diabetics are giving it back because they want to be recognised that they have these problems too. And I’ve seen that a few times where a type 2 diabetic tries to give a bit of advice to a type 2 and then an experienced type 2... Where an experienced type 1 who’s well known within the forum sort of jumps in and goes, you’re type 2, what do you know about this, sort of thing? And all this sort of thing goes on and you’re really thinking, oh, for God’s sake! (Daniel, type 1 diabetes, 26 – 30)

This indicates that, on some forums, having a legitimate illness identity, whether that identity is one of a ‘perfect’ diabetic, as illustrated by Simon, or the more ‘credible’ type 1 diabetes, as illustrated by Daniel, is necessary in order to receive support online. As with previous studies, it was necessary for forum users to adhere to particular norms in order to be accepted into an online community (Galegher et al., 1998; Smithson et al., 2011; Vayreda & Antaki, 2009). This suggests that, while online discussion groups can provide a source of support and empowerment for individuals with LTCs, this support is not provided unconditionally.

4.7 Barriers to the Use of Health Discussion Groups

In addition to participants’ descriptions of their online support networks, both positive and negative aspects, a small portion of interviewees described difficulties that they experienced going online. This was particularly prevalent for those with ME/CFS, many of whom reported sensory difficulties going online and using the Internet. For example, Susan described the effect that being around Internet connections had on her, “It’s difficult
because with me and ME, I’m very, very electro-sensitive... I can only use the Internet for short periods of time, then I have to turn it off, turn my Wi-Fi off” (Susan, ME/CFS, age not given), while Joan described the technical adjustments that she had made to reduce the impact of computers and the Internet on herself, “I use a piece of software which it turns all Internet pages which are white, I can’t look at white pages, I can’t because it literally hurts me so they’re all a gentle dove grey colour” (Joan, ME/CFS, 56 – 60).

While these issues were not mentioned by all interviewees with ME/CFS, it is important not to underestimate the impact that this barrier may have had on the wider group of individuals with ME/CFS. In recruiting participants for interviews, a large number of attendees at support groups commented on their reluctance to go online due to this or similar issues. One woman, upon reading about the study in the newsletter of her local support group, contacted the researcher to say that while she would love to use the Internet and thought that it would be a fantastic resource for people with ME/CFS, she was unable to use computers due to the physical effect that they had on her, notably headaches and vision problems. It is therefore important to consider the potential impact and benefits of online support within the context of these limitations.

Others mentioned the effort that going online took. For example, Rebecca spoke about how her mother usually did research online for her, as she had difficulties going on the Internet. While she could access the Internet through a computer and her iPad, she found it too overwhelming and exhausting, “The Internet is a massive place, it’s knowing that you want to get the right information... it is difficult to sit on the computer, you know, it does drain you, you could be on five minutes and you just think, oh, I could do with a nap now” (Rebecca, ME/CFS, 18 – 25). Similarly, Susan, who blogged about her experiences with ME/CFS, reported the number of steps that creating and publishing a blog involved, notably having her boyfriend type it up from a dictation, “It’s taken me days to research it, I will then dictate it, and you know, what I want to say, and then my boyfriend when he gets the chance will type them up for me, and when I feel up to it, I can go in edit them, add pictures, so it’s done in just small little chunks” (Susan, ME/CFS, no age given).

For others, their difficulties going online related less to their conditions and more to do with individual factors. For example, Lisa spoke about how she did not have Internet access at home because she could not afford it. When she did go online, either at the library or at family and friends’ houses, she avoid looking up anything related to ME/CFS because she preferred to look at more positive things online, “Regarding my health, I’ve ignored the
main ME sites because I've kept the Internet, for some reason, I've kept it as a happy place to go’” (Lisa, ME/CFS, 41 – 45), suggesting again that the conflict on forums described in section 4.6 was off-putting to many individuals.

As interviewees represented a variety of levels of engagement with the Internet, from those who were active daily participants to those who did not use the Internet regularly, a small number of participants referred to their lack of technical expertise as a reason for them not engaging with the Internet more regularly. When asked about why he was not interested in sharing his own experiences online though he enjoyed reading other people’s account of their diabetes, Kenneth responded that he was not sure how to share his experiences and contribute to forums.

To be honest, I’m not all that good with the Internet to do that, to be honest. The only reason. I’d be happy to do it, so long as there’s somebody to tell me how to do it, but I only came to the Internet and computers in the last ten or fifteen years by my daughter. And I haven’t been in a situation where I could do that, so no. But I’d have no problem doing it, but so far I don’t think I’ve any experiences which might help other people, but I may be wrong there. It’s getting on to it that’s the, I mean, you mentioned threads, I’ve never heard of a thread before in my life, you know, I’ve heard of a forum and all this, but a thread. I didn’t know what a thread was. (Kenneth, type 2 diabetes, 71 – 75)

This further highlights the importance of considering the digital divide in relation the use of online support. As mentioned several times throughout Chapters Three and Four, interviewees often drew on their educational background, both explicitly and implicitly, in discussing how they used the Internet for health information and advice. As a result, there is a risk that Internet forums may predominately benefit those who are already catered for among the existing healthcare system (Viswanath & Kreuter, 2007). The implications of the findings of present study for health inequalities online will be discussed fully in Chapter Six.

4.8 Conclusion
This chapter examined the role that the Internet and online support played in the lives of individuals. Interacting with peers online allowed interviewees to empower themselves, drawing on a collective pool of knowledge and support to adjust and improve their health care and their interactions with healthcare professionals. In addition to accessing the experiential knowledge of their peers, the Internet also provided participants with the
ability to access current research and medical practice. Interviewees were able to draw on lay and expert perspectives in order to collaborate with professionals and situate themselves as active participants in the construction of medical knowledge. In this way, forums facilitated individuals to engage with and influence existing health care systems, rather than challenging or replacing these systems.

Despite the empowering effect of participating in Internet forums, as described throughout this chapter, it was clear that they did not offer a ‘one size fits all’ solution for individuals with LTCs. For certain forums and websites, particularly those addressing ME/CFS, the provision of online support appeared to be conditional upon the acceptance of a particular illness identity, one which involved individuals mobilising themselves as a patient group. In addition, despite the accessibility of the Internet as a medium, interviewees still reported barriers to their usage of online forums. These barriers related to both issues with access to the Internet and technology and problems with online health literacy.

The next chapter will explore participants’ perceptions of condition-specific forums as public or private spaces. Issues relating to confidentiality and anonymity online will be explored, and the role of moderators in shaping forum users’ expectations and perceptions of these issues will be addressed.
Chapter Five: Privacy and Anonymity Online

5.0 Overview
In Chapter Four, it was argued that forum members drew on the support that they received online in order to reposition themselves as empowered patients who took an active role in their own health care (Barker, 2008; Hardey, 1999). In this way, individuals described how they reconstructed and reoriented their illness identities from a passive recipient of expert care to members of a reciprocally supportive community. However, an additional issue evident in the data was the ways that forum members developed and maintained their own online identities and presented themselves online (B. Hogan, 2010).

In addition, as described in Chapter Two, the ethics of research into online communities is a debatable issue. Many researchers argue that open access discussion groups represent publically accessible data, and as a result, do not require informed consent for their use for research purposes (Coulson et al., 2007; Elwell et al., 2011; Rier, 2007; Seale et al., 2006). It has been suggested that there is a discrepancy between the perceived and actual privacy of online content (Markham & Buchanan, 2012), and forums that may seem public to researchers and ethics committees may not be viewed as public by their users (Burkell, Fortier, Yeung, Wong, & Simpson, 2014; Harriman & Patel, 2014). As a result, there is a need to explore the factors that influence forum users’ perceptions of public and private spaces online (Bond et al., 2013), and to examine how these perceptions influence individuals’ presentations of self online.

Within this chapter, interviewees’ constructions and expectations of privacy and anonymity online will be outlined. The value and importance that individuals place on online anonymity and the manner in which forum users constructed their online personas to incorporate this anonymity will be highlighted. In addition, individuals’ expectations of forums as public or private arenas will be explored and the factors influencing these perceptions will be outlined. Finally, the role of moderators on Internet forums, and the impact of this role on forum users’ expectations of anonymity and privacy will be considered.

5.1 Interacting Anonymously Online
In this chapter, participants’ perceptions of the Internet and Internet forums as public or private spaces will be explored. While this was directly addressed via the interview schedule, it was also explored through the use of a particular vignette which described
potential attitudes to and concerns about anonymity and privacy online. The use of vignettes is described in more detail in Chapter Two. In this vignette, which is adapted from original forum data, Rachel expresses concerns about the open nature of the forum on which she is posting. Members of the forum reply, with one sharing her fears and the other dismissing her concerns.

Rachel has ME/CFS and regularly posts in a forum used by other people with similar symptoms. She is concerned that the forum can be viewed by anyone, not just the people who contribute to it. She starts a thread on the forum to discuss this and to see if other people feel the same way.

Rachel:
“Some people are revealing some quite intimate info, and I myself often forget that the forum is open to outsiders to view.”

Here are some of the responses that Rachel receives.

Sarah:
“Not too bothered by this as I have never said anything that I would not be prepared to share with the whole world. I tend to think that the more people that know of the devastation that is caused by this illness, the better. I would like to think that some of the stuff is read by the medical profession - though I think not!!”

Jane:
“Hi, I’ve just seen this thread and am rather concerned and wondering whether not to post anymore, to be honest. That’s not just this forum but a lot of open forums too.

People need to realize that as we all get so very down, we may say things on here that we wouldn’t say to family and friends and maybe it’s rather personal.

I shall be having a think as to whether I shall post on here for a while now.”

What do you think about what people have said to Rachel?
What would you say to Rachel?
Do you have anything else to add?

Figure 1: Vignette 1
As described in Chapter One, being able to contact peers anonymously is an important aspect of individuals accessing and receiving support online, particularly for health-related queries (Finn, 1995; Sharf, 1997). Unsurprisingly, this was also the case with many of the participants in the present research. Despite this, a small number of interviewees were happy to share their experiences online without taking steps to disguise their identity. In general, participants felt that the level of anonymity that they experienced online was something that they were in control of, as they could choose how much information about themselves to reveal. There were concerns, however, that the nature of forum usage could lead to the lines between public and private becoming blurred, and that forum users may inadvertently share information that could lead to them becoming identifiable.

5.1.1 “My space to talk about things”: The value of anonymity online
For many participants, anonymity was a pivotal aspect of their Internet use. Accessing support online without having to reveal their identity was something that some individuals placed value on. As a result, a number of interviewees expressed concern at the notion that what they shared online could be linked to their offline lives. For Jennifer, posting something online was “a permanent record”, which could be accessed by people at any stage of her life. Consequently, she was apprehensive about the idea that the information and opinions that she shared on the Internet could be associated with her real name, especially if those opinions had changed over time, “If people know your name, they could find something you’ve written years ago and you might be in a completely different place and think different thoughts completely” (Jennifer, ME/CFS, 36 – 40).

Others expressed concern that what they posted online could give a misleading impression of their lives. Crucially, this was linked to participants’ perceptions of audience – who they felt could access their words. This will be explored in more detail in section 5.2.4. Though most interviewees felt comfortable sharing experiences within a forum setting, it was the potential for others outside the forum to access their words that caused concern. For this reason, many interviewees were reluctant to publically identify themselves online, “People sign with their name, you know, people post pictures of where they live etc., which is all very nice, but I personally wouldn’t do that, because you don’t know who’s looking” (Nicole, ME/CFS, 26 – 30). This was illustrated by Susan, who blogged about her experiences with ME/CFS. She was particularly concerned about protecting her identity online as she worried that her online activity would be seen as evidence that she was fit for work by the Department of Work and Pensions (DWP) and would have an impact on the benefits and allowances to which she was currently entitled.
It’s important to me, that bit of anonymity. I’ve not actually put my name on the blog, I just call it [name of blog]. And that’s because really of potential criticism from somebody like the DWP, because, you know, if they see I’ve written that blog and I’ve got that amount of information on it. They’ll turn around and say, well, crikey, you’re fit to work. (Susan, ME/CFS, no age given)

This highlights the nebulous notions of privacy and anonymity online. As Papacharissi and Gibson (2011) discuss, sharing information online may result in offline consequences, resulting in the boundaries between online and offline spaces becoming blurred. Within the present study, it was not just external agencies that participants were concerned about, however, as interviewees also expressed fears that their families and friends would be able to access what they said. This was particularly important for those who highly valued the support that they were able to access online. As Gemma described it, the diabetes forum she used was “my place and that’s my space to talk about things”. Though both her parents had been diagnosed with diabetes, she had not told them about her own diagnosis. In addition, she had been extremely reluctant to share that information with family and friends, “The only people that know that I’m diabetic is my husband and my best friend, I haven’t told my family and friends, even though my family are, even though my parents are diabetic, I haven’t told them” (Gemma, type 2 diabetes, 31 – 35). As a result, her diabetes was an intensely personal experience, shared with the forum and a select few acquaintances in real life. This meant that anonymity was a pivotal aspect of her condition, “It would really, really bother me if people found that information, if by googling my name, it came up with all this information, I would be devastated really”, and she was unwilling to disclose information about her diabetes to her real-life acquaintances, “I know that if someone I knew was on that forum, like, a friend, or family were on that forum, I would stop using it” (Gemma, type 2 diabetes, 31 – 35).

To a lesser extent, this was echoed by Nicole. Though she had recommended ME/CFS forums to her friends and family in order to enable them to seek support for themselves or to learn more about her condition, she was not comfortable with being identifiable through her posts. In order to counter this, she took steps to make sure that she would not be identified by any family and friends who may access the forums that she suggested. Both Gemma and Nicole were conscious of the need to adapt and modify what they shared online in order to maintain their anonymity.
Yeah, anonymity is the key thing when I’m posting on the Internet. I made the mistake of using the same username as my email address, and I suddenly realised, well, hang on a minute, I’ve just said to my family and friends, if they want support or if they want to read up on it, here’s some forums that I use, and they’re going to know it’s me. So then I changed it to something that they didn’t know. (Nicole, ME/CFS, 26 – 30)

This suggests that, for some individuals, the forums provided them with a ‘safe space’ in which they could access support away from their real-life support networks (Sanders et al., 2011; Sharf, 1997). For these interviewees, however, the safety of the space was tempered by the awareness that their words may be disseminated amongst a wider audience than they intended. Indeed, this awareness was cited by a number of interviewees as an explanation for their lack of engagement with the Internet. For example, in response to the vignette, Stephen suggested that Rachel cease using forums due to concerns about privacy and anonymity, “If you’re finding it difficult not to give personal and intimate information it’s probably better not to use such a forum in the future... I personally wouldn’t be particularly happy in giving that kind of information out” (Stephen, ME/CFS, 56 – 60).

Others suggested that forums, and particularly health-related forums, were unlikely to be accessed by people who were not patients or did not have a particular interest in the condition. Emma felt that people without diabetes would find a diabetes forum “completely boring”. In contrast with Susan, who worried that her blog may be read by the Department of Work and Pensions, she was not concerned about forums being open access, as she thought that they were only likely to be accessed by those who had the condition, “Who is going to want to go onto that site and read through a whole list of people probing diabetic questions, it’s just boring to anybody else. I think if you haven’t got it, well, it is completely boring” (Emma, type 1 diabetes, 41 – 45). This was echoed by Michelle, who felt that the only people who were accessing a forum were likely to be those who had a vested interest in the topic that it addressed and were therefore unlikely to cause any harm with the information that they saw, “I also feel that people going on this website, spending time reading other people’s things, well, they probably know what it is and wouldn’t be thinking of doing any harm with the information they got there” (Michelle, ME/CFS, 41 – 45).

For others, having an identifiable online presence was something that they had consciously chosen, rather than attempting to remain anonymous online. This was the case for Louise, who regularly blogged about her experiences with type 1 diabetes. She described how she had decided to blog as herself rather than an anonymous individual as she had already been
active in the diabetes community for a number of years, and as a result, had a “good network” of peers. By naming herself on her blog, she felt that she was able to “talk freely” about herself, and describe her own situation and experiences, rather than hiding behind an “anonymous persona”. However, she acknowledged the impact that this lack of anonymity had had on her online communications. She described how having her words linked to her offline identity made her consider how they were likely to be viewed by an audience, such as her employer. She attempted to ensure that she was proud of what she posted online and that she would be able to stand by it in any number of situations, “I always vet things with the idea of, OK, would I be happy to discuss this in an interview. If you pulled out one of my posts and said you published this, I would still be proud to talk to you about why I did that” (Louise, type 1 diabetes, 31 – 35).

Despite Louise’s willingness to identify herself online, as her reference to her employer illustrates, there was still a sense that she was managing her performance and persona online. As research on social media suggests (Bullingham & Vasconcelos, 2013; B. Hogan, 2010; Papacharissi & Gibson, 2011), individuals will adapt the information that they share online in order to cater for the ‘lowest common denominator’; that is, cater for the broadest audience possible. For example, Susan’s concept of the lowest common denominator encapsulated government agencies such as the Department of Work and Pensions, and she constructed her presentation of self online in light of this. As a result, Louise and many other interviewees took care to ensure that only certain aspects of themselves were represented online (Bullingham & Vasconcelos, 2013). For some participants, being anonymous represented a key aspect of these online personas. The process through which interviewees maintained their anonymity online is described below.

5.1.2 Constructing an anonymous identity online
Throughout the interviews, there was a sense that anonymity online was something that participants themselves were in control of, regardless of the value or importance that they placed on it. Individuals could take care not to reveal anything that could link their online postings to their offline identity, thereby creating an online persona that provided them with the anonymity that they desired. In particular, interviewees spoke about the tactics that they personally used to protect their identity online, such as self-censorship (Papacharissi & Gibson, 2011). For example, many interviewees did not use their real name online and did not reveal personal details, such as their home location or employer, “I was quite careful at that point that generally speaking there was no specific way of identifying me as an individual. I think it probably mentions on there somewhere where in the country we live,
but not specifically” (Mark, type 1 diabetes, 41 – 45). As a result, participants were actively involved in managing and maintaining their anonymity online.

