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Understanding the networks of those using the internet to support self-management and the role of ties mediated online in supporting long-term condition management. A mixed-methods study.

by

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ABSTRACT

Long-term condition self-management often involves a diverse range of work, including the contribution of strong, weak and less visible ties (Rogers et al, 2014; Vassilev et al, 2013). The increased social reach afforded by the internet calls for an exploration of online support within personal networks of those managing a long-term condition in daily life and this thesis examines the role and contribution of online support within personal networks.

Three papers constitute the core of this thesis; the first of these was a qualitative meta-synthesis, which examined the role of illness work online in self-management support with a view to conceptualising the nature of the field. It implicated the relevance of four network processes feeding into self-management in online communities: (1) collective knowledge and identification through lived experience; (2) support, information, and engagement through readily available gifting relationships; (3) sociability that extends beyond illness; and (4) online disinhibition as a facilitator in the negotiation of online relationships.

The second paper, a secondary analysis of the social network survey data of 300 participants, described the individual and network characteristics of the personal communities of people using the internet and the role of offline support, network resources and community participation in using the internet for condition management. This study found that participants using the internet for condition management also received more offline emotional work than those who did not. No associations were found between using the internet for health and other types of offline support.

The third paper, reports on data from qualitative interviews with 30 participants which included ego network mapping as a heuristic device to frame conversations about who was turned to for assistance. The study aimed to understand the role of ties mediated online within an overall personal configuration of illness related support. The findings show that those using the internet to support management were able to extend their network in response to unmet offline needs, leverage offline support with online support, or substitute offline support with online ties.

This thesis purports to make an original contribution to the research literature through A) showing the network processes and engagement shaping online contact and use of resources for condition management and through B) revealing the ability of those able to draw on the internet for condition management to overcome offline support deficits, leverage and avoid existing support through combining on and offline networks, resources and worlds.

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DECLARATION OF AUTHORSHIP

I, Chris Allen declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Understanding the networks of those using the internet to support self-management and the role of ties mediated online in supporting long-term condition management. A mixed-methods study.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. Parts of this work have been published as:

    Allen, C., Vassilev, I., Kennedy, A., Rogers, A. (2016). Long-Term Condition Self-Management Support in Online Communities: A Meta-Synthesis of Qualitative Papers. 18 (3). e61.

    Allen, C., Vassilev, I., Lin, SX., Culliford, D., Rogers, A. (2018). The contribution of internet use in personal networks of support for long-term condition self-management. Chronic Illness.

8. The design, conduct and write up for each of these papers have been overseen by the project supervisors, Professor Anne Rogers, Professor Anne Kennedy and Dr Ivaylo Vassilev. They are therefore listed as co-authors on each of the above papers. In addition, two statisticians, Dr David Culliford and Dr Sharon Lin provided statistical support on the second paper and are therefore listed as co-authors on that paper.

9. The final, unpublished paper, titled ‘Care Transition 2.0: A qualitative study of work and relatedness of ties mediated online in supporting long-term condition self-management’ was designed, analysed, interpreted and written by myself with supervision, advice and comments from Professor Anne Rogers, Professor Anne Kennedy, and Dr Ivaylo Vassilev. It is currently being peer reviewed.

10. This thesis was designed, analysed, interpreted and written by myself with supervision, advice and comments from Professor Anne Rogers, Professor Anne Kennedy, and Dr Ivaylo Vassilev.

Signed: ....

Date: ....

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I would like to personally thank my brilliant and dedicated supervisors Professor Anne Rogers, Dr Ivalyo Vassilev and Professor Anne Kennedy. I would not have got to this stage, were it not for your expert guidance, counselling and support. I would also like to thank my wife, Helen for her love and support. This year has been incredibly tough. You have kept me going.

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I would like to thank all the participants who have spared their time to talk to me, many of whom welcomed me into their own homes to talk about their experiences of managing chronic illness. I hope this thesis and its associated publications allows your voices to be heard.

Chapter 1: Long-term Condition Self-Management Support, Social Networks and Online Communities.

> “A medication or technological resource can raise energy levels or improve upon ability to perform, thereby increasing the self as a resource, decreasing the need for others as resources, and increasing others’ time and energy for the accomplishment of other tasks” (Corbin and Strauss, 1985, p.241)

1.1 Introduction

There has been growing recognition of the potential role that both the internet and social networks play in broadening and re-directing the agenda for the prevention and management of health and illness (Hunt et al, 2015; Griffiths et al, 2015; Ziebland et al, 2012). In terms of this thesis within this broad agenda, it has aligned with a dedicated research theme aimed at the translation of knowledge into health care practice. Engagement with self-directed support is a research and implementation theme of the NIHR CLAHRC Wessex, whose overall vision is to improve the health of people within the region, whilst ensuring the quality and cost-effectiveness of health care delivery. This PhD thesis sits within this research and implementation theme; which aims to better understand the mechanisms that allow individuals to benefit from their social networks and links to community resources to support engagement with condition management. The current projects within this theme look at engagement with self-management support and social networks with a focus on offline social networks. These projects are supported by a body of research that demonstrate the social context of long-term condition (LTC) self-management and more specifically, the role of others in shaping and supporting self-management practices (Rogers et al., 2011; Vassilev et al., 2011; Vassilev et al., 2013; Reeves et al., 2014). To date, there has been relatively less of a focus on the role of ties mediated online in supporting self-management practices and an understanding of their role within one’s total configuration of personal network support. This is the focus of the three papers constituting the core of the thesis.

This chapter frames the thesis in the context of what from the literature is already understood in relation to LTC self-management and the attempts that have been made to operationalise it. This has typically aimed at eliciting and modifying individual behaviour change, attitude and activities (Kennedy et al, 2007; Lorig et al, 2008; Morgan et al, 2017). In establishing the limitations of more traditional approaches, the chapter moves on to look at patient systems of self-management implementation, drawing on the role of personal networks, including the potential role of online communities and ties mediated online. The social network approach that has been adopted, seeks to support the uptake of available and underused network resources that exist in the everyday worlds of those managing illness (Kennedy et al, 2016), of which online ties increasingly form a part (Ziebland et al, 2012). The availability of online ties brings with them the potential to disrupt the current roles and responsibilities of self-management support, by affording people more options than previously available. By focussing on this aspect, there is the opportunity to better understand the overall contribution to condition management and its leverage, which typically occurs outside of formal care.

Reflecting on my previous clinical work, in both acute and community settings, my contact with those managing a LTC, made me interested in their everyday management strategies, including the hidden work they did. The usage statistics at the time suggested that the internet was becoming an increasing feature of self-management practices (Dutton et al, 2013; Thackeray et al, 2013), yet it was rarely discussed. Many of the patients who elected not to discuss their everyday strategies and knowledge were I feel, experiencing what is discussed in research as a ‘double bind’ (Bowes, 2012; Chiu et al, 2011; Stevenson et al, 2007). They were knowledgeable about their condition and how to manage it but didn’t want to undermine formal care (in this case, me). Such tensions might be limiting the opportunities for collaborative approaches to self-management that considers what people value; as well as their existing approaches to self-management, their existing knowledge, and the resources that they have available to them, including their ability to use them.

This new orientation to LTC self-management is not fully understood. By looking at the role of the internet and online ties in relation to the management of a LTC, amongst the overall personal network support people have access to, I hoped this research, which I would complete whilst working as a clinical academic, would help to give healthcare professionals a better understanding of this hidden work and provide the foundations for future research to incorporate these findings in the implementation of self-management support that makes better use of this work and in doing so, moves away from the prescriptively narrow focus of management that currently exists; towards self-management support that is truly collaborative, that considers supporting people to do all the things they want to do with their lives, in spite of living with a chronic illness.

1.2 The Social and Political Context of Long-Term Condition Self-Management

In the pursuit of ensuring sustainable models of care, considerations about how care is thought about, organised and delivered have over the last two decades, gained traction in political and policy discourse (Bury and Taylor, 2008; Taylor and Bury, 2007; de Silva, 2011). The provision of care in the UK, as with much of the developed world, is facing increased social and economic pressure, in part brought about through increased longevity (demographic transition) and the subsequent switch from an acute to chronic disease profile (epidemiologic transition) (Taylor and Bury, 2007; Bury and Taylor, 2008; Lorig and Halstead, 2003).

Whilst the first half of the 20th century saw people seeking health care for a myriad number of acute concerns, gradually since then, LTCs[1] have come to reflect the greater burden to health (Goodwin et al, 2010). Unlike acute conditions, these typically involve ongoing management for the entirety of an individual's life and are thus costlier (Goodwin et al, 2010). In England, some 15 million people now live with a LTC and the economic cost associated with the provision of care for those affected, accounts for as much as 70% of the countries health and social care budget (NHS England, 2015). The high cost associated with the care of LTCs has seen policy documents and political speeches increasingly stating a financial imperative to care being reconfigured to address the needs of a new disease profile (Jones, 2018). Alongside such changes, has been a focus on the delivery of care that is person centred (Entwistle and Watt, 2013; Epstein et al, 2010). That is, care that moves away from a primarily medical focus (as has

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[1] Any condition, which at present cannot be cured, but can be controlled through medicine and/ or therapy (Department of Health, 2012)

traditionally been seen). Such a focus has traditionally been based around the application of disease standardized solutions that give little regard to the thoughts, feelings and wishes of those with a LTC and what they value (Entwistle and Watt, 2013; Epstein et al, 2010). A move towards person centred care requires health care systems to be configured in a way that serves the interest of those using it, rather than the service itself (Entwistle and Watt, 2013). To this end, patient benefit and financial benefit have become consistent self-management policy bedfellows.

At the level of policy, in response to such changes, the NHS has proposed three tiers of provision; namely case management (for those with multiple complex conditions), disease management (targeting patients at some risk through the provision of guidelines-based programmes in primary care) and self-care support, for those deemed ‘low-risk’, but whom make up some 70-80% of those living with a LTC (Panagioti et al, 2014; Wanless, 2002). The processes and content of care provided within each tier have been identified as qualitatively different (Panagioti et al, 2014). Whilst case and disease management continue to remain largely the domain of health care professionals, it has been suggested that targeted support at the third tier of provision (self-management support) has the potential to bring about the largest impact on health care utilisation, because it has relevance to the largest number of people (70%- 80%) and this tier has therefore become a focal point of policy (Panagioti et al, 2014). The policy movements directed at these ‘low-risk’ self-managers have occurred against the backdrop of a new ideology in which the provision of healthcare in the UK, supports a neoliberal agenda of individualism, through a greater emphasis on individual responsibility for health (Cayton, 2006; Ellis et al, 2017; Ong et al, 2014).

Austerity measures that since 2008 have been employed across much of Europe have accelerated this trend at the level of policy, shifting the burden of responsibility from the state, to the individual, necessitating the need for people to become more responsible for the management of their condition (Ayo, 2012; Koetsenruijter et al, 2015). In turn this perspective has garnered and accelerated the need for ‘fully engaged’ patients, with individual responsibility becoming something of a ‘watchword’ (Rogers et al, 2009). Such a focus has seen idioms such as ‘self-care’, ‘self-management’ and ‘self-management support’ being deployed as euphemisms for demand management strategies (Rogers et al, 2009), the aim of which is to shift the focus towards the realisation of a more sustainable health and social care system, configured in such a way as to support people to self-manage their own health and LTCs effectively[2] (Cayton, 2006).

Whilst 'self-care and 'self-management', have been used interchangeably in the literature, self-management as a concept, is often seen as being specifically related to a LTC, with a focus on controlling and coping with the condition in daily life (Dowson et al, 2004; Jones et al, 2011; Koch et al, 2004). Thus, definitions generally point towards 'self-management' as the daily activities that people take to keep their condition under control (such as steps taken to prevent it getting worse and responding appropriately to symptoms and acute episodes), whilst minimising its impact on one's health and ability to cope with the conditions psychological sequelae (Jones et al, 2011). Managing a LTC such as diabetes, Chronic Obstructive Pulmonary Disease (COPD), Crohn's disease etc. involves self-medication (including the knowledge to adjust doses according to measurements/symptoms etc.), monitoring of biomedical variables (for example peek flow and blood sugar levels) and attention towards diet and lifestyle factors (Conley and Redeker, 2016; Powers et al, 2017; Zwerink et al, 2014). Steps taken such as these, have the potential to minimise the impact of the condition on an individual's physical health, functioning and ability to cope (Gallant, 2003). The extent to which professionals are involved in supporting these practices is likely to vary considerably across the population, across conditions and across the illness career (Boger et al, 2015; Jones et al, 2011; Taylor et al, 2015). Whilst some see self-management as near total independence from formal care, others see it as something that incorporates timely and appropriate access to support when it is required, such as when circumstances change (Boger et al, 2015; Jones et al, 2011). Factors affecting level of professional involvement include the risk of variability (such as exacerbations), the impact of the condition and symptoms on daily life, the complexity of regimes, the extent to which symptoms can be improved, the extent to which complications can be reduced through self-monitoring and actions being taken, multi-morbidity, and the potential for the disease course to be modified (Taylor et al, 2015).

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[2] Flat-packed patients are patients who according to Cayton (2006) 'co-create' their condition experience, with formal health care providing the essential parts, such as providing advice, then the patient putting it together (much like flat packed furniture, with the parts being supplied by the retailer and then later assembled at home).

In this context, ‘self-management’ is seen as representing an ideological shift that moves patients away from their traditional role of ‘passive’ recipient, to empowered individuals, who are active partners in their care (de Silva, 2011). Through repurposing the roles of patients in chronic illness management, it is hoped that individuals, acting as citizens, will make more salient choices about their need to consume costly public services; allowing for reduced pressure on the public purse through reduced (or at least more appropriate) health care utilisation (Jones, 2018; Rogers et al, 2009). Focus therefore turns to the mechanisms through which self-management can be realised, such as self-management support, which has traditionally focussed on the individual managing the condition, as opposed to the networks that might also provide support.

1.3 Self-management support that focuses on individual behaviours

To support this, various self-management support interventions have been trialled, including to the provision of health information (such as through an information leaflet or the internet) (Blickem et al, 2011; Protheroe et al, 2008), self-management skills courses (condition and non-condition specific, professional and lay led) such as the Expert Patient Programme (EPP) (Kennedy et al, 2007; Stenberg et al, 2016), internet interventions (Geraghty et al, 2018; Kennedy et al, 2009; Lorig et al, 2006; 2008; McLean et al, 2016) and web-based support, for example tele health (Gale and Sultan, 2013; Hanlon et al, 207; Salisbury et al, 2015; Salisbury et al, 2016; Vassilev et al, 2015).

The target of interventions, such as these, has often been to elicit behaviour change at the level of the individual. Whilst studies have shown some benefits, such as improvement to self-efficacy, functional ability, symptoms, quality of life, energy, mood and anxiety (Baker and Fayote, 2017; Cadilhac et al, 2011; Gao and Yuan, 2011; Johnston et al, 2007; Jones et al, 2009; Kennedy et al, 2007; McCorkle et al, 2011; Porter et al, 2008; Zwerink et al, 2014), concerns have been raised that the evidence for self-management interventions focussed at the level of the individual is more equivocal than is implied in policy (Gately et al, 2007; Hinder and Greenhalgh, 2012; Kennedy et al, 2007; Jones, 2018). Further, the benefits that have been seen, are likely to be unevenly distributed, with most interventions suffering poor uptake and high attrition rates (particularly amongst men), limiting their impact on eliciting behaviour change to the broader population (Bury and Pink, 2005; Kennedy et al, 2007; Mills et al, 2014). Further, courses are often most frequented by those of higher Social Economic Status (SES) (Mase et al, 2015; Rogers et al, 2008), and include mostly people who are already good existing self-managers, as opposed to those most in need of support (Kennedy et al, 2007).

To make sense of this vastly evolving area of research and pave the way for more effective interventions, a recent synthesis of self-management support interventions, in exemplar LTC's[3], found that effective self-management support should be 1) tailored to the individual with the condition (taking into account their culture and beliefs), 2) tailored towards the specific LTC, and the specific stage, and 3) should be supported through a collaborative and communicative relationship between healthcare professionals and those managing a LTC, in settings that actively promote self-management (Taylor et al, 2015). Increasingly, in line with this, interventions have been condition (including co-morbidity) specific (McBain et al, 2016; Taylor et al, 2015) (as opposed to general, as seen in the EPP) (Kennedy et al, 2007) and have increasingly looked at the needs across different stages in the illness career for different conditions (Jolly et al, 2018; Jordan et al, 2015; Taylor et al, 2015), as well as the appropriateness of interventions for different genders (Arnold et al, 2015; Bove et al, 2016; Galdes et al, 2014; Wyke et al, 2015). Attention has also turned to where and when self-management support should be delivered for it to be most effective, to different people at different times (Kennedy et al, 2013; Reddy et al, 2017; Seligman et al, 2018).

Despite the target of interventions becoming increasingly more specific, the complexity of self-management support means that although many different components have been identified as being effective, it is unclear as to how these components hang together, or the value that each brings, possibly due to the degree of heterogeneity between tested components (Jordan et al, 2015; Makela et al, 2014; McBain et al, 2016; Morgan et al, 2017; Taylor et al, 2014; Zwerink et al, 2014). **Figure 1** below discusses some components that have been found to be effective.

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[3] Stroke, asthma, type 1 diabetes mellitus, type 2 diabetes mellitus, COPD, CKD, dementia, epilepsy, hypertension, inflammatory arthopathies, irritable bowel syndrome, low back pain, depression, progressive neurological disorders (Taylor et al, 2015).

Figure 1: Components of self-management support

1) Providing education about the LTC, in a format that is understood and understanding the patients existing knowledge and everyday management strategies.
2) Strategies to support with the emotional sequalae of illness and adjustment to life.
3) Strategies to support adherence with prescribed treatments.
4) Practical support specific to the LTC, including the implementation of action plans, specifying the steps to follow in the face of changing condition (new or worsening symptoms, exacerbations etc.) and the training of clinical tasks relevant to self-management (i.e. taking a blood glucose reading).
5) Formal arrangements for social support where needed.

Taylor, SJC., Pinnock, H., Epiphaniou, E., Pearce, G., Parke, HL., Schwappach, A., Purushotham, N., Jacob, S., Griffiths, CJ., Greenhalgh, T., Sheikh, A. (2015). A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS- Practical systematic Review of Self-Management Support for long-term conditions. Health Services and Delivery Research. 2 (53).

In order to achieve successful self-management support in non-research settings, a whole-systems approach is needed, with steps being taken to promote self-management at the level of: those with a LTC, health care professionals and health care settings (Taylor et al, 2014). Whilst evidence has pointed towards efficacy in research, this has often poorly translation into clinical practice, with interventions having minimal impact on utilisation or condition management (Kennedy et al, 2013; Thompson et al, 2018).

In addition to a lack of translation into clinical settings, the purpose of self-management has also been problematized (Morgan et al, 2017). For example, a synthesis found that most existing approaches have focussed on a narrow biomedically driven conceptualisation of self-management support, in which there is a focus on compliance, governed by a top down, hierarchal structure (Morgan et al, 2017). Through this, the focus is often on disease control, to the exclusion of all the other things that those with a LTC find to be important (Morgan et al, 2017). Indeed, in time limited clinical consultations, questions focus on what the matter is, considerably more than what matters (Batalden et al, 2015).

The purpose of interventions such as these have led to the appropriateness of many existing self-management interventions being challenged, often because they pay little attention to what those living with a LTC strive for; giving little regard to the everyday strategies that people have found useful (Morgan et al, 2017; Townsend et al, 2006). In narrow self-management support interventions, often biomedical markers, such as HBA1c, blood pressure etc. are said to represent the ‘true picture’ as to how well someone is managing, as opposed to the patient’s own narratives (Morgan et al, 2017; Thille et al, 2014). Less common are approaches that focus on broader, more holistic conceptualisations of self-management support that focus on what people value and move towards helping them manage their condition in ways that accommodate daily life and valued activities (Morgan et al, 2017).

Indeed, whilst focus has turned to providing self-management support that is specific to the needs of a condition and stage, a focus on eliciting individual behaviour change has remained. Such an approach continues to be problematized by the mismatch between the rhetoric of policy and the values of those managing a LTC in everyday life. This is particularly visible in the belief that improved self-management support will reduce costly health care utilisation; since people often see their already minimal use of formal care, as appropriate (Gately et al, 2007). Further, people’s recognition of what is and isn’t appropriate use of formal care, is often built up over many years and based on the pre-existing relationship they have with formal care (Gately et al, 2007). This suggests that a focus on patients alone is unlikely to bring about a change in culture as predicted in policy. In addition, unresolved issues on the supply side affect the translation of interventions that have been effective in research, into real life settings. Whilst it is recognised that health care providers and commissioners should actively promote self-management for it to become a normalised and rewarded component of care (Taylor et al, 2015), it is rarely prioritised by clinicians (Blakeman et al, 2006; Jones et al, 2018; Norris and Kilbride, 2012) or indeed commissioners (Reidy et al, 2016). Multiple ‘operational obstacles’ and entrenched forms of delivery have impacted on the realisation of self-management support in clinical settings, for example, a lack of time in clinical consultations, staffing issues and fragmentated health systems (Appaih et al, 2013; Morgan et al, 2017). Further, utilisation is often supply led, with formal care practices being guided by codes of practice (Chew-Graham et al, 2013), as well factors such as the Quality and Outcomes Framework (QOF) acting as incentives on the supply side (Chew-Graham et al, 2013; Davies et al, 2012), making it necessary for those with a LTC to engage with healthcare professionals, even when they do not feel they need to (attending routine check-ups or reviews for repeat prescriptions etc.) (Gately et al, 2007). Thus, this new orientation towards chronic illness management, requires healthcare professionals to work in different ways to that which they have been socialised to (often professionally and over many years) (Jones et al, 2018).

Perhaps because of this, the existing strategies individuals have, are often not specifically discussed in time limited clinical encounters (Boger et al, 2015). A lack of understanding of hidden patient work, reduces the opportunity for considering the collaborative nature of partnerships as envisioned in policy to emerge (Boger et al, 2015; Gately et al, 2007) and supports a narrower focus to self-management support (Morgan et al, 2017). This orientation fails to properly respond to what patients are already doing (there every day practices), with ‘practitioners’ orientation towards a narrow focus of condition control, undermining people’s own management strategies (Morgan et al, 2017) and a failure to include an analysis of the social practices of everyday life in health and illness (Maller, 2015). Many patients already privilege their independence and already want to take steps to help themselves to stay in good health (Boger et al, 2015). Indeed, self-management, to some degree, is likely to be already established in people’s everyday practices and is often practiced with a reasonable degree of sophistication (Newbould et al, 2006). This is, however, often either unseen or only tacitly acknowledged by healthcare professionals during consultations (Boger, 2015; Gately et al, 2007).

1.4 Internet enabled self-management support

Recently, technology has made it possible for those managing a LTC to take on aspects of condition monitoring and treatments that were once the sole province of healthcare professionals (Morgan et al, 2017; Reidy et al, 2018). For a while now, the internet has increased our access to information (Hardy, 1999) and it is increasingly being recognised as a means through which lay health knowledge can be obtained (Hardy, 1999; Nettleton et al, 2005; Koteyko et al, 2015). Through being able to browse and search for information online, lay people are now considerably more in control over the information that they receive than they were previously (Koteyko et al, 2015; Tan and Goonawardene, 2017). This has reduced the level of information asymmetry between lay people and health care professionals and thus attention is being increasingly payed towards the emergence of informed patients, and the perceived decline in medical authority (Nettleton and Burrows 2003; Hardey, 1999).

Such changes continue to be reflected in recent innovations in digital health, including the quantified-self movement (Lupton, 2016; Majmudar et al, 2015), which has intra alia, created a situation in which those living with a LTC may now have more access to information about their condition than health care professionals (Petrakaki et al, 2018). The use of technology also by passes some of the challenges associated with offline self-management support, with the ability to draw on skills, access, education and support at any time (Pal et al, 2018).

Those with a LTC are increasingly demonstrating an interest in digital technologies to support condition management (Buys et al, 2016) and use is growing. For example, in the context of COPD, a recent study suggested that as many as 86% of patients have access (Disler et al, 2015). In recognition of this, there has been a trend to offer self-management support interventions digitally. The NHS five year forward view points towards the importance of healthcare in the UK keeping pace with the opportunities that technology presents us in coping with the shift towards a more chronic disease profile (NHS, 2014). Indeed, in the face of increased access to technology, policy discourse has turned to the ways in which such innovations can be used to further bring about increased individual responsibility for health, cost savings and improved care for those with a LTC (National Information Board, 2014; 2015). Whilst the technologies that fall within this are diverse, they have emerged from the same focus of responsibilisation that has guided many offline interventions (Petrakaki et al, 2018), in which responsibalised ‘citizens’ are expected to manage using the ‘expanding set of NHS accredited health and care apps and digital information services’ (National Information Board, 2014, p. 6) that are being made available to them. Thus, an accelerated push towards increased self-management activities is increasingly seen as having the potential to be realised through engagement with online resources and digital health interventions delivered through either the internet (eHealth) or through smart phones (mHealth).

There is some evidence that use of digital interventions, such as eHealth and mHealth can increase adherence to prescribed regimes, positively influence health behaviours (Anglada- Martinez et al, 2015; Dale et al, 2016), health status (Farmer et al, 2017) and can be cost effective (Li et al, 2018). Yet, there is a limited number of health apps that have been evaluated using robust methods (compared to the thousands that are available), cost effectiveness is difficult to ascertain (Michie et al, 2017), and little is known of the between group differences of those using these apps; currently limiting their ‘prescribability’ (Byambasuren et al, 2018). However, despite this, health apps are commonly used (particularly in younger people), even if not prescribed (Carroll et al, 2017) and the focus on prescription, somewhat draws on notions of governmentality, particularly in controlling what people can and cannot do to manage their own health (Petrakaki et al, 2018). How people use digital tools in the broader context of their everyday management is likely relevant to understanding issues and rates of compliance/noncompliance, as well as hidden self-management strategies, but has not been addressed.

Until recently, patients have had limited access to prescribed online interventions to support the management of their condition (Bourne et al, 2017). Just one app (for people living with COPD) is currently approved by the NHS (NHS, 2018). This app aims to support self-management outside clinical settings, whilst also providing an alternative to costlier face-to-face Pulmonary Rehabilitation (PR) (Bourne et al, 2017). Whilst the PR component has been evaluated, the self-management aspect has not (Bourne et al, 2017) and it is important to note that despite policy being increasingly enthusiastic about digital solutions for self-management, the NHS has previously had difficulty in regulating and securing quality and safety in this area (Huckvale et al, 2015).

There are also issues of access (van Gaalen et al, 2016). Such issues suggest that the excitement directed at such innovative technologies must be tapered with the reality that those with the most to gain from such solutions, might also be those least likely to use and access them (Dutton et al, 2013; Sarker et al, 2011). A move towards self-management that is increasingly online may create a digital reproduction of inequality, if such issues are not overcome and current modes of offline access are limited in favour of digital proxies (Sarkar et al, 2011). This disparity is recognised in policy, which has focussed on the promotion of digital inclusion, in which it is hoped that ‘even small improvements to digital skills and access could have a significant impact in terms of delivering savings, helping manage increasing demand and tackling health inequalities’ (National Information Board, 2015, p. 4). In a similar vein, digital interventions can both reduce and induce burden of treatment in those managing a LTC, which has the potential to limit uptake, especially if someone has to learn new skills in order to make use of such resources (Morton et al, 2018). Further, consistent with offline self-management support, many online interventions suffer limited uptake and high attrition (Alkhaldi et al, 2016; Pal et al, 2018; van Gaalen et al, 2016), though recent research, has suggested that co-design and PPI involvement can be helpful, particularly in research attrition (Spencer et al, 2017).

More critically, the input of technological innovations has not changed the direction of self-management support, with such interventions often continuing to extend the pursuit of a narrow conceptualisation of self-management, fixated on bio-medical markers and individual behaviour change in the space between formal care and those managing a LTC, rather than looking beyond the patient, professional interface into the everyday settings in which most management occurs. For example, outcome measures in the studies evaluating digital interventions effectiveness have typically focussed on the monitoring of bio-medical markers, behaviour change and treatment adherence (Anglada- Martinez et al, 2015; Byambasuren et al, 2018; Car et al, 2017; Dale et al, 2015; Whitehead and Seaton, 2016).

As with many non-digitally mediated self-management interventions, little consideration is given to the social context of management, even with new technological solutions, performing effective self-management in ‘messy’ daily life is difficult (van Houtum et al, 2015; Lindqvist and Hanson, 2016; Ong et al, 2011). Thus, structured support outside the boundaries of formal care is being increasingly seen as important to LTC self-management, because those living with a LTC spend very little time engaged with healthcare professionals compared to the time spent on activities to manage their condition in daily life (Rogers et al, 2011; 2014). This calls for a more relational, network focussed approach to LTC self-management.

1.5 Social networks and illness work: A move towards a more relational focus to self-management

The foundational work of Christakis and Fowler (2007; 2008; 2011) disrupted the assumption that individual behaviours were the cornerstone of health practices, through bringing about an increased focus on collective network behaviours and the use of social network analysis to study health. Indeed, whilst most management takes place in domestic and community settings (Boger et al, 2015), until recently, interventions have "given little more than a passing wave to [the] social context" (Vassilev et al, 2011, p. 60) of those managing illness, including to the relevance of access to personal network resources, which shape the experience of managing illness (Vassilev et al, 2013; 2014) alongside wider determinants of health (Jones et al, 2018; Marmot, 2010). Traditional self-management support that has been targeted at individual action, has often been found wanting, through a failure to acknowledge the broader set of actors and processes involved in influencing health behaviours (Christakis and Fowler, 2013; Smith and Christakis, 2008) and supporting people to manage (Derose and Varda, 2009; Vassilev et al, 2014). Indeed, whilst healthcare professionals have tussled for legitimacy in their new role of pastor[4], agentic patients have often mobilised less formal resources such as friends, family and the internet to gain an alternative understanding of their condition and how to manage it in daily life (Jones et al, 2018; Waring and Latif, 2017). Because of this, it is necessary for the experience of those living with a LTC to be seen as socially defined experience; making necessary a paradigm shift away from the conventional biomedical model, which was effective in meeting the needs of acute disease, but is unlikely to be effective in meeting the needs of those with a LTC (Newbould et al, 2006).

Thus, increasingly a social network approach is being adopted. Social networks are seen as influencing health (and health behaviours) in several ways. Firstly, through a process of contagion, social networks can influence ideas and behaviours about health (Christakis and Fowler, 2013; Heijmans et al, 2017; Knutsen et al, 2015; Smith and Christakis, 2008). In addition, social networks can also provide resources and support relevant to condition management (Abel 2008; Derose and Varda, 2009; Vassilev et al, 2014). Despite the proliferation in research in this area, a uniform definition of social capital, has remained elusive (Salehi et al, 2018). However, social capital as a concept has come to refer to the resources, influences and social support that are embedded in personal networks and can be realised through network relationships (Lin and Ericson, 2008; Salehi et al, 2018). Thus, social support is an aspect of social capital, representing a type of resource that flows

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[4] By adopting a Foucauldian perspective, healthcare professionals in typical self-management support can be seen as 'pastors', through interventions that attempt to elicit more moral behaviour, with a focus on fostering 'obedient' and 'self-governing' subjects, through programmes posited in policy discourse, such as EPP and conversation skills such as that seen in 'Making Every Contact Count' (MECC) (Jones et al, 2018).

through one's network (Appel et al, 2014; Lin and Erickson, 2008; Salehi et al, 2018). Through their position in a network, individuals are thus able to draw from certain resources, such as social support, that they would otherwise be unable to access (Eriksson, 2011). Because of this, there is a recognition that social capital can contribute to (or hinder) self-management practices (Salehi et al, 2018).

Social capital, as a concept, has been broken down into 'bonding' and 'bridging' social capital (Appel et al, 2014; Lin et al, 2008). Network structure is said to align to the conceptual affordances of bonding and bridging social capital (Appel et al, 2014; Lin and Erickson, 2008), in which close ties are typically seen to provide 'bonding' social capital and weak ties, 'bridging[5]' social capital (Eriksson, 2011; Granovetter, 1973; Lin and Erickson, 2008).

Existing research in this area has shown that living with a LTC, typically involves working within a range and diversity of close, and non-close (bonding and bridging) personal network relationships (Reeves et al, 2014; Kennedy et al, 2014). This research has highlighted the importance of individuals engaging with those around them, in securing work and resources relevant to management (Vassilev et al, 2014). Thus, in moving towards a more networked focussed view of self-management, it is important to consider both the structural characteristics of networks (the social context) as well as the resources (including access to support) that can be realised through the social relationships formed with specific network members (Thoits, 2011).

In the context of chronic illness, the role of others in providing work relevant to self-management is not new, for example Corbin and Strauss (1985) referred to the work required to support someone with a LTC as 'illness work', positing that a large degree of this work occurred within family settings (bonding social capital). Their notion of 'illness work' considers the types of work that are required for LTC self-management to occur and originally included illness (such as the work specifically related to the condition, i.e. supporting with taking medications, taking and interpreting measurements etc.), every day (work related to everyday activities made difficult by illness, for example domestic tasks such as housekeeping, preparing meals etc.) and emotional work (providing comfort

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[5] The term 'bridge' relates to weak ties ability to 'bridge' to new networks, with new embedded resources (Granovetter, 1973; Sabatini, 2009).

when someone is worried or distressed, or providing companionship) (Corbin and Strauss, 1985). Bury (1982) has also shown the important place of biographical work (i.e. the work done to support people to reassess their personal expectations, their capabilities and future plans in response to illness). These lines of work emphasis social processes over a uniform set of experiences, as is suggested in the delivery of self-management support aimed at individual practices. Sociologists have asserted that lay management strategies tend to focus on coping with the many ways in which a condition disrupts daily life, rather than a focus entirely on complying with treatment regimes (i.e. the biomedical model) (Morden et al, 2015), as is evident in narrow self-management interventions discussed earlier (Morgan et al, 2017).

The relevance of kin in providing illness work, is consistent with empirical research in other domains of social life which has shown the centrality of intimate family processes (Dunbar et al, 2008; Graven and Grant, 2014; McMunn et al, 2009). However, these bonding ties, whilst demonstrably important, only reveal a partial view and account of the linkages relevant to self-management. For example, family members have been found to constitute half of all members providing illness related work (Vassilev et al, 2013), demonstrating the importance of understanding the place of ties beyond the traditional family unit. Furthermore, as reflected in prior work (Wellman and Wortley, 1990), different network members provide different types of work - for example friends and work colleagues provide a high degree of emotional work (Vassilev et al, 2013). In addition, networks have been seen to compensate when a normative provider of support is not a network member, for example, when someone doesn’t have a spouse (Vassilev et al, 2013).

Several factors have been seen to relate to the availability and accessibility of social support in personal networks; for example, the size of the network, the networks density, and the characteristics of ties (Moore et al, 2016; Vassilev et al, 2016; Wellman and Frank, 2001). The frequency of contact with ties, the extent to which ties are close and the demographic characteristics of network members (i.e. age, gender, education) have also been important in informing the level of support that is available and the types of resources that are embedded within personal networks (Moore et al, 2016; Wellman and Frank, 2001).

Diversity, specifically access to weak ties, able to provide bridging social capital is seen as important (Granovetter, 1973; Rogers et al, 2014). Aside from health care professionals and intimate ties, those identified in prior research as providing illness work have included friends (Neale and Brown, 2015; Spencer and Pahl, 2006), peers in residential homes (Neale et al, 2018), community and voluntary groups (Koetsenruijter et al, 2016; Portillo et al, 2016; Reeves et al, 2014) and pets (Brooks et al, 2016). Indeed, network diversity (the total number of different types of ties) is seen as a better indicator of access to support and embedded network resources, than size alone, (which is seen as an unreliable measure of access to social support) (Wellman and Wortey, 1990; Vassilev et al, 2016). Indeed, in the context of health, diverse networks are associated with better health outcomes (Holt- Lunstad et al, 2010; Reeves et al, 2014; Vassilev et al, 2016). This is because meaningful engagement with a diverse range of contacts, including weak ties, has the potential to afford individuals greater access to alternative support, knowledge, material resources and opportunities than that which would have been seen in traditional, family centred networks (McMunn et al, 2009; Rogers et al, 2014). In addition, the nature of these ties makes them well suited to certain aspects of illness work. For example, they are easier to negotiate, require less reciprocation to maintain and are thus more durable to loss over time, possibly because of the decreased amount of overall burden of work and relationality involved (Rogers et al, 2014). Ties mediated online are becoming an increasing feature of this.

1.6 Web 2.0 and Online Communities: The emergence of new ties online

Traditionally social networks were embedded in place-based communities, in which, people had more limited opportunity to forge social ties beyond their immediate settings (Rainie and Wellman, 2014). Personal network linkages (either enacted or received) were realised through either face-to-face contact or the telephone (Kim, 2014; Li et al, 2015). More recently people have the means to communicate through digital means (such as email, instant messenger services or social media sites) and such channels are becoming a normative way of connecting to ties, supporting a pervasiveness to existing network contacts (Kim, 2014; Li et al, 2015). Alongside advances such as increased access to telecommunications and affordable travel, this has clearly changed the way we interact and relate to one another, as well as the network resources that are available to us (Rainie and Wellman, 2014). In allowing people to form connections with new people online, people now have greater social reach and thus have more choice and control over who they turn to for support, by bringing distant others to a point of virtual proximity (Atkinson and Ayers, 2010). This has likely had an impact on the support that people have access to, both from existing ties and new ties. Thus, in addition to the internet's information utility and the various opportunities it has presented in relation to mHealth and eHealth; the advent of web 2.0 (the social web) and the subsequent emergence of social applications such as Facebook (that allow for the articulation of connections to others (such as 'friending' or 'following')), likely enables the creation of traditional, offline support mechanisms to exist through online interfaces from both known and previously unknown ties. Indeed, the extent to which online ties now feature as part of daily life has led to calls for personal networks to refer to the relationships that people hold both on and offline (including those held in both, recognising a fluidity to these relationships) (Hampton et al, 2011a; 2011b).