In addition, many reported that a desire to remain anonymous online did not preclude individuals with LTCs from seeking support on forums. Though personal and illness related details were important in assessing and evaluating health information online, as described in Chapter Three, participants felt that it was possible to strike a balance between revealing adequate levels of information and protecting one’s own identity. As Michelle described, it was usually possible to seek advice on specific health-related issues without giving out a large number of personal details, “People might think it’s you, but they can’t be sure and usually you can address all the problem you have without really putting too much things that can identify you” (Michelle, ME/CFS, 41 – 45).

Interviewees also recognised that the nature of Internet forums meant that they typically had time to reflect on their forum contributions before submitting them to the site and could retrospectively remove information from their posts that they considered to be too personal or revealing. This was particularly important for Nicole, who described how she valued one ME/CFS forum over another due to the ability of posters to edit their messages after they had submitted them to the website. This meant that forum users had the ability to ‘take back’ all or part of their posts in order to protect their identity, “I think that’s a good option, or you can change, you can put, edit it to remove critical information, or something, so you can mess around with it, so you can kind of take that away” (Nicole, ME/CFS, 26 – 30). While it was not a feature that she used frequently, she appreciated the safety net that it provided.

Though many interviewees reported that the extent of information shared and subsequent level of anonymity was under the control of the forum members, some expressed concerns that the nature of forum usage could lead to the lines between public and private becoming blurred. In particular, Mark felt that the supportive nature of forums could lead to posters forgetting that they were publically accessible, as they viewed other forum members as “a group of friends that they go and meet with”, thereby forgetting the potential transmission that their words could have, “People in desperation reach out and other people who’ve been in this cosy environment, this kind of warm room full of friends sharing things openly, forgetting that complete strangers can then just look and read” (Mark, type 1 diabetes, 41 – 45).
Similarly, Nicole expressed concerns that cognitive impairments associated with ME/CFS meant that participants were also likely to forget about the open nature of forums. She felt that forum users should be regularly reminded about this fact, and that certain approaches should be mandatory, such as the use of a pseudonym for a forum username, “I think that you should have to have a silly name to use it, because I think that again, people with ME, because of the tiredness etc, I do things now that I wouldn’t dream of doing, just by mistake, I wouldn’t dream of doing when I was well” (Nicole, ME/CFS, 26 – 30).

Overall, participants’ perceptions of anonymity online suggested a degree of impression management, whereby individuals filter and perform their idealised identities online (Goffman, 1959; B. Hogan, 2010). As illustrated, in many cases, this identity was an anonymous one, separate from participants’ offline identities. Even participants who had chosen not to interact anonymously online, such as Louise, were still conscious of the need to present themselves in a particular manner and carefully considered the information that they divulged online. The strategies that forum members utilised in order to maintain these levels of privacy online will be further discussed below in section 5.2. However, there were also suggestions that Internet users’ autonomy and control over what they shared online could be influenced by illness related factors, resulting in individuals inadvertently sharing potentially identifying information.

5.2 Maintaining Privacy Online
Participants also shared their perceptions and experiences around privacy online. It should be noted that privacy refers to a level of control over information, as distinct from anonymity, which relates to non-identifiability (Cirucci, 2015). Within the present study, these perceptions related to Internet forums as public or private spaces, and the influences that these perceptions had on how forum users shared experiences and interacted online. The majority of interviewees perceived forums as public spaces, where their words could be accessed by anyone with Internet access. As a result, many participants spoke about how they moderated their use of forums in light of this, by avoiding disclosing certain information online and considering different mediums of communication, such as live chat, in order to share personal information. In addition, viewing forums as public spaces meant that individuals were also likely to share particular information that they wanted to have transmitted to the outside world.
5.2.1 Participants’ expectations of privacy online

Among the majority of interviewees, the expectation was that what they shared online was not private, and it could be accessed by others. For some participants, the apparent lack of privacy online was not a concern. As Joan put it, “I am an incredibly open person” (Joan, ME/CFS 56 – 60). Some interviewees reported that they considered themselves to be as likely to share information online as they would in face-to-face conversation, “I don’t have a huge number of secrets... I’m not concerned about people knowing stuff because actually if they were standing next to me in a pub I’d probably spout it all anyway” (Julie, type 2 diabetes, 46 – 50).

In general, many participants felt that issues around privacy and anonymity online were just part and parcel of using online forums, and that individuals should not be overly concerned about them, “But really I think it’s there to, if you’re talking to people that have got in the same situation as you I don’t see why it should be an issue to be worried about what you’re putting down” (Rebecca, ME/CFS, 18 – 25). They suggested that forum users should inform themselves about the nature of the Internet and Internet forums, “No, I mean, I think it’s up to individuals to educate themselves about what the Internet’s about really” (Claire, type 1 diabetes, 41 – 45), and decide the level and content of information that they were willing to share, “It’s a case of you’ve really got to accept that if you’re putting it on an open forum you don’t give out anything that you don’t want shouted from the rooftops, as it were” (Ian, type 2 diabetes, 46 – 50).

As discussed in Chapters Three and Four, it is important to acknowledge the educational background of the participants in the present study, and to consider how this may have influenced individuals’ perceptions of privacy online. Just as many interviewees viewed themselves as being sufficiently educated and computer literate to navigate the web as a source of health information, a large number also felt that they were capable of negotiating privacy concerns online. Indeed, Papacharissi and Gibson (2011) describe privacy online as a form of “luxury commodity” (p. 85), arguing that the level of computer literacy required in order to acquire it is inaccessible to many. For example, Karen had a degree in IT, and she felt that this background gave her an advantage when it came to deciding what information to share and what not to share online. Like many other interviewees, she viewed the Internet and Internet forums as public spaces, and this influenced how she interacted with others online, “It’s permanent, it don’t matter what you do with it, it’s up there. So I wouldn’t put anything up there that I wouldn’t want a stranger [to read], do you know what I mean?” She drew a distinction between her experiences and those of her
husband, who did not have the same educational background and as a result, struggled to utilise the Internet in the same way.

_I’m lucky in the sense that I’ve actually studied the Internet and I’ve studied computing, so I have a bit more information than maybe say, like, my husband doesn’t have that much information or nous about the Internet, so he’d be likely to worry about things like that more than me and he’d ask me and I’d say, well, you’re alright to do that but not that._ (Karen, ME/CFS, 41 – 45)

Like Karen, many participants expressed concerns that while they were aware of the public nature of Internet forums, others may not be as savvy as them, and as a result, may experience difficulties navigating concerns around privacy and anonymity online. For example, Michael described how he had encountered a number of people who had shared information online that he felt was inappropriate, “I’m all for frankness and openness but some of the things that I had read I was surprised that people would have put that information in that domain when you think of who could actually see that and that just concerned me a bit” (Michael, ME/CFS, 66 – 70).

This was echoed by Laura, who felt that while she was aware of the public nature of the Internet, others may be more “naive”, and may reveal inappropriate or potentially identifying information, “I guess if I was a bit naive and wasn’t so security conscious I’d probably be blurring out stuff and not realise, oh god, everyone can see this, but it’s quite lucky that I’m very much the other way”. Similarly to Karen, she drew on her own educational and professional background as a healthcare professional to explain how this influenced how she interacted with others online. She carefully managed her online persona in order to maintain her anonymity as well as to present herself in a positive manner, “That’s due to the nature of the work I do. I have to be very careful about my details anyway, so it comes as second nature to me not to disclose anything that could potentially identify me or put me in a bad light” (Laura, type 1 diabetes, 31 – 35).

In particular, participants were concerned that people could inadvertently share information that was inappropriate due to being caught up in the emotion of their circumstances, “It’s very easy once you’re in the heat of the moment and responding to something that you think you could help on, it’s easy to forget that this is a public forum that can be seen by anybody” (Laura, type 1 diabetes, 31 – 35). This was considered to be particularly relevant for those with ME/CFS, some of whom were seen as having limited access to support
networks, “I think sometimes you can say too much on these things... Possibly because they've got no other way of sharing it with people, and this is the only support they've got” (Janet, ME/CFS, 61 – 65), or who may feel particularly emotional about what they were discussing, “I think it’s difficult, particularly if you’re talking to people who you don’t know, who are sort of upset, and I can see from some posts I’ve read that some people don’t have any other place to sort of say stuff” (Sharon, ME/CFS, 51 – 55).

Some participants highlighted how, for those for whom this lack of privacy was an issue, it was possible to access support online without sharing their own experiences. It was suggested that this provided a way for individuals in need of advice and information to access support without having to concern themselves with the need to construct an identity online (Parker, 2014). Daniel described how he had initially accessed support by lurking, or reading forums without participating. Rather than posting his own queries, he instead read through the active threads on the forum to find answers to his questions about diabetes, “You don’t have to log on to post, you can still read through the threads because quite often, and I guess that’s how I started, I didn’t want to post in them I just wanted to feed off the information that people had already spoken about” (Daniel, type 1 diabetes, 26 – 30). Lurking on forums was seen as a way for individuals with LTCs to access support without having to disclose information about themselves, thereby negating certain concerns about privacy, “Even if people don’t feel comfortable with signing up themselves, they can still read about it and they can still help themselves by reading” (Gemma, type 2 diabetes, 31 – 35).

As discussed previously, many interviewees moderated the information that they shared online in order to cater for the lowest common denominator (B. Hogan, 2010). As a result, participants described how they decided not to share information that they considered to be too personal for public consumption. For example, many interviewees spoke about how, while they were happy to share their own experiences online, they avoided sharing information about the people around them. Participants were conscious that while they could control the level of information that they provided about themselves online, others may not be happy to have information shared about them. For example, interviewees were reticent to reveal personal information about their children or other family members, “When I mentioned about my son going through a difficult time... I don’t mean, I don’t mention him, what I mean is, I don’t mention the difficulties he went through and what it was to do with or anything” (Joan, ME/CFS, 56 – 60).
This sentiment was echoed by Louise. While she frequently blogged about her experiences with diabetes, she made a decision not to disclose her experiences with fertility treatments. Though she was conscious that sharing information and experiences regarding in vitro fertilisation (IVF) and diabetes could be of value to others, she felt that the information was “too personal, too vulnerable” to share, despite the potential benefits. Interestingly, she later wrote about her experiencing with IVF after she became pregnant, indicating that her desire for privacy was shaped by the need to control the context in which the information was shared rather than the information itself (Marwick & boyd, 2014; Nissenbaum, 2004, 2011; Papacharissi & Gibson, 2011).

*It took us six years to conceive. We had quite a few cycles of IVF and things. But I chose not to blog about any of that. So the first time I mentioned that on the blog was when I announced the pregnancy, and that was quite a tough decision because in a way I wanted to share what we were going through because no one writes anything about IVF and diabetes, that's such a niche problem. It's very hard to find good information about it. But I just didn't feel I could expose that kind of thing to the Internet. That was too personal, too vulnerable, especially when we were in the middle of it. Now, I have written some stuff about it looking back, so it's interesting. I don't censor much of what I put online, but there are bits that I do.* (Louise, type 1 diabetes, 31 – 35)

5.2.2 Spreading the word: The value of sharing information online
Despite participants’ perceptions of forums as public spaces, or perhaps because of these perceptions, many interviewees reported that they saw a value in sharing their experiences within a public arena. Though participants acknowledged that their words could be accessed by those outside of the intended audience, this was seen as a pivotal aspect of sharing experiences online. This was particularly prevalent among those with ME/CFS, many of whom felt that the Internet and Internet forums enabled individuals to describe the daily realities of living with ME/CFS. Joan described how, rather than censoring herself and avoiding certain topics, she made a conscious effort to describe her experiences in detail in order to educate those who do not understand about the condition, “I’ve never felt the need to, in fact probably the contrary, I would be trying to be as articulate as I could to get it across to people what it’s really like” (Joan, ME/CFS 56 – 60).

This was echoed by Michelle, who reported that she shared experiences online in order to address those who may have family or friends with ME/CFS. By sharing her own experiences online, she attempted to legitimise the experiences of others by validating their
feelings and symptoms, “If you have the partners, or the family watching this kind of website to understand better, if they can see that something their daughters, or whoever, told them about and they can see it said by someone else, maybe they will understand better” (Michelle, ME/CFS, 41 – 45). This echoes some of the discussions from Chapter Four, which suggested that ME/CFS forums facilitate individuals legitimising their illness experiences and arguing for its biomedical origins (Barker, 2008; Fair, 2010).

For other participants, the notion that sharing information and experiences online could be of value to healthcare professionals was highlighted. In response to the vignette, Nicole suggested that medical professionals accessing Internet forums could increase their understanding around ME/CFS, which could translate into improved healthcare for patients, “Sometimes I would like some people from the medical profession to read it and to understand, because the understanding around chronic fatigue is terrible” (Nicole, ME/CFS, 26 – 30). This was of particular importance to Mark, who felt that medical professionals accessing Internet forums for individuals with diabetes would not only lead to increased understanding around diabetes, but would also illustrate to professionals the potential benefits to individuals accessing online support, “I think there needs to be a bit of a sea change in some minds of healthcare professionals, that it’s not actually all bad but that it is a positive experience and it can really help” (Mark, type 1 diabetes, 41 – 45). He hoped that this would lead to them recognising the value of peer support that was available online, and in turn result in doctors vetting and recommending particular forums to individuals. Indeed, this echoes recent trends among clinicians, with suggestions that the ‘cloud of patient experience’ online may provide valuable insights into care unfiltered by healthcare professionals, researchers, or academics (Greaves et al., 2013; Shepherd et al., 2015).

This is what I’m really hoping comes out of your research, that it actually motivates people [healthcare professionals] to go and read the experiences of people in a way that they will not say them to their doctors. And, also read people railing against their specialist for the way they treat people, because if somebody reads that and thinks, oh blimey I do that, then maybe it could cause some behavioural change. Or maybe they would, and this is too much to hope for, they might say to some patients, do you know what you might find really helpful, there are some Internet forums, here’s one I think is really well moderated, you might enjoy reading experiences of other people. I think that it’s such a powerful tool, peer to peer support, I really can’t underestimate how much I
advocate it for people with isolating conditions feeling that they’re struggling, feeling that nobody understands, that nobody gets it. (Mark, type 1 diabetes, 41 – 45)

In addition to individuals filtering what information they shared online in order to manage their online persona (Bullingham & Vasconcelos, 2013; Parker, 2014), interviewees also described how they drew distinctions between where to share their experiences, advice, and information with peers and where not to share this information. As mentioned, the ‘permanent’ nature of Internet forums was discussed by many participants, with some reporting that this made them less likely to discuss particular topics in this arena. This led to forum members utilising other methods of communication, such as live chat, instant messaging, emails, or private messages. This allowed them to discuss topics that were particularly sensitive, “There’s someone I connect with on Twitter who recently lost her mother in fairly tragic circumstances, so rather than replying publically I just direct messaged” (Simon, type 1 diabetes, 36 – 40), or to share identifying information, “Obviously, you don’t give your proper name and address and things like that out, your phone number out, so you go to the private messaging system” (Margaret, type 2 diabetes, 66 – 70). As discussed previously, this illustrates the importance of contextualising information sharing online. Rather than making a blanket distinction about what to share and not share online, participants instead considered the context in which information was shared and who was likely to access this information (Marwick & boyd, 2014; Nissenbaum, 2010, 2011; Papacharissi & Gibson, 2011).

For participants, this often meant seeking out spaces online which were not fully open and publically accessible in order to share information that they considered to be very personal. For example, Lesley described how she used the live chat on the diabetes forum that she was a member of, which enabled her to exchange instant messages with other forum members. Crucially, using live chat meant that the conversation was not stored afterwards and was not publically accessible, even by those who were registered forum members, “If you go on live chat, it's there, and then when you go off, it's gone, if you know what I mean, it's not stored anywhere for anyone else to come and read” (Lesley, type 2 diabetes, 56 – 60). She used this option to talk regularly to other forum members who she considered to be friends, sharing information about their day-to-day experiences with diabetes, “You know, oh, my blood sugar's up today, oh, I've had such a thing for my tea and I shouldn’t have done, and you know, things like that, what we've eaten, the nitty-gritty bits, that's what we tend to do”, as well as more personal information that may not be appropriate for discussion on the forum, “And then we talk personally, you know, how's it going at home,
are you OK, you know, have you been to work today, things like that that you wouldn't put on the forum because that's very personal”.

Despite valuing the privacy that this medium afforded her, she still used the forum to discuss “major problems” with her diabetes over the live chat. As discussed previously, she recognised the impact that sharing experiences openly had on other people, and wanted to be able to offer that support to others, “The point of the forum I think is to help other people who might be like I was doing and just reading, and don’t want to join, and they want to gain something from your experience” (Lesley, type 2 diabetes, 56 – 60).

5.2.3 Audience

Finally, in reviewing participants’ perceptions of privacy on Internet forums, the notion of audience must be considered. Nissenbaum (2004, 2011) suggests that the context in which information is shared influences users’ expectations around privacy. In particular, the people with whom information has been shared have been considered appropriate recipients for the specific information. Given that the majority of interviewees viewed forums as public rather than private spaces, it is necessary to examine who they felt they were sharing information with online.

In line with the expectation that forums were public spaces, for many individuals, their concept of audience extended outside the members who were actively participating in the forum. For example, many interviewees spoke about sharing information online in light of the possibility that their words could be accessed by family and friends. Illustrating the concept of the lowest common denominator (B. Hogan, 2010), Michelle described how she considered the perspectives of her husband and parents in her interactions online. Though she did not think it was likely that they would access an Internet forum, the awareness that they had the ability to read what she wrote meant that she ensured that she could ‘justify’ what she said to them, “I don’t think my husband is reading it, but maybe he is... I think, yeah, he wasn’t supportive, or anything. I would put it in writing if it were true and if he knows about it, because I’ve talked about it with him” (Michelle, ME/CFS, 41 – 45). Similarly, June described a situation when, as a moderator, she reminded a poster who was sharing information about her husband that the forum was publically accessible, and could be accessed by anyone, including the poster’s husband, “Somebody was revealing quite intimate things about their sex life with their husband... [I] said, look, it’s up to you what you want to reveal, but do remember it’s a public forum and anybody including your husband can look” (June, type 1 diabetes, 66 – 70).
For other participants, their concept of audience extended outside their family and friends to include outside parties. This was particularly illustrated by James, who was engaged in an email correspondence with a major figure in ME/CFS research. Through this correspondence, he had become aware that the researcher received email alerts when his name was mentioned online, “I'm also very aware that, well, again, because I've been speaking to [researcher] off record and what not, [researcher] gets alerts whenever [researcher’s] name appears. So I'm very careful that if I refer to him, I actually just put [researcher’s initials]” (James, ME/CFS, 51 – 55). Though James himself was not concerned with the researcher accessing his posts, he wanted to avoid him reading the negative comments that other forum members were making, “It's not because I'm saying anything that I wouldn't want him to read, it's because I know other posters are saying things that are defamatory and unsupportable” (James, ME/CFS, 51 – 55).

In addition to the attention of the researcher, James was aware that the ME/CFS forum that he participated in was a particular venue for public interest. Specifically, he was aware that the forum was occasionally visited by journalists and subsequently referenced in print and online media. He felt that this was done with a view to antagonising the forum members and creating further debate and controversy in order to sell newspapers, “It's basically like they just get a jaggy stick and poke it at people with ME/CFS to see what comes out. And then say oh look, look, I told you they were all mad, look what they're saying about me now” (James, ME/CFS, 51 – 55). While he disagreed with this practice, describing it as “quite deliberate goading”, he used this knowledge to encourage others on the forum to view their posts as “an act of advocacy”. The awareness of the potential dissemination of the forum meant that he saw activity on the forum as an opportunity for members to have their views and opinions relayed outside of the forum, rather than posting in a reactionary manner and adding to the controversy, “Oh, for god's sake, stop with the whinging, or they'll come back and say, if you don't have evidence for that, don't post it, it just makes us all look like we're rabid idiots” (James, ME/CFS, 51 – 55). For James, his presentation of self online meant that he not just adjusted what he said online in order to cater for a broad and diverse audience, but also used his online persona to specifically target this wider audience.

Equally, he viewed the site as an opportunity to challenge some of the misperceptions around ME/CFS. In response to the vignette, he suggested that forum users should provide “real and substantive” accounts of their experiences with the condition, something that he had done in order to reaffirm the existence and reality of his condition, “There was a
doctor posting or at least a guy claiming to be a medical professional, and I challenged him directly by using my experience and saying well, I had this particular experience and there's no way that can stack up against” (James, ME/CFS, 51 – 55). This allowed him to take on the role of an activist, arguing for the legitimacy and recognition of his condition (Barker, 2008; Fair, 2010).

However, it should be noted that this awareness of external audiences was not present throughout the entire sample. Some interviewees held a different perception of forums, viewing them as a more private and personal space. For example, Jennifer drew a comparison between spaces online where “anyone could read it and anyone could respond”, such as comments on the BBC website, and ME/CFS forums. By contrast, forums were seen as less of an unknown quantity, with the expectation that there was a mutual understanding and respect amongst members, “If it was an ME forum, then, yeah, I think it’s nice to know that you can walk into a space that you’ve chosen to and that you know what you’re walking into” (Jennifer, ME/CFS, 36 – 40). This was echoed by Emma, who similarly made a distinction between the diabetes forum that she was active on and the social networking site of Facebook. While she felt that Facebook was accessible by everyone, “Because everyone can get onto Facebook that’s got, you know, access obviously to your account, that’s a different thing because it’s not just people interested in a particular thing, anyone can hit upon your site” (Emma, type 1 diabetes, 41 – 45), she viewed the forum as being much more exclusive. As a result, she was less concerned about revealing personal information on the forum, as she thought it was unlikely to be accessed by anyone without a vested interest in the condition, “So even if you said something very personal, I wouldn’t feel, I would say to her, this is the point of this site, you can be intimate because it is particularly for us” (Emma, type 1 diabetes, 41 – 45).

Though this point requires further discussion, located in Chapter Six, it does suggest support for Nissenbaum’s notion of contextual integrity (2004, 2011). While the majority of interviewees viewed open forums as public spaces, there were exceptions to this. Rather than a strict delineation between public and private spaces online, the context in which the information was shared – in this case, a health-related Internet forum – influenced users’ expectations of by whom their words could be accessed. As mentioned in sections 5.1.2 and 5.2.1, participants raised concerns that the supportive nature of online discussion groups and cognitive impairments associated with ME/CFS could encourage forum users to share information that may be inappropriate or potentially identifying. As a result, it is possible
that the online context in which individuals perceive they are interacting may not accurately reflect the reality of the situation.

5.3 Moderators: The Architects of Perceptions of Privacy and Anonymity Online?
In discussing anonymity and privacy on Internet forums, it is necessary to acknowledge the role of moderators. Typically, moderators are volunteer members who take on an administrative role within a forum. Their duties can include approving the registration of new members, editing and deleting inappropriate posts such as spam or personal attacks on forum members, and steering conversation by directing members away from a particular topic (Coulson & Shaw, 2013; van Uden-Kraan, Drossaert, Taal, Seydel, & van de Laar, 2010). In the case of online research, moderators often act in a ‘gatekeeper’ capacity, i.e., they decide whether or not to allow the recruitment of participants via a particular forum. This was the case in the present study, with four websites (two aimed at individuals with ME/CFS and two aimed at individuals with diabetes) giving permission for materials from the study to be posted on their forum.

As described in Chapter Two, moderators often made an upfront decision in relation to research activity on Internet forums. For example, one of the ME/CFS forums which had been initially considered as a potential route for recruitment was excluded on the basis that the forum was expressly a place for support and that any research activity was banned. It could be considered that the unwillingness of a forum to engage in research activity had an impact on the view of the forum as a private rather than public space. Equally, the willingness of the aforementioned four websites to act as recruitment venues for the present research may suggest that there was a certain perception of open and unrestricted access amongst forum members. As a result, it is necessary to consider the role that peer moderators play in Internet forums, and how this role can influence forum members’ expectations around privacy and anonymity online.

5.3.1 The role of moderators
Of the 41 participants interviewed, four were engaged in some form of moderation. Michelle was a moderator on a foreign language forum and spoke tangentially about her role. The three remaining interviewees, June, Anne, and Mark, were all moderators on one particular forum for individuals with diabetes. All three had type 1 diabetes, were White British and were married with children; Anne and Mark had been diagnosed in their 20s while June had received a diagnosis in her 50s. Mark was educated to degree level, worked in IT, and was involved in both the moderation team and technical aspects of the forum.
June had run a business online since the 1990s, while Anne had used computers as part of her job, but did not have a particular background in the Internet or computers. All three spoke in depth about their experiences moderating the forum, often referencing similar occurrences. As a result, the account of the role of moderators online will be predominately drawn from these three accounts, though comments from other interviewees will be integrated where appropriate.

In the case of the diabetes forum, moderators were selected through a process of ‘peer review’. June, who was involved in the initial inception of the forum, described how the ebb and flow of members’ lives and changes in the levels of activity on the forum meant that there were times when additional or replacement moderators were required. These needs were addressed by a discussion with existing moderators, “You say, oh well, I think we ought to appoint somebody else, has anybody got ideas who might be a good person to appoint? And then you do whatever, you know, you can appoint, you can all agree on it” (June, type 1 diabetes, 66 – 70). Potential moderators were appointed on the basis of their history on the forum and their relationship with other members rather than their medical knowledge, “It’s not so much about how much they know about diabetes, it’s about, have they got a sense of humour, are they good with the other members, are they fairly committed to the forum, you know, have they been around a little while” (June, type 1 diabetes, 66 – 70).

In addition to the duties outlined in the previous section, moderators were often involved in enforcing forum ‘norms’ (Armstrong et al., 2012; Kennedy et al., 2009; Mudry & Strong, 2013). Though these varied between forums, they were typically related to general etiquette (Honeycutt, 2006). For example, moderators ensured that forums remained polite and friendly, by remonstrating posters who insulted or spoke unkindly to other forum members “[Name of forum], for example, they’ve got volunteer moderators, and they will pop up on practically every thread, they’ve got very strict rules... you’re not allowed to bully people, personally attack people, etc.” (Nicole, ME/CFS, 26 – 30). In particular, moderators were involved in welcoming new forum members and encouraging them to stay engaged and involved with the forum, “The moderators are all people that everybody tends to know, because they’re always the first people that come in and welcome you when you’re new onto the site and they’re usually around all day so people will take notice of them” (Margaret, type 2 diabetes, 66 – 70).
As Mark described it, moderators oversaw the content of the forum and ensured that no-one was upset by another poster’s comments. This was particularly important due to the written nature of forums, as the lack of physical cues meant that forum users could “get the wrong end of the stick”. Their role often involved editing or deleting members’ posts if they contained inappropriate information. This could relate to information about the poster themselves, “Suppose you blurt out your home phone number, a lot of the fora if you do that, the first thing they’ll do is blank it and say forum policies, we don’t give that out” (Ian, type 2 diabetes, 46 – 50), or information about others outside the forum, “As a moderator sometimes you go in and you edit out the name of a specific healthcare professional that they’ve mentioned, or their contact details, their phone number, their email address” (Mark, type 1 diabetes, 41 – 45). As a result, moderators typically set the standard in relation to what information was and was not acceptable or appropriate to share online (Stommel & Koole, 2010). Posters who did not comply with these guidelines had their communications altered, and were occasionally banned from contributing to the forum as a result of this activity.

The role of moderators in relation to privacy and anonymity extended beyond an involvement in forum posts, however. Illustrating this, June described a situation where a new member joined the forum on which June was a moderator. The forum member had recently been diagnosed with diabetes, and due to immediate complications associated with her diagnosis, had taken a number of days off work. Rather than using an obscure pseudonym, the poster’s username on the forum was similar to her actual name and consequently, she was relatively identifiable. On her return to work, the poster mentioned the forum and said that it had been helpful in supporting her in the aftermath of her diagnosis of diabetes, “She had said something that she’d had some help from an Internet forum and she was really grateful for it and it had changed how she was thinking about things and she felt that it had made a difference to her” (June, type 1 diabetes, 66 – 70).

Following this, the colleague to whom she had mentioned the forum searched for the forum user’s posts online, and as a result of her username, was able to identify her. She began to comment on her online activities in their shared workplace, “This person who worked with her went looking on all the Internet forums about diabetes, found this person who, as I say, was quite easily identifiable and then started making comments to her at work about things that she had actually said on the forum” (June, type 1 diabetes, 66 – 70).
The forum member approached June to inform her of what was happening and to tell her that she would not be participating in the forum anymore, “She said, look, this woman is spying on me in the forum and everything I say, she’s going back to work and talking about and I’m really upset so I’m not gonna be in the forum anymore”. Despite the fact that this activity was occurring outside the forum, the moderators felt that it required their action, as the poster was consequently unable to access a resource through which she was gaining support, “We all felt much the same that it was a great shame that this woman was being deprived of a resource which was helping her by this other woman who basically was bullying her and was actually being incredibly mean”. June suggested to the forum user that she abandon her current account and re-register on the forum after a short period of time with a different username in order to anonymously access the forum, “I said to her, so what I think you need to do, leave it about a week and join under a completely different name that they can’t identify you by. Which is what happened and she’s still a member”. Meanwhile, June publically commented on the activity, in order to address the woman’s colleague, and to further the impression that the poster had left the forum and would be no longer posting.

*And I put something in public, I think she had made a slight comment about this person in public, so I made a comment in public about how I felt it was a great shame that people had to behave in such a manner and that this woman was depriving her of the help she so badly needed because she has now left the forum and she wasn’t going to get any help, you know, so on and so forth. (June, type 1 diabetes, 66 – 70)*

This example further highlights the role that moderators play in creating and enforcing norms on forums. Individuals’ expectations around privacy and anonymity online are often shaped and influenced by moderators as moderators themselves set and enforce the guidelines around acceptable levels of privacy and anonymity (Mudry & Strong, 2013; Stommel & Koole, 2010). As illustrated above, moderators can take action in order to protect individuals’ ability to access online support anonymously. In addition, moderators frequently edited and adapted posts from other forum members in order to ensure that that guidelines were adhered to.

In this way, it can be argued that anonymity and privacy on online forums represent a form of networked privacy (Marwick & boyd, 2014), where privacy is an ongoing, active process. Information norms are co-constructed by forum users and, in this example, are heavily influenced by moderators. As a result, achieving privacy requires forum users to
not just have the ability to navigate technology, but also to fully understand the norms and context of the forum in which they are interacting.

While forum posts were often edited to ensure appropriate levels of privacy, moderators were also involved in outlining other norms. A key role of moderators was to control the level of medical discussion that occurred on forums, i.e., to outline what medical information and discussion was acceptable and what was not. As described in Chapter Three, the information presented on forums was typically framed in the context of experiential information rather than directive medical advice, and often involved a deferral to healthcare professionals (Sillence & Mo, 2014). For example, Claire described how moderators often directed discussions away from posters’ individual experiences in order to prevent experiences which may run counter to accepted medical advice being shared.

*So if there’s something that’s a bit dubious in what somebody posts back to somebody, a moderator will come and they’ll say, well, I’m not sure I agree with that, that might be right for that person, but generally speaking, kind of thing. And in a really nice way as well, you know? (Claire, type 1 diabetes, 41 – 45)*

This was echoed by Alan, who described how an experience that he had shared in relation to his own healthcare was removed by moderators once other forum members had suggested that it was unsafe. In a discussion around changing needles on insulin pens, he had reported that he changed his lancet every couple of months. Though some forum members had suggested that they used similar strategies, others indicated that this ran contrary to the instructions from manufactures and was unsafe. While Alan reported that his intention was to share his experiences rather than instructing people to follow his example, “So all I was saying was, this was my experience. I wasn't saying to them, this is what you should do”, his post was removed on the basis of comments from other forum members, “I was having a look just now, and it looks to me as though the posting has been removed because a lot of people started saying, you can't do that, you've got to use it every time” (Alan, type 1 diabetes, 66 – 70).

Similarly, moderators also steered conversations towards medical advice where appropriate. Lesley described how she felt that moderators were more likely to post “scary stuff”, which referred to information about the negative consequences about an absence of self-management in diabetes. While this would typically been seen as violating the supportive norm of the forum, as discussed in Chapter Four, the moderators were seen as
striking a balance between supporting forum users and providing them with constructive criticism, “I think the moderators come a little bit closer to doing that than anybody because they can do that, I think” (Lesley, type 2 diabetes, 56 – 60). This suggests that moderators may play a role in modelling self-management behaviours in order to influence other forum members (Kennedy et al., 2009).

However, this enforcement of norms was not something that occurred instinctively. As illustrated by June’s anecdote, the evolution of forum norms represented an ongoing process, whereby rules, regulations, and policies were constantly re-evaluated on the back of forum events (Armstrong et al., 2012). For example, June described how policies and forum guidelines were created on the basis of events, rather than the other way around, “And you know things will happen and you’ll think to yourself, well, I never thought about that happening and now it’s happened we need to make a policy for the future about how we deal with it” (June, type 1 diabetes, 66 – 70).

As mentioned previously, moderators were likely to steer conversations towards medical advice where it was deemed appropriate. This involved a great deal of consideration, however, and was something that some of the moderators described struggling with. In an effort to provide support to forum members, there was often seen to be a need to offer advice and information that was ‘cruel to be kind’. This approach did not occur in isolation, but was negotiated and approved through discussions amongst moderators, before deciding on the best approach to offer help and support to particular forum members.

Where we appear to have difficulty, or somebody appears to be having difficulty grasping answers to the questions that they’re asking and we’re giving, so we have a discuss about what we think is the best way of approaching it to try and form, it sounds wrong to say ‘a united front’, but a more united front, which bits to stress and which bits not to stress because they obviously annoy the person. (Anne, type 1 diabetes, 61 – 65)

This was echoed by Mark, who described how he was conscious that his moderator status allowed him certain privileges that were not offered to other forum users, “That status allows one to, you know, you wouldn’t want to be seen to abusing censorship power by saying, I’m going to have the last word and then lock the thread, nanana nana” (Mark, type 1 diabetes, 41 – 45). He used discussions with fellow moderators to ensure that he was proceeding in a fair and just manner, and occasionally to hand responsibility over to the other moderators if he felt this was not possible, “It’s quite easy in those circumstances just
to say, I’m ducking out of that one, I don’t think I am adding anything positive, but just keep an eye on it, sort of idea. Or, am I being over sensitive here or, kind of thing” (Mark, type 1 diabetes, 41 – 45).

Overall, forum moderators appeared to play an instrumental role in developing guidelines and norms on online forums, both by creating and enforcing expectations of acceptable and appropriate behaviour online. This was particularly evident in relation to perceptions of privacy and anonymity, where moderators edited and adapted posts from other forum members in order to ensure that that guidelines were adhered to, as well as taking broader action in order to protect individuals’ ability to access online support anonymously. As illustrated by moderator activity around acceptable levels of medical advice on forums, these norms and guidelines did not develop in isolation. Instead they were a result of discussions between moderators, with the overall aim of maintaining an equitable and supportive forum.

5.4 Conclusion
This chapter reviewed participants’ perceptions and expectations of privacy and anonymity online. For many interviewees, anonymity online was a pivotal aspect of their usage of Internet forums. As a result, participants carefully managed their online identities in order to ensure that their online persona remained anonymous. There were exceptions to this, however, and concerns were raised that there were situations where individuals could inadvertently share information that could lead to them being identifiable. The majority of interviewees viewed Internet forums as public spaces, where conversations could be accessed by those who were not registered forum members. Consequently, many individuals spoke about how they adapted their use of forums in light of this in order to cater for the lowest common denominator, by keeping certain information private and considering different forms of communication in order to share personal information.