In this emergent ontology, individuals have more choice and control over who they turn to for help and advice, leading to people becoming more networked as individuals (Rainie and Wellman, 2014). Thus, social networks relevant to illness work may now be configured in such a way as to place the individual as the central foci; as opposed to family, neighbourhoods, social group etc. (Rainie and Wellman, 2014). This new social network orientation has been described as 'networked individualism', in which social networks are orientated around looser, more fragmented networks that allow individuals to tap into different sparsely knit social milieu, to meet different needs from an increasingly diverse range of associates (Rainie and Wellman, 2014). Therefore, in increasingly networked times, individuals now have increased reach to new ties and resourceful connections, potentially providing the opportunity to balance the increasingly complex and specialised needs of managing a LTC in daily life, with the mediation of specialized ties beyond that which is immediately available (Rainie and Wellman, 2014).

At the level of the individual, the ability to maintain a large network, is seen as important in accessing support (Lu and Hampton, 2017). Whilst the total number of ties that people can maintain in their network overtime, continues to remain subject to cognitive limits (Dunbar, 1993; Roberts et al, 2009; Sutcliffe et al, 2012), new media, often fosters both increased network size and increased diversity (Hampton et al, 2011a; 2011b), both of which have been shown to have positive implications to the availability of network support and resources (Anderson et al, 2015; Cornwell and Laumann, 2015).

Further, online communities can create more meaningful relationships with new ties, through such relationships becoming more visible and persistent (Ellison et al, 2011). A sense of closeness and familiarity can be fostered through an awareness of major life events, such as those posted in status updates (Hampton et al, 2015). Online communities have been found to give individuals both the awareness of and access to network resources (Hampton et al, 2011a; 2011b; 2016; Lu and Hampton, 2017). Studies have indicated a role for social media in leveraging existing offline support (Shpigelamn, 2018; Steinfield et al, 2008). These platforms have also been seen to support the maintenance of network resources (Ellison et al, 2007). This ‘pervasive awareness’ (Lu and Hampton, 2017) or ‘absent presence’ (Rainie and Wellman, 2014), is supported by functions such as status updates and the ability to send private messages to others, often asynchronously, which is thought to relate to increased levels of perceived social support (Lu and Hampton, 2017; Oh et al, 2014). Recent studies have found associations between frequency of use of online communities and the level of support that people feel they have (Hampton et al, 2011a). The opportunity to signal need to many, through status updates has also been a means through which the needs can be signalled to a broad audience (Ellison et al, 2014; Manago et al, 2012) and research has shown that internet users perceive greater availability of support, than non- users (Lu and Hampton, 2017).

In the context of condition management, new ties might allow new forms of work to emerge or bring about changes in the work of offline ties. It has been recognised for some time, that online communities[6] are particularly good at facilitating the creation and maintenance of weak ties (Ellison et al, 2007; Donath and Boyd, 2004; Van Dijck, 2013). Online communities are said to be facilitative of a larger number of weak tie connections through the technical features of these platforms that lower the cost (reciprocal effort, time taken etc.) of maintaining and communicating with a wider variety of people (Ellison et al, 2014). Offline, these ties have been seen to be important in providing condition

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[6] The notion of ‘community’ is understood to be a conceptualisation of communicating individuals, who share support and have a sense of collective identity (Gruzd et al, 2016).

relevant support (Rogers et al, 2014) and thus it plausible that weak ties online might also provide resources relevant to self-management, as has been seen in earlier research (Drentea and Moren-Cross, 2005; Kavanaugh et al, 2007).

Thus, with multiple systems of support co-existing and the range and diversity of actors involved in an increasingly complex division of labour, there is a clear need to better understand our more networked life and the negotiations around health in this context. Through recognising the broader set of actors involved, better visualisations of the networks implicated in self-management can emerge, which has the potential to allow for resources people already have access to, or potential to access, to be better integrated into the more open systems in which self-management is practiced, including online.

1.7 Chapter Summary

There is a growing recognition that healthcare must adapt to the changing needs of patients in the switch to a chronic disease profile (Taylor and Bury; 2007; Bury and Taylor, 2008). Formulaic self-management support such as those aimed at eliciting improved self-management, by making individuals more responsible for their own health, have largely failed to reduce health care utilisation; one of its key policy aims (Elzen et al, 2007; Kennedy et al, 2007; Newbound et al, 2006; Panagioti et al, 2014; Taylor and Bury, 2007). This is despite the emergence of digitally mediated self-management interventions, which have continued to focus on a narrow conceptualisation of self-management that pays little regard to social context.

There have been suggestions that solutions might be found in the life worlds of those living with a LTC, in which much of the support seen, is delivered away from formal healthcare. These are perhaps the levers that should be pulled to improve the experience of those managing chronic illness in everyday life. However, to do this, a more in depth understanding of the social worlds in which self-management is performed is required. This calls for a network approach to self-management that incorporates an understanding of the role and place of personal network support, which increasingly, online ties form a part of, in providing support amongst ones overall personal network and is thus the focus of this thesis. New forms of support such as these, might reduce the demand placed on individuals and their personal network, by increasing access to relevant support elsewhere.

1.8 Overview of thesis

This exploratory study, using a mixed methods approach, aims to better understand the personal networks of those using the internet to support self-management, as well as better understand the role of ties mediated online in supporting long-term condition management. Through understanding this hidden patient work, which exists in the context of people's everyday management, future self-management might make better use of existing self-management strategies. At the same time, this awareness will also provide a more elaborated understanding of the extent those without the capabilities to draw from online resources in this way, are likely to be disadvantaged.

The following chapter (two), discusses the sensitizing concepts that have informed the studies design. Chapter three rationalises the methods used in more detail, in each of the three stages that make up the core of the thesis, which are listed below:

Stage one: Long-term condition self-management support in online communities: a meta-synthesis of qualitative studies.

> This stage involved a meta-synthesis of qualitative studies, with a view towards building a more contextual understanding of the field, specifically by looking at the mechanisms facilitating the negotiation of LTC illness work in online communities, including the relational nature of online ties in supporting the emergence of illness work. It also informed the direction of the further two stages.

Stage two: The contribution of internet use in personal networks of support for long-term condition management.

> This stage used social network survey data to describe the individual and network characteristics of the personal communities of people using the internet and the role of offline support, network resources and community participation on using the internet to support condition management.

Stage three: Care Transition 2.0: A qualitative study of the work and relatedness of ties mediated online in supporting long-term condition self-management.

> This stage looked at the context and circumstances of engagement with online ties, allowing for a better understanding of their role and place within the personal networks of support for those managing a LTC.

The chapters following this (four-six) then feature the papers from these three stages. Chapter seven contains the discussion and conclusion of the thesis. This section demonstrates the novel contributions this thesis has made to the field, through summarising the findings of the three stages alongside the existing research in this area. Recommendations are then made for future research.

Chapter 2: Sensitising concepts

2.1 Introduction

By using sensitising concepts, it is possible to support the direction in which questions are asked, in relation to the thesis's aims. Consideration of these concepts assists with building a research design likely to elicit credible findings (Clark et al, 2008; Walsh and Evans, 2014). Studying the place of modern technology (including the internet) in care, has been likened to the difficulties of "hit[ting] a moving target" (Cresswell, 2010, unpaginated), because it is difficult to use traditional social theories in a manner which keeps pace with rapidly advancing technologies and the impact that these have on society (Cresswell et al, 2010). Indeed, "whereas definitive concepts provide prescription of what to see, sensitizing concepts merely suggest direction along which to look" (Blumer, 1954, p. 7). This allows for conceptualisations that are sufficient in capturing complex social interactions, whilst having enough simplicity to be useful at an operational level (Smith and Seward, 2009).

The meta-theorising that has informed this research, is Critical Realism (CR) (Archer, 1995; 2002; Bhaskar, 1975; 1986) and the Capabilities Approach (CA) (Sen, 1983; 1987). Actor Network Theory (ANT) (Latour, 2005) was also considered, and is thus briefly discussed in this chapter. This chapter builds an awareness of these concepts and their place in informing the role of mixed methods social network analysis (SNA) in open settings. It informs the content presented in the next chapter, which sets out the methods of the three stages of this thesis in more detail, in combination with the papers that are presented in chapters 4-6.

2.1.1 Critical realism

Critical realism (CR) is relevant to this thesis, through its acknowledgement of the complexity of open systems, in which multiple methods (including quantitative and qualitative methods) are needed to gain a sense of the reality that is being examined (McEvoy and Richards, 2006). CR draws tenets from both positivism (who adhere to a realist ontology- that is, they believe in a singular, knowable reality[7]) and interpretivism (an approach in which there are several, equally valid realities and thus no single objective reality can be predicted) (Lipscom, 2011). CR is not limited by the traditions of research orthodoxies; it looks beyond empirical social reality (what is known), by pulling up the roots to expose the generative mechanisms and underlying structures that influence the social constructions of reality (Lennox and Jurdi-Hage, 2017). CR sees social structures and social relations as central in the explanation of events and phenomena in the social world (Buch-Hansen, 2013; Lipscom, 2011). It has as a layered ontology, in which it is argued that reality is divided across three domains (the empirical, the actual and the real) (Elder-Vass, 2008). The empirical domain reflects the reality that is known about through observation and is thus, most closely aligned to positivism and the natural sciences (Elder-Vass, 2008). The actual extends beyond this, reflecting the things and events that occur (both observable and non-observable) (Elder-Vass, 2008). The real, reflects the generative mechanisms or causal laws (of which in open systems there are many). These cannot be seen and can therefore not be measured using the approaches of positivism; thus, understandings are sought, rather than predictions (Elder-Vass, 2008). Thus, CR's multiple layers of reality, require the employment of multiple methods in order to understand them.

Because the everyday work of chronic illness management takes place in settings that are 'necessarily peopled' (Archer, 1995; 2002) there are more generative mechanisms involved in actions, than which is seen in the natural sciences, thus reducing the opportunity for predictions to occur (McLean and Aroles, 2016). Instead, the causal (generative) mechanisms that bring about actions, do not act deterministically and should therefore be seen as the 'tendency[8]' of a structure to behave in a given way (Smith and Seward, 2009). In complex open settings, these are likely determined by multiple factors (Smith and Seward, 2009). Thus, in moving away from prediction (as with the natural sciences), in CR the focus is on understanding and explaining tendencies, rather than predicting them (McLean and Aroles, 2016). This encourages a focus on identifying,

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[7] A reality that is theoretically fully knowable. It can legitimately be measured, manipulated, correlated, and analysed statistically.

[8] The notion of tendency implies that a cause is only ever a partial explanation for an observed outcome, in which there likely multiple mechanisms acting and interacting in ways that produce the outcome (McLean and Aroles, 2016; Smith and Seward, 2009).

analysing and explaining the different tendencies and their generative mechanisms (McLean and Aroles, 2016). Within this, the role of the individual is acknowledged, but so too is the social world they inhabit, specifically the structural properties that transform and govern observed outcomes (McLean and Aroles, 2016; Smith and Seward, 2009). These structural properties emerge from relations between humans (Bhaskar, 1998). At the level of the individual, people's actions are said to be influenced by wider social, as well as innate psychological conditions (McLean and Aroles, 2016). These causal influences might in turn shape individual agency and thus impact on the choices people make; which are likely also influenced by their capacity (Bhaskar, 1998). Technology is an emergent feature of such capacities.

Whilst CR has largely ignored the role of technological artefacts in networks (Elder-Vass, 2008), scholars such as Ling (2012) have argued that as new technologies (such as the phone and the internet) have become embedded in society, they are increasingly a part of the social structures in which people behave, and thus might bring about generative mechanisms and tendencies. Thus, there is a need to extend this ontology to recognise the increased role of technological artefacts, especially in view of the ways such technologies might extend human capabilities. Sen's (1983; 1985) capabilities approach is relevant here and is therefore considered below.

2.1.2 Capabilities approach

The starting point of CA is the capability an individual has to lead a life that they value (Sen, 1983; 1985). The ontological assumptions of CR make it a compatible and appropriate meta-theory alongside CA, in which technologies such as the internet, may extend human capabilities, and thus bring about causal (generative) mechanisms that realise desired functions (ways of being and the ability to live a good life) (Martin, 2008; 2007; Smith and Seward, 2009). In support of this, a critical realist ontology of human capabilities has been presented (Oosterlaken, 2011; Smith and Seward, 2009) and has been extended to accommodate technological artefacts in its consideration of human capabilities (Lawson, 2010; Oosterlaken, 2011). This, it has been argued, is important for two main reasons. Firstly, technology in a given context, has the potential to expand valuable human capabilities (Oosterlaken, 2011). For example, the internet potentially expands one's capabilities to engage in social interaction with new ties, whilst giving extra opportunities to connect with and thus maintain contact with existing ties (Oosterlaken, 2011). In addition, CA is increasingly being discussed as having value to our relational understandings of technology (Oosterlaken, 2009; 2011; Zheng, 2009). For example, ‘capabilities’ has been referred to as a causal power (Martins, 2006; 2007), which is ontologically consistent with CR. Contextual causality reflects the tendency towards social structures behaving in certain ways (Smith and Seward, 2009). Within the CR ontology, these causal powers (generative mechanisms) are said to emerge from the relationships of constituent parts, creating social structures that are more than these (Oosterlaken, 2011; Smith and Seward, 2009). Consistent with CR, these social structures and mechanisms, come into being through the relationships between people, as well as between people and nature (Oosterlaken, 2011; Smith and Seward, 2009).

The ability for individuals to be active participants in their care, is a feature of this, and is likely to be shaped by the availability of formal and informal support, with such relationships able to have negative, as well as positive influences on an individual’s ability to manage (Entwistle et al, 2012; Entwistle and Watt, 2013). Within this, what is valued and the extent to which it can be achieved, is influenced by an individual’s social world, including the relationships that they hold with both formal care and their wider network support (Entwistle et al, 2012; Entwistle and Watt, 2013; Mol, 2008). Thus, a CA considers an individual’s functional ability and capability (Nussbaum, 2013; Sen, 2009). Functionings reflect ways of being; whereas capabilities speak towards the opportunities that individuals have towards levels of functioning (Entwistle and Watt, 2013). It is said, that having a good life, requires having the capability to perform valued functioning’s (and/or activities) (Entwistle and Watt, 2013). Thus, in this context, a CA allows us to see the extent to which people are able to successfully draw on the range of resources offered by both formal care and personal network resources in their personal network, including online ties (i.e. their total configuration of condition related support) in helping them live the way that they want to live. In this sense then, the internet as technical object, is as an input that might support the attainment of valued capabilities (Haenssgen and Ariana, 2018). Thus, this approach sees the internet as an input that might enhance an individual’s relational capabilities and afford new ties relevant to illness related work (Haenssgen and Ariana, 2018). This approach recognises that individuals place value on different things (Entwistle and Watt, 2013). For example, the functions required to live a certain lifestyle (Entwistle and Watt, 2013). Thus, in looking at capabilities, a space is created in which self-management practices that have traditionally focussed on realising certain desired biomedical markers, might also accommodate, or indeed take a back seat to the way an individual wants to live, considering the activities and things that they value in a way that is truly person centred.

Whilst CA is often considered to be orientated towards the individual, an individual’s capabilities are nonetheless influenced by the social. For example, our relationship with technology shapes social structures (Oosterlaken, 2011) in increasingly ‘socio-technical systems’ (Bauer and Herder, 2009). Capabilities have been described as structures, with internal relations from which causal power (generative mechanisms) can emerge, that allow for certain functions that are both contextual and relational (Smith and Seward, 2009). For example, capabilities emerge through an individual’s own capacity, access to others with the resources to help, and access to ‘things’ (such as an internet enabled computer or smart phone) (Oosterlaken, 2011; Smith and Seward, 2009). Further, it’s relevant to note that the availability of technologies, such as the internet may shape people’s agency in securing certain functioning’s (Coeckelbergh, 2011; Kleine, 2013; Zheng and Stahl, 2011). Thus, technologies can extend human capabilities, when incorporated into interdependent relationships (as per ANT) (Lawson, 2010; Oosterlaken, 2011). For example, sans a network, a computer is simply a configuration of components, but within a network (through ‘black boxing’), its emergent properties make it capable of extending human capabilities (Lawson, 2010; Oosterlaken, 2011). Its relevance however, relates to the nature of the network (value, extent to which it is normalized, social, economic, geographical and political factor as well as ability to use in gainful ways) (Oosterlaken, 2011). These generative mechanisms might create reasons to search for additional support, access new resources and opportunities etc. Ontologically then, issues of access might in turn relate to capabilities, with access to resources that enable or constrain certain activities being determined by factors beyond the level of the individual (Lawson, 2010; Smith and Seward, 2009). Thus, a complete account here must consider the individual and their social world and considers the possible circumstance in which such capabilities might be realised, including for whom and in what circumstances, as per this thesis.

2.1.3 Actor- Network Theory

Actor network theory (ANT) examines the role of non-human actors in networks. ANT has been proposed as a suitable lens through which to understand the influence of technologies on society (Cresswell et al, 2010). As a theory, it seeks to explore the relationship between society and technology (Cresswell et al, 2010; Greenhalgh and Stones, 2010). Within this flat ontology (as opposed to a layered ontology, as per CR's empirical, actual and real levels), society is said to be mutually constructed from human and non-human actors (Cresswell et al, 2010). Like humans, technologies and material things can possess causal power (Elder- Vass, 2008). They might also slot into network positions in the same way as human actors; yet they clearly have different emergent properties (Lawson, 2010). It is necessary to draw a distinction between humans and non-humans in this thesis, because it aims to understand the role of online support and the decisions people take to utilise it, in which consideration of human agency is important. Computers, the internet and material things do not have agency in the same way as humans do and therefore, reducing humans to the status of things through the adoption of ANT is problematic. Further, the difference in structure of human and non-human entities, gives them very different capabilities; by looking at all entities as equal, such differences fall outside of the field of enquiry (Elder-Vass, 2008).

Thus, the criticism that ANT reduces humans to the level of 'things' (Elder-Vass, 2008; Greenhalgh and Stones, 2010; Mutch, 2002) makes it an incompatible meta-theory with the aims of the present thesis, which seeks to put human agency within the lens of enquiry, making CR, in combination with CA's generative mechanisms more appropriate sensitizing concepts. Thus, whilst limited in ways that CR and CA are not, ANTs contribution to this thesis rests in its recognition of things (such as the internet) having causative powers (Elder- Vass, 2008).

Below, these are discussed in relation to SNA in open systems, which further rationalises the studies mixed methods design.

2.2 Social Network Analysis in open systems with human and non-human actants.

A social network represents a set of actors (the people in the network) and the relations or ties between them (Wasserman, 1994; Burt et al, 2012). SNA is typically used to examine how the interaction amongst people can form a network of connections, which can be used to model structures and social relations within communities (Scott, 2012) as well as examine the behaviours and ideas that spread between members (Fowler and Christakis, 2008; Christakis and Fowler, 2011).

SNA has become an increasingly popular approach to understanding the problems social science seeks to address, particularly around those phenomena implicating an understanding of complex social relations (Buch-Hansen, 2013; Edwards, 2010). The accelerated availability of computer programmes that allow for the visualisation and measurement of whole social networks quantitatively, has led to an increased prowess in positivism in SNA, allowing researchers to efficiently map and measure networks (Edwards, 2010). Such attempts have also been used to map online social networks, especially using the connections that are articulated on social media platforms, such as Facebook (Kim and Hastak, 2018). Thus, this has often led to SNA (including that which is done online) being touted as a “hard, mathematical, arid and abstract quantitative approach” (Belotti et al, 2015, p.2). However, increasingly there have been calls to redress the balance of quantitative and qualitative methods that have been used (Bellotti et al, 2015). It has been for example claimed that SNA has too frequently favoured positivist methods at the expense of the richer descriptions of social networks afforded by qualitative methods (Brint, 1992; Emirbayer, 1997; Emirbayer and Goodwin, 1994; Mische, 2003; Crossley, 2010; Belotti et al, 2015). However, since SNA is a particularly versatile field, it is capable of drawing on multiple quantitative and qualitative approaches, capable of bringing about different types of knowledge to explore networked phenomena (Bellotti et al, 2015). This makes it a particularly useful approach for this thesis.

Social networks consist of two elements; namely the nodes and the social ties (Fowler and Christakis, 2008). Nodes represent the individuals within the social network and ties represent the relationship or connections between the nodes (Fowler and Christakis, 2008). Within the wider social networks, lie personal communities which are “networks of sociability, support, and identity, where each person is at the Ptolemaic centre of his/her own universe” (Wellman et al, 1997, p. 28). A personal community is an egocentric network, it looks at an individual’s personal network and the effect it has on an individual (Wellman et al, 1997). With egocentric SNA, the aim is to collect data from individuals (the ego) about their social contacts (their alters) (Wellman et al, 1997).

A core feature of CR discussed earlier is the assertion that the social world consists of open systems. This is important when considering social networks (Kadushin, 2012). Closed systems are networks ‘in a box’ (Kadushin, 2012). They have clear boundaries, for example a hospital ward, a social club, or the traditional family unit (Kadushin, 2012). Open systems on the other hand have no clear boundaries (Kadushin, 2012). CR asserts that social phenomena are caused by complex interactions and mechanisms that exist in open systems (Bhaskar, 1975). We know from prior research that support in relation to LTC self-management often involves the input of multiple actors, operating in unbounded systems- for example, support is likely realised beyond the bounded system of a hospital or home. Within these open systems of support, social networks can be defined either broadly, looking at the entirety of alters the ego connects with in their lifetime (including both strong and weak social ties), or it can focus more specifically at those available in an egos social network who they are most actively engaged with, or whom they rely most on for support or the acquisition of social resources (Marin and Hampton, 2007).

Whilst quantitative SNA is appropriate in looking at the structure of relationships from outside the network, because people have human agency, using only quantitative techniques potentially presents a unilateral, reductionist outside view of a social network (Bellotti et al, 2015; Edwards, 2010). Buch- Hansen (2013) emphasises the need to account for both structure and agency. Since quantitative methods look at ties as binary (they are either present or not), methods that are exclusively quantitative fail to contextualise the meaning of social ties within the network and the effect they may have on the behaviour of people within them (Bellotti et al, 2015; Edwards, 2010; Buch-Hansen, 2013). It is suggested that networks of people with human agency should be examined as structure and a process at the same time (as per the philosophical underpinnings associated with CR); specific connections can be mapped, but there are specific processes (the generative mechanisms) that cause them to exist that should also be considered and can only be understood through engagement with those experiencing it (Bellotti et al, 2015; Edwards, 2010). This can only be done using qualitative methods.

Through qualitative methods, better understandings of the context of relationships and their relational meaning can be gained (Bellotti et al, 2015; Edwards, 2010). In doing so, qualitative methods are better placed to capture the ‘insider’ view of the network as they (the ego) experience it (Jack, 2010). In this case, this is important, since the thesis seeks to understand how people experience support from on and offline contacts. It is also important to see how people perceive their network; as well as the content and the meaning of these ties to the ego. Thus, the flexibility and thick description of qualitative methods means that it is better placed to illustrate the relational work that those managing a LTC engage in, in order to manage their condition by drawing on a range of (on and offline) network ties and resources (Bellotti et al, 2015).

Thus, the use of mixed methods allows the interplay of objective social structures (Fries, 2009); such as the makeup of someone’s social networks as well as the subjective nature of human agency to be explored (Fries, 2009). The objective structures of society, such as the people available in one’s network as well as other objective realities may influence the subjective nature of human agency, such as the decisions people make regarding how they manage their condition and who they approach for help of which, valued activities and capabilities also need to be considered. Thus, as meta-theories, the philosophical assumptions of CR and CA align to the present study, which also recognises the causative mechanisms of technologies. A mixed method approach thus allows for the examination of both the objective social factors as well as intentional subjective action of those being studied (Fries, 2009), of which the following chapter, in combination with the papers, outlines in more detail.

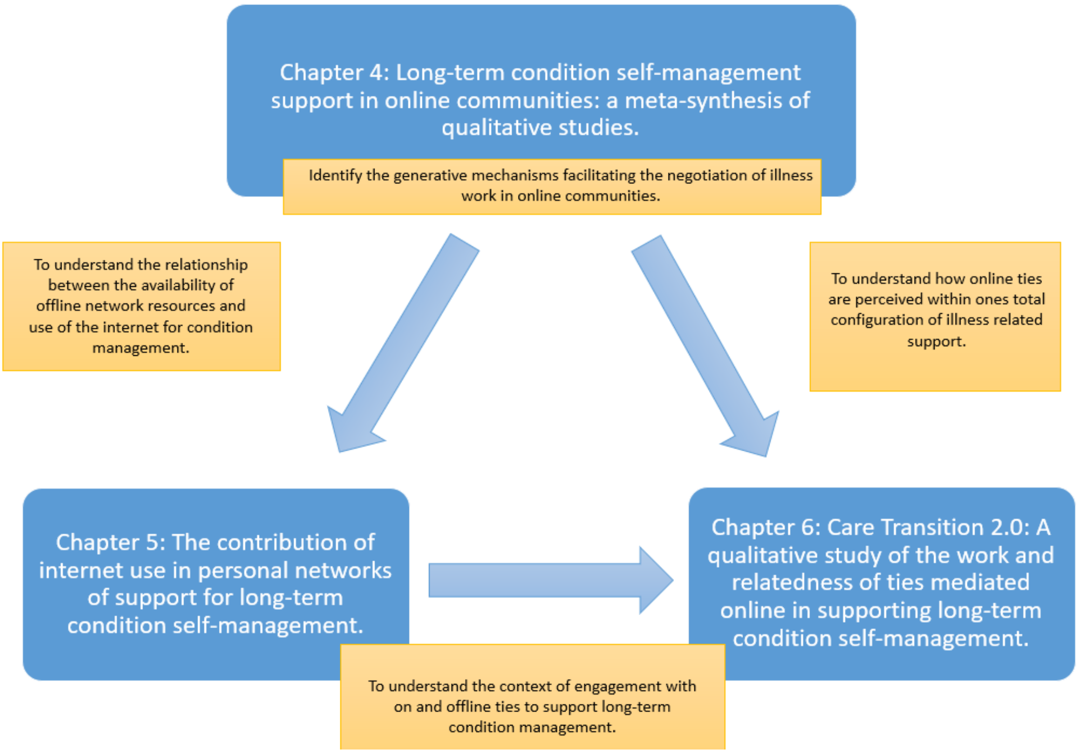
Chapter 3: Methodology

3.1 Introduction

Three papers constitute the core of this thesis. In combination with the papers, this chapter sets out and provides an integrative account of the methods used.

The three methods used were: 1) qualitative meta-synthesis of the literature, examining the role of illness work online in self-management support, to conceptually inform the further empirical research, 2) quantitative secondary analysis of social network survey data pertaining to the use of the internet and offline connections, 3) semi-structured, biographical interviews, including ego network mapping to illuminate the bases of relationality and engagement with online contacts in managing a long-term condition. A summary of the inter-relations between the three papers constituting the core of the thesis is shown in **Figure 2** below.

Figure 2: Model showing the inter-relations between the papers that constitute the core of the thesis.



The research question and objectives for each stage of the research will be discussed in more detail in this chapter. In addition, the decision to use three different approaches will be outlined, including the rationale for the methods that were used. This includes a discussion on the use of the convoy model, that was used to map the support that people had (as is seen in stage two) and as a heuristic device to elicit conversations about the role of specific ties (as is seen in stage three). In justifying the methods used, this chapter necessarily draws on the further explanation of the methods seen in the papers themselves, which are shown in the following three chapters (chapters four, five and six); as well as the research protocol, which can be found in **appendix 1**. Following each stage, the adequacy of each approach will also be discussed.

3.2 Stage one: Long-term condition self-management support in online communities: A meta-synthesis of qualitative studies.

3.2.1 Research question and objectives

3.2.1.1 Research question

What are the mechanisms for self-management support in online communities and how do these support the negotiation of self-management support online?

3.2.1.2 Objective

To build a contextual understanding of the field, specifically by looking at the mechanisms facilitating the negotiation of LTC illness work in online communities, including the relational nature of online ties in supporting the emergence of illness work and thus, allowing for an understanding of how this work might support management in daily life.

3.2.2 Rationale for chosen methods

Qualitative meta[9]-synthesis is an approach to existing qualitative research that seeks to draw meaning through integrating (synthesising) as opposed to aggregating existing evidence (Barnett-Page, 2009; Britten et al, 2017; Timulak, 2014). A line of argument synthesis was used to reveal the mechanisms that might have remained hidden in the individual studies (Noblit and Hare, 1988). This approach interprets the findings as a

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[9] 'Meta' as meaning 'transformation'/ 'at a higher level' (Britten et al, 2017).

whole (Snilstveit et al, 2012; Timulak, 2014) and has been employed in earlier illustrative examples (Pound et al, 2005; Vassilev et al, 2014).

The recent growth of qualitative research in the field has resulted in attention being increasing payed towards methods of synthesising findings (Barnet- Page, 2009 Erwin et al, 2011; Walsh and Downe, 2005). At the same time, concerns have been raised about the extent to which the findings of existing qualitative research are underutilised (Erwin et al, 2011). Qualitative meta-synthesis is one such method that has proved to be effective, and it has been employed in a diversity of areas, including the experience of chronic illness (Campbell et al, 2003; Lamb et al, 2011; Malpass et al, 2009; Pound et al, 2005; Vassilev, 2014). In this instance, it was used to understand the mechanisms supporting illness work online. Patient online communities have been a focal point of qualitative research for some time and thus, there is now an advanced body of qualitative literature, covering a wide range of conditions (chapter four). Through synthesising this collective body of qualitative research, common themes were identified and interpreted, which gave the opportunity for new deeper meanings and insights to emerge through an interpretive process with a view of offering more than the primary studies in isolation (Britten et al, 2017; Erwin et al, 2011; Mohammed et al, 2016; Walsh and Downe, 2005). In this instance, whilst conceptualising the field, this allowed for new understandings of the mechanisms that facilitate the negotiation of illness work online to emerge.

3.2.3 Adequacy

The meta-synthesis in stage one, as with prior exemplar studies, (Malpass et al, 2009; Pound et al, 2005; Vassilev, 2014), used a systematic approach to locate relevant qualitative research. As with previous studies (Pound et al, 2005; Malpass et al, 2009) the included papers were critically appraised (though none were excluded based on quality). Efforts were made to include groups relating to any LTC, to support findings that represented a diversity of illness experiences.

The systematic approach to the meta-synthesis did not occur at the expense of inductive and interpretative analysis; a concern of Thorne (2017). Whilst primarily my own work, the design, conduct and write up of the meta-synthesis, was supervised by AR, AK and IV, which is consistent with the team approach that has been advocated (Thorne, 2017). Whilst the supervisory team and I are researchers working in health, my clinical role and relative inexperience in research, broadened the perspectives involved (Britten et al, 2017) and allowed for different interpretations to emerge, as a product of regular supervisions, which guided critical reflection and the direction of the synthesis.

Thus, the meta-synthesis drew out (with attempts being made to not lose the detail of individual studies) what was known, whilst acknowledging the current knowledge deficits. This resulted in the findings presented in the paper in chapter four being well informed, nuanced and conceptually useful, both in furthering our understandings as to the mechanisms that facilitated the negotiation of illness work online and in setting the course for the further stages of the thesis. In this case, whilst research in this area has alluded to the importance of online ties in meeting needs unmet offline, most studies have not reflected on what is available/not available to people offline; therefore, it is unclear what needs exactly are being unmet. This is reflected in the methodological trends of the included papers (netnography and content analysis of existing posts, rather than direct engagement with those using these platforms). These methods have shaped the existing knowledge in this area.

As Britten (2017) points out, since qualitative meta-synthesis makes use of existing research, quality is intrinsically connected to that of the original papers. It is also important to recognise that the data corpus features the interpretations (the second order constructs) of other researchers (with their own world views and biases), even when first order constructs (the quotes of the participants) are visible (Britten et al, 2017). In addition, the different ways the individual papers can be interpreted (including the impact of the reviewer's values and understanding of the papers), means the process of synthesis is subjective (Snilstveit et al, 2012). Consistent with the reflections in the previous chapter on CR, qualitative meta-synthesis, is limited in presenting truth claims (Thorne, 2017), but it is a useful method in bringing to the fore a better understanding of the possible causative (generative) mechanisms supporting the negotiation of illness work and thus, can provide new insights to researchers, policy makers and those working with people with chronic illness (Britten et al, 2017; Malpass et al, 2009). Importantly in this thesis, as an approach, it paved the way for the further two empirical stages.

Further details of the methods used, including the search strategy, literature appraisal and details of the synthesis are found in the methods section of the paper seen in chapter four.

3.3 Stage two: The contribution of internet use in personal networks of support for long-term condition self-management.

3.3.1 Research question and objectives

3.3.1.1 Research question

What role do personal networks, network resources, illness work, and community participation have on the use of the internet in general, as well as for support in managing a LTC?

3.3.1.2 Objectives

- To describe the individual and network characteristics of people who use the internet for LTC management, including their access to social resources and community participation.
- To explore the role of offline personal network support (illness, practical and emotional work) on the use of the internet for LTC self-management.

3.3.2 Rationale for chosen methods

This stage addresses the quantitative elements of SNA as discussed in the previous chapter. It involved a retrospective, secondary analysis of data from the 'Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (U-Net)' research project (Vassilev et al, 2013), to examine the role of offline support in determining engagement with online support for condition management. This was done to understand the relationship between the availability of offline support (the contextual factors) and the use of the internet for condition management. The methods of which are shown in more detail in chapter five, which features the published paper and **appendix one,** which features the research protocol.

Secondary analysis has been described as an approach to make use of existing data from previously conducted research; usually to answer new questions (Cheng and Phillips, 2014; Williams and Shepherd, 2017). The use of data that has been previously collected, is both advocated for and a common approach to SNA (Williams and Shepherd, 2017). The decision to make use of an existing data set was made following discussions with the supervisory team (AR, AK, IV). Pragmatically, it was decided that as a PhD researcher acting independently, with limited time and material resources, collecting a dataset of similar richness and quality would have been inappropriate, given the availability and richness of the secondary dataset, which was previously collected by a team of researchers, including members of the supervisory team (AR, AK, IV).

The dataset included 300[10] participants' (egos), who took part in the original study (Vassilev et al, 2013). These participants were recruited from 19 GP practices, which were in predominantly poorer areas of Greater Manchester (Vassilev et al, 2013). The participants all had a LTC (diabetes, heart disease, CKD) and thus the sample was appropriate to the aims of this stage.

The ego level data was complimented by a further 2,544 network members (alters) contributing to chronic illness management, thus giving a view of the participants personal network, the resources that they had available through these contacts and the availability of illness work within the network (including the types of work (illness, everyday practical, emotional), as well as network data, such as diversity, fragmentation etc.[11]. These were used to better understand the extent to which ego, alter and network characteristics influenced the use of the internet to self-manage a LTC.

The original study (Rogers et al, 2011; Vassilev et al, 2013) looked at which network members were involved in self-management support and the types of support that they provided. In addition, it looked at the relationship between the amount and distribution of work in those with/without a partner/spouse (Vassilev et al, 2013). It also looked at the ego and network characteristics that related to the support people received (Vassilev et al, 2013). Thus, in addition to the previously unused data it collected on internet use, it collected data relevant to the research question and objectives.

The availability of this data provided the opportunity to contribute to the themes existing research, whilst advancing the use of the existing data. In doing so, burden and risk to new participants was also reduced (Doolan and Froelicher, 2009). Given the de-identified

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[10] The relatively low ego sample reflects a known difficulty in recruiting people from marginalised communities to research (Ellard-Gray et al, 2015).

[11] More complete details of the social network variables use in the analysis can be seen in the paper in chapter five.

nature of the data, this approach presented little risk to existing participants (Doolan and Froelicher, 2009). In addition, this dataset has been used previously for secondary analysis, with successful publication, for example in Forbes (2016), where it was used to examine the social determinants of time spent on self-care.