Additionally, the role that forum moderators play in shaping and enforcing posters’ expectations of privacy and anonymity online was reviewed. By editing and adapting the posts of members, moderators ensured that appropriate and acceptable levels of privacy and anonymity online were adhered to. To this end, forum moderators appeared to play a dual role in relation to privacy and anonymity – they attempted to protect forum members’ abilities to access support anonymously, while reminding individuals that the information that they shared should be tempered by the public nature of the forum. As with other moderator activities such as maintaining supportive norms online and ensuring that general
medical advice was not contradicted, the aim of moderator actions around privacy and anonymity was to enable those with LTCs to access online support, and to support them to manage their conditions.

In the next chapter, the findings of Chapters Three, Four, and Five will be integrated and discussed in relation to the empirical literature and theoretical frameworks introduced at the beginning of the thesis. In particular, some of the recurrent themes across the three chapters will be highlighted.
Chapter Six: Discussion

6.0 Overview
This study used a qualitative approach to examine the use of the Internet and Internet forums by individuals with LTCs. In order to achieve this, three specific research questions were addressed. Firstly, how individuals with ME/CFS and diabetes navigate information and establish trust on health discussion boards was explored. Secondly, the nature of Internet forum usage by individuals with ME/CFS and diabetes was investigated. Lastly, whether online discussion groups represent public or private spaces to forum members, and what influence this has on users’ online identities, was explored. The findings mapped onto three overarching and intertwining themes; namely the process of developing and maintaining trust on forums, accessing support and empowerment online, and forum users’ conceptions of privacy and anonymity. In this chapter, these findings will be examined and discussed, and the results from Chapters Three, Four, and Five will be integrated and interpreted. Next, the strengths and weakness of the current research will be addressed. Finally, the implications of this research for theory and practice will be discussed, and suggestions for future research will be presented, before an overall conclusion is drawn.

6.1 Establishing Trust Online
In Chapter Three, how individuals with LTCs build and establish trust online was explored. Participants described how their use of Internet forums for health information was situated in the context of their use of offline services and systems. In this way, this research supports Nettleton, Burrows, and O'Malley's (2005) contention that individuals’ use of forums is embedded within formalised healthcare settings and participants’ knowledge of health and illness. While accessing health information online appeared to offer interviewees a valuable source of advice, information, and support, they often used this resource as a springboard to further engage with existing health care services. Participants took a pluralistic, pragmatic approach towards online and offline resources, integrating the different sources and drawing on their respective strengths in order to enhance their health care and subsequent well-being (Rochelle & Marks, 2010; Wade et al., 2008). In addition, individuals’ use of resources appeared to be highly contextually dependent, with interviewees seeking health information online for less acute queries, but deferring to health care professionals for more serious issues (Fotaki, 2014; Gage & Panagakis, 2012).

In exploring how individuals assessed the information that they encountered online, interviewees reported that they trusted and valued information that came from official sites,
such as NHS driven sites or the websites of reputable charities related to their condition. As before, this suggests that Internet use for information seeking by those with LTCs is focused in the realm of formal health care, as participants were drawn to generally respected sources. However, there were also indications that an individual’s background influenced their assessment of sources. For example, participants described how they were attracted to approaches that were in line with their own beliefs and experiences. This shows that markers of trust online appear to be situated within individuals’ everyday lives, and as a result, forum users’ assessments of information sources online are contingent and embedded (Nettleton, Burrows, & O'Malley, 2005). Reflecting on this shows support for Kivits's (2006, 2009) argument that the Internet goes beyond an information source; instead, it provides information that individuals interact with, depending on their daily lives and health practices. For the participants in the present study, these health practices were in line with formal healthcare settings, and information that was validated by or supported these settings was valued and trusted.

Similarly, there were suggestions that participants’ use of Internet forums was framed by dominant medical discourses. Despite the divergent perspectives of healthcare professionals and patients around the nature and treatment of ME/CFS (Salmon et al., 2007), within the present study there was a broad deference to conventional medical practices around the condition. For example, on ME/CFS forums, a formal diagnosis of ME/CFS was important, as it represented an external marker of an individual’s credibility and therefore legitimised a poster as a source of advice and information. While this may seem counterintuitive given the contested nature of ME/CFS, it in fact echoes previous research. Giles and Newbold (2011) described how having a formal diagnosis was a central aspect of users’ identities on online mental health communities, despite the fact that many of the forums embodied a resistance to the medical establishment and spoke negatively about interactions with healthcare professionals. Likewise Whelan (2007) reported that a diagnosis of endometriosis represented a key turning point for individuals. It signalled their entry into the patient centred community of individuals with endometriosis, which, despite the difficulties that many experienced in receiving a diagnosis, was policed by the discursive act of medical labelling. The echoes of this in interviewees’ accounts indicates that forum members situate the advice and information shared online in the context of their knowledge about their health and illness (Sillence & Mo, 2014).

Looking specifically at interactions on Internet forums, participants frequently mentioned the importance of developing relationships with other forum members in order to assess
them as sources of advice and information. In particular, interviewees valued receiving information from posters whom they felt had a similar perspective to themselves. This is in line with previous research which indicates that Internet users are more likely to assess user-generated information as credible and indicate that they are going to act on this information when they perceive that this information has been contributed by similar others (Flanagin et al., 2013; Wang et al., 2008). This suggests that markers of credibility and legitimacy online will vary, and while dominant medical discourses are trusted and valued, other notions of credibility are variable between forum members and will be contextualised by an individual’s own background.

This finding also highlights the benefit of developing relationships online. As stated, interviewees valued forum members who had similar backgrounds or perspectives to themselves, and they frequently became aware of these similarities due to interactions that occurred over time. While research suggests that those who lurk on forums can receive similar benefits to those who are active posters (Buchanan & Coulson, 2007; Mo & Coulson, 2010; van Uden-Kraan et al., 2008), the present study shows that interacting with others online allows forum members to develop a pool of peers whom they consider to be useful and trusted sources of information. In addition, these relationships and the degree of familiarity between forum members meant that individuals were able to access a more personalised form of support which was targeted to their specific lifestyle and needs, compared to that provided by healthcare professionals (Keeling et al., 2013).

This point is echoed by other studies. For example, there have been suggestions that with continued participation in a forum, the relevance of the narratives, advice, and information available online increases. Individuals can build up a base of knowledge about their condition, comprised of new information as well as experiences that enforce the reliability of the information and add credibility to different sources (Johnston et al., 2013). As individuals become connected to communities, the information provided through these networks becomes more meaningful and accessible to the participant (Johnston et al., 2013). This research builds on this notion to highlight how these connections are instrumental in individuals with LTCs assessing and evaluating the information that they encounter via online forums.

Developing relationships with others online enabled forum members to put together a detailed picture of posters’ individual circumstances and to look for particular indicators of credibility. Forum users typically respond to requests for personal experiences in a
narrative form, providing readers with enough information to assess how applicable the advice is to their own situation (Sillence, 2013). Within the present study, interviewees could compare and contrast others’ experiences with their own, and draw on their own knowledge and experiences as a patient and a forum user to assess the advice and information that was being provided to them. This allowed forums to be broadly self-policing, as indicated by previous research (Armstrong et al., 2012), as forum members were able to access a group consensus within a single medium. In this way, trust was constructed on the forum, with the community assessing pieces or providers of information as credible.

Despite this, however, interviewees expressed a desire for increased guidance around the use of Internet forums. A number of participants reported that they took part in the present study due to a perceived need to educate healthcare professionals about the use of online discussion groups. This mirrors the results of previous research which indicated that, for individuals with MS, the opportunity to discuss their Internet searches with healthcare professionals was something that they viewed as desirable (Synnot et al., 2014). Interviewees suggested that doctors should recommend trusted websites and forums to their patients and be open to discussing health information garnered from the Internet. Indeed, it has been suggested that the involvement of practitioners in online environments is necessary in order for trust to occur (Nordfeldt, Ågarne-Lindberg, Nordwall, & Krevers, 2013). While this is not supported by the present study, which instead showed that online forums provide a complementary form of support and information to that provided by healthcare professionals, the comments from interviewees around the potential role of doctors indicates that this is an area that requires more detailed consideration. In addition, the degree to which forum members situated the advice and information shared online in the context of their knowledge about their health and illness (Nettleton, Burrows, & O'Malley, 2005; Sillence & Mo, 2014) suggests that the two forms of resources are closely aligned.

Considering that the aim of this research was to explore the experiences of individuals with contested and uncontested LTCs, it is worth reflecting on the implication of this finding in this context. While participants reported using a number of strategies to assess the information that they encountered on the Internet and suggested that they took a critical approach towards looking for health information online, many of these specific strategies can only be attributed to individuals with diabetes. While individuals with diabetes were typically required to seek advice and information online on an ongoing basis and to utilise
it into the daily management of their condition, the lack of consensus around the treatment for ME/CFS meant that the same procedures did not apply. In addition, the absence of biomedical markers of progress such as weight loss, stabilisation of blood sugar levels, and reductions in medication meant that forum users with ME/CFS were often unable to draw on the same evidence base to assess the credibility of information provided on online discussion groups. This suggests that individuals with ME/CFS may experience difficulties accessing some of the reported benefits of forums (Coulson et al., 2007). Similarly, the role of activism on ME/CFS forums, as discussed in more detail in section 6.2, indicates that forums may provide a space for activism and advocacy online, something which was not palatable to all participants with ME/CFS.

Lastly, the level of education of interviewees was frequently cited, both explicitly and implicitly, as a reason for their ability to safely navigate information online. Aspects of presentation online, such as literacy and logic, were highly valued in other forum members, and led to them being assessed as credible sources of information by interviewees. As a result, it is important to acknowledge the link between digital literacy and forum usage. Within the present study, participants who were literate online were able to successfully navigate online discussion groups and were seen trusted and valued members of the community by other posters. Consequently, guidance around navigating health information online may be particularly necessary for those with lower levels of online literacy (Diviani et al., 2015). This point will be further expanded on in section 6.2.

### 6.2 Accessing Support and Empowerment Online

Looking at the results outlined in Chapter Four, the nature of online forum usage by individuals with LTCs was examined. The findings showed that Internet forums acted as a tool of empowerment, allowing people to draw on the shared experiences of others to position themselves as active participants in their own health care and to distance themselves from the traditional sick role (Parsons, 1951). In this way, interviewees armed themselves with information and were better able to have informed conversations and make decisions about their condition (Johnston et al., 2013). Crucially, this support empowered individuals to engage with healthcare services and to be proactive about their own health and the self-management of their condition. As alluded to in the previous section, the findings of the present study indicate that online forums offered an alternative yet complementary venue for forum users to access health-related advice, information, and support, rather than a rejection of the medical profession (Ayers & Kronenfeld, 2007; Henwood et al., 2003; McMullan, 2006; Stevenson, Kerr, Murray, & Nazareth, 2007).
Interviewees described receiving comfort and support from the knowledge that there were others in similar situations, as well as benefitting from the lived experiences of their peers. In this way, the use of online discussion groups can be likened to the creation of patient knowledge (Pols, 2014). Forum members shared ‘tips and tricks’ online, enabling those accessing forums to learn a form of practical knowledge that was distinct from that offered by healthcare professionals. Just as Pols (2013, 2014) described the knowledge sharing that occurred between individuals with chronic obstructive pulmonary disease, whereby they learnt to live with their conditions by developing and sharing contextual, embodied knowledge, forum members drew on fellow patients’ daily lives to transform medical knowledge into techniques that individuals could use to manage their conditions. As discussed in section 6.1, access to this form of experiential knowledge meant that forum users were provided with a more personalised form of support than could be accessed through healthcare professionals. This enabled them to assess and understand their health and health care in the context of other forum members’ experiences (Keeling et al., 2013).

Interestingly, for individuals with diabetes, online forums appeared to offer not just support and information but also motivation to engage in healthy behaviours, suggesting that online support can lead to changes in health behaviour. It has been reported that accessing support from one’s offline network is associated with higher levels of motivation and engagement in health promoting behaviours (Gallant, 2003; McKinley & Wright, 2014; Ng et al., 2014), while Ayers and Kronenfeld (2007) found that the more an individual uses the Internet for health information, the more likely their health behaviour is to change. Laing, Keeling, and Newholm (2011) suggest that participating in a forum allows individuals to develop a strong sense of ownership over their condition, which in turn leads to them becoming more actively engaged with healthcare professionals. In addition, it is also possible that documenting one’s behaviour online, whether through forum posts or online chat, as illustrated in Chapter Four, provides individuals with a sense of accountability. Describing a project where participants shared photographs online of their healthy meals, Parker (2014) reported that those sharing photos took care to ensure not just that their meals were nutritionally balanced but that they were presented in such a way that they appeared appealing to others. She suggested that as participants modelled healthy behaviours for others, they became motivated to live up to their own positive example. In other words, this dual process of inspiring others to eat healthily as well as monitoring their own eating behaviours resulted in benefits for individuals as well as the community in which they were active. This is echoed in the present study, where interviewees described detailed
discussions around weight loss and healthy eating, for example, where they monitored their own behaviour while simultaneously encouraging others to make healthy choices.

Having access to positive role models appeared to facilitate individuals’ reconstruction of their identity (G. Williams, 1984). Forum members were able to interact with others who were controlling, managing, and living with their LTCs. This facilitated interviewees to communicate with realistic role models, and subsequently enabled posters to re-imagine themselves as active, engaged patients. This indicates that online support can result in offline health benefits for forum users, as well as going some way towards buffering the loss of self experienced following the onset of an LTC (Charmaz, 1983). As outlined in Chapter One, communicating with peers online can facilitate a form of narrative reconstruction (G. Williams, 1984), where individuals can reorient their identity from ‘abnormal’ to ‘less out-of-the-ordinary’ (Trondsen & Tjora, 2014). What this study adds, however, is that forum members were facilitated to adjust their illness identity to not just that of an empowered patient (Barker, 2008), but one that is actively motivated to engage in healthy behaviours.

A key feature within the present study was the role that reciprocal support played for interviewees. Participants valued being able to share their experiences and provide support to others, and described the personal gain that they received from this process. These mutually supportive relationships allow individuals to overhaul their role from one in which they merely received instruction and information from healthcare professionals. In this way, forum users were further facilitated to distance themselves from the role of the passive patient (Parsons, 1951) and were instead able to position themselves as caregivers as well as receivers, adding to their sense of self-worth. While this notion has received less attention in the literature, these findings are in line with previous research which suggested that forums allow those providing support and advice to feel valuable and useful (Hadert & Rodham, 2008; Mazzoni & Cicognani, 2014; P. Reeves, 2000). Supporting this argument, Mo and Coulson (2014) suggest that supporting others and sharing stories online helps forum users to understand what has happened to them and to let go of the past. It provides additional evidence of forums facilitating the narrative reconstruction of individuals’ identities (G. Williams, 1984) and addressing the sense of loss of self following the onset of a chronic condition (Charmaz, 1983, 1995). Indeed, it echoes the concept of illness gains described by Asbring (2001), where individuals with LTCs experience new insights and an adjustment in priorities as a result of their condition.
In addition, the findings indicate that while experiential knowledge and peer support were highly valued by individuals, these networks were typically embedded within formal health care systems (Nettleton, Burrows, & O'Malley, 2005) and frequently involved a deferral to healthcare professionals (Silence & Mo, 2014). As a result, forum users drew on both lay and expert perspectives in order to engage with their own health care, and for those with ME/CFS, attempt to influence the progression and recognition of their condition (Arksey, 1994). Similar to the collective pool of shared experiences described in Chapter Three, forums allowed individuals to share, collate, and access scientific knowledge online. In this way, forum users were able to utilise both experiential and scientific knowledge, and could situate themselves as a form of lay expert (Arksey, 1994; Whelan, 2007). This echoes earlier research around overlapping spheres of knowledge, which illustrates how official messages around health and illness are frequently incorporated into ‘folk’ concepts of disease as a form of lay epidemiology (Blaxter, 1983; C. Davison, Smith, & Frankel, 1991).

Notably, while it has been argued that online communities privilege lay knowledge and perspectives over the expert knowledge of health professionals (Burrows et al., 2000), the present study suggests that the input and perspectives of those from the medical profession were also valued. In the case of those with ME/CFS, this contact provided individuals with a sense of legitimacy and appeared to validate not just the existence of their condition, but an acceptance of its biomedical origins. In addition, participants were able to draw on medical terms and frameworks to collaborate with professionals and situate themselves as active participants in the construction of medical knowledge, as described by Arksey (1994) and others (Blaxter, 1983; C. Davison et al., 1991). Like the construction of patient knowledge (Pols, 2013, 2014), forum users were able to successfully blend experiential and scientific knowledge in order to access a ‘third form’ of knowledge, one which was more practical and useful than an approach constrained by the sole inclusion of biomedical perspectives or individual lay opinions.

As acknowledged throughout Chapter Four, it is important to note the educational background of participants in the present study and to consider how their level of education contextualises their Internet use. In examining forums, it should be acknowledged that higher income is associated with the use of ‘interactive’ aspects of Internet, i.e., blogging, chat rooms, and forums (Dutton & Blank, 2013). In addition, research suggests that factors such as age, education, and socioeconomic status all influence how individuals use and interpret the Internet as a source of health information and advice. Notably, those who are younger and more highly educated are better able to use the information that they find
online to manage their health care, adapt their health behaviours, and communicate with
their physicians (Neter & Brainin, 2012). While the impact of this on the findings of the
present study must be acknowledged, there were also suggestions that Internet forums
could serve as an intermediary between those with higher levels of education or biomedical
knowledge and those without. Participants described discussing research with practitioners
and academics online, indicating that forums facilitate individuals to utilise existing
research in order to consolidate themselves as a patient group and to legitimise their
condition using the language and tools of the medical profession. Involvement in a
community of patients online granted forum members access to debates and critiques of
research and innovations related to their condition, which they could access without use of
a gatekeeper, such as a GP. In this way, it could be suggested that forums go some way
towards negating the effects of the digital divide. This argument will be returned to and
further explored in section 6.4.

However, despite the descriptions of empowerment and engagement online, a number of
participants also noted barriers to their access and use of Internet forum. For some
interviewees, these barriers related to their level of experience with the Internet, reflecting
the importance of digital literacy in engaging with online support. For a number of
individuals with ME/CFS, however, these barriers related to their condition, with many
people experiencing sensory difficulties caused by a proximity to electronic equipment
such as Internet routers as well as difficulties looking at screens for prolonged periods of
time. This aspect of the condition is something that has received little attention in the
literature, and is worth highlighting when considering the positive experiences that many
reported from online support. For example, engaging with industry in considering how
these barriers may be circumvented could provide a potentially fruitful avenue of
collaborative research. Increasingly, researchers are highlighting the value of considering
the diverse needs of individuals in utilising technology in healthcare systems. Kayser,
Kushniruk, Osborne, Norgaard, and Turner (2015) cite the importance of addressing user
characteristics in developing aspects of IT systems such as the user interface in order to
maximise health benefits, while Wherton, Sugarhood, Procter, Hinder, and Greenhalgh
(2015) highlight the need for technology to be customisable and aligned with an
individual’s support network in order for it to be effectively utilised. This research adds to
those claims by illuminating some of the specific considerations required in addressing the
needs of those with ME/CFS.
In addition to the technical and psychosocial barriers, others reported negative experiences with Internet forums. While many interviewees described online discussion groups as supportive, non-judgemental environments, there were exceptions to this. In particular, some participants mentioned a degree of conflict and heated debate online across both diabetes and ME/CFS forums. This is broadly in line with previous research, which describes negative interactions on health discussion groups (e.g., Rier, 2007) as well as parenting forums (Brady & Guerin, 2010). In addition, Aakhus and Rumsey (2010) analysed a negative occurrence on an email list for an online cancer support community, and described how the discourse and discussion that followed the initial disagreement were consequential for emotional expression, understanding, and knowledge development among members of the online support community. This suggests that conflict online is a normal aspect of forum usage and does not represent anything distinct about the forums utilised in the present study. Indeed, it may be instrumental in the development of forum norms and community consensus.

However, in the experiences of interviewees with ME/CFS, this conflict frequently appeared to be due to a difference in needs and perspectives between individuals. Examining the accounts of interviewees who had accessed or participated in ME/CFS forums indicated that the focus of these forums is on activism as well as support, and involves individuals attempting to mobilise themselves as a patient group in order to establish ME/CFS as a legitimate condition (Fair, 2010). In addition, ‘being ill’ and having a collective illness identity appeared be central to the existence of ME/CFS sites online (Barker, 2002). While this has been shown to be a central tenet of participation in certain health-related communities (e.g., Koski, 2014) and is in line with how the Internet has been used by contested communities (Fair, 2010; Mazanderani et al., 2013; Sudau et al., 2014), the results of the present study suggest that it is not something that is of interest or palatable to all individuals with ME/CFS.

This is reminiscent of research around ‘hero’ narratives in discourses about cancer, where individuals are expected to conform to a particular construction of those with cancer (Pitts, 2004; Seale, 2002). Sandaunet (2008) reported that participants in an online discussion group were encouraged to circulate socially desirable stories of their experiences with cancer. Many of the forum users who were interviewed expressed a reluctance to introduce negative topics to the group and to deviate from the norm of social desirability on the forum. This is comparable to the experiences of individuals with ME/CFS; however, in the case of the present study, the norms on these forums were negative and politicised, in
contrast with the overly positive norms on cancer forums. Many of the interviewees reported that they found that the content of ME/CFS forums focused on the negative aspects of the condition and lacked any discussion around the ‘light at the end of the tunnel’, something that some participants reported that they found unhelpful. This is echoed by Lian and Nettleton (2014), who argue that a negative and highly politicised discourse in ME/CFS communities online risks silencing its members and may ultimately have a disempowering effect.

Finally, it should be acknowledged that online support may have a particular resonance for different individuals at different points during their illness trajectory. Charmaz (1995) highlights the cyclical nature of adaptation to the diagnosis of a chronic illness, suggesting that individuals’ needs do not remain consistent over time and may fluctuate depending on their own situation and that of their condition. As a result, the services and supports that people access will likely change over time. Similarly, Synnot et al. (2014) reported that, for individuals with MS, their information needs, emotional stages, and expertise about their condition varied continuously. As a result, the usefulness of the Internet as a resource also fluctuated. Considering the potential role of online support in the lives of those with LTCs should be viewed with this fluctuation in mind. In addition, this is a potential area of further research, in order to explore when and under what circumstances online support may be particularly beneficial. This information could guide healthcare professionals in their interactions with individuals with LTCs, and may be similarly useful for forum users and moderators.

6.3 Constructing Privacy and Anonymity Online

In order to explore the ethical implications of the use of forum data in research, participants’ views of Internet forums as public or private spaces were examined, and this was explored in Chapter Five. As described in Chapter Two, the findings support the notion that privacy online is a nebulous concept. For some participants, online discussion boards enabled them to reveal information that was intensely personal and private and that they did not feel comfortable sharing in an offline setting, such as with their family and friends. This suggests that, for some individuals, the forums provided them with a safe space in which they could access support away from their real-life support networks (Sanders et al., 2011; Sharf, 1997).

This does not mean, however, that the information shared on forums represented an unfiltered expression of forum members’ thoughts and feelings. In keeping with Goffman's
(1959) dramaturgical work on identity, participants described a degree of impression management, where they filtered and adapted the information that they shared online in order to create a particular identity for themselves. For many individuals, their adopted online persona was an anonymous one, and they spent time censoring and editing what they shared in order to ensure that their online and offline identities remained separate. In this way, the findings of the present study support previous social media research on the notion of the lowest common denominator, where individuals adapted what they shared online in order to ensure it was appropriate for the broadest possible audience (Bullingham & Vasconcelos, 2013; B. Hogan, 2010; Papacharissi & Gibson, 2011). Interviewees described scrutinising and modifying their online communications in light of the audiences that they felt could access their words, such as employers, family members, journalists, or government agencies.

In order to remain anonymous online, this self-censorship involved avoiding revealing identifying information such as an individual’s place of home or work. As mentioned, for the majority of interviewees, remaining anonymous online was desirable, supporting previous research which indicated that being able to contact peers anonymously is an important aspect of individuals accessing and receiving support online, particularly for health-related queries (Finn, 1995; Sharf, 1997). Even for individuals who did not maintain an anonymous persona online, there was still a sense of managing and monitoring the words and information that they shared. This suggests that maintaining an identifiable online persona is not merely a direct replication of one’s offline identity. Rather, only some aspects of oneself are presented online. However, as highlighted by Bullingham and Vasconcelos (2013), this can be a two way process. While some individuals may carefully share aspects of themselves online in order to present a delicately constructed persona, others may in fact offer their ‘true selves’ online, in cases where their offline self is influenced by societal or family pressure. Within the present study, forums users often utilised both aspects of this presentation simultaneously, describing how they took care to present an anonymous online persona, while at the same time sharing their true feelings and experiences with their condition that they would not feel safe or comfortable sharing with their family and friends. In this way, forums provided a space for posters to perform aspects of their identity unconstrained by offline relationships (Bullingham & Vasconcelos, 2013; Sanders et al., 2011).

Despite this, there were concerns from participants that certain forum members were not engaged in a sufficient level of identity management online, leading to ineffective attempts
at safeguarding privacy. While all interviewees felt that they themselves were in control of the information that they disclosed and were capable of navigating and negating any privacy concerns online, some expressed doubts that other Internet users were as competent at these tasks. Returning to the notion of the lowest common denominator, participants suggested that for some forum users, their version of the lowest common denominator was an unrealistic one that did not account for the public nature of Internet forums (B. Hogan, 2010). Suggested reasons for this included the supportive nature of health discussion groups, cognitive impairments or ‘brain fog’ associated with ME/CFS, as well as a lack of experience or education around the Internet and the nature of social media.

Whilst the digital divide has been discussed in relation to trust, support, and empowerment online, as seen in sections 6.1 and 6.2, this is also relevant in relation to privacy online. This has been highlighted within the literature, with Papacharissi and Gibson (2011) describing privacy online as a form of luxury commodity, arguing that the level of computer literacy required in order to acquire it is inaccessible to many. Similarly, Osatuyi (2015) highlights the link between confidence in Internet skills and privacy, where users who are less confident in their abilities to navigate social media are less likely to engage with these technologies due to concerns about information privacy. As a result, it is important to note that discussions around the use of online health discussion groups by individuals with LTCs may relate to those who have successfully navigated these complexities, rather than a wider population.

In addition, as mentioned previously, the findings of the present study illustrate the notion of privacy online as a nebulous concept. Rather than individuals drawing a clear cut distinction between what they would and would not be comfortable sharing online, it was evident that these situations were contextually dependent and related to an number of unique and individual factors (Nissenbaum, 2004, 2011). For example, forum users described how they shared certain information using private messaging or online chat facilities rather than posting on a public forum, indicating that their desire for privacy was shaped by the need to control the context in which the information was shared rather than a need to keep the information itself private (Marwick & boyd, 2014; Papacharissi & Gibson, 2011). This suggests that navigating the different spaces and performative ‘stages’ of Internet forums (Goffman, 1959; B. Hogan, 2010) requires an awareness of both the social and technical aspects of these forms of social networks (Marwick & boyd, 2014). In addition, as Papacharissi and Gibson (2011) highlight, there is an inherent difficulty in negotiating privacy in networked social environments which were designed for sharing.
rather than privacy. While their argument relates to social media rather than Internet forums, it is evident that parallels can be drawn between the two spaces.

The findings of the present research indicates that there is an extra dimension to the construction of privacy online, one that has received scant attention in the literature to date, and that is the role of moderators. As described in Chapter Five, interviewees described the duties of moderators in a manner that was broadly in line with the findings of previous research. Moderators were typically involved in enforcing forum norms, such as general netiquette, e.g., ensuring that forum users were polite to each other (Honeycutt, 2006). In addition, these norms also related to the type of information that was and was not acceptable to share online. As seen in previous studies, there was a deference to the role of healthcare professionals and the medical profession (Sillence & Mo, 2014), and forum members were expected to couch their support, information, and advice in terms of experiential information (Sillence & Mo, 2014; Ziebland & Herxheimer, 2008) rather than medical direction. Moderators were seen to enforce these guidelines, as well as promoting healthy lifestyles and behaviours, indicating that moderators play a role in modelling self-management behaviours in order to influence other forum users (Kennedy et al., 2009). In this way, moderators were instrumental in determining notions of morality on the forum and ensuring forum members adhered to these notions.

Alongside these duties, however, moderators played a pivotal role in constructing forum members’ expectations of privacy online. In some instances, this took the form of editing members’ posts in the event that they revealed identifying information, such as a name or an email address, as seen in previous research (e.g., Armstrong et al., 2012; Stommel & Koole, 2010). At times, however, moderators’ actions involved a more direct intervention. In this way, it can be argued that anonymity and privacy on online forums represents a form of networked privacy (Marwick & boyd, 2014), where privacy is an ongoing, active process. Information norms are co-constructed by forum users, and in this research, heavily influenced by moderators. This finding has various implications for research around privacy online. Notably, it suggests that, in some cases, moderators may bridge the potential discrepancies between actual and perceived privacy online (Markham & Buchanan, 2012) by enacting and enforcing forum specific guidelines around privacy.

From the perspectives of researchers examining online spaces, this indicates that moderators may act as ‘informants’ about online cultures (Sade-Beck, 2004), and may provide an insight into the views of the community in relation to the acceptability of the use
of online data for research purposes. As noted by a number of researchers (e.g., Burkell, Fortier, Wong, & Simpson, 2014; Harriman & Patel, 2014; Zimmer, 2010), it is often difficult to determine if Internet users are aware of the ways in which their data may be used. In particular, Harriman and Patel (2014) question whether sharing information in a public domain indicates an acceptance of the use of that information for research purposes. The findings of the present study suggest that, while not the equivalent of receiving informed consent from individual forum members, obtaining consent from moderators who are actively engaged in the process of constructing forum users’ expectations of privacy is a potentially useful and ethically compliant route for Internet researchers.

However, it also further highlights the complexity of navigating privacy online. As Marwick and boyd (2014) point out, taking a networked view of privacy requires acknowledging that in order to achieve privacy online, forum users are required to have not just the ability to navigate technology, but also to fully understand the norms and context of the medium in which they are interacting. These dual demands placed on forum users support Papacharissi and Gibson's (2011) argument around privacy as the preserve of those who have the skills and literacy to navigate these online territories. Along with the digital divide, it could be argued that a resulting privacy divide is created, leaving only a select section of the population with the ability to successful utilise online support via forums, social media, or other forms of online interactions.

6.4 Integration and Interpretation of Key Findings

Following discussion of the findings outlined in Chapters Three, Four, and Five, it is necessary to bring together these findings in order to consider their relevance to the existing literature. Firstly, the results indicate that Internet forums offered those with LTCs access to peer support which empowered them to manage their conditions and to engage with health services and healthcare professionals. Rather than facilitating individuals to reject the medical profession and to utilise incorrect or dangerous health information, a concern that is frequently raised by healthcare professionals (Middlemass et al., 2012; Nettleton, Burrows, & O'Malley, 2005; Rupert et al., 2014), forums acted as a springboard for users to further engage with health services. Participants were empowered to distance themselves from the notion of patients as passive recipients of expert care (Parsons, 1951), and were able to draw on the information and the shared experiences that they accessed online in order to participate in shared decision making. Forum users were able to utilise medical language and terminology and the collective pool of patient knowledge to assert themselves as lay experts (Prior, 2003). This enabled them to make informed decisions about their
treatment (Johnston et al., 2013) and to attempt to influence the progression and recognition of their condition (Arksey, 1994).

In addition, reading about the experiences of their peers online enabled individuals to receive advice and information about managing the day-to-day problems associated with living with an LTC, knowledge that was not available through healthcare professionals. Indeed, receiving support and information online and interacting with realistic role models motivated interviewees to engage in healthy behaviours. In this way, Internet forums offered a venue for advice, information, and support that complemented rather than challenged that provided by formalised healthcare settings. There were aspects of this support that were unique to online support and could not be provided by family, friends, or healthcare professionals, like the personalised care offered via forums members (Keeling et al., 2013), the access to ‘tips and tricks’ or patient knowledge (Pols, 2013, 2014), and a sense of not being alone (Bülow, 2004; Sharf, 1997). However, this support ‘bridged the gaps’ between traditional service providers and did not replace or supersede any of the existing supports or services available to those with LTCs. Just as Piette (2010) described an individual’s family and friends as informal caregivers who fill the gaps created by healthcare services by aiding with the practical and emotional challenges of living with an LTC, the support provided via online forums further assisted forum users in the day-to-day management of their condition via the lived experiences of other posters.

This is in line with previous research which argues that there is a form of media convergence between online and offline sources (Seale, 2005) and that broadly similar discourses are available through the Internet as offline media (Pitts, 2004; Rier, 2007; Sandaunet, 2008). Rather than presenting alternative views or perspectives, interactions on forums were framed within the context of formalised healthcare settings and an individuals’ knowledge about health and illness (Henwood et al., 2003; Nettleton, Burrows, & O'Malley, 2005; Sillence & Mo, 2014). There was a deference to the knowledge and position of healthcare professionals, and forum users were encouraged to frame their advice, information, and support in the context of experiential knowledge (Sillence & Mo, 2014). In this way, forums allowed individuals to draw on both lay and expert perspectives in order to access a ‘third form’ of knowledge, one which fell within the boundaries of conventional medical wisdom while simultaneously offering practical advice and information to those living with an LTC.
In addition, the present study highlights the role that online discussion groups can play in forming and shaping the identities of those with LTCs. As discussed, sharing experiences online allows individuals to reposition themselves as active, empowered, and motivated patients who successfully engage in healthy behaviours (Barker, 2008; Parker, 2014). This indicates that the use of Internet forums can address the biographical disruption (Bury, 1982) and the loss of self experienced following the onset of an LTC (Charmaz, 1983). As a result, forum users are facilitated in developing a new identity – one which differs from the passive sick role construct described by Parsons (1951), but one which is also distinct from an individual’s offline persona. Sharing experiences with others online provided interviewees with an opportunity to engage in mutually supportive relationships in which they could mobilise the resources available to them to assist others (Hadert & Rodham, 2008; Mazzoni & Cicognani, 2014; Mo & Coulson, 2014) and which offered them an opportunity to discuss topics that they were not able to share with family and friends (Sanders et al., 2011; Trondsen & Tjora, 2014).

Much as individuals were able to access a third form of knowledge online, Internet forums also provided a space for the development of a ‘third persona’. As before, this persona was developed by drawing on a number of sources of experience and knowledge. Forum users could draw on medical knowledge accessed online in order to present themselves as an activist striving for recognition of ME/CFS, the supportive norms of a forum in order to position themselves as a caregiver, their power and credentials as moderator in order to preserve the privacy of those on the forum. However, as noted by Hogan (2010), these personas are by no means stable, and can differ within the context of a single medium. As illustrated, forum members may inhabit one identity on a public forum, another within a live chat, and yet another within private messages.