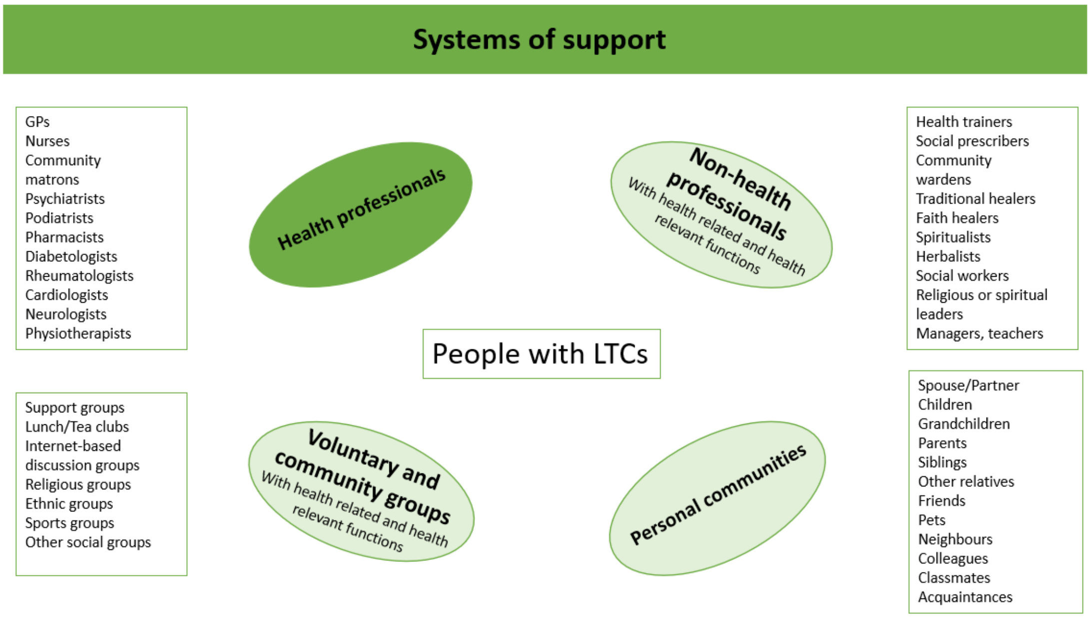
Whilst stages two and three used a convoy model to map the ego’s personal network of support, this stage used it to record the number of ties and the relevant work that was provided by each tie, including the access to resources that they mediated. In stage three, it was used as a heuristic device to support conversations about who was turned to and for what. The background to this approach, as used in this stage, is discussed in more detail below.

3.3.3 The convoy model of social relations

To better understand the circumstances of those managing a LTC and the network resources people draw on, the data collected in the original study used the convoy model of social relations. This was designed to capture the nature of social relations with an emphasis on closeness (Kahn and Antonucci, 1980). This method allows participants to elaborate on the increasingly divergent networks of support that are seen in contemporary society (Antonucci et al, 2014).

The original conceptualisation of the convoy model was intended to give research participants a suitable framework for which to discuss the supportive role of network members. More recently, Pahl and Spencer (2010) have suggested the notion of ‘personal communities’, as representing the microsocial world of the social ties that an individual sees as significant to them. Personal communities can be used as a practical schema for capturing the relationships that people see as important to them and thus, this method allows for the focus to shift from the individual, to the diverse range of contacts within personal networks (such as relatives, friends, community groups, healthcare professionals etc.) (**figure 3**) supporting self-management (Rogers et al, 2014).

Figure 3: Personal Networks

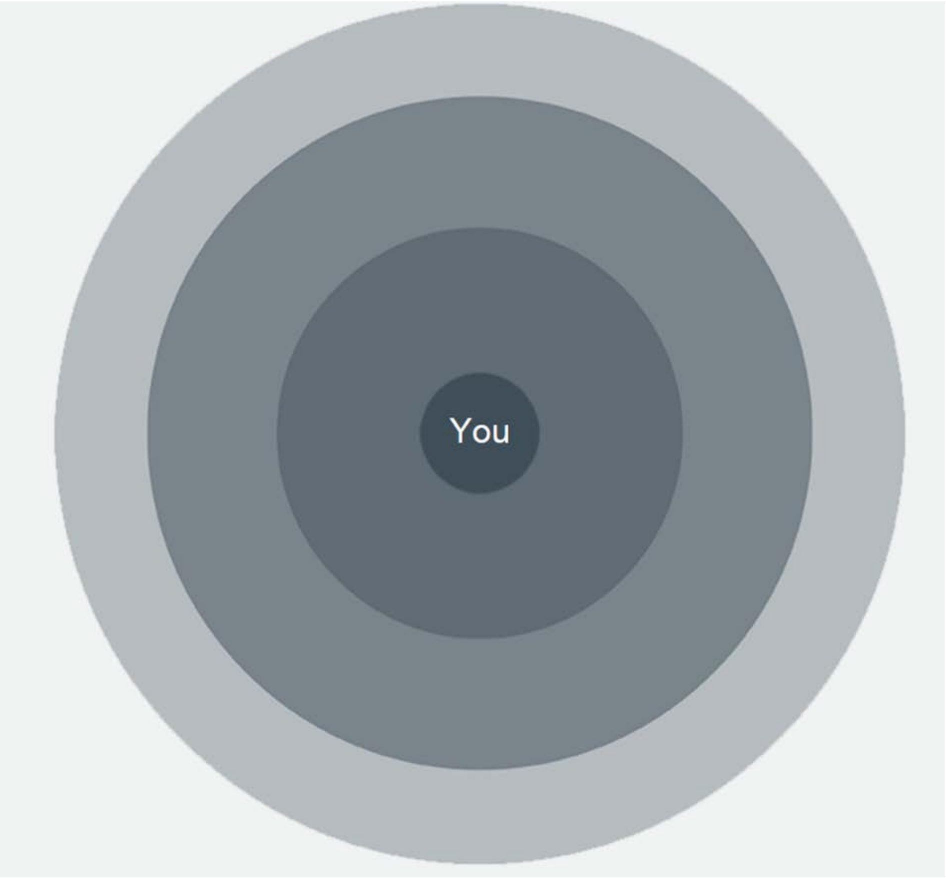


Rogers et al (2011). Social networks, work and network-based resources for the management of long-term conditions: a framework and study protocol for developing self-care support. Implementation Science. 6 (56).

This allows for the full realisation of network resources and support the individual can access and negates the tendency towards positivist assignment of roles within a network, based around the type of relationship (such as assuming the duties of spouse, relatives, and friends etc.) and the recognition, that through a process of suffusion, people may play complimentary and overlapping roles (Kennedy et al, 2014). Thus, this approach makes no assumptions about who features in the participant’s personal network (Pahl and Spencer, 2010).

Through the adoption of the convoy model, with Pahl and Spencer’s (2010) definition of ‘personal networks’, a better recognition of the people and/or groups considered to be important to the individual was enabled. This approach sees participants place network members that are important to them in one of three circles, representing: important, more important and very important (the inner most circle) (**figure 4**).

Figure 4: Convoy model, concentric circle ego mapping tool



Thus, participants are able to describe their network in accordance with who is most important to their management. As such, the use of the convoy model allows for a portrayal of the participants 'micro-social world' in accordance with how they interpret the support that people provide them and the contexts within which it is provided, whilst mitigating bias and preconceptions as to who should be placed based on the type of relationships (for example, feeling the need to place a spouse, even if they are unimportant to management).

In the original study (Rogers et al, 2011; Vassilev et al, 2013), the convoy model was used as a name generator, in which all network members that the ego saw as important to them in supporting management, were placed in one of the three concentric circles, following which further data was collected about the key attributes of each member placed, including their contribution towards condition management.

The further measures used in this stage, are detailed in the paper in chapter five.

3.3.4 Adequacy

In the findings of the secondary analysis, it is not appropriate to make *causal* inferences (Reichenheim and Coutinho, 2010) about the nature of offline support in relation to online engagement. However, given the nature and richness of the data collected in the original study (Rogers et al, 2011; Vassilev et al, 2013), it is appropriate that the findings are used to *describe* the ego and network characteristics that *relate* to engagement with online resources for condition management and the appropriate methods have been used in order to do this. With the recognition that open systems are complex and the observed findings may be the result of many factors (including those that cannot be known), CR is concerned with making better sense of the social world and therefore, whilst the findings generated at this stage cannot be used to make predictions; the findings can be used to explain the possible network and non-network mediated processes driving online engagement (Buch-Hansen, 2013).

Whilst the data collected in the original study featured questions about internet access and use, including access to someone able to fix computer problems, through a component of the resource generator (Webber and Huxley, 2007), because it did not set out to specifically examine this aspect of self-management, the data in relation to online behaviours and skills was more limited than that which would be have been collected in a primary study (Cheng and Philips, 2014). Nonetheless, this stage of the research advances the use of an existing dataset, the work of the wider team and makes a novel contribution to the literature in a previously unexplored, but important area of research.

3.4 Stage three: Care Transition 2.0: A qualitative study of the work and relatedness of ties mediated online in supporting long-term condition self-management

3.4.1 Research question and objectives

3.4.1.1 Research question

What is the nature of engagement with online ties in those who use them to support the self-management of a LTC and how do people perceive the support that is available online in the context of their overall social network?

3.4.1.2 Objectives

- To identify the history, context and circumstances of engagement with online communities for LTC management.
- To understand how people, access and use the online communities for support in relation to different situations and in combination with offline engagement.
- To understand the role and value placed on online communities for LTC management within the context of people's whole configuration of social networks (personal communities of online and offline ties).
- To understand the range of resources that individuals draw from on and offline ties that relate to condition management.

3.4.2 Rationale for the chosen methods

This stage addresses the qualitative elements of SNA as discussed in the previous chapter. In response to the aims of this stage and in view of the methodological (and subsequent knowledge) gap identified in stage one, this stage necessarily involved direct engagement with those using online communities to support the management of a LTC, in order to understand how this support is seen and the role it plays. Thus, this stage involved the recruitment of 30 participants, living in the Wessex area of the UK, who made use of online communities to support the management of a self-identified LTC in daily life. Data was collected through semi-structured, biographical interviews. The convoy model (**figure**

4), was used during the interviews primarily as a heuristic device to support conversations about who network support was sought from, and why.

Further details of the methods can be seen in chapter six and in the protocol in **appendix 1**. Rationales for the chosen methods for this stage are detailed below as well as reflections on their adequacy.

3.4.2.1 Semi-structured, biographical interviews

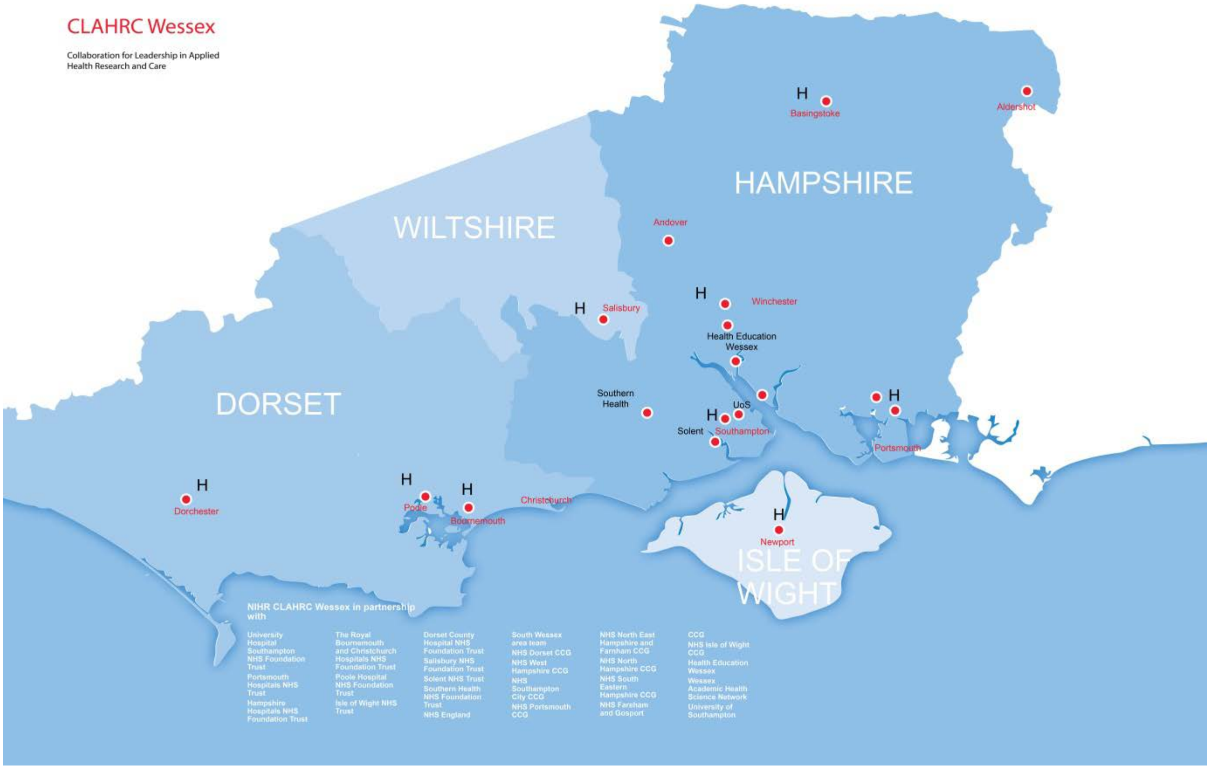
Biographical interviews were used to elicit a chronological narrative of individual's personal exploratory accounts of the phenomena, taking into account the events, people, situations and places relevant to the participant's use of online communities to support LTC management, allowing for a more complete picture of the context of engagement and its situation within a wider system of support to emerge (Roberts, 2002).

This was facilitated through a semi-structured approach that aimed to better understand the role of online communities and ties from the perspective of the participants experiencing them (Bryman, 2012). In semi-structured interviews, the researcher has flexibility to depart from the interview schedule; this allows for the exploration of emergent (often unexpected) themes that nonetheless can illuminate some of the most important aspects of the research (Bryman, 2012). The general direction the interview takes is supported by providing some structure to the interview schedule, which ensures that the questions identified as important in meeting the research's aims and objectives are asked (Bryman, 2012). The semi-structured interview schedule that was created with a focus to answering the research question can be seen in the protocol (**appendix 1**) and centres around the history of engagement with online communities, as well as the nature of support that is provided by on and offline network members placed during the convoy model exercise.

3.4.2.2 Study context

The study population for the interviews in this stage, were people living in the Wessex region of England**,** who use online communities to support LTC self-management. The Wessex region sits in the South of England and can be seen in **figure 5**. The University sits in this area and thus, is an area that the PhD candidate (CA) and the supervisory team (AR, AK, IV) were familiar with.

Figure 5: Sample population of Wessex region



3.4.2.3 Identification of participants and sampling

30 adults were recruited to the study through purposive sampling, thus ensuring only those with relevant experience, who are able to provide rich detail about the place of online ties were included (Palinkas et al, 2015). This was done through only including those who used online communities and ties to support management. In addition, participants were sampled with a variety of LTCs representing different illness experiences.

Several approaches to the identification of suitable participants that met inclusion criteria were used. These approaches are shown in **figure 6**.

Figure 6: Recruitment approaches

This stage of study was actively promoted through social media. This was informed by the approaches seen in prior research (Fenner et al, 2012; Pedersen et al, 2015; Partridge et al, 2015) as well as my own previous research. Twitter and Facebook accounts were set up specifically for the study and promoted the study on a regular basis, including sharing blog posts that were written about the study. A snowball technique was used that made use of existing online contacts, such as CLAHRC Wessex's social media accounts (Twitter and Facebook). Known support groups were also contacted directly through Twitter**.** Posters were displayed in universities, libraries and community centres across the Wessex region. Permission was sought prior to each placement.

In addition, CA attended multiple face-to-face support groups and community groups to talk about the research and gave out a participant information sheets to anyone that expressed an interest in participating. This approach has been used on similar ongoing research in the team.

Potential participants, who expressed an interest in the study, were screened against the pre-determined inclusion/exclusion criteria seen in **figure 7**. Provided they met the criteria below and were happy to take part, they were recruited to the study.

Figure 7: Inclusion/Exclusion Criteria

Inclusion criteria

- Adults (over the age of 18).
- Living with a self-identified long-term condition (defined as any condition that affects someone's health, which cannot at present be cured but can be controlled through medication and therapy)
- Use the Internet or Social Media in the self-management of their long-term condition
- Living within the Wessex region **(figure 5)**.

Exclusion criteria

- Unable to give full informed consent towards study participation.
- Those receiving palliative care.
- English not first language.

Data analysis occurred simultaneously with data collection as part of an iterative process. The decision to stop data collection, once 30 participants had been interviewed, was discussed with all members of the supervisory team (AR, AK, IV) and since no further themes were emerging, and with a view of the original aims and objectives of the research, the decision was made to stop data collection (data saturation) (Saunders et al, 2018). All the interviews were transcribed verbatim by CA, which supported immersion in the data collected.

Except for ethnicity and nationality (all the participants were white, and except for one, British), participant demographics were diverse (location, incomes, education, age, condition). Men were more difficult to recruit, thus additional efforts were made to recruit men, including attending community groups, such as walking football and 'men in sheds'. The sample demographics for this stage of the research are shown in **table 1** below.

Table 1: Sample demographics

	N (%)*
Gender	
Male	13 (43%)
Female	17 (57%)
Age	Mean= 52.0
Income (participants asked if income was lower, the same as or higher than £26,500)	
Lower	16 (53.3%)
Average	7 (23.3%)
Higher	7 (23.3%)
Condition (note some participants had more than one long-term condition)	
Parkinson's Disease	7 (23.3%)
PMR/GCA/Arthritis	5 (16.7%)
Fibromyalgia	5 (16.7%)

Type 1 Diabetes	4 (13.3%)
Mental Health Problems (Anxiety, Depression)	4 (13.3%)
Heart Problems (MI, Arrhythmia)	2 (6.7%)
Multiple Sclerosis (MS)	2 (6.7%)
Lung Fibrosis	2 (6.7%)
Myalgic Encephalomyelitis (ME)	1 (3.3%)
Chronic Pain	1 (3.3%)
Lupus	1 (3.3%)
Hypermobility	1 (3.3%)
Glaucoma	1 (3.3%)
Trigeminal Neuralgia	1 (3.3%)
Psoriasis	1 (3.3%)
HIV	1 (3.3%)
Hepatitis C	1 (3.3%)
Haemophilia	1 (3.3%)
Liver Cirrhosis	1 (3.3%)
Stroke	1 (3.3%)
Epilepsy	1 (3.3%)
Stiff Persons Syndrome (SPS)	1

	(3.3%)
Asthma	1 (3.3%)
County of Residence	
Hampshire	27 (93.3%)
Dorset	2 (6.6%)
Isle of Wight	1 (3.3%)
Marital status	
Married or in a civil partnership	17 (56.7%)
Never married or in a civil partnership	8 (26.7%)
Divorced	2 (6.7%)
Widowed	3 (10.0%)
Ethnicity	
White British	29 (96.7%)
White Swedish	1 (3.3%)
Employment status	
In paid work, education or training	60 (20.3%)
Not in paid work, education or training	236 (79.7%)
Highest qualification	
GCSE	1 (3.3%)
A Levels	3 (10.0%)
NVQ	1 (3.3%)

Professional Qualification	2 (6.6%)
Diploma	1 (3.3%)
Degree	17 (56.7%)
Higher degree	5 (16.7%)
Employment status (some participants performed more than one)	
In paid work (full time or part time)	7 (23.3%)
In full time education or training	3 (10.0%)
Long-term sick/disabled	7 (23.3%)
Retired	13 (43.3%)
Looking after family/home	4 (13.3%)
Voluntary work	4 (13.3%)
Unemployed	1 (3.3%)

3.4.3 Data analysis

3.4.3.1 Framework analysis and inductive thematic analysis

Whilst the framework approach is not aligned to a particular epistemological or theoretical position (Gale et al, 2013), it has been used successfully in the exploration of illness work, as per Brooks et al (2016) who also used convoys to collect the ego net as experienced by the participant, followed by analysis of the nature of that support using framework analysis, with the concept of illness work providing the ‘frame’.

The starting point to the analysis was therefore similar to Brooks et al (2016) in that, illness work was used as the conceptual starting point to the analysis. This provided a useful schema for thinking about the types of work that people turned to from on and offline ties that were placed in the convoy model. In the initial stages of the analysis, this allowed for comparisons to be made easily, both across cases and within individual cases, in which the participants had their own unique biographies, views, experiences and perspectives relating to their utilisation of on and offline ties in supporting illness management (Gale et al, 2013). This allowed for individual case studies to presented, by not losing the details and narratives of the individual participants, whilst facilitating a constant comparative technique, by providing a schema through which the whole dataset could be viewed, giving increased understanding about the types of work that were being performed by on and offline ties. The framework provided a descriptive overview, allowing a holistic visualisation of the entire dataset (Gale et al, 2013). This stage of the analysis was deductive in its approach, in which, efforts were made to search for examples of different types of illness work within the transcripts (Gale et al, 2013; Reichertz, 2014) based on the different types of illness work identified as being important in prior research (Bury, 1982; Corbin and Strauss, 1985; Rogers et al, 2011; Vassilev et al, 2013) and financial and political work, which were added to the framework during initial coding (**figure 8**).

Figure 8: Adapted illness work framework

Type of work		Definitions
Everyday practical work		Discussions around the work involved in supporting practical everyday aspects made difficult by illness.
	Everyday domestic work	Discussions about the work/tasks such as housekeeping, occupational labour, support, and activities relating to diet and exercise, shopping, and personal care etc.
	Everyday work-diet	Discussions about the work/tasks related to non-specific support related to diet (for example shopping and cooking).
	Everyday work- hobbies and exercise	Work related to non-specific support relating to exercise (for example, support with going to the gym, walking etc.)
Co-ordination		Discussions about the negotiations and renegotiations in the ways in which work is done such as what work is done, by whom, when, how and why.
Illness (specific) work		Discussions around the work involved in taking medications, taking and interpreting measurement; understanding the condition and its symptoms, making appointments.
	Medical	Illness (specific) work discussions supported by evidence-based practices, often medical knowledge.

Experiential	Illness work based on experience and observation, such as people’s experiences of taking certain tablets and the side effects that they have had as a result etc.
Translation and mediation	Work relating to the translation of abstract knowledge into practical advice that can be implemented.
Emotional work	Discussions around the work involved in comforting when worried or anxious about everyday matters, such as health and well-being.
Biographical work	Discussions around the work relating to the reassessment of personal expectations, future-plans, capabilities, personal identities, relationships and biographical events.
Contingency and Improvisation	Discussions about the work involved in getting things back on track, after disruption.
Financial work	Discussions about the work needed to raise money, either through employment (including self-employment) or through benefit entitlement etc.
Political work	Discussions around the work done to ensure more even distribution of resources relevant to condition management, for example, activism directed at improved access to condition related treatments and financial support, for example Personal Independence Payments (PIP).

Bury, M. (1982). Chronic disease as a biographical disruption. Sociology of Health and Illness. 4. pp 167-182.
Corbin, J. and Strauss, A. (1985). Managing chronic illness at home: three lines of work. Qualitative Sociology. 8. 224-247. Rogers, A., Vassilev, I., Sanders, C., Kirk, S., Chew-Graham, C., Kennedy, A., Protheroe, J., Bower, P., Blickem, C., Reeves, D., Kapadia, D., Brooks, H., Fullwood, C., Richardson, G. (2011). Social networks, work and network-based resources for the management of long-term conditions: a framework and study protocol for developing self-care support. Implementation Science. 6 (56). Vassilev, I., Rogers, A., Blickem, C., Brooks, H., Kapadia, D., Kennedy, A., Sanders, C., Kirk, S., Reeves, D. (2013). Social Networks, the ‘Work’ and Work Force of Chronic Illness Self-Management: A Survey Analysis of Personal Communities. PLOS ONE. 8 (4). pp 61-69.

Following this, the approach moved towards inductive thematic analysis (Reichertz, 2014), with the emergent themes concentrating on the participant’s discussions about who they turned to for different types of work in different circumstances over time and how this related to the types of work that were available/not available to them offline (**figure 9**). Thus, the approach was theoretically driven, but inductively generated. The process of inductive thematic analysis followed that of Nowell et al (2017). This stage, was supported by earlier familiarisation and immersion with the data, both through transcribing the interviews, use of the illness work framework (**figure 8**) and re-reading the interview transcripts, which supported the visualisation of the breadth and richness of content, as well as informing the initial direction of the analysis through understanding some of the emergent patterns (Nowell et al, 2017) between use of on and offline ties for different types of work. Following this, initial codes were generated, that reflected the reasons the participants gave for seeking different types of work from different on and offline (as well as those known both on and offline) network members in relation to the support they had on and offline, during different stages and under different circumstances. These codes provided the basis for the emergent themes and subthemes (Nowell et al, 2017). Following coding, all the potentially relevant codes were collated into early themes and subthemes, to capture the context of engagement with different on and offline network resources. These were discussed with all members of the supervisory team, to reflect on whether the identified themes reflected the data that was collected (Nowell et al, 2017) in relation to the context of engagement with on and offline ties for different types of work. Following this, the themes were clarified, and discussions were held about how the themes and sub themes fitted together and the emergent narrative of the data (Nowell et al, 2017). Coding and organising the codes into themes and subthemes was an iterative process, in which existing themes were tested with new data, allowing for the creation of new themes, as well as the refinement of existing ones. This process continued until data saturation was achieved, when the decision was made that no new themes were emerging from the data (Saunders et al, 2018).

Figure 9: Inductive thematic analysis emergent themes and subthemes

Theme: Online network extension in response to unmet offline needs	**Theme: Online community engagement as leverage of offline tie action**	**Theme: Substitution of offline emotional work with online ties through protective avoidance**
Online engagement as a strategy for addressing deficits in support needs that are seen as essential to the management of a long-term condition during specific stages of the illness career, but are unavailable offline.	Engagement with online resources seen as a strategy for eliciting (leveraging) desired offline support and resources from lay and professional ties.	Online engagement seen as a strategy to substitute certain aspects of illness work offline, with online support, despite offline support being available.
Subtheme: Lack of offline medical information at critical moments. A lack of offline information about the management of the condition, particularly from what would be normative providers of medical advice, for example health care professionals. This was either through lack of time in clinical consultations, difficulty getting an appointment, or contested medical knowledge. **Illustrative example:** "No, because you know, the GP he never has that much time to talk to you. And quite honestly, I am not	**Subtheme: Backstage leveraging of resources from healthcare professionals** Use of online ties and conversations as a backstage to formal consultations, where the self can be presented as a candidate for certain treatments, referrals and resources. The backstage allowing for knowledge acquisition about what is available and how it can be acquired. **Illustrative example:** "Well I went back to my doctor, after speaking to people online and said 'look, I think it's this'. And he said, 'you need to have this test and that test' and so I had them done and there was sort	**Subtheme: Biographical avoidance, through online substitution** Mobilising support away from existing offline ties as a way of maintaining a sense of self, maintaining existing biographies and the way existing ties evaluate them. **Illustrative example:** "Because when you are diagnosed, you become like this person with the disease…but my friends and family, they know me how I was before and whilst they can still know that there are things that are different now, I have a long-term condition to manage, I don't really feel like I want to share my

sure he knows that much about it. Not as much as these people online” **Subtheme: Lack of access to people with lived experience relevant to the implementation of self-management in daily life.** A lack of offline network members, particularly those living with the same condition able to provide knowledge about the illness particularly that gained through lived experience. This included access to people managing illness alongside activities or life events and the ability to adjust self-management practices. The creation of a modus Vivendi. **Illustrative example:** “Um….and that that might help me speak to other people in a similar boat and um…you know, exchange assistance on how to manage long term conditions whilst studying and working and having family and things…so, and there are a lot of people who do it, so that is why.” **Subtheme: Lack of access to people able to offer emotional work, from a place of understanding.** A lack of people offline with the same condition, resulting in a deficit in emotional work, particularly that which came from a place of understanding of the everyday difficulties and frustrations of managing the condition. A lack of people who ‘got it’ offline. **Illustrative example:** “I think we all established a good friendship that’s helped by knowing that you feel understood. Um…its really hard to explain what the condition can do to you, to like your loved ones, your friends, your family; that love you and want to care for you but can’t understand. How could they? Um…every bit as much as they want to.	of no other logical reason- so he agreed with me [laughs].” **Subtheme: Frontstage leveraging of support from lay offline ties through illness reification** Online conversations with others with the same condition used to demonstrate/leverage existing and future needs for support, through a process of illness reification (i.e. that the condition is real, by nature of it being something other people also experience). **Illustrative example:** “Um…it lets me give some explanations to my wife that it’s not just me, because she can get frustrated. If you can imagine, the last five years, it is a rarity for us both to be in bed in the morning. Because she will get up and I will already be downstairs. And so, that helps, being able to explain it to her.” **Subtheme: Frontstage leveraging of support from lay offline ties through online presentation of self.** Online disinhibition allowed new presentations of self, providing the opportunity to use identity indicators online, to express support needs to less intimate offline ties. This supports disclosures about illness that are difficult and painful to discuss offline. Also used to remind people that they might need support, when offline support wanes. **Illustrative example:** “I was gradually starting to just talk a little about, you know, my health…but never actually, you know, going I have this and this is my situation…and then I got my wheelchair and I was like, right, people are going to see me in my wheelchair, right, I am going to post a photo…on Facebook”	whole insight with them, I don’t mind sharing through my Twitter, but I don’t want to share it with my close friends and family”. **Subtheme: Moral avoidance, through online substitution** The decision to mobilise support away from existing offline ties through the recognition that supportive ties offline lead busy lives, have lives of their own, or the belief that they are bored of discussions about their condition and its impact. **Illustrative example: “**She is not interested…my daughter is a strange one, because I don’t want to talk to her about it, because I feel like I don’t want to weigh her down, so I have pushed that support away.” **Subtheme: Protective avoidance, through online substitution** Recognition that offline ties provide essential tangible support offline, particularly practical everyday work. Steps taken to negotiate the support that can be performed elsewhere, away from offline ties as a way of safeguarding against the loss of ties seen to be essential in management of condition. **Illustrative example:** “I mean there are some people on there who will say, who will advise other people like ‘don’t keep moaning at your partner about this, because its not healthy. Use us and kind of spread it”

So, there is that gaps there, in anyone's life to different degrees."	**Subtheme: Offline support mobilisation through online presentations of need** Mobilisation of offline ties, through online communities, such as Facebook to acquire tangible support such as lifts, childcare etc. Nature of online communities means needs can be projected to large offline network, matching needs with offline tie availability. **Illustrative example:** "I did have an emergency appointment come through a while ago and couldn't get a baby sitter, so I just said on Facebook, you know, 'can any of my friends have the boys for just and hour' and my friend around the corner said 'oh, no worries, I am free'…there is a lot of interlocking support. It makes coordinating things easier.	

This approach was supported by computer assisted qualitative data analysis software (CAQDAS), specifically NVIVO 11 (Silver and Lewins, 2014), which was used to sort and organise the data from detailed coding, towards higher levels of abstraction (Nowell et al, 2017). Wallcharts were used to support different visualisations of the emergent themes and subthemes, as per **figure 9** above, until the final three themes that are discussed in the paper in chapter 6 were agreed on.

3.4.4 Adequacy

As with all qualitative research, this stage of the thesis did not seek to be statistically representative (Pope and Mays, 2006). Instead, it aimed to explain the nature and role of online ties, as seen by those using them to support chronic illness management.

Several steps were taken to ensure this stage of the research was conducted rigorously, in order to ensure it was adequate in meeting the research aims and objects. Firstly, there is visible alignment between the research question, methods and analysis (Morse et al, 2002). In addition, the approaches used have been clearly articulated, both in the thesis and in the paper shown in chapter six. This is important, as the methods, including the way in which the data was collected is intrinsically linked to the research findings (Mays and Pope, 2006).

To minimise (though not entirely remove) the various compositional and social factors that might influence analysis (including my own influences) a research diary was kept, which included my responses and reactions to events that occurred during the research process (Mays and Pope, 2006). Whilst at the time I was in a clinical role, I approached the interviews as a social researcher (as reflected in the participant information sheet). However, my clinical role was not hidden. Whilst the participants were not patients in my care and were drawn from non-healthcare settings, my orientation likely shaped both the conduct of this stage, the data that was collected and how it was interpreted (Mays and Pope, 2006).

In partial mediation of this, the research process was meticulously documented, including reflections on the transcripts during coding (Cresswell, 2014). As part of an iterative process, participant verification occurred throughout the data collection phase (Morse et al, 2002). Through this process, data was regularly checked to ensure responses aligned to what the research set out to explore; which also allowed for stock to be taken of what remained unknown and required further exploration in subsequent interviews (Morse et al, 2002).

In addition, as with stage one, whilst primarily my own work, the design, conduct and write up of this stage was supervised by AR, AK and IV, this allowed for the early transcripts to be coded by several members of the research team (CA, AK, IV), allowing for alternative viewpoints to emerge and be considered (Gale, 2013). The subsequent coding framework and emergent themes were discussed during regular (peer debriefing) supervisions with (AR and IV), which also supported the accuracy of emergent themes (Cresswell, 2014). This provided a forum through which interpretations could be discussed, providing the opportunity for alternative interpretations to be considered and thus ensuring that the emergent themes were a fair reflection of the participant's narratives and the reality they were experiencing (Creswell, 2014). This iterative process also allowed for new interpretations to be verified using earlier data (Morse et al, 2002).

This stage of the research was relevant in its exploration of a previously underexplored, hidden patient system of implementation that responds to the methodological gap identified in stage one and the need to better understand the place of online ties within wider personal network support. Thus this stage is relevant in making a novel contribution to the field (Mays and Pope, 2006).

3.5 Ethics approval

Stage one made use of existing published research and therefore no ethical approval was sought for this stage of the research. In stage two, ethical approval for the original study was obtained from the Greater Manchester Research Ethics Committee in February 2010 (ref:10/H1008/1) as well as approval for the secondary analysis as part of the ethics application covering stage three, from the University of Southampton's Ethics Committee (ERGO) (REF:19132**)**. The ethics documentation, including the participant information sheet and consent form, can be found in the **appendix 1-3**, which also contains a more detailed discussion of the ethical considerations.

Chapter 4: Long-term condition self-management support in online communities: A meta- synthesis of qualitative studies.

4.1 Abstract

Background

Recent years have seen an exponential increase in people with a long-term condition (LTC) using the internet for information and support. Prior research has examined support for LTC self-management (SM) through the provision of illness, every day and emotional work in the context of traditional offline communities. However, less is known about how communities hosted in digital spaces contribute through the creation of social ties and the mobilisation of an online illness 'workforce'.

Objectives

To understand the negotiation of LTC illness work in patient online communities and how such work may assist the SM of LTCs in daily life.

Methods

A systematic search of qualitative papers was undertaken using AMED, CINAHL, Cochrane Database, Delphis, Embase, International Bibliography of Social Sciences, Medline, PsychInfo, Scopus, Sociological Abstracts and Web of Science for papers published since 2004. 21 papers met the inclusion criteria of using qualitative methods and examined the use of peer-led online communities in those with a LTC. A qualitative meta-synthesis was undertaken and the review followed a line of argument synthesis.

Results

The main themes identified in relation to the negotiation of Self-Management Support (SMS) were: 1) Redressing offline experiential information and knowledge deficits; 2) The influence of modelling and learning behaviours from others on SM; 3) Engagement which validates illness and negates offline frustrations; 4) Tie formation and community building; 5) Narrative expression and cathartic release; 6) Dissociative anonymity and

invisibility. These translated into a line of argument synthesis in which four network mechanisms for SMS in patient online communities were identified. These were *collective knowledge and identification through lived experience*; *support, information and engagement through readily accessible gifting relationships; sociability that extends beyond illness;* and *online disinhibition as a facilitator in the negotiation of SMS.*

Conclusion

Social ties forged in online spaces provide the bases for performing relevant SM work that can improve an individual's illness experience, tackling aspects of SM that are particularly difficult to meet offline. Membership of online groups can provide those living with a LTC with ready access to a SMS illness 'workforce' and illness and emotional support. The substitutability of offline illness work may be particularly important to those whose access to support offline is either limited or absent. Furthermore, such resources require little negotiation online, since information and support is seemingly gifted to the community by its members.

4.2 Introduction

Population aging has resulted in an increased prevalence of long-term conditions, which has resulted in increased expenditure on the provision of care for those affected (Rogers et al, 2011; de Silva, 2011). As a consequence, self-management has become an increasingly important paradigm in health care delivery and the promotion of self-management of long-term conditions is now an enduring feature of health care policy (DOH, 2005; 2010; 2015). This meta-synthesis of qualitative papers seeks to explore the self-management of long-term conditions in the relatively new context of online communities.

The current economic and philosophical landscape of the National Health Service (NHS) necessitates the need for illness work to be delegated to those with a long-term condition and policy makers hope this will reduce health service utilization (Vassilev et al, 2011) and improve health outcomes (de Silva, 2011; DOH, 2005, 2010). The need for self-management is reinforced by the fact that those living with a long-term condition spend very little time engaged with health care professionals compared to the time spent on activities that are required to manage their condition in daily life (Rogers et al, 2011; 2014).

Recent research has begun examining the social context of long-term condition self-management and, more specifically, the role of others in shaping and supporting self-management practices (Rogers et al, 2011; Vassilev et al, 2011; 2013; Reeves et al, 2014). In particular, research conducted by Vassilev et al (2013) demonstrate the importance of work in long-term condition self-management, particularly in respect of one's illness work force, those in one's network who provide assistance in the self-management of their condition through illness, everyday, and emotional work, which can include a biographical dimension (Vassilev et al, 2013; Corbin and Strauss, 1985; Bury, 1982). Types of illness work suggested by Vassilev et al (2013) and Rogers et al (2011) include:

- Illness (specific) work: work such as taking medication, taking and interpreting measurements, understanding condition and its symptoms, and making appointments
- Everyday work: tasks such as housekeeping, occupational labour, support, and activities relating to diet and exercise, shopping, and personal care.
- Emotional work: work related to comforting when worried/anxious about everyday matters, such as health, well-being, and companionship (including a biographical dimension relating to the reassessment of personal expectations, capabilities, future plans, personal identity, relationships, and biographical events)
- Contingency/improvisation: the work involved in getting things back on track
- Translation/mediation: the work involved in translating abstract knowledge into practical knowledge that can then be implemented
- Coordination: the negotiations and renegotiations in the ways in which work is done, such as what work is done, by whom, when, how, and why
- Advocacy work: work done by others on one's behalf Weak social ties also contribute to illness work by affording greater access and transmission of information between network members; the value of these ties lays in their quantity rather than their intensity (Rogers et al, 2014).