Returning to the experiences of individuals with contested and uncontested LTCs, it has been suggested that online support groups may offer a particular role for those with contested chronic illness due to the lack of agreement surrounding the nature and treatment of the condition (Chen, 2012). However, the findings of the present study indicate that this is not necessarily the case. As described, a diagnosis was highly valued on forums, and members who had received an official diagnosis of ME/CFS were seen as more credible and legitimate sources of information than those who had not (Giles & Newbold, 2011; Whelan, 2007). This is in contrast with the notion of ‘scientific self-diagnosis’ described by Copelton and Valle (2009) on forums for those with coeliac disease. This indicates that there was an acceptance of the role of medical professionals on forums, rather than solely...
valuing and privileging lay perspectives (Burrows et al., 2000). Supporting this, while there were indications that forum users with ME/CFS sought information that supported the notion of ME/CFS as a biomedical rather than psychological or psychiatric condition (Hawkes, 2011; Smith & Wessely, 2012), they did so by reading and discussing ongoing research and communicating and collaborating with healthcare professionals and researchers working in the area. This provided individuals with a sense of legitimacy as patients, as it validated their condition as a credible biomedical entity. In addition, participants were able to draw on medical terms and frameworks to collaborate with professionals and situate themselves as active participants in the construction of medical knowledge, as described by Arksey (1994) and others.

However, as outlined in section 6.2, ME/CFS forums frequently tended to slant towards activism, whereby they used these integrations of lay and expert perspectives to mobilise themselves as a patient group (Fair, 2010; Mazanderani et al., 2013). For many of the interviewees in the present study, this focus on activism in addition to support meant that the forums were often perceived as potentially hostile environments rather than safe spaces (Lian & Nettleton, 2015; Sharf, 1997). While conflict and controversy on forums is common (Brady & Guerin, 2010; Rier, 2007), and may indeed be instrumental in the development of forum norms and community consensus (Aakhus & Rumsey, 2010), the negative reactions of many interviewees to this indicates that online activism was not necessarily desirable to all those with ME/CFS. By contrast, for many interviewees with diabetes, forums offered support with the daily management of their condition and provided a useful resource which motivated them to engage in healthy behaviours, despite occasional conflict.

Overall, the findings indicate that participating in Internet forums and online communities can provide individuals with LTCs with a valuable form of support which complements the supports and services offered by formal health services and can empower and motivate them to manage their condition. However, it is important to consider the potential role and impact of the digital divide and inequalities on online access and forum usage. As highlighted, interviewees frequently drew on their educational background, both explicitly and implicitly, in discussing their use of Internet forums. While the present study did not collect data on socioeconomic status, merely levels of education, this finding still has relevance for the notion of the digital divide. In addition, this is in line with previous research which suggests that more highly educated individuals have higher levels of online
literacy and are more likely to find information online that improves their health (Dutton & Blank, 2013; Neter & Brainin, 2012).

Similarly, aspects of presentation online, such as literacy and logic, were highly valued in other forum members and led to them being assessed as credible sources of information by interviewees. Considering the role that relationships played in individuals’ forum usage, where interacting with other forum members over a prolonged period of time led to posters receiving personalised help and support (Johnston et al., 2013), this indicates that those who do not conform to these standards may be excluded from developing these types of relationships. This highlights that the digital divide extends beyond the notion of barriers to access to barriers to literacy, with those who are able to navigate both the social and technical aspects of forums (Marwick & boyd, 2014) gaining the most benefit. As a result, it is likely that a reliance on discussion boards as a form of support for those with LTCs may serve to further disenfranchise those who are already marginalised by existing healthcare systems (Viswanath & Kreuter, 2007).

Thus while much of the present study described the benefits of online support, it is necessary to temper the discussion of these benefits by acknowledging that these benefits may predominately apply to those individuals who are already successfully utilising existing sources of support. For example, Bell (2014) described how women’s use of sources of support and information around their infertility, such as the Internet, was shaped by their expectations around healthcare and level of social capital, with women of high SES proactively seeking information. With this in mind, the specific processes described in this and previous chapters, such as the notion of forums as self-policing and the degree to which discussion boards are situated within the usage of health services, may not apply in other contexts. Despite this, there was evidence that forums could serve as an intermediary between those with higher levels of education or biomedical knowledge and those without, and thus may have the potential to negate rather than enhance the effects of the digital divide and health inequalities online.

In addition, the findings indicate that concerns around privacy are perceived as an additional barrier to those with insufficient levels of digital literacy accessing support online. Nutbeam (2000) argues that in order for health literacy to occur, individuals are required to have both the confidence and the skills to gather information, understand it, and actively appraise it. Interviewees suggested that the utilisation of forums was a complex process, and achieving privacy was a difficult yet pivotal aspect of this utilisation. As
outlined in section 6.3, the results of this study show that privacy online is a nebulous concept. Achieving privacy requires an understanding of networked privacy (Marwick & boyd, 2014) and the role of contextual factors such as forum norms and the function of the moderators, as well as the technical aspects of navigating around an Internet forum. As a result, maintaining an online persona, which for many of the participants in the present study meant remaining anonymous and carefully considering where to share personal information, risks becoming the preserve of a select few (Papacharissi & Gibson, 2011). This means that research into the use of health-related forums must consider the impact of inequalities on forum usage, and particularly highly contextual and nuanced factors such as privacy. In order to contribute to the body of knowledge in this area, this research highlights the need to examine how privacy is situated within online literacy.

6.5 Methodological Strengths and Weaknesses

This present study took a qualitative approach, as the aim of the research was to explore the experiences of individuals with LTCs. Qualitative research is concerned with understanding the experiences of individuals as they go about their daily lives within a social context (Gubrium & Holstein, 1997). This approach allowed an examination of how the Internet is embedded into individuals’ lives (Nettleton, Burrows, & O'Malley, 2005). In particular, semi-structured interviews were used to explore the views and opinions of individuals with LTCs in relation to Internet forums. As described in Chapter Two, this approach facilitated the consideration of the perspectives of those under research, i.e., individuals with LTCs (I. Holloway & Biley, 2011). This was particularly important as the aim of the research was to examine the lived experiences of participants, something that is best explored within a qualitative setting (Elliott et al., 1999).

The use of semi-structured interviews enabled a flexible approach to data collection and provided participants with an opportunity to discuss the topics that were salient to them. This allowed individuals to bring in issues that were external to the direct aim of the research and to embed their experiences within a broader context, such as their use of health services. Notably, this is something that could not be achieved using a quantitative or a less flexible methodology. This was particularly valuable given the inclusion of a contested illness in the sample, as it allowed participants to discuss their condition using their own perspective and frame of reference, which may differ from that of healthcare professionals and researchers (Salmon et al., 2007; Smith & Wessely, 2012).
In addition, the use of vignettes created from existing forum data as prompts provided a realistic way of considering a number of perspectives in responding to the individual scenarios depicted (Jenkins et al., 2010). This also provided a useful springboard for discussions around public and private spaces online, as described in Chapter Five, creating arguably more rich and detailed data than would be generated from interviews alone. Indeed, participants responded favourably to the vignettes, indicating that they reminded them of experiences that they had had, “One of your vignettes actually brought home something that did happen” (June, type 1 diabetes, 66 – 70), and were representative of interactions on particular forums, “Are you sure you didn’t take this from [forum name]? It was just I’m sure I’ve read stuff that’s close to this, it’s very real” (James, ME/CFS, 51 – 55), and experiences with LTCs, “It’s a very true to life reflection of what it is like to live with ME” (Nicole, ME/CFS, 26 – 30). This suggests that the vignettes used in the present study were seen as realistic by participants, and therefore were valid and reliable research tools (Gould, 1996).

Despite this, a number of methodological weaknesses must be acknowledged. While care was taken in selecting diabetes and ME/CFS as appropriate examples of LTCs within which to explore the use of Internet forums, this was done without a full awareness of the sensory difficulties associated with ME/CFS. As discussed in Chapter Four and section 6.2, many individuals with ME/CFS described difficulties created by proximity to electronic equipment or Internet routers as well as difficulties looking at screens for prolonged periods of time. As a result, any recommendations or implications around the benefits of online support from the present study will likely not be applicable to some with ME/CFS due to this additional barrier to online access. Nevertheless, the number of active ME/CFS forums located during the recruitment process for this research, as well as the high proportion of ME/CFS Internet users reported in previous research (Knudsen et al., 2012), indicates that there is a large community of individuals with the condition online.

While the present study, like much qualitative research, was concerned with the notion of theoretical generalisability (Sim, 1998) rather than providing a representative sample of the population, it is still necessary to acknowledge that interviewees were self-selecting, and as a result, there was a possibility of response bias. As noted above, this was likely the case with some participants with ME/CFS. In addition, while attempts were made to recruit interviewees from a variety of online and offline sources in order to include a variety of perspectives and viewpoints, this was not always rigidly adhered to. For example, though a number of recruitment avenues were planned for individuals with diabetes, the initial
forums targeted proved to be more fruitful than anticipated, resulting in nearly three-quarters of interviewees with diabetes being recruited directly from Internet forums. By contrast, just over a quarter of those with ME/CFS were recruited from forums, with the remainder recruited from offline sources. As a result, the positive role that forums play in the lives of those with diabetes compared to those with ME/CFS may be overstated. Similarly, while the use of online and offline recruitment sources was adopted in an attempt to overcome the effects of the digital divide (Goldfarb & Prince, 2008), the frequent discussion of inequalities online throughout the findings of the present study and the overrepresentation of interviewees educated to degree level indicates that this was not successful.

In light of this, it may be useful to briefly reflect on alternative directions that this research could have taken. Given the relatively exploratory nature of the research, it could be suggested that taking a mixed methods approach may have provided a valuable insight into the topics under study. Considering concerns over the representativeness of the sample, a large-scale quantitative approach may have provided a more appropriate method of comparison between the two groups and would have allowed for a more targeted sampling strategy. Similarly, while this research provided some valuable insights into forum usage, online literacy, and the digital divide, the lack of additional quantitative data makes it difficult to extrapolate the findings to other contexts. Collecting additional data around socioeconomic status as well as education, for example, would have further illuminated these findings.

In addition, considering that Chapter Four indicates that participating in online forums can have an impact on users’ lives by means of empowerment and support, the use of a standardised questionnaire would have allowed for a direct assessment of this. Looking at the previous literature, there have been suggestions that online support can extend into users’ offline lives by means of empowerment (Bartlett & Coulson, 2011; Mo & Coulson, 2010; van Uden-Kraan et al., 2008) and tangible support (Coulson et al., 2007). However, larger quantitative studies have suggested less positive results, with Salzer et al. (2010) reporting increases in psychological distress and decreases in quality of life for women with breast cancer assigned to an online peer support condition over a twelve month period, compared to a control group. By utilising solely qualitative methods of data collection, no opportunity was provide to further examine this issue. Overall, while there were strengths and weaknesses associated with the methodological approach of the present study, it
remains an appropriate context in which to explore the views and experiences of individuals with contested and uncontested LTCs.

6.6 Implications and Recommendations for Practice and Future Research

Having reviewed the findings of the present study and reflected on the strengths and weaknesses of the research, it is necessary to consider the impact and relevance of these findings. In order to do this, the implications of the present study and its findings for further research and practice will be described.

The results indicated that trust was constructed on forums, with the development of individual relationships between forum members and the communal knowledge of health and illness determining whether or not information and information providers were seen as credible. Consequently, forums were broadly self-policing mediums, supporting the findings of previous research (Armstrong et al., 2012; Sillence, 2013). Despite this, a number of interviewees reported a desire for increased guidance and communication around the use of forums from healthcare professionals. Many reported that they would like others to receive similar solace and support from discussion boards as they themselves had received, and felt that an increased awareness among healthcare professionals about the uses and benefits of forums would be valuable.

However, previous research suggests that healthcare professionals are sceptical about the use of the Internet for health information and advice (Nettleton, Burrows, & O'Malley, 2005; Rupert et al., 2014) and doubt the abilities of lay individuals to assess the quality of the information that they encounter online (Middlemass et al., 2012). Indeed, the rise of social networking sites appears to have increased these fears (Househ, Borycki, & Kushniruk, 2014; Seymour, Getman, Saraf, Zhang, & Kalenderian, 2015). This indicates that future research could explore this issue and examine the concerns of healthcare professionals about online support. Addressing these issues may encourage discussions between patients and healthcare professionals, something that people have indicated is desirable (Seymour et al., 2015; Synnot et al., 2014). Research on the outcome of this approach, however, has been mixed. Owens et al. (2012) found that an attempt to involve healthcare professionals in a forum for discussing self-harm among young people was unsuccessful, with professionals citing both time constraints and uncertainty about how to interact with forum users as reasons for not engaging. Despite this, the community thrived and provided a supportive environment for members. This point has been highlighted by other researchers, who note that healthcare professionals are not necessarily skilled in
Internet communications (Dedding, van Doorn, Winkler, & Reis, 2011; Hart, Henwood, & Wyatt, 2004; McMullan, 2006). As a result, more investigation is required in order to determine what role healthcare professionals could play in the provision of online support, and how this role could be optimised in order to ensure that existing benefits for those with LTCs remain.

In addition, it could be argued that there is a need for the knowledge and experiences shared on forums to be harnessed. This has been highlighted by Pols (2013, 2014), who suggested that there is potential for the knowledge available on forums to be translated into ‘techniques’, which could be then shared with other patients and professionals. She argues that while this knowledge is available on forums, it is typically framed within the context of an individual’s experience, and as a result, it may be difficult for a casual reader to draw upon the tips and tricks contained within. She suggests that patient organisations could be involved in developing strategies to capture this information in a searchable, easy to access format. Interestingly, this is an approach that has been used within other fields. Mumsnet, a large UK-based parenting forum, routinely publishes books created from posts made on its discussion boards (Pedersen & Smithson, 2013). These guides include advice, support, and information around pregnancy, parenting, and raising babies and toddlers. The existence of these books indicates that there is a commercial market for the translation of forum knowledge into print form or other media. While they have not been explored empirically, this strategy is something that could be potentially useful for individuals with LTCs.

In particular, the level of detailed support described by those with diabetes in Chapter Four suggests that the support, advice, and information shared on diabetes forums may translate particularly well to this form of dissemination. Compiling information in a similar format may have a number of potential benefits, and would expand on many of the discussions raised within the present study. Firstly, it would enable forms of emotional and informational support to be delivered to those who may be unable or unwilling to participate in forums. It could be argued that that nature of dissemination would go some way towards addressing the literacy and privacy barriers to forum access described throughout Chapters Three, Four, and Five. Secondly, given the lack of clarity around the potential role of healthcare professionals in online forums, the compilation of information could take the form a collaborative effort between forum users and healthcare professionals. This could potentially negate concerns about the accuracy of the information available online (Middlemass et al., 2012; Nettleton, Burrows, & O'Malley, 2005), and provide patients with access to advice and information based on the lived experiences of
their peers which has been assessed and authorised by an ‘official’ source. For example, teams of forum users could compile information from forum posts, and this information could be assessed by healthcare professionals in order to ensure that it does not contradict existing medical guidance. Finally, this form of information could be incorporated into diabetes education programmes. This would allow those with diabetes to be presented with both medical and experiential information around the condition.

While this is a recommendation based on the findings of the present study, it is one that would need to be considered on the basis of future research. The acceptability of the translation of this information needs to be evaluated, as well as the most appropriate format or medium (e.g., book, website, leaflet, etc.) for this to take. Similarly, issues around the credibility of the information provided would require careful consideration. The results of the present study indicate that assessing information online involves a nuanced and multifaceted approach, and a number of strategies are implemented in order to establish trust. As a result, research is required in order to consider how information of this nature would be assessed out of the context of an interactive online discussion group. In addition, this approach may benefit from the inclusion of a quantitative approach, where the benefit and impact of disseminating patient knowledge is evaluated longitudinally.

Suggesting that this may offer a means of circumventing barriers to forum access is not to suggest that these barriers do not require further exploration. As highlighted in section 6.2, a number of individuals with ME/CFS described how sensory issues related to their condition left them unable to access the Internet. This is something that could warrant further consideration, as it has not received much attention in the literature (Badham & Hutchinson, 2013). In addition, as mentioned earlier, this could provide a potential direction for industry collaboration. However, a more pressing topic that requires discussion is the notion of the digital divide and online literacy (Diviani et al., 2015). As stated, the results of the present study suggest that while online support may be a valuable resource for those with LTCs, an increasing reliance on electronic communication may merely help those who are already catered for within existing healthcare systems (Viswanath & Kreuter, 2007). As a result, the application of sociology in ongoing technological research is desirable in order to address potential areas of inequality. Research suggests that, with the right approach such as increased availability and appropriate training, online access may be a means of addressing inequalities associated with health and healthcare provision (Brodie et al., 2000; Connolly & Crosby, 2014; Cotten & Gupta, 2004), indicating that there is potential for technology to act as a positive tool in
reducing inequalities. Thus care needs to be taken to ensure that this aspect of technology use is addressed in any future eHealth developments, and that the role of the digital divide and its impact is carefully considered in commissioning, conducting, and evaluating health services research.

In addition, the present study also highlighted potential directions for future research into the nature of Internet forums. As outlined in Chapter Five, moderators played an influential role within forums and were instrumental in setting and enforcing forum norms. This indicates that the nature of forums can be highly variable and may be dependent on a select few users. Supporting this finding, O’Neill, Ziebland, Valderas, and Lupiáñez-Villanueva (2014) described the concept of ‘superusers’ who created user-generated health-related content online on a daily basis and consequently were responsible for shaping the information that others accessed. Based on the findings of this research, further qualitative work that directly explores the experiences, views, and perspectives of moderators and superusers would be beneficial (e.g., Johnston et al., 2013). Addressing this notion in future research would provide a valuable insight into the dynamics of health discussion boards and allow a deeper understanding of how these resources can be harnessed in order to facilitate the management of LTCs. For example, Lekka, Efstathiou, and Kalantzi-azizi (2014) suggest that peer moderators can be successfully trained in basic counselling skills, such as the use of open ended questions, in order to create a more supportive environment for forum users. Their findings indicated that this could be achieved without disrupting the peer support relationship; however, further research could explore the potential tensions arising from training a select number of forum users and assigning them a ‘quasi-professional’ status (Kennedy et al., 2009).