Online communities are particularly good at facilitating the creation of weak ties (Ellison et al, 2007; Donath; 2007; Donath and Boyd, 2004; Van Dijck, 2013). As a result, community membership may afford people a larger, more diverse social network than would otherwise be available because ties mediated online are not restricted by temporal, spatial, or geographical limitations that typically define offline social networks (Donath, 2007; Coulson, 2014). Those with more diverse social networks are said to self-manage their long-term condition better compared to those with fewer social ties (Reeves et al, 2014); however, this has only been explored in the context of offline social networks and there is a clear need to better understand the role of online contacts in the self-management of long-term conditions.

An existing review by Ziebland and Wyke (2012) conceptualizes seven domains through which patient experiences online influence health. These domains were finding information, feeling supported, maintaining relationships, affecting behaviour, experiencing health services, learning to tell the story, and visualizing the disease (Ziebland and Wyke, 2012). Although this review was useful in framing the landscape of peer-to-peer support online due to its focus on understanding the exchange of experiential information on health, it did not specifically focus on long-term condition self-management. Moreover, the changing landscape of online communities in relation to the proliferation in the ways in which people access them makes them more relevant to our daily lives because ties mediated online are now more immediately available (Anderson, 2015; Smith, 2015).

In this context, it’s relevant to understand the extent to which social ties created in these online spaces contribute to long-term condition self-management through the negotiation of illness work (illness work is described as the visible and invisible activities of long-term condition self-management) (Vassilev et al, 2013). In recent years, the study of self-management support has introduced a focus on the mechanisms of networks that mediate self-management support for long-term conditions and the influence this has on the mobilization of resources (Rogers et al, 2011; Vassilev et al, 2011; 2013; 2014). Although there has been increasing awareness of the significance of the Internet as a forum for support and engagement for self-management support (Ziebland and Wyke, 2012), previous studies have not specifically focused on the mechanisms of such networks and how they may mediate long-term condition self-management support. Offline, three mechanisms linking social networks and health-related outcomes exist: sharing knowledge and experience within a community, access and mediation of resources, and an awareness and ability to deal with network relationships (Vassilev et al, 2014). It is clear that in offline networks, those with a long-term condition need to be able to navigate their personal social networks and negotiate and renegotiate existing relationships (Vassilev et al, 2014). Although Vassilev et al's (2014) article successfully demonstrates the negotiation of self-management support in traditional offline social networks, these specific aspects have not been explored in terms of online communities. Thus, this meta-synthesis aims to generate an elaborated understanding of the negotiation of self-management support and illness work in patient online communities for those with a long-term condition. This is relevant for informing the design of online interventions.

4.3 Methods

4.3.1 Qualitative Meta-Synthesis

A meta-synthesis draws on the subjective and interpretive nature of existing qualitative research to construct more complete and plausible understandings of reality than what is currently available from the existing literature. There are several approaches to qualitative synthesis; in this instance, Paterson et al's (2001) process of meta-synthesis was used. Like secondary analysis, qualitative synthesis involves reinterpretations, but the analysis is generated from already existing published findings of other authors (Britten et al, 2002). Such data exist in the form of first- and second-order constructs (Paterson et al, 2001). The first-order constructs represent direct feedback from the study participants and the second-order constructs represent the key findings of the researchers (Paterson et al, 2001). The third-order constructs relate to the interpretation of the findings of the articles based on the synthesized first- and second-order constructs (Paterson et al, 2001). Paterson et al (2001) explains this process by stating that: "The authors of primary research reports have constructed the research findings in accordance with their own understanding and interpretation of the data" (p.6); subsequently, "The meta-synthesists have constructed an aggregated account based on their own interpretations of the primary researchers' constructions. Consequently, the meta-synthesists deals with constructions of constructions" (Paterson, 2001, p. 7). As such, the process moves beyond the findings of the original papers to generate more complete understandings of the phenomena being investigated because it pulls together and makes use of concepts derived from multiple studies, using a wide variety of methods, contexts, and interpretive frameworks (Vassilev et al, 2014; Paterson et al, 2001).

By including articles that used different methods, examined different types of online communities, and different conditions, this meta-synthesis is able to add to the existing evidence base, bringing research data from an initially narrow focus (i.e., a specific condition and online community) toward a broader interpretation of long-term condition illness work in online settings.

4.3.2 Inclusion/Exclusion Criteria

To guide the systematic search of the literature, the research team (CA, IV, AK, AR) agreed on the following predetermined inclusion and exclusion criteria, taking into account the aims of the meta-synthesis. The predetermined inclusion criteria were (1) studies examining the use of online communities for those with a long-term condition (including communities hosted on social media sites such as Facebook and Twitter), (2) studies that focused on online communities from a naturalistic open setting, (3) research between 2004 (the year the term “Web 2.0” became popularized) and 2015 (when the search took place), and (4) research that used qualitative methods. The predetermined exclusion criteria were (1) studies not written in English, (2) research including interventions, (3) research from the perspective of health care professionals/carers/relatives, (4) research that only used quantitative methods, (5) literature reviews and review papers, letters to the editor and editorials, commentaries and feature articles, dissertation theses, reports, conference papers, and abstracts, (6) studies only on traditional Internet use and without an interactive social component (ie, Web 1.0 and blogs), and (7) studies with a commercial, advertising, or marketing focus, where levels of bias could be seen as high.

4.3.3 Search Strategy

A systematic approach was used to locate the relevant published research studies in the area of online communities and long-term conditions. Because online communities in relation to health have been explored across a multitude of professional and theoretical concepts, health, social care, psychology, and sociology databases were searched. The systematic search of the research literature used the following databases: Allied and Complementary Medicine Database (AMED), Cumulative Index to Nursing and Allied Health Literature (CINAHL), the Cochrane Database of Systematic Reviews, DelphiS, EMBASE, the International Bibliography of Social Sciences (IBSS), MEDLINE, PsycINFO, Scopus, Sociological Abstracts, and Web of Science. The searches were conducted using a predetermined search strategy, using the search terms in (**Figure 10**).

Figure 10: Pre-determined search terms.

“Social media” OR “Social network site*” OR “web 2.0” OR “Health 2.0” OR “discussion board*” OR “discussion forum*” OR “forum*” OR “online support group*” OR “electronic support group*” OR “online communit*” OR “patient online communit*” OR “facebook” OR “twitter” OR “tweet*” OR “myspace” OR “patientslikeme” OR “patients like me” OR “second* life”

AND

“Chronic” OR “Chronic disease” OR “Chronic Illness*” OR “Long term condition*” OR “Long-term condition*” OR “Long term health condition*” OR “LTC*” OR “chronic pain*” OR “pain*” OR “fibromyalgia” OR “chronic obstructive pulmonary disease” OR “COPD” OR “diabet*” OR “irritable bowel syndrome” OR “IBS” OR “heart disease” OR “HIV” OR “AIDS” OR “Stroke”*

AND

“Self-management” OR “self management” OR “Self-care” OR “Self care”

The systematic review of the available literature occurred in August 2015. The search strategy using the aforementioned databases located 1944 research articles. Titles and abstracts were reviewed against the inclusion criteria; from this, hard copies of 79 articles were obtained. These were screened against the inclusion/exclusion criteria (by CA, AK and IV), resulting in a total of 14 papers. A further 10 papers were found through submersion in the research literature and through the reference lists of eHealth articles read by the research team. From this, a further seven papers met the criteria for inclusion. All selected papers were discussed by the team in view of the objectives of better understanding the contribution of online social networks in long-term condition self-management. This process can be seen in **Figure 11** and a summary of the included articles can be seen in **Table 2**.

Table 2: Articles included in the meta-synthesis and quality appraisal scores using the Critical Appraisal Skills Programme (CASP) tool.

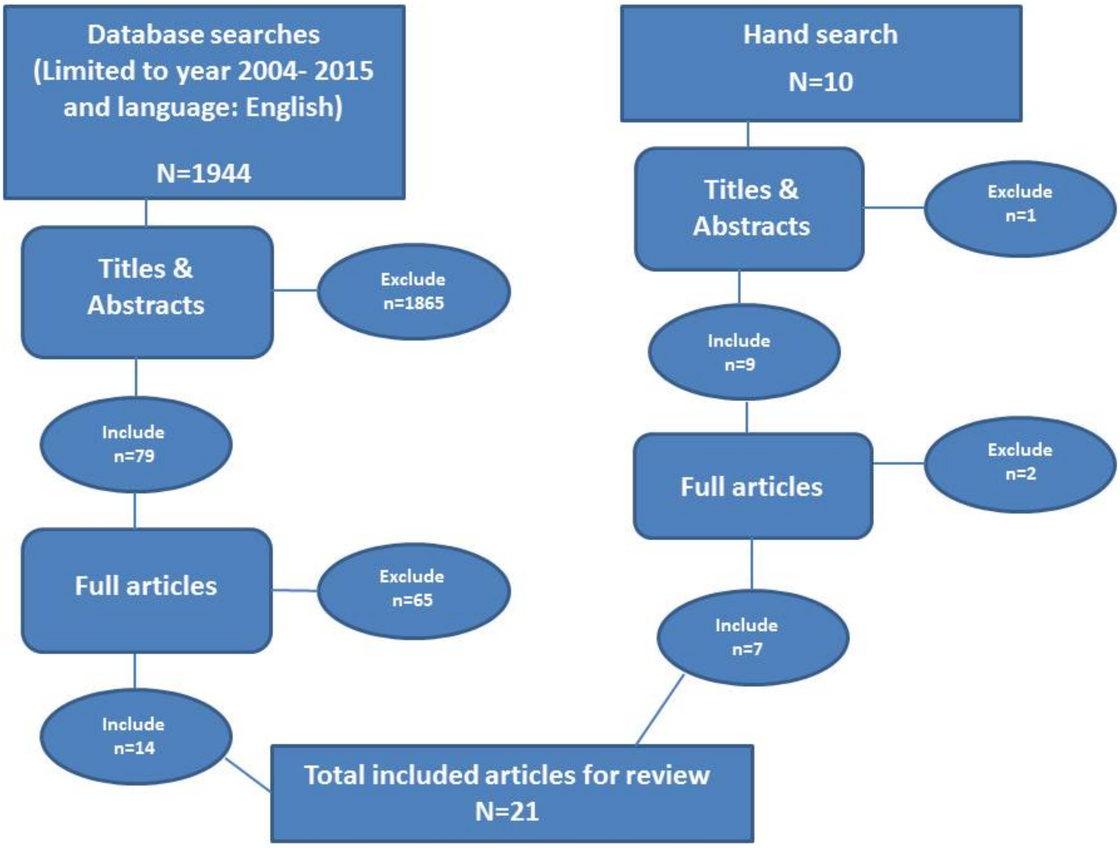
Study	Condition	Platform	Method	Sample	Study details	CASP score^{a}
Attard and Coulson (2012)	Parkinson disease	Disease-specific discussion board/forum	Qualitative thematic analysis of messages posted to a discussion board	1013 messages posted to the board between 2003-2010	To explore the experiences of members of a Parkinson's disease forum	9
Barker (2008)	Fibromyalgia	Disease-specific discussion board/forum	Thematic analysis	249 participants in Fibrospot	Examines the conflicts between lay and expert knowledge in electronic support groups	9
Brown and Altice (2014)	Opioid dependence	Disease-specific discussion board/forum	Grounded theory approach	121 threads from 13 discussion boards in a 26-month period	To identify facilitators of self-treatment by online buprenorphine/naloxone users	9
Coulson (2014)	Alcohol use disorder	Disease-specific discussion board/forum	Inductive thematic analysis-netnography	738 messages on 3 UK-based discussion boards	To explore in-depth how members of online alcohol use disorder communities engage with peer-to-peer support	9
Coursaris and Liu (2009)	HIV/AIDS	Disease-specific discussion board/forum	Content and thematic analysis	5000 postings(not disclosed how many participants contributed to this)	To provide an in-depth understanding of social support exchanges in online HIV/AIDS self-help groups	8
Greene et al (2011)	Diabetes	Facebook	Content analysis	233 wall posts and 457 discussion topics	Examine the content of communication in Facebook communities dedicated to diabetes	8
Hadert and Rodham (2008)	Arthritis	Disease-specific discussion board/forum	Interpretive phenomenological approach	60 users who posted 87 initial messages + 314 users who posted 981 replies	To discover how and why the online arthritis message board was used	9
Kazmer et al (2014)	ALS	Patients Like Me (an online community that connects people with the same condition)	Inductive thematic analysis	1000 randomly selected messages from an available 2500 messages posted between Feb 2006-Nov 2008	How and why knowledge is shared among the distributed participants in the PLM-ALS threaded discussion forum	9

Kirk and Milnes (2015)	Cystic fibrosis	Disease-specific discussion board/forum	Online ethnographical approach	279 individuals who participated in forum over a 4-month period	To explore how online peer support is used by young people and parents to support self-care in relation to cystic fibrosis	9
Loanne and D'Alessandro (2013)	Motor neuron disease/ALS	Disease-specific discussion board/forum	Content analysis	499 posts made by 133 participants	Explores whether social capital can exist in an online health community for people affected by MND/ALS	8
Matura et al (2012)	Pulmonary hypertension	Disease-specific discussion board/forum	Qualitative descriptive methodology	Convenience sample (all posts in 2010)	To determine how patients with pulmonary hypertension use online discussion boards	9
Mazzoni and Cicognani (2013)	Systematic lupus erythematosus	Disease-specific discussion board/forum	Content analysis	118 posts corresponding to 118 authors	To explain the demand/supply of social support through the Internet in relation to the description of personal illness experience	9
Merolli et al (2014)	Chronic pain	Did not specify; patients recruited through Facebook, Twitter, Daily Strength, and Patients Like Me	Thematic content analysis; online survey	218 people with chronic pain who completed an online survey	To examine what social media therapeutically affords people with chronic pain who are self-managing their condition	9
Mo and Coulson (2014)	HIV/AIDS	Disease-specific discussion board/forum	Thematic analysis of completed online surveys	115 participants who completed an online survey	To explore the potential empowering and disempowering outcomes of online support group use by those with HIV/AIDS	9
Rodham et al (2009)	Complex regional pain syndrome	Disease-specific discussion board/forum.	Interpretive phenomenological analysis	60 participants who posted or commented on a post on a discussion forum in a 4-month period	To explore how an online message board designed for patients and carers of patients with CRPS was used; specifically, sought to explore the exchanges that took place on the online message board	10

Van Berkel et al (2015)	ALS, diabetes, ADHD	Disease-specific discussion board/forum	Deductive thematic analysis	5532 posts from seven message boards	To examine whether empowerment processes occur on message boards discussing medicines used to treat three chronic conditions as well as examining the quality of information that is shared	9
Van Uden-Kraan et al (2008a)	Fibromyalgia, arthritis, breast cancer	Disease-specific discussion board/forum	Content analysis of postings to a discussion board/forum	Random sample of 1500 postings to discussion board/forum for fibromyalgia, arthritis, breast cancer	To explore who uses online support groups, what topics are discussed, and what self-help mechanisms are used in these groups	8
Van Uden-Kraan et al (2008b)	Fibromyalgia, breast cancer, arthritis	Disease-specific discussion board/forum	Semi-structured interviews, inductive analysis	32 participants	To explore if, and in which ways, patients feel empowered by participation in patient online communities	9
Wentzer and Bygholm (2013)	COPD and fertility problems	Disease-specific discussion board/forum	Qualitative analysis using critical interpretation and narrative analysis	4301 posts to 2 forums	Is communication in online patient support groups a source of individual and/or collective empowerment?	8
Willis (2014)	Arthritis	Disease-specific discussion board/forum	Ethnomethodology	20 members across 4 communities	To understand how patient with arthritis use patient online communities to exchange illness related information to better manage their long-term condition	9
Zhang et al (2013)	Diabetes	Facebook	Case study	Case study of a Facebook group with 30,000 users	Explores Facebook as a platform for health information and communication, specifically what the characteristics of the Facebook diabetes group and its members	8

[a] Maximum score is 10.

Figure 11: Flowchart of systematic search strategy, process and selection of research papers for review.



4.3.4 Quality Appraisal

The included papers were critically appraised according to the Critical Appraisal Skills Programme (CASP) checklist for qualitative research (by CA) (CASP, 2013). The checklist allows qualitative research evidence to be appraised systematically, guiding the reviewer about the results, their validity, and their transferability (CASP, 2013). The results can be seen in **Table 2** and demonstrate the included articles represented high-quality research; therefore, they were all included in the analysis.

The findings of this synthesis are limited by the methodology of many of the included papers (Coulson, 2014; Barker, 2008; Brown and Altice, 2014; Coursaris and Liu, 2009; Greene et al, 2011; Hadert and Rodham, 2008; Kazmer et al, 2014; Kirk and Milnes, 2015; Loane and D' Alessandro, 2013; Matura et al, 2013; Mazzoni and Cicognani, 2014; Merolli et al, 2014; Mo and Coulson, 2014; Rodham et al, 2009; van Berkel, 2015; van Uden Kraan et al, 2008; Wentzer and Bygholm, 2013; Willis, 2014; Zhang et al, 2013) , which used either "netnography" (a specific form of ethnography adapted to computer-mediated communities) (Kozinets, 2013) or other approaches that did not directly engage participants nor did they provide consent toward participation in the study. Although the approach of using the comments of others from public online communities without their specific consent is considered ethical by current British Psychological Society (a representative body for psychology and psychologists in the United Kingdom) guidelines (Hewson et al, 2013), it meant that it was not possible to observe more intimate encounters (eg, direct messaging, email, texting, telephone conversations, or even meeting offline) that may have emerged over time. This meant the behaviour of participants was not affected by the presence of a researcher in the community, but it also meant that only what members elected to post could be used as research data.

Only three articles (Merolli et al, 2014; Mo and Coulson, 2014; van Uden-Kraan et al (2008) specifically engaged network members. It is possible that because these papers directly engaged those using these communities that they permitted a greater discussion of how people experienced them. Thus, they were perhaps more likely to discuss the negative and the positive aspects of community membership. It may have been that in the other articles, those with bad experiences were less likely to post negative experiences, such as flaming (a hostile online interaction) caused by toxic disinhibition, which led to people being rude or angry toward others in ways that they would not be offline (Suler, 2004; 2016). This kind of behaviour had the potential to make people feel personally attacked if they expressed opinions that were different to other members (Mo and Coulson, 2014). Additionally, these articles were perhaps more likely to demonstrate concerns about misinformation (eg, people sharing inaccurate or harmful information) and people presenting themselves as experts (Merolli et al, 2014; van Uden-Kraan et al, 2008). Therefore, to some extent the positive feel of the other articles may be a result of their methodology; however, there was no shortage of articles that have identified the potential harms (Borzekowski et al, 2010; Biddle et al, 2008; Brotsky and Giles, 2007; Fox et al, 2005; Krishna et al, 2013; Jelenchick et al, 2013; Rosen et al, 2013; Weitzman et al, 2011; Moses et al, 2014) and ethical issues (Moses et al, 2014; Denecke et al, 2015) surrounding online communities.

4.4 Results

The long-term conditions examined in relation to online communities were diverse and clearly projected different illness experiences. They included heavily stigmatized conditions such as alcohol and substance use disorders (Coulson, 2014; Brown and Altice, 2014) and human immunodeficiency virus and acquired immune deficiency syndrome (HIV/AIDS) (Coursaris and Liu, 2009; Mo and Coulson, 2014); medically contested conditions, such as fibromyalgia (Barker, 2008; Merolli et al, 2014; van Uden-Kraan et al, 2008a; van Uden-Kraan et al, 2008b) ; and extremely physically disabling conditions, such as Parkinson disease (Attard and Coulson, 2012), arthritis (Hadert and Rodham, 2008), chronic obstructive pulmonary disease (COPD) (Wentzer and Bygholm, 2013), cystic fibrosis (Kirk and Milnes, 2015), and motor neuron disease (Kazmer et al, 2014; Loanne and D'Alessandro, 2013).

4.4.1 Patient online communities' involvement in long-term condition self-management second order synthesis of concepts

To synthesise the data, the papers identified were read and logged into extraction forms (by CA). The extraction form used was adapted from a previous meta-synthesis. These were used to ensure the multiple concepts in the included papers were translated into one another. The extraction form included: demographics, condition, group type, principal research question/aims, methodology/data collection strategy, principal findings, subthemes, theoretical concepts, conclusions and study limitations. Within these extraction forms we also included all the verbatim quotes from the participants (first order constructs); this allowed us to see that the quotes from the participants fitted logically into the second order constructs (the original author's interpretations) of the original papers.

Since the second order constructs are interpretive, the concepts across the papers are presented in different ways. To synthesise the findings and concepts of the different papers into one another (second order synthesis), we experimented with different visualisations of the second order constructs used in the existing papers and examined the different arrangements of the key concepts from these studies. This involved a number of iterations before the final conceptualisation of second order constructs were agreed (by CA, IV, AK, AR). Following the synthesis of the second order constructs, six second order constructs were identified that illuminated how the social connections forged online, contribute to long-term condition self-management. From this, the synthesised second order constructs (taken from translating the key themes in the included papers) were brought together and then reconfigured as a line of argument, towards better understanding the negotiation of illness work in patient online communities.

4.4.1.1 Redressing offline experiential information and knowledge deficits

Members were frequently drawn to online groups through an unmet offline need for condition specific information that is: easy to understand (van Uden-Kraan et al, 2008), can be customised to their specific needs (Brown and Altice, 2014; Greene et al, 2011; van Uden-Kraan et al, 2008, Willis, 2014), is based on patient experience (Kazmer et al, 2014; Mo and Coulson, 2014; Zhang et al, 2013) and is freely available at their convenience (Mo and Coulson, 2014). The need for accessible, accurate and up to date information was often directed by inadequate access to information offline, whereby community members felt let down by information providers in their offline worlds (Hadert and Rodham, 2008; Mo and Coulson, 2014). This was often fuelled by time restraints and power relationships experienced in offline consultations which appeared to inhibit information seeking (Hadert and Rodham, 2008). Membership of an online community appeared to be a useful way of mitigating this, by affording members with greater access to information (Greene et al, 2011; Hadert and Rodham, 2008; Mo and Coulson, 2014; van Uden-Kraan et al, 2008). Network members were able to use these online communities to filter and navigate condition specific information created by peers, in accessible language, at their convenience. This allowed the redressing of information asymmetry by affording individuals information their health care professional (HCP) did not feel they needed, withheld from them or provided in a format they did not understand (Mo and Coulson, 2014).

The information available in the groups frequently pertained to lived illness experience (Barker, 2008; Greene et al, 2011; Kazmer et al, 2014). Members favoured this information over the presumed expert knowledge of HCPs, whereby validity was bestowed on embodied illness experience (Barker, 2008; Greene et al, 2011; Kazmer et al, 2014). Indeed, posts would insinuate that ‘expert patients’ had a higher degree of condition specific knowledge than HCPs (Kazmer et al, 2014). These ‘expert patients’ were able to, through community action and shared knowledge, assist one another to locate information elsewhere (Coursaris and Liu, 2009; Kazmer et al, 2014) (both online and offline). Whilst some had concerns about the validity of the information posted (van Uden-Kraan et al, 2008), the information was frequently validated using a process of community vetting (Greene et al, 2011; Zhang et al, 2013) with members intervening when bad information was posted (van Uden-Kraan et al, 2008). This suggests that membership in these communities facilitates improved health literacy and resource navigation by pooling the collective knowledge and lay expertise of its members who have a vested interest in better understanding their condition (Coursaris and Liu, 2009; Greene et al, 2011).

4.4.1.2 The influence of modelling and learning behaviours from others on self-management

The included papers all demonstrated online communities' ability to enable members to reach out to peers for practical, illness specific advice. The peers that they connected with were able to develop expertise about daily treatment practices through trial and error, giving them valuable knowledge and information about the daily practicalities of self-managing a long-term condition that extended beyond the empirical evidence available to HCPs (Greene et al, 2011; Kazmer et al, 2014; Willis, 2014). This afforded members an enhanced understanding of how to integrate multifaceted treatment regimes to balance the complexities of self-management in daily life (Greene et al, 2011; Kazmer et al, 2014; Kirk and Milnes, 2015; Willis, 2014). Users learnt from the self-management approaches of others by observing their self-management strategies, discovering new more efficient strategies and subsequently testing out these new strategies with their peers (Willis, 2014). From this, they were able to select an approach that best met their needs (Willis, 2014).

The sharing of experiential information in online communities is an important feature in shaping the experience of those living with a long-term condition because the information shared in these communities frequently favoured patient centred goals as supposed to HCP centred metrics (Greene et al, 2011; Hadert and Rodham, 2008; Kirk and Milnes, 2015). This information was easier for members to configure to their specific needs and was less rigid than the information and self-management strategies provided offline (Brown and Altice, 2014; Greene et al, 2011; Hadert and Rodham, 2008; Kirk and Milnes, 2015; Willis, 2014).

4.4.1.3 Engagement which validates illness and negates offline frustrations

Having access to the online community made members feel less alone and provided a reference for what was a normal illness experience (Coulson, 2014; Attard and Coulson, 2012; Barker, 2008; Hadert and Rodham, 2008; Kirk and Milnes, 2015; Mo and Coulson, 2014; van Uden-Kraan et al, 2008). Members, who often lacked solidarity offline, were able to build a collection of symptoms into a shared identity (Attard and Coulson, 2012; Barker, 2008; Kirk and Milnes, 2015; Matura et al, 2013; Mazzoni and Cicognani, 2014). Offline, members found it difficult to get a real understanding from friends and family and were able to use these online spaces to express these frustrations with a network of people who seemingly understood the challenging nature of self-managing their illness (Barker, 2008; Hadert and Rodham, 2008; Mazzoni and Cicognani, 2014; Mo and Coulson, 2014). This was particularly the case in communities for conditions that lacked visible external cues or where the somatic nature of the illness was contested (Barker, 2008; Hadert and Rodham, 2008; Merolli et al, 2014). This disparagement strengthened group solidarity and allowed users to feel validated and believed through engaging and identifying with other network members (Barker, 2008; Hadert and Rodham, 2008).

Meeting people who understood the challenging nature of self-management, allowed members the opportunity to be positively appraised for accomplishments that their offline contacts might not recognise as achievements (Greene et al, 2011; Rodham et al, 2009). Members were commended for the achievement of smaller self-directed goals as opposed to ones set by HCPs (Greene et al, 2011; Rodham et al, 2009). This worked to motivate group members to believe in treatment recommendations, shared beliefs and practices, thus encouraging treatment compliance (Attard and Coulson, 2012; Wentzer and Bygholm, 2013).

The sharing of condition narratives, enabled members the opportunity to re-evaluate their situation through lateral and downwards social comparison. Being able to see how others cope with their condition reassured members that they could manage their condition through education, adjustment, adaptation and acceptance (Coulson, 2014;

Hadert and Rodham, 2008; Matura et al, 2013; Merolli et al, 2014; van Uden-Kraan et al 2008; Willis, 2014).

4.4.1.4 Tie formation and community building

Communities often demonstrated a clear sense of comradery, with the communities inferring strong community structures, cultural norms and group orthodoxies (Attard and Coulson, 2012; Greene et al, 2011; Kirk and Milnes, 2015; Loane and D’Alessandro, 2013; van Uden-Kraan et al, 2008; Zhang et al, 2013). Many of these communities appeared to promote a positive, inclusive culture, bringing people of diverse backgrounds together to meet a shared purpose (Attard and Coulson, 2012; Loane and D’Alessandro, 2013; Mo and Coulson, 2014; Zhang et al, 2013). This sense of belonging, coupled with a shared lived experience of the condition and frustrations with offline support, facilitated the creation of friendships (Attard and Coulson, 2012). This creation of community led to members integrating the community into their everyday lives (Loane and D’Alessandro, 2013 van Uden-Kraan et al, 2008). Members used endearing terms such as ‘family’ and ‘friends’ and would frequently engage in non-condition related conversations, suggesting that the communities had facilitated strong bonds between members (Attard and Coulson, 2012; Coursaris and Liu, 2009; Mo and Coulson, 2014; van Uden-Kraan et al, 2008), with relationships evolving into offline spaces (Mo and Coulson, 2014; van Uden-Kraan et al, 2008) where tangible benefits such as offers of accommodation could be realised (Mo and Coulson, 2014).

In several instances users connected with these communities to mitigate loneliness and isolation in their offline worlds (Loane and D’Alessandro, 2013; Merolli et al, 2014; van Uden-Kraan et al, 2008), which appeared to be particularly important in instances where the disabling nature of the condition had led to an erosion of offline support and a reduced ability to form social ties in offline settings (Loane and D’Alessandro, 2013; Merolli et al, 2014; van Uden-Kraan et al, 2008). Often, network members faced clear social disadvantage in their offline worlds, but online belonged to lively, vivacious communities with resources of information and support being offered freely as a public good to community members (Loane and D’Alessandro, 2013).

4.4.1.5 Narrative expression and cathartic release

These communities provided a safe environment for the sharing of condition narratives. The process of narrative sharing offered immediate psychological relief since members often felt unable to express negative emotions offline due to the perceived need to maintain a positive social front (Hadert and Rodham, 2008; Rodham et al, 2008). Some members found sharing experiences easier online, preferring to talk to strangers online about their illness experience than with their offline contacts (Merolli et al, 2014; Mo and Coulson, 2014; van Uden-Kraan et al, 2008). These online spaces provided them with a community of people ready to listen to their concerns and provide them emotional support and refuge (Merolli et al, 2014; Mo and Coulson, 2014; van Uden-Kraan et al, 2008). Because these communities made members feel more able to openly express the need for support, they were possibly more likely to receive it and it is therefore perhaps unsurprising that some users felt more supported online (Hadert and Rodham, 2008).

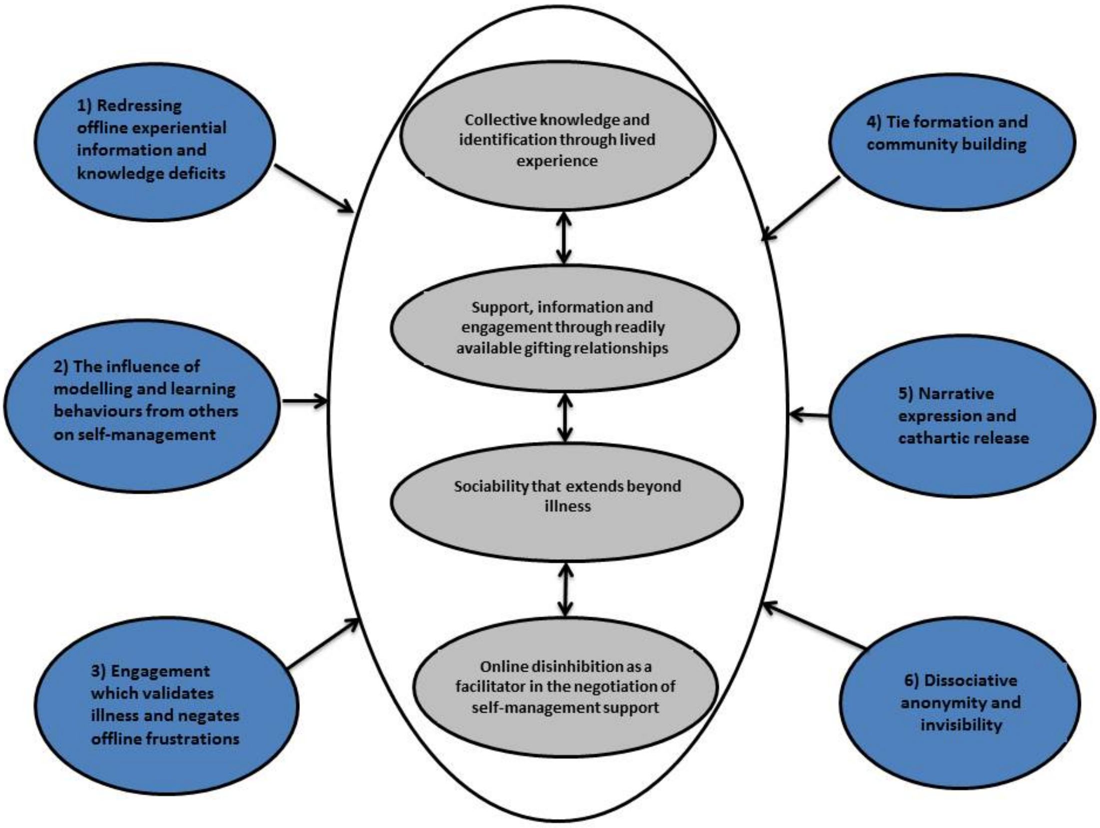
4.4.1.6 Dissociative anonymity and invisibility

Acquiring certain types of sensitive information, that may be important in developing a holistic self-management strategy such as information pertaining to sex and incontinence, appears to be easier to navigate in these online communities due to the presence of benign disinhibition and dissociative anonymity (Suler, 2004). This appears to have an empowering effect, by allowing members to ask questions that they would otherwise be too embarrassed to seek in their physical worlds (Attard and Coulson, 2014).

4.4.2 Understanding the significance of negotiating self-management support and 'illness work' in online communities- third order synthesis

Following a process of synthesis the second order constructs described above were reconfigured towards understanding what is significant about the negotiation of self-management support and 'illness work' in online communities for those living with a long-term condition. This translated into a line of argument synthesis in which four network mechanisms for self-management support in online communities were identified. A summary of the 2nd and 3rd order constructs is shown in **Figure 12**. In exploring the significance of online support networks compared to traditional offline ones, we drew on previous research examining the social context of long-term condition self-management and the network mechanisms involved in negotiating illness work (Rogers et al, 2011; Vassilev et al, 2011; 2013; 2014). This allowed us to examine whether similar mechanisms of self-management support exist and are mobilised online.

Figure 12: Summary of 2nd (blue) and 3rd order (grey) constructs in relation to the negotiation of self-management support in patient online communities.



4.4.2.1 Collective knowledge and identification through lived experience

Given that “the internet has changed people’s relationship with information” (Fox, 2011, p. 1) it is perhaps unsurprising that the ability of these communities to provide information featured highly in the included papers. Information and actionable advice based on lived experience contained highly specialized forms of experiential information that was unobtainable offline. These communities facilitated patient empowerment by affording members the right to explore the self-management of their condition in the context of their daily lives. This patient empowerment perspective facilitated by membership in these groups, promoted a fundamentally different sets of roles for HCPs and patients, whereby the collective knowledge created through lived experience is seen as more useful in the self-management of a long-term condition in daily life than medical knowledge. In line with previous research, these communities appear to foster empowerment and the potential to change the relationship between healthcare professional and patient, from one of compliance to one of shared ownership (Barak et al, 2008; Bartlett and Coulson, 2011).

In addition to the availability of co-created experiential knowledge, the presence of distributed health literacy enabled community members to find the information they required. Online social ties can act as health literacy mediators (Edwards et al, 2015) in a process of distributed health literacy between network members, allowing network members to benefit from the health literacy of others in their network; who may give them greater access to the information needed to manage their condition.

In offline consultations, a mediator such as close friend or family member is often present to help the person comprehend what is being discussed (Vassilev et al, 2011) and individuals can capitalise on the resources and links made with members of their social networks offline (Edwards et al, 2015). People's knowledge about their condition is often shaped by others with the same condition in their personal networks (Vassilev et al, 2011;2014). However, this resource may not be available to everyone, for example in rare conditions, or in situations where open discussion is difficult. People appear to be able to substitute offline information deficits with online contacts, whereby community members benefit from the health literacy skills of their peers. Examples included network members assisting in resource navigation (Coursaris and Liu, 2009) and explaining medical terminology (Hadert and Rodham, 2008; Mo and Coulson, 2014; Zhang et al, 2013).

Additionally distributed knowledge and information in these communities constituted a by-product of the continued engagement of network members (Matura et al, 2013; Mazzoni and Cicognani, 2014). Communities generated value through members "co-creating their own service encounter" (Mazzoni and Cicognani, 2014, p.167). Members were able to select the features that they required and request, receive or search for information at their convenience (Mazzoni and Cicognani, 2014). Unlike offline encounters, a permanent record is made, which allows members to benefit from cumulative experiential information generated over time (Kazmer et al, 2014; Loane and D'Alessandro, 2013). Though for some, the sheer volume of information available, made it difficult to find the specific information they needed (van Uden-Kraan et al, 2008), which further signposts the need for community members to assist in the navigation of resources in these communities. Essentially, the strength of these communities drives the availability of the information. Many communities have a defined core group of members (Cobb et al, 2010; van Mierlo, 2014) whose informational and experiential knowledge can be disseminated to other members who may be less well informed. As Lester et al (2004) hypothesizes, whilst not everyone in the group knows as much as this expert core, they do know how to access expert members, who in turn know how to access information.

Whilst the provision of information should be considered an important component of any long-term condition self-management package (McShane et al, 2014), information on its own has been found to have very little or no effect on self-management (Blickem et al, 2011) and it is these communities ability to tie information to real life parables that is most fascinating. Everyone’s needs are highly specific, therefore self-management support must be tailorable. Members of these communities felt restricted by a lack of flexibility, choice and control in self-management strategies dictated by HCPs, but could use these communities to observe the practice of others, adapting their self-management strategy to meet a specific problem or a change in their condition (Greene et al, 2011; Merolli et al, 2014), through navigating the available information and deciding the approach which best met their needs (Willis, 2014). This is perhaps why the co-constructed authoritative knowledge of community members built around the lived experience of self-managing a long-term condition in daily life was so valuable. Patient online communities appear to deliver a highly individual experience through the co-creation of community content. For example, it is perhaps unlikely that the traditional patient education perspective model of information would be able to disseminate highly experiential information such as how someone with diabetes can count carbohydrates to enable drinking sessions without risking ketoacidosis (Greene et al, 2011), but such facets of information are clearly useful to someone with diabetes wanting to self-manage their condition.

In addition to information and health literacy mediation, these communities facilitate the negotiation of illness emotional work and its biographical dimension, whereby emotional work relates to the provision of comfort when someone is upset, anxious or worried about everyday issues such as their health, wellbeing and companionship (Rogers et al, 2011). Biographical dimensions of emotional work are associated with the revision of expectations, capabilities, plans, identity, relationships and biographical events (Rogers et al, 2011) and these online communities have a role in the realisation of these components, particularly in allowing members the opportunity to reframe their lives (Coulson, 2014; Hadert and Rodham, 2008; Matura et al, 2013; Merolli et al, 2014; van Uden-Kraan et al, 2008; Willis, 2014).

By engaging in online communities, individuals were able to gain emotional support that they had been unable to access in their offline worlds and by connecting with those with a shared embodied experience were able to feel normal (Coulson, 2014; Attard and Coulson, 2012; Barker, 2008; Hadert and Rodham, 2008; Merolli et al, 2014; Mo and Coulson, 2014; van Uden-Kraan et al, 2008). Through collective identification these groups facilitate engagement, allow individuals to make sense of their situation and allow them to receive positive appraisal for successful self-management practices (Greene et al, 2011; Rodham et al, 2009). Furthermore, through lateral and downwards social comparison these online communities allowed members the opportunity to compare their illness narratives with one another, enabling them to reassess their expectations, capabilities and plans, whilst empowering them to realise that successful self-management is achievable (Coulson, 2014; Hadert and Rodham, 2008; Matura et al, 2013; Merolli et al, 2014; van Uden-Kraan et al, 2008; Wentzer and Bygholm, 2013; Willis, 2014). Thus through collective identification and engagement these online communities provided the opportunity for validation, reassessment, and appraisal. But for some, this was upsetting as it made many negative aspects of the disease visible, some of which they may not have considered (van Uden-Kraan et al, 2008).

4.4.2.2 Support, information and engagement through readily available gifting relationships

In addition to navigating network contacts, those with a long-term condition need to negotiate and renegotiate existing relationships, roles and engagement with network members. Negotiating help offline is frequently accompanied by obligations and expectations and may be restricted by time (Vassilev et al, 2014). Such obligations and expectations were not visible in the online communities explored here. Requests for help (resource mobilisation) were rarely targeted at a specific network member; often requests for assistance were to the group as a whole, leading to many replying. This information is frequently gifted, with no reciprocal expectation, making help less tangible but potentially easier to obtain online than off.

In much the same way as gifting relationships stock UK blood banks (Titmuss, 1970) members of these networks gift these communities with information and support freely (Hadert and Rodham, 2008; Loane and D'Alessandro, 2013; Merolli et al, 2014; Mo and Coulson, 2014; van Uden-Kraan et al, 2008; Zhang et al, 2013). Much like donating blood, the decision to volunteer information cannot "of course, be characterised by complete, disinterested, spontaneous altruism" (Titmuss, 1970, p. 89). Information and emotional labour is gifted to these communities by its members, who are potentially motivated to do this through a sense of obligation or through some awareness of need. Like donating blood, there may be "some expectation and assurance that a return gift may be needed and received at some future time" (Titmuss, 1970, p. 89). In this sense these online communities operate much like a gift economy with information and support being freely given, with little expectation of reciprocation, but fuelled by the desire that someone else may find the information useful and the pride of building a community (Greene et al 2011; Loane and D'Alessandro, 2013; Mazzoni and Cicognani, 2014; Merolli et al, 2014; Mo and Coulson, 2014). .

The process of sharing information appeared to have a useful dual purpose, providing information for those in need, but also affording others with their altruistic need to impart the knowledge that they had accumulated (Greene et al, 2011; Loane and D'Alessandro, 2013; Mazzoni and Cicognani, 2014; Merolli et al, 2014; Mo and Coulson, 2014) . Being able to offer information that others may find helpful appeared to foster feelings of validation and self-worth, feelings that are often suppressed by illness (Merolli et al, 2014). The voluntary provision of information was part of these groups culture and occurred more frequently than in response to direct questioning. Whilst offline peer mentors have benefited from providing support through finding meaning and social reinforcement of their own self-management behaviours, gift exchange in these online communities is different to that in offline support groups. Offline, the process of sharing has been found to improve the internal capacity of individuals to cope with stress and can be a motivating factor in long-term condition self-management through mediating lifestyle changes and affording new self-management tools (Vassilev et al, 2014). However, offline these gift exchanges may fail because the recipients of the intended gift may not turn up. Because of the asynchronous nature of the internet, members can post information and support which others may benefit from at a later time. Furthermore, these gifts have the potential to benefit anyone who accesses the group, whereas this kind of gift offered offline can only benefit those physically present, since no lasting record is made of the encounter. Because of the giving nature of such communities, there is a wealth of information and support that requires little or no negotiation.

4.4.2.3 Sociability that extends beyond illness

In these communities, conversations frequently extended beyond illness into everyday matters and interests (Hadert and Rodham, 2008; Mo and Coulson, 2014; van Uden-Kraan et al, 2008) which seemed to provide 'social hooks' for continued community involvement. Whilst people appear to migrate into these online communities due to offline information and emotional deficits, it is perhaps these hooks that result in continued engagement. Members spent time relaxing in these online communities (van Uden-Kraan et al, 2008) and enjoyed being able to socialise (Merolli et al, 2014) which appeared to be particularly appreciated in circumstances where the presence of illness had led to the erosion of offline contacts (Merolli et al, 2014; van Uden-Kraan et al, 2008). Members looked forward to their online interactions with one another and enjoyed telling others about their day: "I have just got in from a lovely evening and couldn't wait to get on and see if there was any mail for me….I thought I would share with you the events of the evening" (Hadert and Rodham, 2008, p.189). For many, engagement with these online communities had become part of their daily routine: "You should really see it as a book. You're in the middle of a story. And when you put the book down at night, you really want to continue reading the next morning." (van Uden-Kraan et al, 2008, p.409). These communities accompanied members throughout their day (van Uden-Kraan et al, 2008) and this may become increasingly important in the future as smart phones continue to integrate these technologies into our daily lives (Barkhuus and Polichar, 2011).

The presence of a long-term condition may place greater salience on support from family and close friends, reducing the opportunities to build and maintain contacts that extend beyond this. Socialising with people online and being able to build relationships with new people allows individuals to build new networks of influence that extend beyond intimate offline contacts. Consequently, those whose condition may have eroded the ease with which they can build and maintain weak social ties, appear to benefit from being able to substitute for this by building new networks of contacts in patient online communities. However, that this support often remained online was a source of frustration for some who wanted to extend their relationship into offline spaces but were restricted by geography (Attard and Coulson, 2012). Despite this, the ability to proactively extend networks that may have been eroded by the presence of a long-term condition is important since research suggests that those with a larger network of contacts consisting of both friends and family typically see the most favourable outcomes (Gallant, 2003).

The ‘internet paradox’ paper contains an argument that the internet, as a social technology may reduce socialisation and psychological well-being (Kraut et al, 1998). Such concerns were voiced in Mo and Coulson’s (2014) paper: “…I noticed that my real-life relationships were declining due to the time I invested in the on-line community” (Mo and Coulson, 2014, p. 990). However, being able to access these communities enabled those whose social ties had been eroded through illness (Merolli et al, 2014; Rodham et al, 2009) to build new opportunities for sociability: “through fibromyalgia you lose a lot of personal contact. Because you can’t go to birthday celebrations anymore, because you forget things, you’re often too tired and so on. And in this way you can rebuild your social contacts” (van Uden-Kraan et al, 2008, p.412). These communities may allow members to reach out to peers when offline socialisation is not possible. Thus being able to access peers online has the potential to mediate feelings of isolation and loneliness. Later research by Kraut et al (2002) into the internet paradox found that whilst those using the internet generally experienced positive effects on social involvement, communication and emotional well-being, the extent to which these benefits were realised was associated with offline support, whereby extraverts with good pre-existing offline social networks fared better than introverts with reduced offline support. Additionally research by Kuss and Griffiths (2011) found that extroverts use social media for social enhancement, whereas introverts use them as a means of social compensation (Kuss and Griffiths, 2011). Whilst these findings weren’t in the context of patient online communities it does suggest that introverts managing a long-term condition in these online communities may be distanced from offline social networks able to provide more tangible support in spite of being able to use the internet to access a more diverse network.

4.4.2.4 Online disinhibition as a facilitator in the negotiation of self-management support

Being able to act anonymously online highlights the presence of managing moral identity work operating in these communities. Those with a long-term condition may decide that the need to be both independent and autonomous is so important that they choose not to activate offline support despite it being available (Vassilev et al, 2014). As such these online communities may protect offline relationships and allow those living with a long-term condition to negotiate illness work whilst remaining both independent and autonomous.

Suler's (2004; 2016) theory of an online disinhibition effect suggests that people behave differently on the internet due to the presence of dissociative anonymity, invisibility, asynchronocity, solipsistic introjection, dissociative imagination and minimization of status and authority (**figure 13**).

Figure 13: The Online Disinhibition Effect

Dissociative Anonymity: People may feel that their online actions cannot be attributed to their person. In a process of dissociation, people may feel they do not own their online behaviours.

Invisibility: Online, people know that others do not know what they look like. This may make people feel more able to do things on the internet that they would not do offline.

Asynchronicity: Online interactions often do not occur in real time. Not having to cope with someones immediate reaction to something that has been said or done may disinhibit people.

Solipsistic Introjection: The absence of face-to-face cues may alter normal self-boundaries. Because people cannot see what others look or sound like online, they may introject others into their own psyche.

Dissociative Imagination: People may feel the online world is not real and that the people they interact with online are not real people.

Minimization of Status and Authority: Online, there is often an absence of authority figures, this means people may feel they can act more freely.

Suler, J. The Online Disinhibition Effect. Cyber Psychology and Behaviour, 2004. 7(3): p. 321-326.

Dissociative anonymity, invisibility and the minimization of status and authority appear to have a positive impact on the negotiation of self-management support online in the included papers. The presence of 'benign' disinhibition appears to facilitate the negotiation of self-management support in patient online communities since people may be reluctant to seek certain types of support in their offline worlds due to societal and self-stigmatisations. Whilst the online disinhibition effect may explain some of the harmful behaviours driven by toxic disinhibition that is visible in some of these communities (Mo and Coulson, 2014), the disinhibiting nature of online communication appears to be mostly positive in allowing people to reach out to others for self-management support.

People are able to move around the internet anonymously (Suler, 2004; 2016). Whilst in some of these groups people reveal their identity, many used pseudonyms. As Suler (2004; 2016) highlights, the internet gives people the opportunity to separate their offline persona from their online actions. As such, through a process of dissociation, “The online self becomes a compartmentalized self” (Suler, 2004, p. 322), which in the context of patient online communities appears to allow people to reach out to peers for information and emotional support without endangering their offline self. Suler (2004; 2016) suggests that this can facilitate rapid, or falsely intimate relationships, which might explain why such strong bonds appear to form in these online communities. Talking about stigmatised conditions is challenging offline. These online communities enable people to talk about their illness whilst remaining anonymous: “…at the time I wasn’t capable nor [ready] to approach an [aids service organization] nor disclose my status. I had so many guilty questions that I needed to talk to someone who would not know anything about my life nor recognise me” (Mo and Coulson, 2014, p.987).

Even when everyone’s identity is known, people can feel invisible online (Suler, 2004; 2016). This is protective and facilitates the negotiation of self-management support. Since online communication lacks non-verbal cues, people do not have to worry about how they look or sound (Suler, 2004). They can write, examine and edit posts before sending, allowing complete control over disclosures and expressions. This editorial control is lacking in offline communications. This disclosure scrutiny and editorial freedom can lead to people feeling more comfortable discussing even everyday matters online (Turkle, 2012). Community members felt empowered to disclose due to this increased control: “this is an excellent medium for me to be able to control my interactions” (Merolli et al, 2014, unpaginated). But because of the lasting record associated with computer mediated communication, some were sceptical in spite of this increased control: “I do not want to disclose my personal and painful journey via a social network site for it to be highlighted by others and ‘used’ as a way to finish me in my job” (Merolli et al, 2014, unpaginated)

Additionally, since online communication lacks non-verbal cues people do not have to worry about the non-verbal responses such as frowns, shaking of heads or other non-verbal signs of disapproval (Suler 2004, 2016), which may inhibit offline disclosures. Offline, when people discuss emotional matters, they often avoid eye contact, thus these online communities offer “a built in opportunity to keep one’s eyes averted” (Suler, 2004, p. 322), thus avoiding awkward moments where “the rheumatologist sneers a bit” (van Uden-Kraan et al, 2008, p.410).

The presence of benign disinhibition generates group resources as it facilitates conversations about stigmatised or taboo subjects which others may find useful and validating. It also provides a safe and effective environment for the negotiation of support, allowing people to freely discuss personal and/or embarrassing health narratives, which may be particularly important to those whose condition is heavily stigmatised as well as potentially enabling those with less stigmatised conditions to ask questions about more sensitive aspects of living with a long-term condition (Coulson, 2014; Suler, 2004). For some, these online communities represent the only place where information and support for self-management can be negotiated: “only they know that I have HIV and my doctor, nobody else. They are my virtual family” (Mo and Coulson, 2014, p.988).

4.5 Conclusion

This research strengthens our socialized understanding of long-term condition self-management by taking into account the illness work of social ties mediated online and the role such ties may have in the management of a long-term condition in daily life. Effective self-management support utilises resources and networks that are available in the everyday lives of those with a long-term condition, which operate outside of formal healthcare and this meta-synthesis has shown that these are available online and important to people. Those with a long-term condition appeared to reach out to these online communities’ due to an unmet offline need for information and/or emotional support. This substitutability of illness work has been seen before in offline social networks (Vassilev et al, 2011) and in this instance it clearly signposts the importance of these online communities in negotiating illness work particularly where access to support offline is absent or limited.

It is clear that these communities afforded many benefits that have the potential to positively shape someone's experience of living with a long-term condition. In this regard, to some extent, the findings of this meta-synthesis necessarily overlap with the work of Ziebland and Wyke (2012). Certainly, the facility of these online communities to help people: find information, feel supported, maintain relationships, experience health services, learn to relate, visualise their disease and affect behaviour (Ziebland and Wyke, 2012) were all visible in the included papers and may all help to positively shape self-management. The distinction between this paper and that of Ziebland and Wyke (2012) is the specific focus on online social networks contribution to long-term condition self-management illness work and the affordances of community membership rather than the impact of online patients' accounts of experiences with health and healthcare.

This meta-synthesis has demonstrated that there are several benefits to members of patient online communities over and above those available to people simply searching for the experiential accounts of others. Membership of these online communities affords those living with a long-term condition ready access to a self-management support illness workforce, particularly in relation to illness and emotional work. However, in contrast to offline social ties, these online communities provide social ties that require significantly less maintenance, less reciprocation and are easier to negotiate, potentially due to the presence of benign disinhibition and the gifting economic relationships of these online spaces whereby information and support is donated freely, as a public good, with no immediate expectation of reciprocation. Unsurprisingly, everyday work appears largely absent in online self-management support perhaps due to the need for physical presence to assist in household tasks, shopping or personal care. There is some suggestion in the research literature of relationships evolving into more intimate communication channels and offline spaces (Mo and Coulson, 2014; van Uden-Kraan et al, 2008) and it is therefore not unreasonable to suggest that 'everyday work' may emerge in these relationships over time.

Importantly, social ties forged in online spaces can perform self-management work that can improve an individual's illness experience and can reach areas that are particularly difficult to navigate offline. Because of this patient online communities appear to be a promising place for the negotiation of self-management support for long-term conditions that may supplement and support offline information and support and should be included in future papers exploring the social context of long-term condition self-management.

4.6 Study limitations and future research

The majority of the included papers examined patient online communities that existed on condition specific discussion forums and boards. In contrast, newer applications such as Facebook and Twitter are poorly represented in the existing research literature with no existing research examining long-term condition self-management support in the context of Twitter. There is also a need for future research to conceptualise how best to support those wishing to utilise these resources in their self-management strategy (such as computer literacy, resource navigation and training). Additionally, interventions that seek to better engage the lay natural helpers and super users present in these communities could allow us to understand and use this underutilised resource.

Since many of the papers involved in this review used methods that did not directly engage those using these communities, there is potentially a bias towards the sharing of positive experiences. There is a need for future research to directly engage with members of these communities to find out why people are reluctant to post and illuminate how these communities help people manage their condition in daily life. Such research would also allow us to further develop our understanding of illness work online, whilst also helping us better understand such work in the context of pre-existing offline support.

Chapter 5: The contribution of internet use in personal networks of support for long-term condition self-management.

5.1 Abstract

Objectives

To describe the individual and network characteristics of the personal communities of people using the internet and the role of offline support, network resources and community participation in using the internet for condition management.

Methods

Secondary analysis of survey data using logistic regression analysis to determine the factors associated with differential internet use for condition management. This study involved 300 participants from 19 primary care providers in Manchester in 2010 and 2011.

Results

Using the internet is associated with age, deprivation, education and having access to a personal network member who understands how to fix computer problems. Those using the internet for condition management received more offline emotional work. No associations were found between using the internet for health and other types of offline support. Those using the internet for support reported lower levels of happiness.

Conclusion

Network processes and engagement shape online contact and use of resources for condition management. Those with access to personal networks who provide emotional work are likely to make use of online resources during non-crisis situations, suggesting that these resources act as an extension of offline network support. Those with greater levels of unhappiness may more frequently look to the internet for support.

5.2 Introduction

The internet has long been recognised as a means through which lay health knowledge can be obtained (Hardey, 1999) and it has become an increasingly utilised resource for health information (Thackeray et al, 2013; Zach et al, 2012). Because managing a long-term condition is complex, being able to locate and draw upon relevant information is increasingly seen as a pre-requisite of successful long-term condition self-management (Blickem et al, 2011). At the same time, it appears that those who are most likely to benefit from the information utility of the internet (e.g. older people, those who are socially and economically marginalised and those with a long-term condition) are also those least likely to use and access it (Zach et al, 2012 and McAuley, 2014). Whilst it is anticipated that digital access will in the longer term reduce social divisions (Andreassen and Dyb, 2010), empirical evidence supporting such assertions remains limited (Chou et al, 2013; Latulippe et al, 2017) and there are indications that technologies may accentuate inequalities (Zach et al, 2012; Latulippe et al, 2017; Rogers and Mead, 2004). In marginalised communities, digital inequalities persist not through lack of access, which has been shown to poorly predict the utilisation of digital health resources (Zach et al, 2012; Sarker et al, 2011), but through differentiated use and failure to draw upon online resources (Zach et al, 2012; Sarkar et al, 2011; Robinson et al, 2015). Strategies to support digital health uptake have been shown to have limited impact. Even when people have been equipped with free internet access they do not readily draw on online health resources (Rogers and Mead, 2004; Robinson et al, 2015). People with access to the internet might lack the necessary skills and knowledge to be able to use it successfully (Zach et al, 2012; Latulippe et al, 2017) and as the internet proliferates in our daily lives, more nuanced second level digital inequalities have revealed themselves, which in the context of condition management, may limit people's ability to engage with online health resources and integrate them into their everyday lives (McAuley, 2014). The efficacy of strategies aimed exclusively at increasing access to disadvantaged communities, such as the accelerated push to provide internet enabled computers in public spaces remains limited (Wagner et al, 2005), suggesting that second level inequalities are not fully understood. It is this divide that needs to be more closely considered and is the focus of this paper.

Whilst digital health inequalities have been the focus of several review papers (Latulippe et al, 2017; Huxley et al, 2015), most have concentrated attention on who makes use of such resources and how they can be better designed to meet the needs of disadvantaged communities. Empirical evidence has also demonstrated the importance of training and technical skills on the utilisation of digital resources (Latulippe et al, 2017; Choi and Dinitto, 2013). Less attention has been given to the role that networks may have in compensating for unequal access and differentiated use, particularly in marginalised communities who are said to have more restricted digital engagement (both in terms of access and differential use).

Previous research suggests that those from lower socioeconomic status groups draw information from trusted strong ties rather than from information sources outside of their personal networks such as that provided by the internet (Zach et al, 2012; Burnett et al, 2008). Thus, network resources might support engagement with digital self-management in a way that has not previously been recognised. Personal networks (consisting of a broader set of actors involved in self-management such as relatives, friends, community groups, health care professionals and non-health care professionals) have been shown to play a role in supporting people to manage long-term conditions, both through the provision of information but also to the provision of other types of 'illness work', such as illness, everyday practical and emotional work (Rogers et al, 2011; Vassilev et al, 2013). 'Illness work' relates to work carried out by others to support tasks specific to a condition, such as taking medication, assisting with interpreting measurements and understanding the condition. 'Everyday practical' work relates to support with domestic tasks that those living with a long-term condition might find more difficult, such as housekeeping and occupational labour. 'Emotional work' relates to providing comfort when worried or anxious (Rogers et al, 2011; Vassilev et al, 2013).

Research has pointed to the relevance of online communities as a form of social compensation in replacing or supplementing offline interpersonal relationships (Collins and Wellman, 2010). However, the substitutability and supplementation of the internet for health based upon the availability of offline 'illness work' has not been specifically explored. Furthermore, there has been little focus on the influences and processes relating to differential use and the role and availability of supportive offline practices in the utilisation of digital resources for self-management. Availability, types of support and the potential role that networks have in compensating for unequal access and differentiated use, have not been specifically explored and is the focus here. The research reported in this paper sought to examine the role of offline social resources and support with reference to notions of personal networks and illness work in an urban, marginalised community. To study the participation divide, it was relevant to explore the social, cultural and economic context of digital engagement (Robinson et al, 2015) in relation to general internet use and internet use for condition management.

5.2.1 Research question

What role do personal networks, network resources, illness work and community participation have on the use of the internet in general, as well as for support in managing a long-term condition?

5.2.2 Objectives

- To describe the individual and network characteristics of people who use the internet for long-term condition management, including their access to social resources and community participation.
- To explore the role of offline personal network support (illness, everyday practical and emotional work) on the use of the internet for long-term condition self-management.

The above objectives informed the variables selected for the analysis which were discussed by all members of the team.

5.3 Methods

The present study makes use of the data from the ‘Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (U-Net)’ research project (Vassilev et al, 2013). The data set has been used for secondary analysis with successful publication, for example in Forbes et al (2016). Full details of the original studies design, sampling and data collection are detailed in Rogers et al (2011) and Vassilev et al (2013) and for clarity will not be repeated here. Participants from the original study were recruited from 19 primary care providers, which were located in economically deprived areas of Greater Manchester (Vassilev et al, 2013).

Three-hundred participants were recruited to the study between April 2010 and January 2011 (Vassilev et al, 2013). In this present study, four participants were excluded because their internet use responses were absent or incomplete. In the initial study, data collection was through face-to-face interviews in the participant’s home. Using a name generator approach, personal network data was collected using a concentric circle diagram which aimed to map the personal communities of the respondents (Vassilev et al, 2013). Through this, participants were asked to place the network members they considered to be important in relation to the management of their condition. Network members the participant felt to be the most important were placed in the inner most circle of three, then those considered less important placed in the next circle, and those less important than those in the outer circle. Participants were able to place as many network members in the circles as they wished, allowing for the full diversity of those involved in illness work to be revealed (including relatives, friends, health care professionals, neighbours, etc.) (Vassilev et al, 2013).

Through this approach, the study included a total of 2,544 network members who contributed to long-term condition management. Thus, the dataset contains rich data on the participant’s personal network, the resources that they have available through these contacts and the availability of illness work in their personal network, which were used to better understand the extent to which individual and network characteristics influence the use of the internet to self-manage a long-term condition.

5.3.1 Ethics statement

Ethical approval for the original study was obtained from the Greater Manchester Research Ethics Committee in February 2010 **(ref:10/H1008/1)** as well as approval for the secondary analysis from the University of Southampton’s Ethics Committee (ERGO) in July 2016 **(REF:19132)**.

5.3.2 Measures

5.3.2.1 Internet use variables

Participants of the original study were asked questions about their internet use over the past 6 months. They were asked whether they had used the internet in general (but not for health-related matters) or whether they had used it to either find more about their condition such as its causes, symptoms and treatments or to use online self-health groups (either through reading the comments of others, or specifically taking part in online discussions). They were also asked questions about their internet access and if they were not currently using the internet to support self- management, if they were likely to in the future.

5.3.2.2 Socio-demographic and health measures

Socio-demographic characteristics included gender, age, index of multiple deprivation (IMD) score, income, education, marital status, ethnicity, employment status and self-reported happiness. Number of conditions and length of time with main condition were used as a proxy for health status (as per previous studies using this data (Vassilev et al, 2013)).

5.3.2.3 Social network dimensions of long-term condition management relationships

The participants of the research were asked about the characteristics (such as age, gender, relationship to the participant, number of years known, how far away they lived, how often they were in contact) of each network member that they identified as important to them in managing their condition. Network members were coded into one of eight categories representing possible types of relationship to the participant, these were: partner/spouse, close family such as children, grandchildren, etc., other family, friends, health professionals, community groups, pets and other.

The size of support network was created from the number of network members with a score of greater than zero for at least one work dimension. Additionally, for each network member, the participant was asked if they also had diabetes, heart disease or kidney disease.

5.3.3 Personal network participation and resources

A resource generator was used as a measure of access to network resources offered by members of the network (Webber and Huxley, 2007) (**Figure 14**), such as being able to access someone who knows how to fix computer problems, which has been used separately in the analysis.

Figure 14: Questions in the resource generator

Do you currently have access to someone who?	
A1	Can repair a broken-down car
A2	Is a reliable tradesman
A3	Can speak another language fluently
A4	Knows how to fix problems with computers
A5	Is good at gardening
A6	Has a professional occupation
A7	Is a local councillor
A8	Works for the local council
A9	Can sometimes employ people
A10	Knows a lot about government regulations
A11	Has good contact with the local newspaper, radio or TV
A12	Knows a lot about health and fitness
A13	Knows a lot about DIY
Do you currently know anyone who would…?	
B1	Give you sound advice about money problems
B2	Give you sound advice on problems at work
B3	Help you move or dispose of bulky items
B4	Help you with small jobs around the house

B5	Do your shopping if you are ill
B6	Lend you a small amount of money
B7	Give you career advice
B8	Discuss politics with you
B9	Give you sound legal advice
B10	Give you a good reference for a job
B11	Get you cheap goods or ‘bargains’
B12	Help you find somewhere to live if you have had to move
B13	Lend you a large amount of money
B14	Look after your home or pets if you go away

Webber and Huxley (2007). Measuring access to social capital: the validity and reliability of the resource generator-UK and its association with common mental disorder. Social Science and Medicine. 65. pp 481-492.

The resource generator has been used in previous research to measure the availability of social resources within personal communities of support (Webber and Huxley, 2007). It has been validated for use in English settings (Webber and Huxley, 2007).

Since prior research has demonstrated the importance of personal community participation in long-term condition self-management in marginalised communities, participants were also asked for the number of hobbies and social activities in which they were involved with.

5.3.3.1 Measuring the availability of illness work

The survey questionnaire was devised to quantify the contribution made by each network member (Vassilev et al, 2013). This questionnaire consisted of 13 items addressing different aspects of the illness, everyday practical and emotional domains of illness work (Vassilev et al, 2013) (**Figure 15**).

Figure 15: Types of chronic illness work, and questions used in the study

Types of work	Questions used
Illness work	This person helps me with the day-to-day management of my long-term condition. This person helps me when I need to re-arrange things due to my health problems. This person helps me understand advice so I know what I have to do to manage my condition. This person helps me with things related to medications. This person helps me organise tasks related to my condition, including arranging appointments with health care staff, getting prescriptions etc. This person stands in for me or stands up for me when I am unwell or unable to stand up for myself. This person comforts me when I am worried or anxious about my health problems
Everyday practical work	This person helps me with the day-to-day running of my household. This person helps me with things related to my diet. This person helps me with things related to physical activities and exercise.
Emotional work	This person makes me feel good about myself. This person helps me value and enjoy life. This person helps me achieve personal goals.

Vassilev et al (2013). Social Networks, the ‘Work’ and Work Force of Chronic Illness Self-Management: A Survey Analysis of Personal Communities. PLOS ONE. 8 (4). e59723.

As per Vassilev et al (2013) participants were asked to rate network members according to their perceived contribution to each type of work on a Likert scale (1: not at all, 5: a lot). The total for each was then calculated to obtain a score for each network member for each type of work; addition of these gave a total for each type of illness work available in the participant’s personal network. In addition, participants were asked if they had any negative illness work in their network. For example, someone whose behaviour makes condition management difficult.

5.4 Analysis

The dataset was split into three groups relating to participants use of the internet; those who do not use the internet (group A) (55.7%, n = 165), those who have access to and use the internet, but do not currently use it to help them manage their condition (group B) (18.6%, n = 55), and those who use the internet to help them manage their condition, representing differentiated use for condition management (group C) (25.7%, n= 76).

The analysis involved two stages. In stage one, we conducted univariate and multivariate logistic regression analysis to examine internet use in general (comparing those who did not use the internet at all (group A), with those using the internet, both in general and for condition management (group B and C together). Multivariate logistic regression analysis included all variables with a univariate relationship to each group at a $p < 0.05$. From this, we arrived at a final model to identify characteristics of (i) the participant, (ii) access to network resources (as measured through the resource generator) and personal network participation (as measured by the number of hobbies and activities), and (iii) the network characteristics and the availability of illness work in the personal network, were associated with internet use in general.

In stage two, we then carried out the same analysis to arrive at a final model to describe the factors associated with differential internet use for condition management. This stage looked specifically at those who used the internet, but for differentiated use (i.e. comparing those who use the internet, but not for condition management (group B) with those using the internet for condition management (group C)). Those not using the internet at all (group A) were excluded from this stage of the analysis.

5.5 Results

5.5.1 Sample ego level socio-demographic characteristics

Most of the participants were men (64%, n = 193). The mean age of the participants was 65 years, with participant’s ages ranging from 20 years to 93 years. Participants were predominantly white (86%, n = 259), over half (55%, n = 165) were married. Income for three quarters of the participants was under £20,799 per annum (75.3%, n = 189). Around 20% (n = 60) were in work. **Table 3** demonstrates the sample ego level characteristics of the participants.

Table 3: Ego Level Descriptive Analysis

Ego characteristic	N (%)*
Gender	
Male	193 (64.3%)
Female	107 (35.7%)
Age	Mean= 65.3 (SD=12.7)
IMD Score	Mean= 37.5 (SD=19.3)
Income	
Low income (up to £20,799 pa)	189 (75.3%)
High income (more than £20,800 pa)	62 (24.7%)
Condition	
Diabetes (type 1 and 2)	180 (60%)
CHD including high blood pressure	242 (80.7%)
Kidney disease	31 (10.3%)
Highest qualification	
No qualifications	63 (28.6%)
Qualifications up to A level	94 (42.7%)
Degree or higher	63 (28.6%)
Marital status	
Married	165 (55.0%)
Not married	135 (45.0%)
Ethnicity	
White	259 (86.3%)
Non-white	41 (13.7%)
Employment status	
In paid work, education or training	60 (20.3%)
Not in paid work, education or training	236 (79.7%)

Number of conditions	Mean= 2.8 (SD=1.3)
Number of years with main condition	Mean=10.2 (SD=8.5)
General Health	
Good	149 (49.7%)
Fair	101 (33.7%)
Poor	49 (16.3%)
Time spent each day managing condition	
Up to 30 min per day	162 (59.6%)
30- 1 hour per day	63 (23.2%)
Over 1 hour per day	46 (17.2%)
Happiness (scaled 0-100)	Mean= 69.41

*N (%) except where otherwise stated

Sample ego level internet use demographics Most participants did not use the internet (55.7%, n = 165), which was in line with our expectations in studying a predominately older (mean age 65.3) more economically deprived (mean IMD 37.5, 75.3% with a low income) group living with a long-term condition. Sample ego level internet use demographics can be seen in **Table 4.**

Table 4: Ego level Internet access and use descriptive analysis

Internet use	**N (%)**
Access to the internet at home?	
Yes	157 (52.3)
No	143 (47.7)
If you don't have access at home, do you have access to the internet elsewhere?	
Yes	8 (5.6)
No	135 (94.4)
Uses the internet?	
Yes	131 (43.7)
No	165 (55.0)

Used the internet in the last 6 months to help manage a condition?	
Yes	76 (25.7)
No	220 (74.3)
If not using the internet in the last 6 months for health, would you like to use the internet in the future for health?	
Yes	22 (10.0)
No	198 (90.0)
If not using the internet, would you like to use the internet in the future for health?	
Yes	12 (7.3)
No	153 (92.7)
Access to someone in network (whole) who knows how to fix computer problems?	
Yes	158 (52.7)
No	142 (47.3)
Access to an immediate family member who knows how to fix computer problems?	
Yes	76 (25.3)
No	224 (74.7)
Access to a wider family member who knows how to fix computer problems?	
Yes	12 (4.0)
No	288 (96.0)
Access to a friend who knows how to fix computer problems?	
Yes	42 (14.0)
No	258 (86.0)
Access to a neighbour who knows how to fix computer problems?	
Yes	5 (1.7)
No	295 (98.3)
Access to an acquaintance who knows how to fix computer problems?	
Yes	9 (3.0)
No	291 (97.0)

*N (%) except where otherwise stated

Of the 165 participants who did not use the internet at all 76.4% (n = 126) had no access elsewhere to a computer linked to the internet. 67% (n = 110) of this group had no access to someone in their network who knows how to fix computer problems. Access was most commonly through an immediate family member (29.8%, n=39), but this was comparable to those not using the internet (21.8%, n = 36) and was not statistically significant. It was noted that those using the internet, were much more likely to have a friend to help them fix problems (22.1%, n = 29) than those not using the internet (7.9%, n = 13, p=0.000). It was less likely that this support came from a neighbour (3.1%, n = 4), colleague (6.1%, n = 8) or acquaintance (7.6%, n = 10).

The group using the internet for condition management used websites mostly for information (89.5%, n = 68). Reading the comments of others on online communities with the same condition accounted for 23.7% (n= 18) of responses, whilst engagement in online discussions about illness was rare (5.3%, n = 4). Of the group not using the internet, very few had an interest in using the internet in the future to help them manage their condition, either through using health websites for information (7.3%, n = 12) or internet support groups for people with the same condition (4.8%, n = 8).

5.5.2 Internet use in general: Univariate logistic regression analysis

At the univariate level examining internet use, men more frequently used the internet than woman (OR 0.613, p = 0.05, 95% CI 0.376–1.000). Age was negatively associated with use (OR 0.924, p = 0.00, 95% CI 0.902–0.947), whereas income (OR 5.833, p = 0.00, 95% CI 3.031–11.226) and formal qualifications (OR 5.282, P = 0.00, 95% CI 2.558–10.906) were positively associated.

Access to a network member who can fix computer problems was positively associated with internet use (OR 3.822, p = 0.00, 95% CI 2.354–6.205) and increasing association with internet use was also seen in those involved in more than one social activity (OR 2.160, p = 0.03, 95% CI 1.079–4.342).

Participants with more everyday practical work in their network were more likely to use the internet (OR 1.035, p = 0.01, 95% CI 1.009–1.063), but they were also more likely to experience negative illness work (OR 2.368, p = 0.00, 95% CI 1.418– 3.953). No associations were seen between the other types of illness work and use of the internet in general. Full univariate logistic regression analysis results examining internet use can be seen in **Table 5**

Table 5: Internet Use in General: Univariate Logistic Regression Analysis

		95% confidence interval		
	Odds Ratio	**Lower**	**Upper**	**P**
Ego level characteristics				
Gender (reference male)				
Female	0.613	0.376	1.000	0.05
Age	0.924	0.902	0.947	0.00
IMD Score (based on Nov 2007 ratings)	0.985	0.973	0.997	0.01
Income (reference low income; up to £399 pw or £20,799)				
High Income (£400 or more pw or £20,800 or more pa)	5.833	3.031	11.226	0.00
Highest qualification (reference no qualifications)				
Qualifications up to A level	5.282	2.558	10.906	0.00
Degree or Higher	5.814	2.645	12.776	0.00
Marital Status (reference married)				
Not married	0.497	0.310	0.796	0.00
Ethnicity (reference white)				
Non-white	1.103	0.569	2.137	0.77
Employment (reference in paid work, education or training)				
Not in paid work, education or training	0.156	0.080	0.306	0.00
Number of conditions	0.817	0.681	0.981	0.03
Length of time (in years) with main condition	0.974	0.947	1.002	0.07
General health (reference good)				
Fair	0.688	0.411	1.154	0.15

Poor	0.625	0.321	1.217	0.16
Time spent each day managing condition (reference up to 30 minutes per day)				
30 minutes- 1 hour per day	0.819	0.453	1.480	0.50
More than 1 hour per day	0.798	0.411	1.549	0.50
Happiness	1.706	0.983	1.179	0.11
Network characteristics				
Access to people in network with the same condition (reference no access)				
Access to at least one person, with one of the same conditions	0.942	0.501	1.769	0.85
Access to at least one person for each of the conditions the ego has	1.730	0.999	2.995	0.05
Number of network members	1.058	0.999	1.121	0.06
Number of frequent contacts	1.071	0.084	0.991	1.16
Number of local neighbourhood support	1.056	0.950	1.172	0.31
Number of different agents in the network	.989	0.825	1.185	0.90
Local or dispersed network (reference local)				
Dispersed network	1.201	0.745	1.937	0.45
Total number of resources available	1.112	1.069	1.157	0.00
Does the participant have access to someone who knows how to fix computer problem? (reference does not have access to someone)				
Has access to someone	3.822	2.354	6.205	0.00

Total number of hobbies and social involvements (reference none)				
One	1.277	0.681	2.395	0.44
Two	2.160	1.079	4.324	0.03
Three or more	2.800	1.481	5.293	0.00
Illness work in network				
Illness work	0.995	0.974	1.015	0.62
Everyday practical work	1.035	1.009	1.063	0.01
Emotional work	1.002	0.991	1.013	0.74
Negative illness work in the network? (reference no)				
Yes	2.368	1.418	3.953	0.00

5.5.3 Internet use in general: Multivariate logistic regression analysis

The final model accounts for 79.1% of the variance in the sample. As with the univariate analysis, age was negatively associated with internet use (OR 0.924, p = 0.00, 95% CI 0.896–0.953). Those with a higher IMD (more deprived) were less likely to use the internet (OR 0.979, p = 0.02, 95% CI 0.961–0.997). Again, education was positively associated with internet use (OR 4.273, p = 0.00, 95% CI 1.822–10.020). Access to someone in the participant's network who knows how to fix computer problems remains significant (OR 4.213, p = 0.00, 95% CI 2.140–8.294), but there is no indication of the importance of the type of this relationship. The full model can be seen in **Table 6**.