Finally, this research aimed to provide some guidance on the ethics of conducting research into online spaces. It was concluded that forums are predominately viewed as public spaces, and forum members adapt what they share online in light of this perception. This is similar to research on Facebook, which indicates that while there are privacy concerns about the medium, information posted on Facebook is tailored towards a broad social audience (Burkell et al., 2014). This has implications for the use of forum posts as data, as it suggests that in the case of health discussion boards, participants generally expected that what they shared online would be accessed by a broader audience beyond those whom they were directly interacting with. However, as mentioned previously, the findings of this study are likely to be highly context specific, and this should not be taken as a blanket suggestion that will apply to all health discussion boards. What this research does indicate is the role
that moderators play in shaping forum users’ expectations around privacy and anonymity online. While research has highlighted potential gaps between actual and perceived privacy online (Bassett & O’Riordan, 2002; Harriman & Patel, 2014; Markham & Buchanan, 2012), the findings of this study indicate that moderators can provide researchers with an idea of the acceptability of an online space as a venue for research. As a result, these findings represent a way of harnessing the information provided by individuals online in order to provide feedback for practice and services which can be used for the ultimate improvement of patient experience. While this approach has been employed in a number of recent studies (Greaves et al., 2013; Shepherd et al., 2015), they have typically utilised publically accessible data, such as blogs or tweets, without seeking individual consent from users or administrators. The present study suggests a method of harnessing online data in a manner that may be both ethically sensitive and practical for researchers.

6.7 Conclusion
The present study aimed to qualitatively explore the views and experiences of individuals with LTCs in relation to Internet forums. The findings show that forums provided a medium for individuals to access information, advice, and support that supplemented rather superseded the supports and services provided by family, friends, and healthcare professionals. In addition, the usage of forums was grounded in an individual’s knowledge about health and illness and empowered users to engage with health services. Though ME/CFS discussion boards provided sites for activism as well as support, this activism was collaborative, with forum members drawing on medical terms and frameworks to situate themselves as active participants in the construction of medical knowledge.

Overall, it appeared that Internet forums offer a valuable resource for individuals living with the daily management of LTCs. This was particularly evident for those with diabetes, as the shared experiences online of others empowered and motivated them to manage their conditions and engage in healthy behaviours. However, consideration of these benefits must be tempered by reference to the level of online literacy required in order to utilise forums for health information and advice. As well as navigating concerns around misinformation online, forum users are also required to be sufficiently skilled in order to understand both the social and technical aspects of the spaces in which they are interacting.

In conclusion, this research provides a unique insight into the online experiences of individuals with LTCs. By examining the use of Internet forums within contested and uncontested conditions, the intertwined themes of trust, support, empowerment, and
identity online have been explored and highlighted. The findings of this study offer valuable perspectives that can be used to improve the experiences of those living with and managing of LTCs, as well as providing a useful foundation for future research.
Chapter Seven: Conclusion

7.0 Final Reflections

This thesis drew across a number of academic disciplines in order to present insights into the use of Internet forums by individuals with LTCs. As a result, it is necessary to briefly reflect on some of the key findings of the research and to highlight how they align with the existing research.

Forums resulted in the production of collaborative knowledge, where the self-policing nature of discussion boards allowed users to access a group consensus within a single medium. Members were facilitated to assess the information that they accessed online against the benchmark of other views and experiences that had been shared on the forum, as well as their own experiences with their condition. The integration of information and experiences enabled the dialogues on the forum to transition from information to contextual, embodied knowledge (Pols, 2013, 2014). In this way, health-related knowledge on the forums was co-produced through the iterations and negotiations of scientific information and lived experiences presented on the forums (Keeling et al., 2013). The community of forum users developed shared understandings and created knowledge structures which could in turn be utilised by those who accessed the forum (Neal & McKenzie, 2011). Crucially, this knowledge involved both lay and expert perspectives on health and illness and allowed forum members to access this third form of knowledge, which was more practical and useful that knowledge constrained by the sole inclusion of biomedical information or individual lay opinions.

The development of this third form of knowledge was aided by the development of trust on the forums. Rather than making a binary decision to act or not to act on the information that they accessed online, forum users instead had a much more nuanced approach to trust. Individuals with LTCs took a pragmatic, pluralistic approach to online resources. The process of establishing trust online was embedded and contextualised within an individual’s beliefs about health and illness (Netleton, Burrows, & O'Malley, 2005), their backgrounds and everyday lives (Kivits, 2006, 2009), and their relationships with forum members (Johnston et al., 2013). In addition to the individual methods of navigating forums, trust, much like knowledge, was also constructed on discussion groups. The shared experiences presented online enabled the community to collectively assess pieces or providers of information as credible.
In summary, this thesis had highlighted and emphasised the contextual and nuanced role that forums play in the lives of individuals with LTCs. The process of accessing and utilising online support and health-related knowledge via discussion boards was one that was embedded in users’ daily lives and healthcare practices. Rather than this process being a cause for ‘celebration’ or ‘concern’ (Nettleton, Burrows, & O'Malley, 2005), it was instead contingent on a number of individual, contextual, societal, and community-related factors.
References


of patient reported outcomes in a pragmatic, cluster randomised controlled trial. *BMJ (Clinical Research Ed.),* 346, f653. doi:10.1136/bmj.f653


193


Frost, J. H., & Massagli, M. P. (2008). Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another’s data. *Journal of Medical Internet Research, 10*(3), e15. doi:10.2196/jmir.1053


Lee, C. (2009b). The role of Internet engagement in the health- knowledge gap. *Journal of


the forum offers space for new forms of femininity to emerge online. Women’s Studies International Forum, 38, 97–106. doi:10.1016/j.wsif.2013.03.004


analysis. *International Journal of Qualitative Methods, 8*(1), 76–84.


Appendices

Appendix A: Participant Information Sheets
A.1 Diabetes participant information sheet

Participant Information Sheet

SOCIAL SUPPORT FROM THE INTERNET - THE EXPERIENCES OF PATIENTS WITH LONG TERM ILLNESSES

You are being invited to take part in a research study. Thank you for taking the time to read this information leaflet. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. This information sheet explains why we are doing the research and what your participation will involve. Taking part in this research is voluntary and you are under no obligation to participate.

What is the purpose of this study?
The purpose of this research is to find out about the experiences of patients with long-term illnesses who use the Internet. To do this, we will be interviewing people with chronic illnesses throughout the UK. Addressing this question will add to previous research on the use of online discussion groups, or forums, by patients, and help researchers and health professionals to understand the role that Internet forums play in the lives of chronically ill patients.

This study is being carried out as part of a PhD project at the University of Manchester. Ellen Brady is the PhD student and is supervised by Dr Caroline Sanders, Dr Ivaylo Vassilev and Professor Anne Rogers. These people make up the research team and their contact details are listed at the end of this information sheet. The research is being run and funded by the Centre for Primary Care, School of Community Based Medicine at the University of Manchester and the Medical Research Council.

Why was I asked to take part?
We would like to understand the views and experiences of people with diabetes living in the UK. You have been invited to contribute to this study as a person with diabetes who may use the Internet to read about or discuss your health. We would like to talk to people with a range of different views and experiences.
Your level of use of the Internet is not an issue, as we are interested in speaking to both frequent and infrequent users. Anyone with type 1 or type 2 diabetes in the UK over the age of 18 is invited to take part.

**Do I have to take part?**
Your participation is entirely voluntary. It is up to you to decide whether or not to take part, but you can discuss your decision with friends and family if you want. You should read through this information sheet carefully to see what is involved in the study and what will be asked in the interview. We will invite you to sign a consent form before the interview to show that you have agreed to take part.

If you decide to take part, you can withdraw from the study at any time without giving a reason. The contact details of the research team are given at the end of the information sheet in case you decide to stop taking part.

**What happens if I decide to take part?**
If you decide to participate in this study, you will be invited to take part in an interview to talk about your illness, your support networks and your use of the Internet. This will last between 30 and 60 minutes. We will ask you a range of questions, but the interview will be informal and you will be able to stop at any time. You do not have to answer any questions that you do not want to answer. The interview will be audio-recorded because it is hard to take note of what people say and listen carefully at the same time. Afterwards, the interview will be typed up. We do this to help us remember what people say and to ensure a full and accurate account of the views that are presented.

The interview will take place by phone or in person, whichever is easier for you. If you would like to be interviewed over the phone, we can call you at a time that is convenient for you. If you would like to be interviewed in person, we can speak to you at your home or another convenient location. We will only need to interview you once, but if you would prefer to take part in two or more short interviews rather than one longer interview, we can arrange that.

**Are there any benefits to my participation?**
There are no direct benefits to your participation in this study. However, you may find it an interesting experience. Taking part will give us a better idea of the views and experiences of people with diabetes, and will help researchers and health professionals to understand the role that the Internet plays in the lives of chronically ill patients.

**Are there any risks involved in participating?**
There are no known risks associated with participating. Everyone who takes part in the study will remain anonymous. Interviews will be arranged at a time and a place that is convenient to you. You can stop taking part in the study at any time and you do not have to answer any questions that you do not want to. Some people may find it distressing to discuss their experiences with diabetes and their support networks and use of the Internet. You do not have to discuss any issues that you do not feel comfortable discussing.

**What happens if I do not want to take part?**
If you do not want to take part in this study, no further action will be taken. You will not be contacted again by the research team and none of the health care services that you receive will be affected.
Will my taking part in the study be kept confidential?
Everything that you tell us during interviews is completely confidential. All papers and notes relating to the study will be kept in a locked filing cabinet at the University of Manchester. Typed notes and electronic audio files will be stored on a password protected computer. Notes and computer files will not be played or shown to anyone outside the research team. We have to keep these files for ten years so that research reports can be made and so that the accuracy of the information can be checked. After ten years, all information will be destroyed.

When we type up the recordings made during the interviews and write about the results of the research, all personal details will be removed so that no-one will know who you are. No real names will be used, including the names of anyone that you mention in your interview, such as your doctor or other healthcare professionals. If you are interested, we will send you a summary of what we find out in the study.

You are free to talk about your participation in this study with your family and friends if you wish to do so.

What will happen if I don’t want to carry on with the study?
You can withdraw from the research at any time, either during, in the middle or after the interview. If you decide not to take part after the interview, the recording of the interview will be deleted and will not be used in this study.

What will happen to the results of the research?
Results from the study may be published in social sciences journals and health care journals or presented at conferences. No information that could identify participants will be included in the results. It is important to tell people about the findings of this study to help researchers and health professionals understand the role that the Internet plays in the lives of chronically ill patients.

What do I need to do next?
A researcher will contact you to see if you would like to take part in this research. If you agree to be interviewed, we will arrange an interview, either by phone or in person, at a time and location that is convenient for you. Before the interview we would like you to sign a consent form. If you do not want to take part, then please tell the researcher.

Thank you very much for taking the time to read this information sheet.

Further information and contact details
If you have any questions regarding the study, please contact Ellen Brady or another member of the research team at the Centre for Primary Care, University of Manchester.

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Participant Information Sheet

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What is the purpose of this study?
The purpose of this research is to find out about the experiences of patients with long-term illnesses who use the Internet. In particular, the research aims to look at the social support gained from the Internet by people with chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME). To do this, we will be interviewing people with ME/CFS throughout the UK. Addressing this question will add to previous research on the use of online discussion groups, or forums, by patients, and help researchers and health professionals to understand the role that Internet forums play in the lives of chronically ill patients.

This study is being carried out as part of a PhD project at the University of Manchester. Ellen Brady is the PhD student and is supervised by Dr Caroline Sanders, Dr Ivaylo Vassilev and Professor Anne Rogers. These people make up the research team and their contact details are listed at the end of this information sheet. The research is being run and funded by the Centre for Primary Care, School of Community Based Medicine at the University of Manchester and the Medical Research Council.

Why was I asked to take part?
We would like to understand the views and experiences of people with ME/CFS living in the UK. You have been invited to contribute to this study as a person with ME/CFS who may use the Internet to read about or discuss your health.
Your level of use of the Internet is not an issue, as we are interested in speaking to both frequent and infrequent users. Anyone with ME/CFS in UK over the age of 18 who uses the Internet is invited to participate.

Do I have to take part?
Your participation is entirely voluntary. It is up to you to decide whether or not to take part, but you can discuss your decision with friends and family if you want. You should read through this information sheet carefully to see what is involved in the study and what will be asked in the interview. We will invite you to sign a consent form before the interview to show that you have agreed to take part.

If you decide to take part, you can withdraw from the study at any time without giving a reason. The contact details of the research team are given at the end of the information sheet in case you decide to stop taking part.

What happens if I decide to take part?
If you decide to participate in this study, you will be invited to take part in an interview to talk about your illness and your use of the Internet. This will last between 30 and 60 minutes. We will ask you a range of questions, but the interview will be informal and you will be able to stop at any time. You do not have to answer any questions that you do not want to answer. The interview will be audio-recorded because it is hard to take note of what people say and listen carefully at the same time. Afterwards, the interview will be typed up. We do this to help us remember what people say and to ensure a full and accurate account of the views that are presented.

The interview will take place by phone or in person, whichever is easier for you. If you would like to be interviewed over the phone, we can call you at a time that is convenient for you. If you would like to be interviewed in person, we can speak to you at your home or another convenient location. We will only need to interview you once, but if you would prefer to take part in two or more short interviews rather than one longer interview, we can arrange that.

Are there any benefits to my participation?
There are no direct benefits to your participation in this study. However, you may find it an interesting experience. Taking part will give us a better idea of the views and experiences of people with ME/CFS, and will help researchers and health professionals to understand the role that the Internet plays in the lives of chronically ill patients.

Are there any risks involved in participating?
There are no known risks associated with participating. Everyone who takes part in the study will remain anonymous. Interviews will be arranged at a time and a place that is convenient to you. You can stop taking part in the study at any time and you do not have to answer any questions that you do not want to. Some people may find it distressing to discuss their experiences with ME/CFS and their use of the Internet. You do not have to discuss any issues that you do not feel comfortable discussing.

What happens if I do not want to take part?
If you do not want to take part in this study, no further action will be taken. You will not be contacted again and none of the health care services that you receive will be affected.
Will my taking part in the study be kept confidential?
Everything that you tell us during interviews is completely confidential. All papers and notes relating to the study will be kept in a locked filing cabinet at the University of Manchester. Typed notes and electronic audio files will be stored on a password protected computer. Notes and computer files will not be played or shown to anyone outside the research team. We have to keep these files for ten years so that research reports can be made and so that the accuracy of the information can be checked. After ten years, all information will be destroyed.

When we type up the recordings made during the interviews and write about the results of the research, all personal details will be removed so that no-one will know who you are. No real names will be used, including the names of anyone that you mention in your interview, such as your doctor or other healthcare professionals. If you are interested, we will send you a summary of what we find out in the study.

You are free to talk about your participation in this study with your family and friends if you wish to do so.

What will happen if I don’t want to carry on with the study?
You can withdraw from the research at any time, either during, in the middle or after the interview. If you decide not to take part after the interview, the recording of the interview will be deleted and will not be used in this study.

What will happen to the results of the research?
Results from the study may be published in social sciences journals and health care journals or presented at conferences. No information that could identify participants will be included in the results. It is important to tell people about the findings of this study to help researchers and health professionals understand the role that the Internet plays in the lives of chronically ill patients.

What do I need to do next?
Ellen Brady will contact you to see if you would like to take part in this research. If you agree to be interviewed, we will arrange an interview, either by phone or in person, at a time and location that is convenient for you. Before the interview we would like you to sign a consent form. If you do not want to take part, then please tell the researcher.

Thank you very much for taking the time to read this information sheet.

Further information and contact details
If you have any questions regarding the study, please contact Ellen Brady or another member of the research team at the Centre for Primary Care, University of Manchester.

Ellen Brady, PhD Student
Phone number: 0161 275 7652
Email: ellen.brady@postgrad.manchester.ac.uk

Dr Caroline Sanders
Email: caroline.sanders@manchester.ac.uk

Dr Ivaylo Vassilev
Email: ivaylo.vassilev@manchester.ac.uk
Professor Anne Rogers
Email: anne.rogers@manchester.ac.uk
Appendix B: Participant Consent Form

Participant Consent Form

SOCIAL SUPPORT FROM THE INTERNET - THE EXPERIENCES OF PATIENTS WITH LONG TERM ILLNESSES

Participant identification number:

Please read through the following statements carefully and initial each box to show that you agree to take part. If you do not want to take part, please hand the form back to the researcher without initialling any of the boxes.

1. I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I have the right to withdraw from the study at any time without giving a reason.

3. I understand that the information collected will be submitted for examination to the University of Manchester, and that it may be presented and/or published in academic journals and at conferences, but that no individual will be identifiable from the information.

4. I understand that the interviews will be audio recorded.

5. I agree to take part in the above study.

Name of participant    Date    Signature

Name of researcher    Date    Signature
Appendix C: Ethical Approval Letter

The University of Manchester

Secretary to Research Ethics Committees
Room 2.004 John Owens Building
Compliance and Risk Office
University of Manchester
Oxford Road
Manchester; M13 9PL
Tel: 0161 275 2206/2046
Fax: 0161 275 8697
Email: research.ethics@manchester.ac.uk
Ref: ethics/12232

Dr Caroline Sanders
National Primary Care Research and Development Centre (NPCRDC),
School of Community Based Medicine,
Williamson Building.

3rd October 2012

Dear Dr Sanders,

Research Ethics Committee 4

/Brady, Sanders, Vassilev, Rogers: Exploring the use of online social networks by patients with chronic illnesses: online and offline dynamics (ref 12232)/

I write to thank Ms Brady and Dr Vassilev for coming to meet the Committee on 26th September 2012 and to confirm that it gave the above research project, after the submission of amendments / clarifications, a favourable ethical opinion.

This approval is effective for a period of five years and if the project continues beyond that period it must be submitted for review. It is the Committee’s practice to warn investigators that they should not depart from the agreed protocol without seeking the approval of the Committee, as any significant deviation could invalidate the insurance arrangements and constitute research misconduct. We also ask that any information sheet should carry a University logo or other indication of where it came from, and that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a university computer or kept as a hard copy in a location which is accessible only to those involved with the research.