Table 6: Internet Use in General: Multivariate Logistic Regression Analysis

		95% confidence interval		
	Odds Ratio	**Lower**	**Upper**	**P**
Age	0.924	0.896	0.953	0.00
IMD score	0.979	0.961	0.997	0.02

Highest Qualification (reference no qualifications)				
Qualifications up to A level	4.273	1.822	10.020	0.00
Degree or higher	5.041	1.935	13.134	0.00
Access to someone who knows how to fix computer problems (reference no access to someone who knows how to fix computer problems)				
Has access to someone who knows how to fix computer problems.	4.213	2.140	8.294	0.00

5.5.4 Internet use for condition management: Univariate logistic regression analysis

The significant findings at a univariate level were that those using the internet for condition management had less diverse relationships in their network (OR 1.441, p = 0.02, 95% CI 1.060–1.959). They also had a greater availability of emotional work in their network (OR 1.027, p = 0.01, 95% CI 1.006–1.047), but reported being less happy (OR 0.839, p = 0.03, 95% CI 0.719–0.979). No associations were seen with the other types of illness work on using the internet for health. This can be seen in **Table 7**.

Table 7: Internet Use for Condition Management: Univariate Logistic Regression Analysis

		95% confidence interval		
	Odds Ratio	**Lower**	**Upper**	**P**
Ego level characteristics				
Gender (reference male)				
Female	0.734	0.343	1.570	0.43
Age	0.998	0.969	1.028	0.91
IMD Score (based on Nov 2007 ratings)	0.990	0.972	1.008	0.29

Income (reference low income; up to £399 pw or £20,799)				
High Income (£400 or more pw or £20,800 or more pa)	1.562	0.728	3.351	0.25
Highest qualification (reference no qualifications)				
Qualifications up to A level	1.478	0.457	4.781	0.51
Degree or Higher	1.437	0.422	4.902	0.56
Marital Status (reference married)				
Not married	0.794	0.385	1.638	0.53
Ethnicity (reference white)				
Non-white	0.774	0.292	2.055	0.61
Employment (reference in paid work, education or training)				
Not in paid work, education or training	0.799	0.384	1.664	0.55
Number of conditions	0.928	0.717	1.200	0.57
Length of time (in years) with main condition	0.977	0.936	1.019	0.27
General health (reference good)				
Fair	1.186	0.540	2.606	0.67
Poor	1.650	0.559	4.873	0.37
Time spent each day managing condition (reference up to 30 minutes per day)				
30 minutes- 1 hour per day	1.969	0.763	5.082	0.16
More than 1 hour per day	0.972	0.355	2.665	0.96
Happiness	0.839	0.719	0.979	0.03
Network characteristics				
Access to people in network with the same				

condition (reference no access)				
Access to at least one person, with one of the same conditions	2.249	0.843	6.995	0.10
Access to at least one person for each of the conditions the ego has	1.684	0.763	3.716	0.20
Number of network members	1.041	0.959	1.130	0.34
Number of frequent contacts	1.082	0.968	1.211	0.17
Number of local neighbourhood support	0.958	0.829	1.106	0.56
Number of different agents in the network	1.441	1.060	1.959	0.02
Local or dispersed network (reference local)				
Dispersed network	0.583	0.281	1.210	0.15
Total number of resources available	1.034	0.980	1.091	0.23
Does the participant have access to someone who knows how to fix computer problem? (reference has access to someone)				
Does not have access	0.883	0.424	1.838	0.74
Total number of hobbies and social involvements (reference none)				
One	0.719	0.257	2.016	0.53
Two	0.592	0.206	1.700	0.33
Three or more	0.733	0.282	1.908	0.53
Illness work in network				
Illness work	0.998	0.967	1.030	0.89
Everyday practical work	1.017	0.980	1.055	0.37
Emotional work	1.027	1.006	1.047	0.01

Negative illness work in the network? (reference no)				
Yes	1.578	0.765	3.251	0.22

5.5.5 Internet use for condition management: Multivariate logistic regression analysis

The final model suggests that those using the internet for support receive more emotional work from their network (OR 1.030, p=0.006, 95% CI 1.009–1.052); but were less happy (OR 0.810, p=0.014, 95% CI .686–0.958). This suggests the importance of emotional support as a facilitative factor in using the internet to find out more about living with a long-term condition. These can be seen in **Table 8.**

Table 8: Internet Use for Condition Management: Multivariate Logistic Regression Analysis

		95% confidence interval		
	Odds Ratio	**Lower**	**Upper**	**P**
Happiness	0.810	0.686	0.958	.014
Total emotional work	1.030	1.009	1.052	.006

5.6 Discussion

Our findings indicate that there are network and non-network processes that shape the uptake of online engagement and use of resources for long-term condition management. In this instance, personal networks appear to be important in providing technical support in relation to accessing the internet in general. Those without someone in their network who understands how to fix computer problems, were less likely to use or access the internet. Adoption may therefore be shaped by social learning, peer assistance and normative influences from within the network.

People who were using the internet were (compared to those who did not) better connected to their communities and had a greater access to resources in their network. (It is important to note, that these associations were not statistically significant at a multivariate level, suggesting the existence of confounding factors such as age, level of deprivation and education which appear to be more relevant to internet use.) Prior research has found associations between online and offline network engagement (Hogeboom et al, 2010) and it is easy to see how lack of access in a world where people are increasingly connected to one another online can isolate, particularly as digitally mediated communication becomes a normative way for keeping in contact and arranging offline contact (Collins and Wellman, 2010). This evidence supports the notion that those with a diversity of contacts and personal community participation offline have better access to resources.

People using the internet for long-term condition management were less happy and had more emotional support compared to those who used it, but did not report using it for health. There was no statistically significant association between happiness and emotional work. Thus, a plausible interpretation is that there are two different pathways, which relate to using the internet to support condition management; a network mediated pathway, through which high availability of offline emotional work acts as encouragement for engagement with condition management and a non-network mediated pathway whereby, feeling unhappy about the condition prompts people to use such resources. Firstly, we concentrate on the possible network mediated pathway.

The utilisation of online resources for long-term condition self-management management may posit as an extension of offline support and indicate positive engagement with network members. Network members often influence key decisions around treatment, illness response and recognition, behaviour, health trajectories and outcomes (Perry and Pescosolido, 2012). The higher level of emotional work done for people who are using the internet for long-term condition management may indicate higher levels of collective efficacy, supporting the individual to go online to find practical solutions and develop a better understanding of their condition. Such engagement may reflect the network response to the changing needs over the illness trajectory (Perry and Pescosolido, 2012) through the extension of offline support, for example lifestyle change or the adoption of new activities related to condition management (Vassilev et al, 2014). Here, the internet is situated as a proactive strategy to help people find out more about their condition, with possible benefits to one's sense of autonomy and control over their life.

Since those using the internet for condition management were less happy, this might suggest a possible temporal continuum of need, with those experiencing a period when things are not going well, negatively influencing their personal happiness. It is possible that this acts as a driver to the use of online resources in search of answers or a way in which their situation may be improved. We have seen that at a univariate level, those with negative illness work in their network are more likely to use the internet. This could suggest that the internet has a role in empowering people to seek information independent of their personal network, who might make the adoption of good self-management practices difficult. It is also possible, as has been seen in an earlier review that people may not wish to burden their personal networks (Allen et al, 2016). (We cannot, however, rule out the possibility that use of the internet for condition management makes people unhappy, possibly through exposure to negative illness trajectories through downwards and lateral social comparison.) Therefore, access to online support might be an indication of the avoidance or absence of offline support, thus acting as a substitute.

5.6.1 Limitations

As usual, it is not appropriate to make causal inferences from secondary data. There is a deliberate bias towards poorer participants who are less likely to use the internet. This, in addition to the sample population coming from a specific location in the north of England, may make the findings less generalisable to the wider population. The response rate in the initial study was low and is possibly due to its focus on a marginalised community.

There are also limitations related to the use of secondary data, specifically around the internet variables, which in a future study would benefit from a continuous variable to allow the extent of utilisation and patterns of use to be more carefully considered. In this instance though, since most of the sample had not used the internet for condition management, the groupings were appropriate to allow distinction to be drawn between those using the internet for support and those who do not, even when it is available. Future research would benefit from a wider understanding of the values and beliefs of network members on internet use to better understand the diffusion of normative practices such as digital self-management across networks. We hope the exploratory findings here prompt such a study.

5.7 Conclusion

To our knowledge, this is the first paper to date that directly examines the impact of the availability of personal networks; network resources and illness work in a marginalised community on using the internet in general, as well as for condition management.

As in previous studies (Zach et al, 2012; Rogers and Mead, 2004), the results demonstrate that despite the proliferation of digital technologies into many other aspects of our everyday lives, issues around the lack of perceived utility of such resources to health are likely to persist. Most of the participants in this research did not use the internet and most of these had very little interest in becoming digitally engaged in the future. Such resources will fail if people are unable to recognise their utility and how they might be relevant to their lives.

We found that the demographics of the two internet use groups were largely similar and conclude that the group using the internet to support condition management, may be doing so through network mediated and non-network mediated pathways. The role of personal networks in providing this encouragement, support and education through emotional work is perhaps underappreciated. We argue that the emotional work seen in offline personal networks acts as encouragement to support individuals living with a long-term condition to use online resources to support self-management, potentially making them more aware of their illness, increasing their self-efficacy and empowerment through reduced information asymmetry. Crucially, those with access to the internet have the opportunity to navigate their network in this way, whereas those without, are more reliant on finding the necessary resources and support needed for self-management within their offline personal network. Future interventions to support the utilisation of digital health resources might consider the importance of personal networks in the uptake and use of such resources.

Chapter 6: Care Transition 2.0: A qualitative study of the work and relatedness of ties mediated online in supporting long-term condition self-management

6.1 Abstract

Western countries are said to be experiencing a ‘care transition’ characterised by reduced state involvement in chronic illness management in response to socio-political movements aimed at meeting the challenges presented by an increased prevalence of chronic illness. Amongst these changes has been web 2.0’s rising importance, with increased attention being paid towards the ways it might promote self-management practices, particularly in providing a range of knowledge and opportunities for management. Networked individualism offers a lens through which to examine self-management support in this context. Whilst previous research has illuminated the relevance of personal networks in supporting long-term condition management, it is relevant to consider the place of ties mediated online in self-management support, the types of support that are drawn from them and the strategies involved in eliciting support from a combination of on and offline ties. This study examined the work and relatedness of online ties in long-term condition self-management of 30 participants, who used online communities. Participants were asked about the role of on and offline ties and ego network mapping was used to frame conversations about who is turned to and the nature of this support. Notions of Illness work were used as a conceptual starting point, followed by inductive thematic analysis. Participants drew on online ties in response to unmet offline needs, or to limit the impact of illness on offline ties. In addition, online ties could be used to leverage required actions from offline ties.

6.2 Introduction

How care is thought about, organised and delivered has, over the last two decades, changed dramatically (Bury and Taylor, 2008; Taylor and Bury, 2007; De Silva, 2011). Such a focus has been largely driven by increased longevity (demographic transition), a shift from an acute disease to chronic disease profile (epidemiologic transition) and the social and economic pressures associated with these changes. In a process described as a 'care transition' (Bury and Taylor, 2008) new forms of emergent care include an increasing role for patients as self-managers. In much of Europe, including the UK, the latter has been hastened by recent austerity measures that have shifted greater responsibility for managing health from the state to the individual (Ayo, 2012; Ellis, 2017; Koetsenruijter et al, 2015). Under circumstances such as these, it is plausible that reduced state involvement could create a situation in which new sources of collective support are called upon.

In line with these changes is the internet's growing place in people's everyday interactions, including in relation to health, with online communities being increasingly seen as a place where support is provided, particularly in connecting people to others with the same condition (Willis, 2018). This proliferation has been support by the increasing portability of online communities, through the increased access and use of portable connected devices, such as tablets and smartphones that make people both easier to reach and more immediately available, regardless of geographical proximity (Anderson, 2015; Smith, 2015).

With these new potential forms of support entering the arena of care, it is relevant to consider their place in self-management and the types of resources that are drawn from them. To date, consideration of the care transition has focussed on the refashioning of the professional and lay roles in supporting self-management practices (Bury and Taylor, 2008; Taylor and Bury, 2007), with less attention paid to the social worlds of those managing chronic illness (Greenhalgh, 2009), of which ties mediated online form a part (Hadert and Rodham, 2008; Merolli et al, 2014). In focussing principally on professional and patient roles, the current conceptualisation of care transition fails to acknowledge the broader contributions of personal networks[12] which have been seen as important to help seeking and increasingly to self-management support (Pescosolido, 2006; Rogers et al, 2011; Rogers et al, 2014; Vassilev et al, 2011; 2014). Indeed, there is gap between the rhetoric of care transition and the everyday worlds of those managing a LTC (Greenhalgh,

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[12] Pahl and Spencer's (2010) define personal networks as the people and/or groups that are considered important to the individual at a particular time.

2009; Lawn et al, 2011). Thus, a relational understanding of the full range of on and offline resources drawn on by those managing LTC needs to be developed, which will allow for a greater visualisation of the context of engagement with an increasingly diverse range of connections in the face of potentially reduced state sponsored care and the increased social reach afforded by the internet.

The internet, specifically the social web (web 2.0[13]) offers individuals greater scope to draw from a greater variety of resources, through increased agentic reach towards a set of relationships and resources that are no longer temporally and geographically constrained (Atkinson and Ayers, 2010; Lawson, 2007). The impact of such relational shifts has been examined in the context and configurations of personal networks, for example Rainie and Wellman (2014), who have suggested networked individualism as a new network orientation characterised by people being increasingly connected as individuals. Through increased agentic action and reach, networks relevant to self-management support may now be configured in such a way as to place the individual as the central foci (as opposed to family, neighbourhoods, social groups etc.), giving them greater potential to tap into different sparsely knit social milieu to meet different needs (Raine and Wellman, 2014).

Prior research has shown that in the context of chronic illness, successful management requires the availability of, and ability to locate and negotiate relevant network resources (Vassilev et al, 2014). Yet, with the recognition that the work involved in keeping someone well is becoming increasingly specialised and complex (Vassilev et al, 2011), this is likely to involve having to draw from different types of support in response to different problems (Perry and Pescosolido, 2012; Wellman and Wortley, 1990), of which online ties are increasingly likely to feature. The conceptual foundations of Corbin and Straus's (1985) 'illness work', has previously helped in providing a starting point for further conceptualising the division of labour across personal networks in long-term condition management, with 'work' being understood as the knowledge and activities that are relevant (either directly, or indirectly) to LTC management, including who does what and when (**figure 16**).

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[13] Web 2.0 refers to the emergence of a more participatory internet, giving people the ability to create their own content and connect with other people.

Figure 16: Types of Illness Work

Illness (specific) work: Work such as taking medication, taking and interpreting measurements; understanding the condition and its symptoms, making appointments.

Everyday work: Tasks such as housekeeping, occupational labour, support and activities relating to diet and exercise, shopping and personal care.

Emotional work: Work related to comforting when worried/anxious about everyday matters such as health, well-being and companionship.

Biographical work: Relates to the reassessment of personal expectations, capabilities, future plan, personal identities, relationships and biographical events.

Contingency/improvisation: The work involved in getting things back on track.

Translation/mediation: The work involved in translating abstract knowledge into practical knowledge that can then be implemented.

Co-ordination: The negotiations and renegotiations in the ways in which work is done such as what work is done, by whom, when, how and why.

Vassilev, I., et al. (2013). Social networks, the 'work' and Work Force of Chronic Illness Self-Management: A Survey Analysis of Personal Communities. PLOS ONE. 8 (4). pp 61-69.

Rogers, A., et al. (2011). Social networks, work and network-based resources for the management of LTCs: a framework and study protocol for developing self-care support. Implementation Science. 6 (56).

In consideration of who provides support and in what context, a more nuanced understanding of who people turn to in different situations is emerging, which is rarely in line with our normative expectations of a dyadic focus on a primary set of intimate ties. For example, Vassilev et al (2013) found that whilst family members often provided large amounts, they constituted less than half of the support received. Gallant et al (2007), in research looking at the influence of family and friends on chronic illness, suggested that people found it easier to talk to acquaintances such as work colleagues about their health than intimate ties and research has shown that people are able to ask favours of people they barely know (Rogers et al, 2014).

Research examining how people decide who to turn to, often describes a process that is purposeful and deliberate (Kennedy et al, 2014; Perry, 2012). Needs are determined, then networks are navigated to find the people/groups best placed to provide support (Perry and Pescosolido, 2012; Vassilev et al, 2014). In the case of condition management, this is likely to be both contextual and adaptive, resulting in practical and purposeful intent towards the activation of particular ties in certain situations (Perry and Pescosolido, 2012; Vassilev et al, 2014; Wellman and Wortley, 1990). These may also offer the opportunity to bypass difficulties experienced in negotiating/accessing resources from dominant offline ties (Allen et al, 2016). Factors such as a having the appropriate skills and knowledge, have all been explored in the literature as reasons to call on certain ties (Wellman and Wortley, 1990; Small, 2009; 2013; Perry and Pescosolido, 2010; 2015). However, even when ties are identified as being the most appropriate links to turn to, they are often bypassed in favour of people who are simply available (Small, 2013). Yet with the internet being situated as an everyday setting for people to reach one another in temporally efficient ways that allows individuals to be ‘absently present’ (Rainie and Wellman, 2014) and ‘virtually proximate’ (Atkinson and Ayers, 2010) the notion of availability takes on new meaning.

The increased social reach the internet affords means that individuals are now likely to have greater choice and control about who they call on for support in managing their condition, including increased options to mobilise support that is not available, or not wanted in offline networks. Research has pointed towards an increasing role for online support in self-management practices (Allen et al, 2016; Kingod et al, 2017; Ziebland and Wyke, 2012) which is supported by the ease of which new ties can be mediated online (Ellison et al, 2007; Donath and Boyd, 2004; Donath, 2007). These ties might become particularly relevant in the face of offline support deficits and the contrasting ‘gifting’ nature of relationships in online communities, whereby support is often given freely with little reciprocal expectation (Allen et al, 2016; Hadert and Rodham, 2008; Loane and D’Allesandro, 2013; Merolli et al, 2014). Through the shared experience of managing a condition, online peers might be uniquely placed to provide support for the everyday aspects of management collectively (Hartzler and Pract, 2011; Ziebland et al, 2012) and in so doing, extend personal illness related resources beyond what has been traditionally available. In addition, through the decentred self, individuals can now present themselves in different ways on and offline, which might support the realisation of different network resources (Bullingham and Vasconcelos, 2013; Goffman, 1990; Robinson, 2007). Different faces might be used in different situations and through this, the opportunity to bring forward certain aspects (front staging) of themselves, whilst concealing others (back staging), in support of securing certain network resources (Bullingham and Vasconcelos, 2013; Goffman, 1990).

There are suggestions that online ties have relevance, particularly in meeting needs that are unmet offline (Allen et al, 2016; Sanders et al, 2011). However, the context of such multi-faceted engagement is not fully understood, as previous studies have concentrated on online group phenomena in the absence of understanding its weave with everyday management. Thus, there is a deficit in our understanding as to the role that such ties come to serve within personal networks as a whole. With ever increasing access to new forms of support that are emerging, it is important to understand the context and circumstances in which online and offline ties are called upon, which also provides a basis to understand care transition in the context of the wider pool of actors involved in self-management. In this regard, this research responds to both sociological calls to better understand the wider arena of self-management support (Pescosolido, 2006) and Taylor and Bury’s (2007) concern to test the theory of a care transition empirically with reference to the public practices of self-management and how the relationships involved are conceptualised by those managing a condition.

6.3 The study

6.3.1 Sample

Purposeful sampling was used to recruit 30 participants in the south of the UK, who used online communities to support the self-management of a self-identified LTC[14]. The mean age of the participants was 52. They were predominantly on lower incomes (53% having an income lower than £26,500), but highly educated (56.7% having a degree). Most of the participants were either out of work through long-term sickness or disability (n=7) or retired (n=13).

6.3.2 Data collection

Data was collected over 18 months using semi- structured biographical interviews (Roberts, 2002) to elicit a narrative of ties activated both on and offline in response to self-management needs, allowing for a more complete picture of the context of engagement and its situation within a wider system of support to emerge. Ego network mapping was used as a heuristic device, which allowed for a visualisation of the resources, networks and relationships associated with the relevant facets of self-management and has been adapted and used in previous work to examine the full diversity of illness related work in personal networks (Allen et al, 2018; Brooks et al, 2016; Forbes et al, 2016; Rogers et al, 2011; Vassilev et al, 2013) (**figure 16**). This approach allowed the participant to describe their network in accordance with the resources they drew from a diverse range of supporters. The interviews were recorded and lasted 45-180 minutes. They were transcribed verbatim.

6.3.3 Analysis

Illness work (**figure 16**) was used as a conceptual starting point to the analysis, following which, inductive thematic analysis was used to identify the strategies used to draw illness work from on and offline network resources. Thus, our approach was theoretically driven,

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[14] Participants were recruited with several LTCs, representing a diverse range of condition experiences, including type 1 diabetes, Parkinson's disease, Polymyalgia Rheumatica (PMR), Giant Cell Arteritis (GCA), fibromyalgia, heart problems, Multiple Sclerosis, lung fibrosis, Myalgic Encephalomyelitis (ME), chronic pain, lupus, Human Immunodeficiency Virus (HIV)), Stroke, Hepatitis C, Asthma, Stiff Persons Syndrome and Epilepsy. Many had more than one condition.

but inductively generated. The authors met on a regular basis to discuss the on-going analysis and to explore and confirm the emergent themes, before arriving at the final three themes.

6.3.3.1 Ethics

Ethical approval was granted by the University of Southampton's Ethics Committee on 01/07/2016, **ID 19132**.

6.4 Results

Whilst placement within the concentric circles mostly resulted in groups and contacts being seen as either 'online' or 'offline' contacts, further exploration revealed a more complex process of suffusion. Support moved in both directions. Contacts initially established online, frequently become offline contacts. Likewise, contacts already known offline, often featured in online networks too. Where possible, distinction was drawn between ties already known offline and new ties formed online in the results.

The results indicated the use of online ties in network and illness management strategies. The context of engagement followed three main themes. Participants drew from online communities in response to deficits in offline support, they used online ties to leverage support or action from offline ties and they used online ties as a substitute to offline support.

6.4.1 Online network extension in response to unmet offline needs

Online communities allowed participants to employ proactive strategies to shape their network with a variety of ties that they perceived to be best able to meet their needs at specific times. Through using online communities, they were able to reach out and extend their network in response to perceived deficits in several lines of work, including illness (both medical and experiential), emotional and translational. These were related to current, as well as forecasted needs, occurred across the illness career, but particularly at diagnosis, or in response to a change such as a new treatment (for example in response to symptoms) adopting a new activity (such as taking up a new hobby), or biographical event (for example having children).

Scant encounters with formal, unresponsive healthcare systems presented as a feature of online engagement. Lack of formal diagnosis, which was common in conditions that are difficult to diagnose (Nettleton et al, 2005), meant participants were unable to tap into formal healthcare provision, making online peers more relevant- for some becoming the only condition related support they had. Even at the point of diagnosis, participants often received poor or incomplete explanations of their condition and how it should be managed.

> “I don’t just mean I knew nothing about Parkinson’s, I didn’t know anything about medication, I didn’t really know anything about symptoms, I didn’t know anything about support. I knew literally nothing at all.” (P12, F).

Incomplete explanations and use of inaccessible medical terminology by formal care, particularly at diagnosis, or when discussing certain treatment options, often resulted in the participants being unsure of what exactly they were supposed to do, as seen in prior research (Li et al, 2014). This lack of translation often resulted in participants having to speak to people online to make sense of what had been discussed:

> “They do probably tell me, but for them, it’s just a word, they just say it, it’s like, do you really understand what Dopamine is? And their words, they are not in my normal vocabulary, I am not a scientist, so I don’t know what it means, I’m not too sure they do either.” (P22, M)

Eventual changes in habits were often attributed to supportive online contacts providing a more satisfactory understanding of the reasoning behind prescribed practices. Online, peers took the time to translate abstract biomedical concepts into terms that were relevant and could be understood:

> “I didn’t know that I needed to check my blood sugar that many times a day. I was told I needed to check. But I didn’t know why. I never thought to ask. I didn’t really understand the numbers on the screen. So, I would check and see like 15 [mmols] and not really know that that was way too high. So, I started to think, you know. Why am I checking?” (P3, F)

The self-management practices of others played out across a ‘performative stage’ online, for example, participants talked about seeing the pictures their peers posted of their current blood sugar levels (Bullingham and Vasconcelos, 2013). This was influential, particularly during the stages immediately after diagnosis, helping participants to see self-management as an acceptable and normal practice and something that other people were also having to do (Willis, 2018). Being able to speak to others about why they measured their blood sugar, allowed for the translation of something that had previously been an abstract concept (e.g. checking an arbitrary number on a screen, without understanding what they were supposed to do) into something that was understood and was implementable.

Lack of timely access to formal, specialist care was relevant. One participant, after receiving a diagnosis of MS, had to wait 3-months to see a specialist. During this time, online communities became the only condition specific support she was able to access. Beyond diagnosis, more formal support was rarely available when questions arose, or specific problems were encountered. Often these problems were not seen by respondents as serious enough to seek urgent care but were still seen as urgent enough to require a response.

> “Yeah, if I have got a problem, I will go there (online community) first. Mainly because I can only see the consultant every few week’s (P8, F).

Participants rarely had access to offline contacts with the same condition. Thus, whilst many felt that their offline intimate network provided emotional support, it did not come from a place of shared understanding (Green et al, 2011). Online ties were often seen as better placed to offer support, through their shared embodied experience:

> “They try, but as hard as they try to understand, they won’t ever understand what it’s like. Like even though they are amazing at it, um…they won’t truly understand. I think like, I need somebody that actually gets it…you know, even just one person.” (P15, F)

Lack of network members with the same condition also limited the availability of offline experiential knowledge. This limited participant’s ability to integrate static information into everyday activities; with many wanting to connect with people experiencing similar everyday challenges relating to specific symptoms, complications and procedures but also too everyday activities such as work, participation in sport, or pregnancy (Hartzler and

Pract, 2011). Participants used online communities to locate and draw from people online with these experiences and the capacity to help:

> "I haven't officially put people into [boxes], but I will know that they are like the tech groups and there are kind of eating disorder groups and exercise groups…I just put people into their little files and I file them away until I need them". (P3, F)

Such a strategy related to current and forecasted needs. Participants often planned what their *future* network needs might look like and having access to those with experience of managing the condition alongside something that they planned to do was often seen as important:.

> "So, like for me, if I was looking to have children, again that's going to be a new thing for me, me now exercising a lot, it's a new thing for me. So, I need advice from someone who knows what it's like and what they do" (P9, F)

Here the online presentations of others were important (Bullingham and Vasconcelos, 2013), particularly in the sharing of interests, which facilitated the location and appraisal of online ties most likely to be able provide specific experiential knowledge (for example, people making it visible that they have diabetes and cycle competitively). Being able to reach out and connect with new contacts online facilitated the tailoring of self-management practices bypassing the prescriptively narrow focus of formal healthcare (Morgan et al, 2017), which was frequently less accommodating of everyday valued activities, such as going out drinking with friends, not always following a strict diet etc. This is in line with the notions of strategic noncompliance (Campbell et al, 2003; Demain et al, 2015) and participants rarely wanted to adjust their life to the procrustean bed offered by rigid self-management practices, instead drawing from online ties to create a modus vivendi:

> "And if you go to the Diabetes website, it advises you that when you get in from a night out, you have a bowl of pasta. I am not going to sit there at 3am in the morning making pasta. I am going to have cheesy chips or a kebab". (P3, F)

With the recognition that there were limits as to what formal care could offer (Gately et al, 2007), this provided the opportunity to push back against the prescriptive focus of formal care (Morgan et al, 2017), facilitated by the ability to draw from new online ties who were often 'activated' due to their experience of managing alongside a very specific everyday activity (going on holiday, doing a long-distance bike ride) or biographical event (starting a new job, having children). The experimental advice drawn from online peers based on their own approaches of trial and error plugged the absence of lay and critical experiential expertise within the participants offline personal network and provided a compliment to prescriptively narrow, but empirically focussed offline advice:

> "I would say that the online stuff compliments the primary care. Because I think the primary care gives me…It gives me the insulin, it gives me the basics that I need to, you know, keep me alive, but the online stuff gives me the knowledge to tweak it, to make it work best for me. (P7, F).

The above alludes to the continued importance of formal care in providing medicine, but the complimentary role of others online in learning the skills to adapt self-management to daily life (Hartzler and Pract, 2011). This allowed for a degree of pragmatism in being selectively non-compliant with some self-management practices (Campbell et al, 2003; Demain et al, 2015), whilst adopting the next best method, that 'would do', if it allowed for participation in day to day activities.

Having to provide advice in line with formal guidance and evidence was seen as a limitation of formal care, which was often deemed to be too risk averse:

> "They wouldn't have the lived experience, because they have not been in that situation. I don't know whether, it's difficult because I'm not sure…whether they would be brave enough, whether they would feel able to give you advice, because they wouldn't necessarily want to take responsibility if it didn't work out for you" (P5, M).

Advice from online ties would often go beyond what the participants felt healthcare professionals could feasibly provide; not having managed the condition themselves. Often this was not medical advice per se (such as not knowing whether to tell a prospective employer about a condition) but was relevant to decisions about everyday situations made challenging by illness (Hartzler and Pract, 2011). Whilst prior research, such as

Campbell et al (2003) has pointed toward the complimentary role of experiential knowledge in supporting the integration of self-management practices around daily life in this vein, this type of support was often unavailable in the participant's personal networks, creating a deficit that was necessarily addressed through online engagement. Since the participants felt that this could only come from someone with these experiences, online ties facilitated an adaptive approach to everyday self-management that would have been difficult to achieve without being able to reach out to new online ties to mitigate offline support deficits. Whilst it is plausible that this type of support could be located offline, particularly as there is some overlap with the features of offline peer support groups (Portillo et al, 2017), there were many reasons that made online support more relevant, such as feeling too intimidated to attend a face to face group (though some after initially chatting to others online, later set up their own offline group, or attended an existing one), being unable to get there (distance and access to transport), lack of suitable groups (especially in rare conditions, or conditions that are more common in older people such as Parkinson's[15]).

The ability to locate and draw from support online allows new possibilities for an adaptive approach to self-management that would not have been possible without it. As such, lack of people offline with the same condition featured as an offline support deficit and the internet provided a means through which such support could be easily located and called upon.

6.4.2 Online community engagement as leverage of offline tie action

Online communities were used to leverage support from existing offline professional and lay network members. Whilst the participant's management of their conditions typically involved minimal professional involvement, it was necessary for formal support to be drawn upon in ensuring aspects of care such as ensuring the right medications were prescribed and/or the correct referrals to more specialist care made. Activity with online communities was used as leverage for formal services. Conversations with a pool of people online, led to a wider understanding of the range of possible treatment options

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[15] Some of the participants interviewed, who had Parkinson's, did not want to attend the face-to-face group, as they felt it was mostly attended by people much older than themselves. Instead preferring to connect with others online of similar age, who they shared more similarities with.

helping people to negotiate treatment that best reflected their holistic needs. Accordingly, conversations with peers online helped hone the information that was sought to only what they couldn’t find out for themselves:

> “Yeah, you have to, before you go in, you have to formulate in your head the salient points, of what you are going to put across quite quickly, you know you are going to go in there with almost bullet points” (P18, M)

Conversations with online peers helped frame needs with a view towards securing resources during consultations. Thus, in this context, online communities were a backstage (allowing for knowledge acquisition and rehearsals) for the presentation of a self in formal consultations (Bullingham and Vasconcelos, 2013). For example, information gained from online peers frequently presented in formal consultations and was used to demonstrate candidacy toward certain treatments (such as a new medication, or a new device, such as an insulin pump), new equipment (such as perching stools, rails) and financial support (such as personal independence payments):

> “And then that made me think: ‘ah, ok, I need to be proactive and I need to push my GP for other tests and other possibilities” (P15, F)

This moved the participants away from a position of relative passivity when decisions were made about their care, to one of choice and control.

Conversations online also helped to leverage support from offline personal network members. Participants were often frustrated with offline personal network members who did not understand their condition, how it should be managed, or the impact their condition had on their ability to participate in daily life and fulfil existing responsibilities. Whilst such frustrations were partly addressed by talking to other people online who ‘got it’, online conversations were also useful in leveraging offline support through several approaches. Participants showed offline ties their online conversations with those with the same condition. This provided illness reification, acting as a confirmation that their condition was real and was experienced by others. Presenting themselves in this way was important, particularly in those with invisible or contested illnesses, in legitimizing their condition, the difficulties they encountered because of it, and reinforcing their needs. Impression management saw participants revise or adjust their online presentation of self, to offline ties, with a view of signalling current and future needs (Bullingham and

Vasconcelos, 2013; Robinson, 2007). This was done for example through the deliberate sharing of videos, pictures or articles (identity indicators) (Bullingham and Vasconcelos, 2013; Hodkinson and Lincoln, 2008) about their condition, or of them receiving treatment to areas where offline personal network members were likely to see them, such as on Facebook. This worked to reinforce support needs and thus, leverage support:

> “They forget…the only time they ever really remember is when I put the pictures of me receiving the IVIG, because I do that. Because I think, actually ‘hello’, I am actually ill, I am poorly and then all of a sudden they remember…all of a sudden people will be like ‘is there anything we can do?’, ‘do you want us to pop over…social media has helped me remind people” (P30, F).

Participants also used sites such as Facebook to talk about their condition for the first time with less intimate offline ties, allowing them to express parts of themselves that they had previously suppressed offline. The greater levels of editorial control offered by platforms such as Facebook allowed for a degree of impression management not available offline (Bullingham and Vasconcelos, 2013). This supported disclosures about illness that might have been difficult to openly discuss with offline contacts. Suler’s (2004; 2016) now seminal work on online disinhibition, suggests that online communities, even when identities are known, can facilitate sensitive disclosures, such as that relating to chronic illness. In this context, online platforms operated as a safe space in which the participants could talk about their condition and its potential impact on their life. Some of the participants likened this to ‘coming out’ about their condition, or in the context of Parkinson’s ‘dropping the P bomb’:

> “I was gradually starting to just talk a little more about, you know, my health, or not being able to do something and feeling frustrated or being so tired or whatever, but never actually, you know, going I have this and this is my situation. Um…and then I got my wheelchair and I was like, right, people are going to see me in my wheelchair, right, I am going to post a photo of myself in my wheelchair, on Facebook” (P2, M)

Telling less intimate ties about their condition by posting online, was seen as less painful than having to tell people individually (with online communication often being asynchronous and lacking visual cues, limiting personal exposure to the reaction of the bomb going off). Whilst not a goal directed disclosure per se, by making offline ties aware of their condition, the participants hoped that future support could be leveraged using these sites. In addition, sites such as Facebook were useful in maintaining existing offline relationships that were vulnerable to loss over time, especially where illness restricted participation in normative social events. In this context, participants were able to manage and maintain a larger pool of network resources that could be mobilised when needed. For example, participants were able to use sites (Facebook in particular) to leverage specific support from people they knew offline, who knew about their condition. Goal directed strategies such as these, included lifts to hospital, arranging emergency childcare etc. and matched immediate needs with availability and a desire to help in a temporally efficient way:

> “So, I did have an emergency appointment come through a while ago and couldn’t get a baby sitter, so I just said on Facebook, you know, ‘can any of my friends have the boys for just an hours’ and my friends around the corner said, ‘oh no worries, I am free’…there is a lot of interlocking support. It makes coordinating things easier” (P29, F).

That support can be negotiated in online communities in this way, supported this participant by matching immediate needs with availability, in which status updates provided a means through which needs could be signalled to a broad audience (Ellison et al, 2014; Manago et al, 2012). Thus this request was targeted at the participant’s entire local network (albeit through digital means), which meant the participant did not feel like a burden, because support was volunteered.

6.4.3 Substitution of offline emotional work with online ties through protective avoidance

Avoidant strategies were used in response to biographical work and moralisation, with the fragmentation of on and offline illness support networks supporting the substitution of offline support, through the utilisation of different, seemingly unconnected ties operating primarily online. Most of the participants did not want their offline networks to perceive them as unwell and privileged the maintenance of existing roles through negotiating support away from their intimate network:

> "My daughter is a strange one, because I don't want to talk to her about it…I am still very much meant to be helping her. And it is still very much that way around" (P12, F)

Privacy, a desire to maintain the way in which existing ties evaluated them and the importance placed on maintaining a sense of self (Bullingham and Vasconcelos, 2013; Robinson, 2007), led to some participants being reluctant to tell network members about their condition. However, this often reduced the availability of offline resources, making engagement with online ties more relevant, through the ability to negotiate support anonymously and thus, masking their offline self (Bullingham and Vasconcelos, 2013). Participants did this in several ways. Some participants had multiple accounts, one for talking to people they knew, featuring their real name and picture, and one for people with the same condition, in which they would often use a pseudonym. Some participants deliberately established supportive networks online in areas where it was felt that offline ties would be unlikely to see their condition related discussions:

> "I tend to keep the Diabetes thing away; I tend to keep it to the Twitter account, but my Facebook, that's my close friends and family. I don't, I don't really want them to have as much access to it, I don't want them to have as big an insight into this, but the online community, I don't really mind". (P9, F)

This reflects impression management (Bullingham and Vasconcelos, 2013; Goffman, 1990). Whilst this participant did not hide her identity, she identified that her family mostly used Facebook and would thus be unlikely to see the discussions she was having with her peers on Twitter. She noted however, that she would have found it embarrassing if these posts were read by her more intimate ties, suggesting multiple presentations of self, being presented in ways that are context specific and relate to the awareness of different audiences operating on and offline (Bullingham and Vasconcelos, 2013).

Many of the participants had built a model in their mind of who they would and wouldn't turn to for certain types of support. Prior work has shown a reluctance to seek help from offline ties (Sanders et al, 2011). In particular, adult children were often actively avoided through the moralisation of decisions to involve them. Often this was driven through not wanting to be a burden, being aware of others life pressures and wanting to maintain a sense of control over their relationship: “I have got three sons, they are preoccupied with their own lives” (P27, M). This also led to underutilisation of formal healthcare provision and the moralisation of seeking support from formal care:

> “I think I might be injecting into veins and all sorts of things which you don’t want to kind of be phoning up the diabetes team everyday and be like ‘that patient’ but there are people that are more than willing to give their advice online.” (P7, F)

Protective, avoidant strategies were employed to safeguard the valuable work of offline networks, who for most participants due to their proximity, provided most of the everyday illness related support, especially in relation to everyday domestic duties. These protective network strategies worked to safeguard the availability of this support, which was often seen as essential, by preventing the (perceived) threat of erosion through ‘over use’ and through awareness of alternative supportive ties operating online:

> “Because they are so vital, I don’t want to be the one that moans and groans and I am not saying people don’t have that right, because of course they do, but I would rather not have that element with them, because we are so close…it’s not that I am hiding anything, it’s just, if I am going to have a moan about something, I will do it on there.” (P13, F)

> “You can speak to people who you don’t know, so you don’t really care so much. I know that sounds awful, but to some extent they are expendable”. (P29, F)

The availability of people online and the ease through which support could be negotiated, often resulted in support being sought there. That this support was accompanied by less of the difficulties and pressures associated with offline support was important (Sanders et al, 2011). In contrast to offline support, the overconsumption of online support was not an active concern.

> "You are worried about burdening your friends. I previously would have sat and like thought very hard about whether I should phone someone and who I should phone, like who did I call last time?" (P29, F).

Often this was because support was requested generally, rather than being directed at a specific individual and therefore people volunteered their support, often with little expectation that such a favour would be returned in the future. Thus, in this context, needs were matched with availability and a keenness to help.

6.4.4 Case studies

The case studies below, including their ego-nets, shows the relevance of on and offline ties to individual cases, in which the participants had their own unique biographies, views, experiences and perspectives that related to their utilisation of a range and diversity of on and offline ties in supporting the management of their condition in daily life. The presentation of these contrasting case studies, better highlights the detail and narratives of the individual participants' use of on and offline ties and their personal circumstances that have led towards such multifaceted engagement.

These case studies demonstrate the importance of recognising the fluidity between on and offline ties and the importance of considering the relevance of both to long-term condition self-management support.

To protect the participant's anonymity, pseudonyms have been used throughout, including the names placed during the convoy model exercise. In addition, some biographical details have been changed, though this has been done so as not to alter the overall narratives of the participants.

6.4.4.1 Case Study 1- Mark

Mark is a 29-year-old man, who works as a researcher. He is married and lives with his wife, Susan, in a small house in a large city.

A few years ago, he was diagnosed with ME and recently, has had to start working on a part time basis, due to his fatigue. He has recently also started using an electric wheelchair, brought for him by his supportive parents.

Mark has quite a diverse network of on and offline contacts. Offline, he is supported mostly by his wife and a few close friends. Though he also sees his parents regularly, but rarely speaks to his dad about his health.

He is a member of a Facebook group for people suffering fatigue through any cause. He enjoys being a member of this group and connecting with other people who ‘get it’. He has tried other online groups before but prefers this one, because it is more positive. Positivity is one of the group’s mantras and much of the groups conversations extend beyond illness, to everyday interests, such as films and Netflix series people have watched recently. He enjoys joining in with these discussions, which give a less condition related focus to his self-management, through support that is rooted in activities that he enjoys.

Offline, he has two friends who also have the same condition, though he sees them rarely face to face (due to both their conditions) and therefore, talks mostly to them online, through Facebook and instant messaging services. Both friends have given him emotional support and where they have had the condition for a while, have also been able to share practical advice with him.

He has found it useful to talk to others online with the same condition, about more intimate things that he would not feel comfortable discussing with his wife. He also uses online communities to talk to people about his future intention to become a father and can get advice about this, from people who have experience of being a parent, whilst managing fatigue. Online ties have also been able to provide practical advice, relevant to current everyday activities, such as advice relating to accessibility.

His use of Facebook allows him to keep in contact with many people, many of which he feels he would otherwise have lost contact with. Through sites such as Facebook, he is able to make requests to his entire network for support and has used it to discuss his condition, something that he feels is important in helping him get different types of support from many different types of people, who often have very specific knowledge and skills. His ego-net is shown in **figure 17** below.

Figure 17: Case study 1 network map

6.4.4.2 Case Study 2- Nadine

Nadine is a 27-year-old, student teacher. She lives in the city, with her boyfriend in a flat.

She has type 1 diabetes and was diagnosed in her first year of college. Initially she poorly managed her condition and developed some complications because of this (such as retinopathy). She rarely checked her blood sugars, as she wasn't sure exactly why she was meant to.

She rarely spoke to any of her offline contacts about her condition. At the time, she didn't have a boyfriend (he has since become important) and she didn't want to discuss her condition with her family, who she felt didn't understand anyway.

Her consultant recommended that she starts to blog about her experiences of diabetes, which she did. Since then, she now follows and is followed by several thousand people on Twitter and has also set up an online community for people with diabetes. Through this, she has also gained access to people with specific experiential knowledge, such as people with experience of mental health problems and diabetes, certain diets and diabetes, and those with experience of insulin pumps.

She has also now set up, with someone she originally met online, a local diabetes peer support group, who meet regularly. Many of the people she attends this with, have become offline friends, but their relationships she feels have been strengthened through the perverseness of online contact. Her ego-net is shown in **figure 18** below.

Figure 18: Case study 2 network map

6.4.4.3 Case Study 3- Anna

Anna is 69 years old. She lives on her own, in a small bungalow in a residential cul de sac in a small town, close to the sea and is retired. Anna was born in Sweden but has lived in the UK for a long time (over 30 years). She is divorced and has no contact from her ex-husband. She has a very restricted social network. She has a daughter, but she lives someway away and is rarely able to offer support. Her granddaughter was placed in the inner most circle. Whilst she rarely sees her, she provides emotional support when she comes to visit.

Anna was diagnosed with Giant Cell Arteritis (GCA) a few years ago, after a long period in which she was unwell, but had not had a formal diagnosis. During what was a very difficult time, she had very little access to support. A year after being diagnosed, still feeling unsupported, both through poor experiences with healthcare and a lack of offline support, she joined a PMR/GCA online group, hosted on Health Unlocked. Her initial post introducing herself, was answered by someone who lived about 2 miles away, called Vera and they ‘just clicked’. Vera introduced her to one of her friends, Bonnie who also had GCA and they have since also become good friends, exchanging physical and emotional support when either of them is feeling unwell. They also set up a local support group for people in the area with the condition to attend; meeting a need that there had previously been no local provision for. Her ego-net is shown in **figure 19** below.

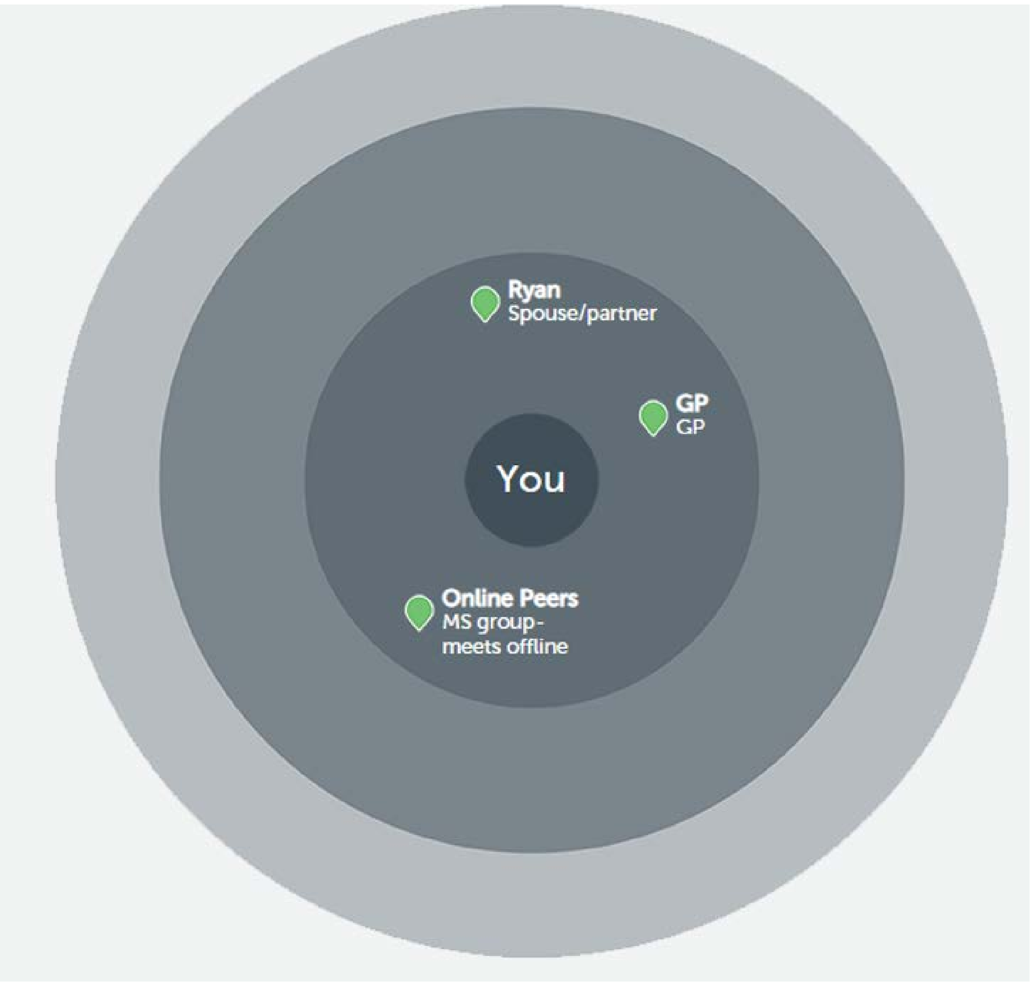
Figure 19: Case study 3 network map

6.4.4.4 Case Study 4- Suzanne

Suzanne is 67 years old. She lives with her husband, Ryan in a small village in Hampshire. The village is very green and has lots of outdoor space (which they both like) but is very small and therefore only has a small local shop and a pub. Suzanne and her husband have recently moved to the south, from the north after they both retired and have a very restricted local network. Their children live someway away, but they talk over the phone and internet regularly.

Suzanne was diagnosed with MS, whilst living in the north and has been having difficulty accessing MS related support since she moved to the South. On speaking to a friend who she met at a fatigue management course, when she lived in the North of England, she found out about a group of local women with MS, who meet regularly in a local coffee shop. The group have a Facebook page, which she joined in order to decide if she wanted to attend. After talking to people online from the group, she attended the coffee morning and has since become good friends with many of the group's members, meeting with a few of them outside of the group setting. She is also able to maintain contact with the wider group when they are not meeting physically, through the complementary Facebook group, which she feels has helped strengthen and maintain these new relationships. Her ego-net is shown in **figure 20** below.

Figure 20: Case study 4 network map



6.4.4.5 Case Study 5- Debbie

Debbie is 33 years old and lives with her husband, two kids and multiple pets (cats, dogs and a lizard) in a local authority owned home, in a small town in the South of England. Debbie was diagnosed with Fibromyalgia and ME a year ago and often struggles with daily domestic tasks because of pain and fatigue she experiences. Her husband works full time and is rarely at home. Whilst she also works part time, most of the domestic duties, including supporting their two children, fall to her. She finds this difficult but can get local support through a local parenting website and the parents at her children's school also have a Facebook page.

She asks for help through these pages when she needs extra support with her children, such as arranging emergency childcare if she needs to attend medical appointments at short notice. She also reciprocates when she feels able, which is important to her. As such, online communities provide her a sense of perceived social support, an awareness of her social network and its nested resources, whilst also providing a means through which this support can be mobilised efficiently. Her ego-net is shown in **figure 21** below.

Figure 21: Case study 5 network map

6.5 Discussion

These findings bring into focus the elements and configuration of what can be thought about as a new, digitally mediated stage of care transition (2.0). Whilst care transitions leitmotif was for care to be delegated to the individual with chronic illness as part of a political refashioning of lay and professional roles in supporting chronic illness management (Taylor and Bury, 2007), this stage of care transition reflects the changing nature of support in response to the social affordances of web 2.0. In this new modus operandi, connected individuals are situated as the central foci in their network and can use this position to meet their needs by drawing on a mixture of on and offline resources (Rainie and Wellman, 2014). This was supported through increased access to a range of resources and increased opportunity for multiple presentations of self that could be employed as a strategy to secure network resources, often in ways that allowed for the maintenance of control and normalcy offline (Bullingham and Vasconcelos, 2013).

Under conditions of complexity, the participants used agentic strategies that were purposeful, adaptive and future looking to overcome support being either unavailable or unwanted offline, or that required some leverage to be realised. Having access and the ability to appropriately draw on what was often quite informal resources[16], provided an enabling context for self-management that allowed for adaptive responses to formal cares more limited offering. Through affording those managing a LTC more choice and control in the everyday management of their condition, including the opportunity to mobilise away from the intimate ties traditionally implicated in self-management, care transition 2.0 sees participants being able to increasingly manage illness on their own terms. This has resulted in a further refashioning of the professional and lay roles involved in self-management and the place of offline ties, with new work increasingly being taken up by supportive ties online.

The new patient role of care transition 2.0 fitted the idealized notion of a ‘good self-manager’ (Ellis et al, 2017). Participants were remoralised (i.e. they took responsibility for their own health, often because they felt they had to), they were knowledgeable about their condition (through drawing on different types of information from professional and lay sources) and they used this knowledge in an active way to support the decisions they made (such as tailoring self-management strategies to suit certain lifestyles) (Ellis et al, 2017). Within this, the shifting patient professional interface has accelerated the turn of

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[16] Many of the online communities the participants discussed using had no moderation or professional involvement.

managed consumerism, discussed as a feature of care transition and in turn, has resulted in the further waning of medicines dominant role in chronic illness management (Barker, 2008; Nettleton et al, 2005). The participants were often able to confidently leverage required actions from healthcare professionals, through the knowledge they acquired from online peers. Research has alluded to the empowering processes of online communities (Barak et al, 2008; Brady et al, 2017; van Berkel et al, 2015) and earlier work in this area has pointed towards the increased access to health information that the internet affords too laity, as something that was likely to bring about such changes (Hardy, 1999). Certainly, it appears that patient choice is no longer based solely on the options presented by healthcare professionals, as Mol (2008) argues; with an increasing role being seen for online ties in this context. This is relevant, as formal self-management support has often been criticised as not accommodating the 'messiness' of people's lives (Ellis et al, 2017), limiting the efficacy of 'one size fits all' approaches to self-management support (Jones, 2011), such as that seen in the expert patient programme (Kennedy et al, 2007; Gately et al, 2007), itself seen as a facilitative factor of care transition (Taylor and Bury, 2007). The range and diversity of support people can now call on and the varying ways in which they can do it, has allowed such tensions to be overcome; offering a degree of flexibility that has often been absent in prescriptively narrow self-management support (Morgan et al, 2017).

New online ties had a greater or lesser salience under different conditions and existing ties could be leveraged to provide support in new ways, with the nature of these relationships informing the way on and offline ties were used. The participants online and offline networks often operated as overlapping fields with their own internal logics and support expectations. Online ties were often deliberately kept at a distance that was 'just right' (Miller, 2016). Their fleetingness, ease of negotiation and gifting nature, meant that online support was often seen as something that would always be available, irrespective of the level of effort directed at supporting these relationships; in contrast to offline ties that required purposeful effort to maintain (Sanders et al, 2011; Vassilev et al, 2014), but were seen as essential. As a result, online involvement could be 'powered up' and 'powered down' (Perry, 2012), creating flexible personal networks capable of providing a buffer to the fluctuating needs of those managing chronic illness; which the state has often struggled to provide (Francis et al, 2018; Hinder and Greenhalgh, 2012; Greenhalgh, 2009; Lawn et al, 2011). This was articulated in the frustrations the participants had in trying to access formal care in times of need, positing online networks as an adaptive response to care transition. As such, online ties, due to their condition related expertise (Hartzler and Pract, 2011), were often called on to provide information that once would have been largely the province of professionals (for example, whether a symptom was a normal).

Offline intimate ties were typically seen as lacking the necessary knowledge and experience to be able to respond in the same way as online peers to these types of request and were thus rarely turned to for advice. However, they necessarily provided support that required physical, as opposed to digital proximity, notably by supporting everyday practical work, such as helping with cleaning, shopping, transportation etc. when the participants were unable to (though this was not common). This work was essential and the awareness of supportive ties operating online, provided a means to which the saliency of this work could be maintained. This relational work has been seen previously in the context of weak ties, through which involvement is seen to limit the extent to which relationships are adjusted to accommodate illness and in turn supporting a less condition related focus to important intimate relationships (Rogers et al, 2014). Thus, a feature of care transition 2.0 is a narrowing of roles performed by intimate ties to only the support that cannot be readily performed through engagement with less intimate ties online. Though online communities (particularly Facebook) appear to have a role in the way in which offline support (particularly from less intimate ties) is maintained and mobilised that might result in more tangible support being realised from less intimate ties in response to requests for support, which has been seen in research elsewhere (Ellison et al, 2014; Vitak and Ellison, 2012) and might also facilitate the maintenance of a greater number of ties able to provide tangible support during times of needs (Anderson et al, 2015; Cornwell and Laumann, 2015).

Less visible in the participants narratives, but likely a feature of this stage in care transition is the ability for collective political action to occur through such communities; allowing participants to call out care that is left wanting (Barker, 2008; Griffiths et al, 2015). Certainly, the participants were able to leverage treatments that they had seen that others online had been offered and the opportunity to coordinate a political response to regional variances in the support that is available, or poor care provision is likely to give patients a greater role in shaping what care the state provides and sites such as Mumsnet have already demonstrated influence on provision (Griffiths et al, 2015).

6.5.1 Implications

The care transition (Taylor and Bury, 2007) and the rolling back of the state's involvement in chronic illness management (Ellis et al, 2017), has result in a deficit in contemporary healthcare provision, which is articulated through the participants struggles with accessing formal care. In the digitally able, this deficit is filled through the combination of on and offline networks, resources and worlds.

The NHS five year forward view states that the delivery of care in the UK needs to take advantage of the opportunities presented by technology to care for an increasingly aging population (NHS, 2014). Thus, an accelerated push towards self-management activities is increasingly seen as one being realised through more engagement with online resources and digital interventions (Hunt et al, 2015). The studies participants were mostly well educated and as a result, often presented as digitally able. Their ability to confidently engage with online resources is likely to have had an impact on the way in which they constructed their support. It is presumptuous to assume that all will be able to meet the refashioned patient role of care transition 2.0 in this way, because access and ability are unequally distributed; with older, more economically deprived individuals, particularly those living with a LTC being less likely to be able draw from online resources (McAuley, 2014; Zach et al, 2012). Those lacking either access or the ability to draw on online resources in this way, may lack the necessary network infrastructure to be able to adapt to this refashioned patient role and will be more reliant on support being available through existing networks. However, as the internet becomes a normative way of keeping in touch (Collins and Wellman, 2010) those without, may risk further marginalisation through the more restricted network support they are likely to be able to draw from.

6.6 Conclusion

Demographic and epidemiological transitions have created a situation in western countries, including the UK, whereby socio-political movements have reduced state involvement in long-term condition management, with an increasing focus on patients self-managing their own condition. Alongside this care transition has been an increasing role for the internet in supporting self-management, particularly in supporting people to reach out to new ties in the face of offline support found wanting.

Whilst care prior to these changes was largely carried out away from formal care, it is important to understand how those living with a LTC draw on a range of on and offline resources to support the management of their condition, given the reduced state involvement in care, but also the increasing potential for care to be realised elsewhere. To our knowledge, this is the first study to look at online support in the context of wider network support, particularly that looks at the context and circumstances related to online and offline network engagement in supporting chronic illness management. The participants demonstrated purposeful and practical intent in selecting the network members that they saw as best able to meet their needs. Unsurprisingly, offline support continues to be essential in support in which physical presence is required, yet the internet gave people the opportunity to realise support away from both professional and lay support, which has brought about a new stage in care transition. A concern is that this transition places those who lack the ability to draw on these resources appropriately, at a disadvantage and understanding how those from more marginalised communities adapt to this changing landscape of care should be the focus of future research.

Chapter 7: Discussion and Conclusion

7.1 Chapter Introduction

This thesis aimed to further the social understanding of the place of online ties in personal self-management practices and processes. The research presented in this thesis, makes a novel contribution to a rapidly growing and increasingly crowded field of research through an illumination of the place of online ties, within the wider personal systems of support people have access to. In doing so, it extends the understanding of how online ties can and do fulfil valuable illness work in those with the capability to draw on them in meaningful ways. This thesis began by outlining the approaches to traditional self-management support, which have generally focussed on individual behaviours and refashioning of lay and professional roles. These approaches have largely failed to bring about changes in health care utilisation or improve the experience of those managing a chronic illness in daily life. In view of this, attention is increasingly being paid towards the role of personal networks in self-management, of which, online ties are increasingly a part of. The role of personal networks in condition management is recognised as important, but their contribution to everyday self-management is often hidden and under examined.

With the recognition of the need to develop a networked understanding of the role and place of the internet and online ties within one's personal network, in the self-management of a LTC in everyday settings, this thesis sought to better explore and thus better understand:

1) The generative mechanisms of self-management support in online communities, including their role in supporting the negotiation of self-management support online.

2) The role personal networks, network resources, illness work, and community participation have on the use of the internet in general, as well as for support in managing a LTC.

3) The nature of engagement with online ties in those who use them to support the self-management of a LTC, including how people perceive this in the context of the contributions of their overall personal network.

Whilst the findings of these have been discussed within the papers that constitute the core of this thesis, this chapter allows for the findings to be synthesised and thus, discussed in the context of one another. In pulling together the findings of the thesis, the place of the internet and online ties in supporting a more holistic focus to self-management practices as well as meeting the fluctuating demands of chronic illness, is discussed. Considerations of how this new orientation might impact on those without access and the capability to draw on these resources are also made, which leads to recommendations for the direction of future research. Firstly, the findings of the individual papers will be briefly summarised.

7.2 Summary of findings

7.2.1 Stage one: Long-term condition self-management support in online communities: a meta-synthesis of qualitative studies.

This stage of the thesis is published in the Journal of Medical Internet Research. To aid clarity, the results for this stage are cited as Allen et al (2016) in the discussion.

The findings of the meta-synthesis suggested that four network mechanisms supported the negotiation of illness work in online communities. These were 1) collective identification and knowledge through lived experience, 2) support, information and engagement through readily available gifting relationships, 3) sociability that extends beyond illness and 4) online disinhibition as a facilitator in the negotiation of self-management support (Allen et al, 2016).

As with prior research, e.g. Sanders et al (2011), the findings suggested a possible role of online communities and the online ties they mediate, towards the supplementation and/or substitution of offline support with online resources (Allen et al, 2016). This suggests that online ties might become increasingly relevant in the face of offline support being either unavailable, or unwanted. The social mechanisms and the nature of online ties appear to make them a suitable substitute or supplement to offline networks (Allen et al, 2016). These assertions though, required further exploration in stages two and three of this thesis, especially since the included studies tended to focus on online group phenomena in the absence of understanding its weave with everyday life.

This is important, because it is recognised that behaviours enacted online are likely to be drawn in response to offline support (Miller, 2006; Rainie and Wellman, 2014; Subrahmanyam et al, 2008; Quan-Haase et al, 2017). Thus, studies that only examine online behaviours, may fail to fully contextualise the needs and values ties come to serve and when they become relevant. In the context of health, it is problematic to make general inferences about the integration of online worlds into the everyday lives of people, without an elaborated understanding of the relationship between these worlds. Research, for example Kivits (2009) and Sanders et al (2011) have pointed towards the importance of understanding the internet and online ties in the context of that which is available offline.

Thus, whilst these findings illuminated the generative mechanisms supporting the negotiation of illness work online, this stage (on its own) was unable to show both how the availability of offline illness work relates to the use of online resources and how those with a LTC decide to negotiate certain aspects of illness work for LTC management both online and offline, during certain stages of their illness (i.e. initial genesis, change in symptoms, crises etc.). Thus, these findings whilst both novel and important, are necessarily complimented by the findings of stages two and three which gave further indication as to the role online ties play in the self-management of the digitally able.

7.2.2 Stage two: The contribution of internet use in personal networks of support for long-term condition management.

This stage of the thesis is published in Chronic Illness. To aid clarity, the results for this stage are cited as Allen et al (2018) in the discussion.

With the recognition that existing research has focussed on online support, without understanding its weave with everyday life and the findings of the meta-synthesis suggesting the utilisation of online resources in response to offline support deficits (Allen et al, 2016), this stage, using social network survey data from the Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (U-Net)' research project (Rogers et al, 2011; Vassilev et al, 2013), looked to better understand the extent to which the availability of offline support influenced engagement with the internet for condition management. Consistent with prior research (Latulippe et al, 2017; Huxley et al, 2015) age, level of deprivation and education were associated with use of the internet in general. In addition, network access to someone able to fix computer problems, was also significant, suggesting a possible diffusion of these skills across networks (Allen et al, 2018).

In those using the internet, the findings suggested that use for condition management, was related to greater access to offline emotional work. Whilst not associated with the availability of offline emotional work, those using the internet to support condition management were less happy, which is consistent with earlier research looking at support more generally (Leung and Lee, 2005). The contrast in these findings suggested that both network (possibly *collective efficacy*) and non-network mediated (possibly *avoidance*) processes shape engagement with online resources for condition management (Allen et al, 2018)

Whilst, no associations were found between the availability of other types of work (illness and everyday practical) and network characteristics (such as size, diversity, fragmentation etc.) and the use of the internet for support, the quantitative nature of this stage provided a limited snapshot of online behaviour (concentrating on internet use in the past 6 months). To illuminate these network processes and with the recognition that chronic illness requires engagement with different network resources at different times in response to different problems (Morris et al, 2018), there was a need for engagement with those using online ties to support management in order to create a more nuanced picture of the role of on and offline ties. These findings then are supported by stage three, discussed below.

7.2.3 Stage three: Care Transition 2.0: A qualitative study of the work and relatedness of ties mediated online in supporting long-term condition self-management.

This study specifically looked at the place of online ties, within someone's overall personal network, to better understand the context in which online ties are turned to and how they shape self-management practices. The findings suggested that those with the capability to draw on online ties were able to meet previously unmet needs and leverage work from existing offline ties. In addition, access to less intimate ties online, provided the opportunity to actively avoid the negotiation of work (particularly emotional) from the intimate offline ties that have traditionally been implicated in support (Dunbar et al, 2008; McMunn et al, 2009). The capability to draw on a combination of online and offline resources in this way, led to the participants being able to overcome shortcomings in formal care, as well as move aspects of illness work away from intimate ties, which in turn supported the adoption of a less condition focussed approach to self-management, in which participants were often selectively non-compliant of rigid, prescribed self-management practices (Morgan et al, 2017), in favour of approaches that better accommodated the messiness of everyday life (Ellis et al, 2017) and valued activities (Entwistle and Watt, 2013).

7.3 Discussion

These findings, seen together demonstrate that the internet and online ties are changing the landscape and orientation of self-management in those with the capability to draw from them gainfully. Thus, as has previously been suggested, on as well as offline ties (and in recognition of the fluidity of these relationships, those known in both) should be seen as part of one's personal network (Hampton et al, 2011a; 2011b). In stage three, the findings pointed towards a new, technologically mediated stage of care transition (2.0). In this stage of care transition, in which reduced state involvement has necessitated the need for support to be drawn elsewhere, the availability and capability to draw on online resources and ties mediated online both 1) supports a holistic focus to management, through which broader interpretations of self-management support can be realised (including the realisation of valued activities) and 2) meet the fluctuating demands of LTC management in daily life, thus reducing the impact of the condition on the individual and their intimate ties. These affordances coalesce with the suggestion in prior research that access to a diverse range of ties (of which, the internet provides further network diversification) increases both access to resources (more so than network size) and ability to cope with the demands of managing a LTC in daily life (Holt-Lunstad et al, 2010; Reeves et al, 2014; Vassilev et al, 2016). Such affordances will now be discussed in more detail.

7.3.1 Person centred care- a move towards what is valued

The thesis has shown the nature of online ties (both those known already offline and new ties mediated online) are well suited to several important facets of self-management. For those with the capability to draw from them, online ties positively shaped their experience of managing a LTC in daily life. The capabilities approach, discussed in chapter two of this thesis, reflects the capability of individuals to live life in a way that is valued (Sen, 1983; 1985). This approach can become the bases for exploring the goals processes and outcomes of self-management support. CA was therefore adopted as a sensitizing concept, because it was felt that the internet, in the context of condition management, would be likely to feature as an input that could be used to extend human capabilities. In relation to the present thesis, this reflects one's ability to use the internet in ways that support a more holistic focus of self-management; allowing individuals to live a good life, despite illness. In returning to the arguments made for the present study, self-management support in focusing on individual behaviour change, has often fixated on a narrow interpretation of self-management, that places an emphasis on bio-medical markers as a measure of self-management success (Morgan et al, 2017), to the relative exclusion of what people value, which is ability to live a good life, despite illness (Entwistle and Watt, 2013). Ties online were often used as an alternative to formal cares more limited, un-holistic offering.

In stage three, frustrations with formal care were visible in nearly all the interviewed participant's narratives and was a background factor leading to increased engagement with online ties. Comments about the limited length of time (often between 5-10 minutes) in clinical consultations alluded to the difficulty of shared care and truly collaborative relationships emerging as envisioned in utopic policy (Jones, 2018). This also limited the extent to which everyday management could be discussed and provided little negotiating room, through which more accommodating self-management practices could be supported. This included a lack of experiential knowledge, that is valued by those managing a long-term condition and often reflects the knowledge that people feel they need in order to successfully manage a LTC in daily life (Allen et al, 2016; Brady et al, 2016b; Hartzler and Pract, 2011; Kennedy et al, 2014). Whilst patients, across all conditions, have expressed a need to be treated as individuals by healthcare professionals (Boger et al, 2015), the participants rarely received advice tailored towards their wants and needs; this, despite the rhetoric of policy that emphasises a patient orientation and the need for more person-centred care (Department of Health, 2013).

A lack of understanding as to what people valued, led to participants turning to online ties, who had themselves experience of implementing self-management in daily life

(Hartzler and Pract, 2011), but the decisions about everyday management that were made because of online engagement were almost always made without renegotiating these practices with formal care, through a recognition of their more limited, narrow offering. A double bind in consultations, also often meant these everyday strategies remained hidden, which is consistent with research showing the difficulty people have in discussing the illness work they do online, with healthcare staff (Bowes, 2012; Chiu et al, 2011; Stevenson et al, 2007). Thus, rather than being an opportunity for collaborative partnerships to emerge between patient and healthcare provider, in which everyday management activities were discussed and considerations were made as to the how management could be adapted to the needs of individuals, formal care was often simply side-lined to that of a support role (used for prescriptions, onwards referral etc.).

This was through the affordances of online ties, able to support a more holistic focus to self-management, through providing the opportunity for judgements to be made that better accommodated chosen lifestyles (Allen et al, 2016; Hartzler and Pract, 2011). Thus, adding a new dimension to strategic non-compliance (Demain et al, 2015), with management activities reflecting the approaches that best allowed for participation in daily life, whilst also mitigating the impact of outright non-compliance (i.e. a compromise, reflecting the next best approach). Thus, in this context engagement with online ties was a way to adapt self-management to chosen lifestyles (Boger et al, 2015), allowing the realisation of lives that were valued.

This was difficult to achieve through offline ties, since many of the participants lacked people in their offline network with the same condition. In some cases, their condition was so rare, that no offline peer support group existed (such as stiff persons syndrome). Thus, online ties provided access to people who understood the challenging nature of managing a LTC in everyday life, as well as access to their experiential knowledge, which was often highly specific and beyond that which formal care could provide.

In addition, alongside the side-lining of formal care, stage three showed an often-deliberate side lining of the close ties traditionally implicated in self-management, potentially illuminating the non-network mediated process of online engagement seen in stage two (Allen et al, 2018), in which online resources are utilised through offline network avoidance. This to, was in response to the value placed on maintaining a sense of self and the biographies of existing relationships, which is known to be important to those managing a LTC (Boger et al, 2015; Minet et al, 2011). As an approach, side lining intimate ties meant minimising disruption to the lives of people the participants cared about, which was facilitated by certain aspects of support (particularly emotional) being taken up online instead. Awareness of these processes adds clarity to the reduced happiness in those utilising online resources, through non-network mediated pathways in stage two (Allen et al, 2018). Through the provision of a salient outlet, in which frustrations could be shared with an audience who were seen to better understand through their shared embodied experience, online ties were able to remove, or at least mitigate some of the focus of illness management, away from intimate ties, by providing a ‘safe space’ (Brady et al, 2017; Sanders et al, 2011; Trondsen and Tjora, 2014) in which support, could be easily realised.

7.3.2 Online ties and the fluctuating demands of LTCs

The findings of the thesis support the notion that online communities provide extra diversity to people’s networks and increase access to resources relevant to self-management, through supporting the increased reach towards new ties, with a variety of nested resources and condition related experiential knowledge. Research examining social capital and network resources has often suggested that access to ‘nested support systems’ provides a stress-buffering function (Cattel, 2001; Stockdale et al, 2008). In this manner, diverse networks are said to be protective, through providing more stable access to a greater range and diversity of resources, allowing people to better cope with the fluctuating demands of chronic illness to daily life better than those in smaller, more restricted networks (Holt-Lunstad et al, 2010; Reeves et al, 2014; Vassilev et al, 2016).

In those with the ability to draw from online resources, online ties now likely feature as part of a network response to the fluctuating needs of chronic illness. Whilst stage two was unable to show this, through only examining internet use over a six-month period (Allen et al, 2018), the narratives of the participants in stage three showed increased online tie engagement, when specific problems were encountered (meeting the increased demands on the individual with the condition and their personal network), but often played a more marginal role when things were going well. The nature of these ties made them well suited to this, because maintaining access required little or no reciprocal effort.

The findings suggest that being able draw from online ties and resources, allowed individuals to exert control in situations where they would have previously had few options beyond reliance on formal care or in the absence of this, intimate ties. This is reflected in the decisions taken to negotiate support away from the professional and intimate ties that have traditionally been implicated in support seen in stage three. The demands placed on personal networks and formal care have traditionally been most visible in what Morris and Sanders (2018) describe as 'critical moments', that either reflect a large event, such as the initial genesis of a condition, a diagnosis, or several smaller changes that put pressure on self-management and those involved in providing support. Such moments have traditionally placed pressure on both the individual and their close ties (Morris and Sanders, 2018; Wittenberg et al, 2013). It is known that the networks implicated in self-management support can be shaped through illness, in which changes to membership, network dynamics, structure and function are common (Perry, 2006; Perry, 2012; Vassilev et al, 2013). Yet in the move away from traditional place-based communities, through increased connectivity, individuals can now mobilise resources beyond that which is immediately available (which has traditionally been intimate ties, living proximately). This gives those managing a LTC (provided they have the capability to do so) the opportunity to forge new ties to help them cope practically and emotionally with the challenging nature of their illness, whilst mitigating some of the pressure that might have previously been imposed on intimate ties.