Finally, I would be grateful if you could complete and return the attached form at the end of the project or by the end of August 2013.

We hope the research goes well.

Yours sincerely,

[Signature]

Dr Deborah Bentley
Secretary to University Research Ethics Committee 4
Appendix D: Recruitment Materials

D.1 Participants with diabetes – email to forum gatekeepers

Hello,

I am a PhD student in the Institute of Population Health at the University of Manchester. As part of my research, I am looking at the views and experiences of people with diabetes who use the Internet, and particularly Internet support groups. Addressing this question will add to previous research on the use of online discussion groups by patients, and help researchers and health professionals to understand the role that Internet forums play in the lives of chronically ill patients.

To do this, I would like to interview a number of people with either type 1 or type 2 diabetes about their experiences with their illness and their use of the Internet. With your permission, I would like to recruit interviewees through the [forum name] by starting a thread on the research section of the board with information about the study and my contact details. I have attached an information sheet which will be distributed to potential participants with more details on the study.

I have registered on the forum, but as I do not have any posts yet, I am unable to PM the moderators or administrators to request permission to recruit participants. I can be contacted by email (ellen.brady@postgrad.manchester.ac.uk) or phone (0161 275 7652) if you have any questions or would like to discuss this further.

Thank you,
Ellen
D.2 Participants with diabetes – message to be posted on forums

Hi everyone,

My name is Ellen Brady and I am a PhD student at the University of Manchester in the UK. As part of my research, I am looking at the views and experiences of patients with long term illnesses who use the Internet and particularly Internet forums. Addressing this topic will add to previous research on the use of online discussion groups by patients, and help researchers and health professionals to understand the role that Internet forums play in the lives of chronically ill patients.

In particular, I would like to know more about the experiences of people over the age of 18 with diabetes (both type 1 and type 2) throughout the UK. In order to do this, I would like to interview a number of people with diabetes about their use of the Internet. I am interested in speaking to both frequent and infrequent Internet users, as I would like to talk to people with a range of views and experiences.

These interviews will take place by phone or in person, whichever is easier for you, and will last 30 to 60 minutes. Everything that is said during the interview will be kept confidential. If you think you would like to take part, I can send you an information sheet with more details on the study.

If you are based in the UK and would like further information, or to take part in the study, please contact me by email at ellen.brady@postgrad.manchester.ac.uk or by phone at 0161 275 7652. You can also PM me.

Thank you,
Ellen
D.3 Participants with diabetes – magazine advertisement

A researcher at the University of Manchester would like to hear from people aged 18 or over who have type 1 or type 2 diabetes and use the internet to find out information about their condition. They are studying the experiences of people who use online discussion groups as part of a study that could help to improve support services for people with diabetes.

For information contact Ellen Brady on 0161 275 7652 or ellen.brady@postgrad.manchester.ac.uk
D.4 Participants with ME/CFS – email to forum gatekeepers

Dear [name of forum],

I am emailing you in relation to research on ME/CFS. I apologise if this is not the correct email address to use, and I would be grateful if you could put me in contact with whoever is appropriate.

I am a PhD student at the University of Manchester in the UK. As part of my research, I am looking at the views and experiences of patients with ME/CFS who use the Internet and specifically Internet forums. Addressing this topic will add to previous research on the use of online discussion groups by patients, and help researchers and health professionals to understand the role that Internet forums play in the lives of chronically ill patients, particularly those with ME/CFS.

In order to do this, I would like to interview a number of people with ME/CFS about their use of the Internet. With your permission, I would like to recruit UK based interviewees through the [name of forum] by starting a thread with information about the study and my contact details. If you do not wish the website to be involved in this research, please let me know and I will not attempt to recruit forum users.

My email address is ellen.brady@postgrad.manchester.ac.uk and I would be happy to discuss this further.

Thank you,
Ellen Brady
D.5 Participants with ME/CFS – message to be posted on forums

Hi everyone,

My name is Ellen Brady and I am a PhD student at the University of Manchester in the UK. As part of my research, I am looking at the views and experiences of patients with long term illnesses who use the Internet and particularly Internet forums. Addressing this topic will add to previous research on the use of online discussion groups by patients, and help researchers and health professionals to understand the role that Internet forums play in the lives of chronically ill people.

In particular, I would like to know more about the experiences of people over the age of 18 with ME throughout the UK. In order to do this, I would like to interview a number of people with ME about their use of the Internet. I am interested in speaking to both frequent and infrequent Internet users, as I would like to talk to people with a range of views and experiences.

These interviews will take place by phone or in person, whichever is easier for you, and will last 30 to 60 minutes. If you would prefer, you can complete several shorter interviews rather than one longer interview. Everything that is said during the interview will be kept confidential. If you think you would like to take part, I can send you an information sheet with more details on the study.

If you are based in the UK and would like further information, or to take part in the study, please contact me by email at ellen.brady@postgrad.manchester.ac.uk or by phone at 0161 275 7652.

Thank you,

Ellen
D.6 Participants with ME/CFS – email sent to ME/CFS support groups

Dear [name],

I am a PhD student in the Institute of Population Health at the University of Manchester. As part of my research, I am looking at the views and experiences of people with ME/CFS who use the Internet, and particularly Internet support groups. To do this, I would like to interview people with ME/CFS about their use of the Internet, and I was hoping that I might be able to publicise my research within the [name and location of support group].

If you thought that people may be interested in taking part, I could send out information sheets with more information on my study and my contact details to be distributed to the support group attendees. Alternatively, I could drop into the support group meetings to briefly introduce myself and to answer any questions that people may have. If you would not like the [name of support group] to be involved, please let me know.

Thank you,
Ellen
Appendix E: Interview Materials
E.1 Demographic questionnaire

Social support from the Internet – Demographic questionnaire

Please answer each question by ticking or putting an X in the appropriate box

1. What is your current age?
   - 18-25
   - 26-30
   - 31-35
   - 36-40
   - 41-45
   - 46-50
   - 51-55
   - 56-60
   - 61-65
   - 66-70
   - 71-75
   - 76+

2. What is your gender?
   - Male
   - Female

3. What is your ethnicity? Please tick the appropriate box below

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>White - English / Welsh / Scottish / Northern Irish / British</td>
<td></td>
</tr>
<tr>
<td>White - Irish</td>
<td></td>
</tr>
<tr>
<td>White - Gypsy or Irish Traveller</td>
<td></td>
</tr>
<tr>
<td>White - Any Other White background</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Black Caribbean</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Black African</td>
<td></td>
</tr>
<tr>
<td>Mixed / Multiple ethnic group - White and Asian</td>
<td></td>
</tr>
</tbody>
</table>
Mixed / Multiple ethnic group - Any Other Mixed / multiple ethnic background

Asian / Asian British – Indian
Asian / Asian British – Pakistani
Asian / Asian British – Bangladeshi
Asian / Asian British – Chinese
Asian / Asian British - Any other Asian background
Black / African / Caribbean / Black British – African
Black / African / Caribbean / Black British – Caribbean
Black / African / Caribbean / Black British – Any other Black / African / Caribbean background
Other ethnic group – Arab
Other ethnic group – Any other ethnic group
Any other
Not known/not provided

4. What is your relationship status? Please tick the appropriate box below

<table>
<thead>
<tr>
<th>Relationship status</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single</td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td></td>
</tr>
<tr>
<td>Separated, but still legally married</td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td></td>
</tr>
<tr>
<td>In a registered same-sex civil partnership</td>
<td></td>
</tr>
<tr>
<td>Separated, but still legally in a same-sex civil partnership</td>
<td></td>
</tr>
<tr>
<td>Formerly in a same-sex civil partnership which is now legally dissolved</td>
<td></td>
</tr>
<tr>
<td>Surviving partner from a same-sex civil partnership</td>
<td></td>
</tr>
</tbody>
</table>
5. Who do you live with in your current home? Please tick the appropriate box below.

<table>
<thead>
<tr>
<th>Living situation</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>Live alone</td>
<td></td>
</tr>
<tr>
<td>Spouse/partner</td>
<td></td>
</tr>
<tr>
<td>Parent(s)</td>
<td></td>
</tr>
<tr>
<td>Children under 18</td>
<td></td>
</tr>
<tr>
<td>Children over 18</td>
<td></td>
</tr>
<tr>
<td>Other family</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td></td>
</tr>
<tr>
<td>Tenants</td>
<td></td>
</tr>
</tbody>
</table>

6. What is your highest level of education? Please tick the appropriate box below.

<table>
<thead>
<tr>
<th>Highest level of education achieved</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 - 4 O levels / CSEs / GCSEs (any grades), Entry Level, Foundation Diploma</td>
<td></td>
</tr>
<tr>
<td>NVQ Level 1, Foundation GNVQ, Basic Skills</td>
<td></td>
</tr>
<tr>
<td>5+ O levels (passes) / CSEs (grade 1) / GCSEs (grades A*- C), School Certificate, 1 A level / 2 - 3 AS levels / VCEs, Higher Diploma</td>
<td></td>
</tr>
<tr>
<td>NVQ Level 2, Intermediate GNVQ, City and Guilds Craft, BTEC First / General Diploma, RSA Diploma</td>
<td></td>
</tr>
<tr>
<td>Apprenticeship</td>
<td></td>
</tr>
<tr>
<td>2+ A levels / VCEs, 4+ AS levels, Higher School Certificate, Progression / Advanced Diploma</td>
<td></td>
</tr>
<tr>
<td>NVQ Level 3, Advanced GNVQ, City and Guilds Advanced Craft, ONC, OND, BTEC National, RSA Advanced Diploma</td>
<td></td>
</tr>
<tr>
<td>Degree (for example BA, BSc), Higher degree (for example MA, PhD, PGCE)</td>
<td></td>
</tr>
<tr>
<td>NVQ Level 4 - 5, HNC, HND, RSA Higher Diploma, BTEC Higher Level</td>
<td></td>
</tr>
<tr>
<td>Professional qualifications (for example teaching, nursing, accountancy)</td>
<td></td>
</tr>
<tr>
<td>Other vocational / work-related qualifications</td>
<td></td>
</tr>
<tr>
<td>-----------------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td>Foreign qualifications</td>
<td></td>
</tr>
<tr>
<td>No qualifications</td>
<td></td>
</tr>
</tbody>
</table>

7. What is your current employment status? Please tick the appropriate box below

<table>
<thead>
<tr>
<th>Employment</th>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employed</td>
<td></td>
</tr>
<tr>
<td>Self-employed</td>
<td></td>
</tr>
<tr>
<td>Out of work and looking for work</td>
<td></td>
</tr>
<tr>
<td>Out of work but not currently looking for work</td>
<td></td>
</tr>
<tr>
<td>A homemaker</td>
<td></td>
</tr>
<tr>
<td>A student</td>
<td></td>
</tr>
<tr>
<td>Retired</td>
<td></td>
</tr>
<tr>
<td>Unable to work</td>
<td></td>
</tr>
</tbody>
</table>
E.2 Participant interview schedule

Introduction
- Reiterate the nature of the study, the reason for contact with this particular interviewee and the proposed length of the interview.
- Remind the interviewee that their interview is being tape recorded, if it is taking place by telephone, and that all identifying information will be removed from interview transcripts.
- Allow interviewee an opportunity to ask questions and check that they are happy to continue.

Participant’s health and illness
Can you tell me about your illness and your day to day life?
- What kind of health problems do you have?
- What, if any, changes has your condition made to your day to day life?
- What do you do to look after yourself and manage your condition?
- What aspects of your condition do you find hardest to manage?

Informal support
Can you tell me what kind of help and support you receive for your condition from your family and friends?
- Who helps you? What do they do?
- Would you talk to your family/friends/neighbours if you had a problem or were worried about your condition?
- Who would you talk to?
- Would you like more help and support?

Formal support
Can you tell me about the experiences that you’ve had with doctors and health professionals in dealing with your condition?
- Have any of these experiences been particularly bad or good? Why?
- Have you been happy with the advice and treatment that you’ve received?
- Would you like more help and support from doctors/health professionals?

Internet usage
- Do you ever go on the Internet to read about or discuss your condition?
- What kind of websites do you use?
- How often do you use it/them?
- How do you use it/them? (e.g. to look for advice, information, support?)

**Experiences of Internet websites/forums**
- Why do you use X [website mentioned by interviewee]?
  Prompt: Why do you think other people use it?
- If participant does not use health related websites] Why don’t you use health related websites and/or discussion boards?
- What do/did you get out of it?
  Prompts: How would you describe what the Internet/websites/forums means to you to people who don’t know it?
- What do/did you like/dislike about the Internet/websites/forums?
  Prompts: What do you think other people like/dislike about it?
- [If participant uses/used health related websites infrequently] Why do you use X infrequently?
  Prompts: What would make you use it more frequently?
- [If participant does not use health related websites] Would you ever start using health related websites and/or discussion boards?
  Prompts: What would make you use health related websites?
- How do you think your experience of X compares to your experiences with family/friends/health professionals?
  Prompts: Are there differences in what you talk about/look at online compared to what you talk about with your family/friends/health professionals?
  Are there differences in how useful the Internet/websites/forums is compared to your family/friends/health professionals?
- Sometimes people describe Internet discussion boards as ‘safe spaces’. Can you tell me what you think about that?
  Prompts: Is anonymity on the Internet/websites/forums important to you?
  Have you ever written anything online that you wouldn’t want anyone who knows you to read?
  Do you think that what you say online is private?

**Other**
- What else do you use the Internet for?
- Do you have any further comments or questions?
Closing

- Remind the interviewee of their right to withdraw from the study, and that any identifying information will be removed from interview transcripts. Remind interviewee of contact details and encourage them to ask questions at any stage.
E.3 Interview vignettes

E.3.1 Vignette one

Rachel has ME/CFS and regularly posts in a forum used by other people with similar symptoms. She is concerned that the forum can be viewed by anyone, not just the people who contribute to it. She starts a thread on the forum to discuss this and to see if other people feel the same way.

Rachel:

“Some people are revealing some quite intimate info, and I myself often forget that the forum is open to outsiders to view.”

Here are some of the responses that Rachel receives.

Sarah:

“Not too bothered by this as I have never said anything that I would not be prepared to share with the whole world. I tend to think that the more people that know of the devastation that is caused by this illness, the better. I would like to think that some of the stuff is read by the medical profession - though I think not!!!”

Jane:

“Hi, I’ve just seen this thread and am rather concerned and wondering whether not to post anymore, to be honest. That’s not just this forum but a lot of open forums too.

People need to realize that as we all get so very down, we may say things on here that we wouldn’t say to family and friends and maybe its rather personal.

I shall be having a think as to whether I shall post on here for a while now.”

What do you think about what people have said to Rachel?

What would you say to Rachel?

Do you have anything else to add?
**E.3.2 Vignette two**

John has diabetes. He posts on an Internet forum for people with diabetes to describe some symptoms he has been experiencing. Another forum member suggests a possible diagnosis for John’s symptoms and advises him to talk to his doctor. John would like to print out information about the possible diagnosis and bring it with him to his doctor, but he is worried that his doctor will think he is rude.

John:

“I’m wondering if I should print out information on it and take it in? Or would that be rude? I really like this doctor and don’t want to offend her or her assistants…”

Here are some of the responses that John receives.

Mary:

“It is totally fine to print out info and take it to a doctor, as long as it is from a reputable medical source, I do it all the time. A good doctor will know that they don’t know everything and will be happy to have a look.

If you have a doctor that is too arrogant to read anything, and is delusional enough to think they know everything, then get a new doctor!”

Adam:

“No! I do it all the time! Usually just one or two short pages, and only if I plan on discussing that exact issue with the doctor during that appointment.

Probably also wait until you have established a good relationship with the doctor also. Going into a first visit with a giant folder of information is probably not the best approach.”

Mark:

“We are now in the Internet age, and many doctors have got used to this, though there are some out there still adjusting to their patients doing this. But any doctor who has confidence and is not on an ego trip won’t be fazed by it.

A doctor not being interested in learning new things with their patient will be a VERY out of date doctor in today’s day and age.”

What do you think about what people have said to John?

What would you say to John?

Do you have anything else to add?
E.3.3 Vignette three

Molly has fibromyalgia. She starts a thread on an Internet forum describing her symptoms and how the disease affects her. She uses the thread as an opportunity to explain her condition to people who do not understand fibromyalgia and to write down some of the things that she would like to say to them.

Molly:

“Some days I feel so tired. My body weights a ton, my whole body aches. I have no energy. Even though I have been in bed all night, I am going to have to go back to bed again. Please understand how I feel, I don't want to live my life in bed. It is not my choice, the choice has been taken away from me.

I hope this helps the non believers to understand just a little of what we go through on a day to day basis.”

Here are some of the responses that Molly receives.

Sam:

“Thanks for this. You have expressed what I am too exhausted to explain. Really struck a cord - well much more than one if I am honest. I have really struggled this winter and your eloquent words helped me when I was feeling particularly low. I wouldn’t want anyone to feel how I feel, but it does help to know you are not alone.”

Donna:

“This forum is making such a big difference to me, as not many folk understand how I'm feeling. I try not to talk about it to family as I feel they roll their eyes as though I bore them.”

Peter:

“I would love to print this off and give it to my work colleagues, my boss, my partner and my family. It was like reading how I feel everyday. No one does understand this illness even when they pretend they do.”

What do you think about what people have said to Molly?

What would you say to Molly?

Do you have anything else to add?
**Appendix F: Participant Information**

**F.1 Summary participant demographic information**

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Age</th>
<th>Condition</th>
<th>Ethnicity</th>
<th>Relationship Status</th>
<th>Living Situation</th>
<th>Education</th>
<th>Employment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alan</td>
<td>Male</td>
<td>66-70</td>
<td>Type 1</td>
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*Demographic information was not available for Susan*