In addition, the nature of online ties (ease of location, number of people available, lack of reciprocation in order to maintain overtime), as demonstrated in the stages one and three, makes them well suited to dealing with certain emergent problems, not least because they can be easily 'powered up' and 'powered down' when problems are encountered that exceed an individual's capacity. The findings of the meta-synthesis (Allen et al, 2016), were reinforced in the participants narratives in stage three. Which further demonstrated that the nature of these ties, makes them well suited to meeting some of the fluctuating needs of chronic illness. These ties (in contrast to those offline), were seemingly always available (ease of access, someone always online), required no reciprocal effort in order to be drawn from (readily available, gifting relationships), were often able to offer very specialised advice relating to specific problems (through the body of experiential information developed over time) and were easy to detach from when they were no longer required (Allen et al, 2016). Consistent with prior research, looking at support more generally, stage three showed that online communities have a role in securing resources from those already known offline, with sites such as Facebook both supporting the awareness of embedded network resources, and providing a platform through which, offline support needs could be signalled to less intimate ties offline, with access to a wide variety of resources (Hampton et al, 2011a; 2011b; 2016; Lu and Hampton, 2017). This supported the notion that even with ties previously known offline, access through digital means supported the realisation of resources relevant to management that might otherwise have been unrealised.

In addition, whilst not always wanted, online ties mitigated the impact of reduced state involvement in LTC management. There is a recognition that formal care has often struggled to be responsive to the fluctuating needs of LTCs (Francis et al, 2018; Lawn, 2011). Thus, given the availability of this support, it is unsurprising that when barriers to formal care were encountered, online ties were turned to. In line with this, studies have shown that static online health resources are often turned to, when difficulties are faced accessing formal care (Amante et al, 2015) and these findings suggest that online ties support management, when access to formal care is restricted. Whilst a lack of responsiveness of formal care, including during ‘critical moments’ (such as the initial genesis of the condition, worsening symptoms or control) was in part overcome through engagement with online ties (within certain limits- i.e. online ties couldn’t respond to emergencies[17], or prescribe needed medications[18]), that participants were having to buffer a failure in state funded care, with online ties problematizes the notion that being able to appropriately draw from online ties, increases people’s choice and control in how they manage their condition, as suggested in earlier research (Powell and Boden, 2012) and in part, this thesis. Whilst these ties (as discussed above) often supported a more holistic focus to self-management practices, when significant problems were encountered, many of the participants wanted more professional involvement and felt let

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[17] Though one of the participants described her partner speaking to online ties to understand how to respond when she was hypoglycaemic.

[18] Though participants did discuss changing the dose of medications they already had access to on the advice of online ties, particularly insulin.

down during these critical moments. During more difficult times, lack of contact with professionals was rarely a ‘choice’ and was more normally related to difficulties in accessing a formal care system that was unresponsive to their needs[19]. The provision of information at diagnosis was often extremely poor, necessitating the need to turn to online resources, either to translate or overcome the rudimentary (sometimes entirely absent[20]) information that should have been provided. In those without access to such resources, this becomes even more problematic and should be a concern to policy makers, especially if the turn towards digital self-management solutions, further restricts access to offline support.

7.3.1 Second level digital inequalities and new barriers to self-management

In this thesis, the participants had access to a greater range and diversity of resources, through online contact (both from ties already known offline and new ties). The internet and ties mediated online is a feature of this and it should be recognised that the use of resources to extend one’s capabilities to self-manage, is in itself, related to capability. Whilst the findings point towards the increasing relevance of both the internet and ties mediated online to self-management practices, access and use across the population remain unequal (Dutton et al, 2013; Robinson et al, 2015; Sarker, 2011).

The use of two separate samples (in stage two and three), one drawn from a marginalised population in which the majority of the sample did not use the internet for condition management (Allen et al, 2018) and one in which participants were recruited specifically because they used online communities (stage three), magnified the disadvantage faced by those lacking access and capability to draw from online resources in ways that support self-management practices and adaption to the repurposed patient role of care transition 2.0. Those involved in stage two were thus more reliant on being able to find the necessary support in their offline network, limiting their ability to meet the fluctuating demands of chronic illness, or make use of online ties in support of a broader, more holistic focus to their self-management practices.

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[19] Most of the appointments the participants attended, fitted the needs of the service and when they needed it, there were often no appointments.

[20] As a clinician, hearing people describe online engagement as a response to being diagnosed with conditions as life changing as Parkinson’s and MS, without receiving any explanation as to what is was or how it should be managed made me feel incredibly upset and uncomfortable.

With attention being increasingly paid towards the use of online resources to support self-management, concerns have been raised about who is likely to be using them (Robinson et al, 2015). It is important to be cautious when considering the possible place of online ties in providing support in more marginalised populations, especially if similar support is not made available offline. Disadvantaged groups, who have traditionally faced the poorest health outcomes (Marmot et al, 2010; Navarro, 2009), are less likely to be able to successfully draw from online ties to support self-management, and thus, any push towards the realisation of increased self-management practices online, is likely to lead to a digital reproduction of inequality, especially where unequal opportunities to plug support deficits might mean reduced access to support.

Even though access to the internet is increasing, second level digital inequalities have persisted (Dutton et al, 2013; Robinson et al, 2015; Sarker, 2011). These affect people's ability to use these resources in meaningful ways (Dutton et al, 2013; Robinson et al, 2015; Sarker, 2011). Digital health literacy is an important part of this and is concerned with the ability to draw from online resources (Bautista, 2015). This involves having the ability to search, acquire, make sense of, critically appraise, communicate and apply online health information, with a view to maintaining or improving health (Bautista, 2015). In the context of health, digital skills are also required to successfully use online communities and form new ties. This includes understanding how to present oneself in online spaces, which includes having the awareness of the extent to which online disclosures are private/public (Brady et al, 2016a; Bullingham and Vasconcelo, 2013). This is complex and requires understanding the social and technical aspects of various platforms in which online ties can be negotiated (Brady et al, 2016a; Marwick and boyd, 2014). However, as this thesis has shown, the affordances of being able to successfully draw on resources in this way are significant, thus calling for steps to realise increased digital literacy in those lacking these skills.

In addressing these concerns, digital skills courses are now being (socially) 'prescribed', through a widening digital participation programme.[21] (Tinder Foundation, 2016). Whilst not empirically tested in the case of chronic illness, the participants who received training

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[21] This programme has delivered digital skills to over 200 thousand people across the UK, many of whom went on to search for information about their health for the first time after attending the course (Tinder Foundation, 2016).

have accessed formal healthcare less, feel more informed about their health, and have become more confident in engaging with online health tools (Tinder Foundation, 2016). Thus, this suggests that it might be possible to reduce the impact of second level digital inequalities and in doing so, bring about new forms of chronic illness management in marginalised populations. In addition to this, network solutions might also exist, which will be discussed in more detail, when recommendations for future research are made below.

7.4 Implications

This thesis and the papers within it, have shown the importance of considering online ties within someone’s overall personal network of support, including both the increased access and awareness of the resources of existing offline ties as well as the opportunities to reach out to new supportive ties online, to meet aspects of support that are either absent or unwanted offline. These ties, due to their nature have been useful in supporting a broader, more holistic focus to self-management support and in being responsive (albeit with limitations) to the fluctuating demands of chronic illness management, in ways that removes pressure from the individual with the condition as well as intimate ties.

As the case studies in **chapter 6** demonstrate, there is an increasing fluidity between on and offline relationships. Ties initially mediated online (often due to offline support deficits), frequently become known offline, where more tangible support is often realised. In addition, the pervasiveness of online contact with existing ties can increase a sense of closeness, make people more aware of their networks resources and provide a platform through which support can be mobilised (Lu and Hampton, 2017). It is imperative that future research looking at the place of personal communities in providing support in open settings, considers peoples on and offline ties, whilst recognising the increasing fluidity between these networks (Hampton et al, 2011a; 2011b).

Whilst it is difficult to control for confounding factors, there is evidence that use of online communities for condition management also improves the bio-medical markers, that are so frequently used as a measure of successful management, for example Lictchman et al (2018) found increased glycaemic control in those with higher engagement. Thus it is perhaps surprising that so far, policy has largely side-stepped acknowledging the role of peer-to-peer support online, especially in view of the previous enthusiasm of offline peer led support. The areas that have been discussed in policy are those deemed less risky, for example, the provision of static health information and encouraging patients to provide feedback on their care (Hunt et al, 2015). With the internet and ties mediated online increasingly taking on valuable illness work that supports people's everyday implementation strategies, considerations as to how these can be brought into wider systems of support are called for. Such considerations should also look to ensure equal opportunities to draw from these resources in meaningful ways, such as through the promotion of digital skills training.

7.5 Limitations and future research

Whilst the papers in this thesis have made an original contribution to the research literature, there are notable limitations. These have been discussed in the included papers and for clarity will only be briefly returned to here, in view of setting the course for future research.

7.5.1 Network digital skills

The use of a secondary dataset in stage two limited the extent to which digital skills could be seen across the ego's personal network. The role of digital skills in personal networks could be addressed in future research, through the consideration of these skills across the network, using established digital skills scales, such as that developed and later validated by van Deursen et al (2016). It is known that the extent to which individuals use technologies typically arises through networks. For example, access to a network member with the capability to fix computer issues was related to internet use in stage two (Allen et al, 2018). In networks where use of the internet is not normalised and where the technical skills required to make use of such resources are not valued, people are less likely to access or use these resources (DiMaggio and Garip, 2014). In these networks, people are also less likely to see how such resources might be relevant to their everyday lives (Boyd, 2014) and levels of self-exclusion remain high (Ennis et al, 2012). It is important to recognise that technical ability is often a resource that can be shared between network members (DiMaggio and Garip, 2014), which might call for ways in which the nested technical abilities of personal networks can be realised. A future network study looking at this in more detail, would advance our understanding as to the extent in which network digital skills are relevant in supporting online engagement and digital self-management practices. Within this, types of use, as well as frequency should be considered.

In addition, the findings support the signposting of digital skills training through GENIE. GENIE is an evidence based, facilitated online health intervention that aims to raise awareness of peoples existing personal networks of support, whilst signposting to possible future engagement with wider community networks (Kennedy et al, 2016). With the expansion of digital skills training that is becoming available, GENIE could be used to signpost those interested in learning how to make better use of online resources to community resources, that may help develop these skills. In addition, the groups that people turn to through the GENIE intervention, could be supported by an online group, which might have a place in supporting the development of new relationships and give people a greater awareness of these new ties.

7.5.2 Longitudinal analysis of on and offline ties

In the third stage, the responses were drawn from a mixed group of participants, who lived in the South of the UK. These participants were mostly well educated and as a result, often presented as digitally able. Their ability to confidently engage with online resources is likely to have had an impact on the way in which they constructed their support.

A future longitudinal study might support a better awareness of the role of online ties over time. Whilst the interviews focussed on stages of management and featured discussions about online ties at key moments (such as the initial genesis, diagnosis, crises, flare up etc.), this was subject to recall bias. Whilst longitudinal methods would not remove this entirely, it would provide the opportunity to collect further network maps, to understand the extent to which certain ties become important overtime. Since principally, in the interviews the convoy model was used as a heuristic device, future research could concentrate on using these to better understand the network typologies associated with more/less online ties, with data drawn from a larger sample as per Vassilev et al (2016).

7.6 Conclusion

In view of a recognised, but largely hidden aspect of self-management support, this thesis set out to provide a better visualisation of the full range and diversity of on and offline ties implicated in contemporary self-management support. With an increased focus on those with a LTC becoming more responsible for the management of their condition, in response to the transition from an acute, to chronic disease profile, various forms of self-management support have been explored. Even with the recent input of technology, these have largely focussed on eliciting individual behaviour change. More recent recognition of the role of personal networks in self-management have made relevant, the exploration of the role and place of online ties, within people's everyday management strategies.

This thesis has made a novel contribution to the field, through illuminating the mechanisms supporting the realisation of online illness work, the network and non-network mediated process supporting engagement with online resources and the context and circumstances in which online ties become relevant in those with the capability to draw from them. These findings have illuminated a largely hidden patient system of implementation, in which online ties are used in combination with offline ties to support a more holistic focus to self-management and act as a buffer, which limits the impact of the fluctuating demands of LTCs in daily life. In the digitally able, the deficit in contemporary health care provision making these affordances relevant is met through the combination of on and offline networks, resources and worlds. In this context then it is right for concerns to be made about the lack of access that some face and future research should turn to the ways in which this might be realised in marginalised groups (who already face unequal self-management opportunities), if we are to avoid a digital reproduction of inequality, in the face of reduced state involvement in LTC care.

Appendix 1 Research Protocol

Protocol

Study Title: Exploring illness support in online and offline social networks for people who have a long-term condition

Researcher(s): Chris Allen

Funder: NIHR CLAHRC Wessex

Organisation supporting this proposal: The University of Southampton

Purpose:

Long-term condition self-management has become an increasingly important paradigm in healthcare delivery; and its promotion is now an enduring feature of health care policy (Wanless, 2004; DOH, 2005; DOH, 2010; DOH, 2015). The need for self-management is reinforced by the fact that those living with a long-term condition spend very little time engaged with healthcare professionals compared to the time spent on activities that are required to manage their condition in daily life (Rogers *et al.*, 2011; Rogers *et al.*, 2014).This makes engagement with self-directed support a necessary component of successful illness management.

Engagement with self-directed support is a research and implementation theme of the NIHR CLAHRC Wessex; whose overall vision is to improve the health of people within the Wessex region, whilst ensuring the quality and cost-effectiveness of health care delivery. This PhD project sits within this research and implementation theme; which aims to better understand the mechanisms that allow individuals to benefit from their social networks and links to community resources to support engagement with condition management; and in doing so, improving access to community resources. The current projects within this theme look at engagement with self-management support and social networks with a particular focus on offline social networks; examining the use of social network tools such as GENIE to assess, engage and link people into social activities and support as well as projects that are examining the self-management resources (and their effectiveness) of people with a long-term condition. These projects are supported by a body of research that demonstrate the social context of long-term condition self-management and more specifically, the role of others in shaping and supporting self-management practices (Rogers *et al.*, 2011; Vassilev *et al.*, 2011; Vassilev *et al.*, 2013; Reeves *et al.*, 2014).

It is understood that effective self-management support utilises resources and networks that are available in the everyday lives of those with a long-term condition, which operate outside of formal healthcare. Notions of 'work' have been used in previous research to describe activities associated with long-term condition illness management (Allen et al, 2016; Bury, 1982; Corbin and Strauss, 1985; Reeves et al, 2014; Rogers et al, 2011,2014; Vassilev et al, 2011, 2013) some examples of this 'illness work' as explored in the current literature are shown in **figure 1** below.

Figure 1: Types of illness work in the current literature

Illness (specific) work: work such as taking medication, taking and interpreting measurements, understanding condition and its symptoms and making appointments.

Everyday work: tasks such as housekeeping, occupational labour, support and activities relating to diet and exercise, shopping and personal care.

Emotional work: work related to comforting when worried/ anxious about everyday matters, such as health, well-being and companionship (including a biographical dimension relating to the reassessment of personal expectations, capabilities future plans, personal identity, relationships and biographical events).

Vassilev, I., et al., Social Networks, the 'Work' and Work Force of Chronic Illness Self-Management: A Survey Analysis of Personal Communities. PLOS ONE, 2013. 8 (4): p. 61-69.

Contingency/improvisation: the work involved in getting things back on track.

Translation/mediation: The work involved in translating abstract knowledge into practical knowledge that can be implemented.

Coordination: the negotiations and renegotiations in the ways in which work is done, such as what work is done by whom, when, how and why.

Advocacy work: work done by others on ones behalf.

Rogers, A., et al., Social networks, work and network-based resources for the management of long-term conditions: a framework and study protocol for developing self-care support. Implementation Science, 2011. 6 (56).

The proliferation of the internet and more specifically online communities in our daily lives, means that for many such systems of support may exist online (Allen et al, 2016). Such online resources may act to supplement or substitute traditional modalities of offline social support and it is important to understand its role and value within someone's whole configuration of illness support. The purpose of this research is therefore to extend our knowledge of the importance of social networks in long-term condition self-management support (illness work) to online communities and the social ties that are established and maintained online. This study will use a parallel mixed method approach, using separate approaches and data sources, to better illuminate the overall phenemena of long-term condition self-management support using both online and offline social network resources.

Background:

Stage 1 of this research involved a meta-synthesis of qualitative papers that examined the use of patient online communities in those with a long-term condition (Allen et al, 2016). The aim of this meta-synthesis was to understand the negotiation of long-term condition illness work in patient online communities and how such work may assist in the self-management of a long-term condition in daily life (Allen et al, 2016). The results of the meta-synthesis found that social ties forged online provide the basis for performing relevant self-management work that can improve an individual's illness experience and can be a particularly useful resource in tackling aspects of self-management that are particularly difficult to meet offline, the substitutability of online social ties for some illness work appeared to be particularly important for those experiencing dissonance in their existing offline support (Allen et al, 2016).

Whilst this stage was useful in framing the availability of support and the mechanisms for which such support can be realised online for those with a long-term condition, the papers included in the meta-synthesis did not explore online self-management support in the context of pre-existing offline social networks; often using approaches such as netnography (Kozinets, 2013) that did not directly engage people using these resources; therefore not exposing the context within which they are used.

In the context of health, it is important to understand the integration of online worlds into the everyday lives of the people who use these communities as a resource for self-management; including the nature of the relationships and their power to facilitate self-management practices in those with a long-term condition, using both online and offline ties (including those that are known both online and offline). Previous research looking at online communities has too often focussed exclusively on online support; rather than examining it in the context of someone's total overall configuration of support. Such research has failed to illustrate the context within which these online resources are used and embedded; and as a result, less is known about how those with a long-term condition decide to negotiate certain aspects of illness work both online and offline, or how different situations (such as a new diagnosis, a change in treatment, or a flare up of a condition) may result in re-negotiating online/offline relationships. Understanding how people decide whether to seek self-management support online or offline is important, specifically in understanding the nature of the support they negotiate both online and offline and how periods of illness relate to this; which is potentially important in understanding the resources that are needed in different situations.

This research therefore fills a relevant gap in the literature, through its aim to explore the negotiation of support online in the context of pre-existing offline support, whilst also aiming to understand how someone's offline support and resources may influence their use of the internet for long-term condition self-management. The use of a parallel mixed methods design is indicated in this instance, because it allows the research to examine the phenomena's context through the collection of qualitative data providing levels of richness, depth and profundity that would otherwise be unavailable in a study just using exclusively quantitative methods. It also allows us an 'insider view' of participant's social networks as experienced by them, including the process of how they make decisions about who to turn to for support in different contexts and circumstances; which can only be realised through an in-depth exploration of their experiences.

Whilst this 'insider view' is useful in understanding the context within which online support is realised, it is also clearly important to understand the factors that relate to the use of online resources; such as: the association of ego, alter and network factors, as well as the availability and quality of offline illness work. This will be determined using quantitative secondary analysis. Through this, we can better understand the factors that may shape someone's use of the internet as a resource for self-management beyond what is known from previous research that has looked at the association of socio-demographic characteristics on the use of the internet to manage a condition (Pfeil et al., 2009; Correa et al., 2010; kontos et al., 2010; McAndrew and Jeong, 2012; De Cock et al., 2014; Haight et al., 2014). Whilst the existing research has demonstrated the importance of socio-demographic characteristics on internet use, it is clear that factors beyond socio-demographic characteristics, such as who we are connected with and the support we receive (both good and bad) in managing illness, may influence decisions to use the internet for illness management.

By looking at how people make sense of the resources available to them from their online and offline social networks and by looking at the network factors that may influence the use of the internet to self-manage a condition (such as the availability of support offline), this research will fill a relevant gap in the current literature. Such knowledge is particularly relevant for informing the development of online interventions that are useful to people; as well as giving us a better understanding of the relative importance of such technologies in the overall system of self-management support. Furthermore, it is expected that this research will better explain why some make use of online resources, whilst others do not; thus potentially addressing issues of inequality that may prevent some making use of resources that could improve their illness experience- potentially allowing future interventions to be targeted to more specific areas of need.

This parallel mixed methods stage of the research will use 2 stages; **stages 2** will use qualitative semi-structured interviews and a heuristic concentric circle mapping exercise to examine peoples experience with online and offline networks of support and **stage 3** will involve a secondary analysis of data from the Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (UNET) research project to look at the factors that contribute to the use of the internet for long-term condition self-management.

Research Question

Stage 1: Meta-synthesis of qualitative papers

To understand the negotiation of long-term condition illness work in patient online communities and how such work may assist the self-management of long-term conditions in daily life.

Stage 2: Qualitative Interviews and concentric circle exercise of peoples experience with online and offline networks of support.

What is the context and circumstances of engagement with patient online communities in those who use them to aid the self-management of a long-term condition and how do people perceive the support that is available in the context of their overall social network?

Objectives:

I. To identify the context and circumstances of engagement with online communities for health and illness.
II. To understand how people access and use online communities for support in relation to different situations, over time and in combination with offline engagement.
III. To understand the role and value placed on online communities for long-term condition management within the context of peoples whole configuration of social networks (personal communities and offline social ties)

Stage 3: Secondary analysis of data from the Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (UNET) research project.

What are the network level, network member and individual level factors that are associated with using the internet for long-term condition self-management?

Objectives:

IV. To describe the individual and network characteristics of people who use the internet for long-term condition self-management.
V. To explore the role of offline network support (illness, emotional and pratical) and network type (e.g. diverse, family, restricted) on the use of the internet for long-term condition management.

Method

Stage 1: Qualitative meta-synthesis (completed)

A systematic search of qualitative papers was undertaken using various online databases for articles published since 2004. A total number of 21 papers met the inclusion criteria of using qualitative methods and examining the use of peer-led online communities for those with a long-term condition. A qualititative meta-synthesis was then under-taken and the review followed a line of argument synthesis.

Stages 2 and 3 are to be completed in parallel using different data sources, to give a view of the overall phenomena of network support.

Stage 2: Qualitative Interviews and concentric circle exercise of peoples experience with online and offline networks of support.

Semi-structured interviews will be used, including a concentric circle exercise which will be used as a heuristic device to facilitate a more open discussion about the context and circumstances on online engagement and the support available in participants personal communities, as well as the importance of specific network members in supporting long-term condition self-management, specifically with regards to the roles and responsibilities of network members towards long-term condition illness work. The interview schedule can be seen in the protocol in **appendix 1.**

The semi-structure interviews will provide a series of open ended questions based on the phenomena being examined. The open ended nature of these questions provide opportunity for exploration of interesting themes as they emerge in the course of the interview. Thus it is anticipated that this method will give the researcher freedom to probe the interviewee to elaborate or to follow a new line of inquiry, which may be introduced by the respondent’s answers. The use of semi-structured interviews in this stage of the research allows for further elaboration of the meaning and contribution of relationships within an individual’s network, as well as the nature of the context and content of the illness work that they undertake, considering the support that is available in the entire configuration of social support.

Stage 3: Secondary analysis of data from the Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (UNET) research project.

This aspect of the study will make use of data collected during the Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (UNET) research project.

This dataset contains rich data on the participant's social network and the availability of illness work in their personal network, which will be useful in better understanding the extent to which ego, alter and network characteristics, as well as the availability of illness work (both positive and negative) influence the use of the internet to self-manage a long-term condition.

The participants of this study will be split into three distinct groups using the data collected during the UNET interviews and postal questionnaires about their use of the internet. These groups are as follows:

A) Don't use the internet.
B) Use the internet, but not for managing their condition.
C) Use the internet to help them manage their condition.

Materials

Stage 2: Qualitative Interviews and concentric circle exercise of people experience with online and offline networks of support.

The semi-structured interview schedule and concentric circle mapping exercise is shown in **appendix 1.**

Stage 3: Secondary analysis of data from the Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (UNET) research project.

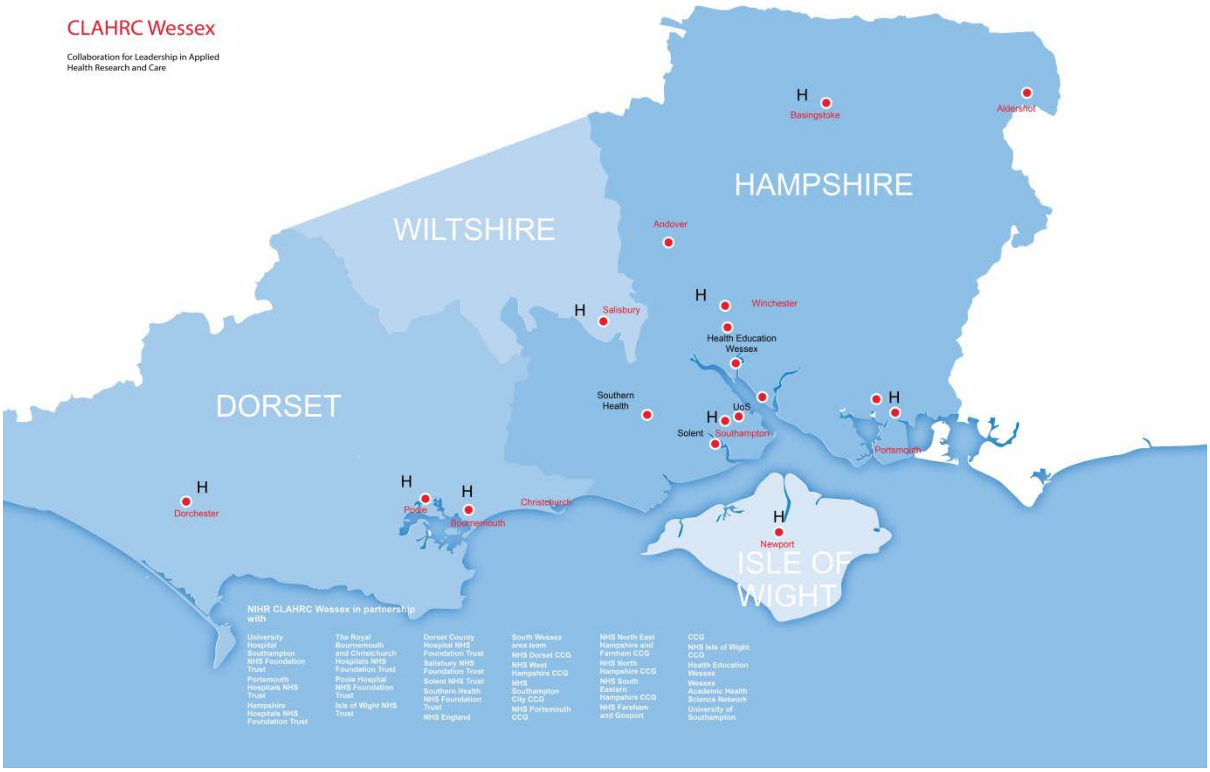
The secondary data was derived using a postal questionnaire and face-to-face interviews using a name generator; which asked participants to identify network members which were important to them in the management of their condition. Further quantitative information was then collected about the characteristics of the network members which were identified.

Participants

Stage 2: Qualitative Interviews and concentric circle exercise of peoples experience with online and offline networks of support.

The study population for the qualitative semi-structured interviews will be people living in the Wessex region (which can be seen in **figure 2** below), who use online communities (on any platform) to support long-term condition self-management. For the purposes of this research, we use the Department of Health’s (2010) definition of a long-term condition, being any condition which cannot, at present be cured; but can be controlled by medication and other therapies. The sampling strategy is broad; and uses convenience, maximum variation, purposeful, snowball and self-selection sampling techniques.

Figure 2: Sample population of Wessex region



The sample frame is the Wessex region, which sits in the South of England. The region is a convenient (convenience sampling) to the location of the University, allowing the sample to be easily reached. The sample frame contains a diverse population, the area contains: larger clinical commissioning groups (CCG's) with older populations and more rural areas, areas with lower deprivation and better health, smaller CCG's with older populations and more rural areas, areas with younger adults and university cities. The area also contains CCG's of high and low Index of Multiple Deprivation (IMD) scores, and numbers of over 60's above and below the national average.

In addition, people with any long-term condition (as supposed to a specific condition; such as Diabetes) can potentially be a participant in the study. It is therefore anticipated that the variation in participant's condition will be diverse, and will project different illness experiences that will illuminate the many different motivations and perceptions of online community use, the value placed on them, and the context within which it is used. It is also expected that there will be considerable variability in the perceived importance of online resources for condition management, and the extent to which these technologies are embedded in the daily lives of the participants. Because the sample is expected to be made up of people with different socio-demographic characteristics and different long-term conditions, the sample is expected to have a wide range of variation on the dimension that is being explored.

The intention is to purposefully sample 30 adults (or until data saturation is achieved) who use online communities (on any platform) for support in the self-management of their long-term condition in daily life. In order to best understand the phenomena of online communities in long-term condition self-management, we will purposely sample people with a variety of long-term conditions and with different amounts of time since diagnosis, which will offer a variety of illness experiences in the sample. Whilst some elements for purposeful sampling can be identified pre- interviews (such as a range of conditions, time since diagnosis, age etc) they will also be identified from the responses that we get in an iterative process. Through this iterative process, the nature of the purposeful sampling will change as new ideas or theories emerge around the use of on and offline social networks and so will, as with other qualitative research change and take shape as part of this iterative process. The iterative nature of theoretical sample design is essential to producing high quality data as it provides the opportunity to analyse the data as the sampling progresses and it is normative for the researcher to add to or to change the emphasis of the sample design so as to ensure robustness of the theories generated around off and online relationships. To ensure that this iterative and staggered process can take place, we will stagger the timing of interviews. However, it has been considered that there is an element of opportunistic sampling (those who respond are anticipated to have an interest in the topic and are likely to constituent key informants), especially given that the primary method of recruitment is through social media.

Because of the degree of variance in participants, and the breadth of the research aims and objectives, it is anticipated that around 30 participants will be needed to reach data saturation, a conceptual stopping point when no new themes emerge from the data. Recruitment to the research project will stop when 30 participants have participated, or sooner if data saturation has been achieved. Any participants who enquire about participating in this research after 30 people have been recruited, or before if data saturation has been achieved will receive a reply thanking them for their interest, but that the study is now closed.

The sample is also a self-selected sample as participants will opt-in to the study by contacting the research team by email after seeing information about the study through social media, through a poster, or after seeing a presentation at a local face-to-face support group. It is anticipated, that those participating in the research might tell their contacts about the study, and provided their contacts meet the inclusion criteria for the study and decide to contact the research team they can also be recruited, so there will also be an element of snowball/chain sampling.

In order to do this, several approaches to the identification of suitable participants that meet the inclusion criteria for the study will be used:

- Primarily recruitment will be through social media- with Twitter and Facebook accounts set up specifically for the purpose of this study. These accounts will promote the study and disseminate the study’s findings at a later date. To ensure posts are seen, both Twitter and Facebook accounts will post every 2 days. It is anticipated that the post will be shared by other accounts, including that of the PhD candidate, but postings will always originate from the accounts set up specifically for this research. In addition posts will also be made to known support groups- as well as groups that we become aware of on both platforms; this will be done once in the first instance, then again after a week, then every month after that for each group. This is to give all members of the group an opportunity to find out about the research, whilst at the same time giving new members the opportunity when they join the group at a later date. This frequency will however avoid being annoying, or inconvenient to members of the group who do not wish to participate, by minimising their exposure to the posts beyond what is necessary to give others the opportunity to participate. Examples of how the accounts are set up and how they will post are shown in **appendix 3**.

- Posters will also be displayed in the university, local libraries and community centres- approval will be sort to display in these areas prior to placing the poster. The poster will contain an email address through which more information can be requested and a research pack including invitation letter and participant information sheet can be sent.

- Attendance at local face-to-face support groups- local face-to-face support groups will be contacted to arrange attending a group to give a short presentation about the research. Attendees at the support groups will be given an email address that they can email for more information about the study, which they can email for further information and to request a research pack which will contact a invitation letter and a participant information sheet. Attendees at the group will be under no pressure to participate in the study, but are able to ask questions and can be provided with a research pack including a invite letter and a participant information sheet if they are interested. In this case they will need to be given at least 48hrs to read the participant information sheet and consider if they would like to be involved in the study. Once they have decided they would like to participate they will need to contact the PhD candidate on the email provided in the participant information sheet.

Stage 3: Secondary analysis of data from the Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (UNET) research project.

The participants of the original dataset were randomly sampled from the Diabetes and Deart Disease registers of 19 GP surgeries between April 2010 and January 2011. Invitation letters were sent from the surgeries, following this, participants interested in taking part in the research returned a reply slip, agreeing to be contacted by a researcher to arrange to take part in the study and to take consent.

These surgeries were mostly in deprived areas of Greater Manchester. The quantitative component of this study, which involved a face to face interview and postal questionnaire to collect the data, had 300 participants. The 300 participants of this study are older people who are chronically unwell people and reside in a deprived area. The participants of this study consented to their data being used for future analysis and the data is open for research purposes.

Procedure

Stage 2: Qualitative Interviews and concentric circle exercise of peoples experience with online and offline networks of support.

The study will predominantly be advertised through social media (Twitter and Facebook) accounts set up specifically for this research. To ensure posts are seen, both Twitter and Facebook accounts will post every 2 days. Samples of the post can be seen in **appendix 3**. Twitter posts are limited by the formats 140 character limit.

This will include a contact email which people can use to express an interest in participating in the study. In addition to social media, posters will also be displayed in libraries and in university buildings, but only after specific approval, prior to placement. The poster, which can be seen in **appendix 2** will also have an email contact, that those who are interested in participating can contact to request a research pack. Additionally, the email address will be provided at face-to-face groups when explaining the research, people interested in taking part can again email to request a research pack.

Once people have expressed an interest about participating in the study, provided they meet the inclusion criteria, they will be provided a research park, which will include the Letter of Invitation and Participant Information Sheet; this will be sent by email to the participant.

The participant will be given sufficient time (at least 48hrs) to read through all the written information to consider whether they would like to participate. Participants who then wish to take part in the study or find out further information, will be prompted to, through the Patient Information Sheet, contact the PhD candidate through email. The researcher will then contact (ideally by telephone- but by email if no number is provided- followed by telephone) the potential participants who have emailed, answer any questions they may have and if the person is happy to take part in the study, a convenient location and date will be arranged. Ideally, interviews will take place in participant's homes or at a place which is convenient to them to reduce response burden. However, if participants prefer, they can be completed at the university, at which point travel costs will be met provided they are travelling from within the Wessex region.

On the date of the interview, the participant will have a further opportunity to ask any questions before the researcher takes fully informed consent, prior to starting the semi-structured interview. The researcher will clarify with the potential participant that there is no obligation to participate in the research and that they will remain free to withdraw from the study at anytime.

Following fully informed and valid consent, participants undertaking the study will complete a short face-to-face semi-structured interview, which will involve a heuristic concentric circle mapping exercise. The whole interview will take approximately 1 hour and will be recorded, which will be specified in the Patient Information Sheet and will be clarified at the time of giving consent and on commencing the interview. The whole interview will be audio recorded.

The interview schedule to be used is attached as an **appendix 1** to this protocol. The interviews are however semi-structured in nature, so the interviews will typically involve extra probes in response to the participants answers. As part of the semi-structured interview, the concentric circle diagram will be used as a heuristic device to help participants identify people, groups, or service providers (network members) (both online and offline) who they consider to be important to them in the management of their condition. Participants will then be asked to place the most important people, groups, or service providers in the inner most circle of the diagram, the less important (compared to the first group) in the next (middle) circle and those who are important, but less than the other two groups in the out most circle of the diagram. They will then be asked why they put certain people or groups in each of the circles, and the value of each network member of specific types of support.

Following this, some quantitative socio-demographic and health data will be collected, participants may have already given answers to some of the questions in the qualitative interview and if this is the case, these specific questions will not be repeated. This data is being collected to demonstrate the characteristics of the sample, and will not be quantitatively analysed.

After the interview, the researcher will check that the participant is happy for everything that they have said to be included in the analysis. The researcher will also leave details with the participant about access to follow up or support if this is needed.

Once the interview is over, the participant will be asked if they would like to see the final report and feedback any comments, this is voluntary and they are under no obligation to do so.

Data analysis

Stage 2: Qualitative Interviews and concentric circle exercise of peoples experience with online and offline networks of support.

Following the recorded qualitative interviews, the interviews will be transcribed by the PhD candidate and will be coded using Computer Assisted Qualitative Data Analysis Software (CAQDAS) such as NVIVO.

Data analysis for the qualitative component will be through qualitative thematic analysis. From the data collected, the researcher will look for emergent themes relating to how people navigate and negotiate the support that is available both online and offline and how periods of illness are related to who they turn too for specific type of support.

Stage 3: Secondary analysis of data from the Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (UNET) research project.

From this, data analysis will initially involve describing the groups on three levels.

A) Individual (ego) (socio-economic status, gender, number of conditions, ethnicity)
B) Network member level (alter) (e.g. type of relationship, gender, frequency of contact, distance)
C) Network structural level (e.g. network size, density, overall amount of network support, availability of illness work within the network (both positive and negative)

Univariate analysis will be used to look for statistically significant associations and following this the dataset will be split into two distinct groups: those who do not use the internet to manage their condition, and those who use the internet to help them manage their condition. This will be followed by multivariate analysis, using logistical regression to examine the statistical outcome of more than one variable at a time.

Ethical issues

In social research, ethics is defined as a matter of principled sensitivity to the rights of others (Gilbert, 2013). Care has been taken to safeguard the participants of the study from harm. The measures and safeguards put in place will be discussed here, and are based around the ethical principles of autonomy (a person has the right to make choices, they should be able to make and informed decision about what happens to them), beneficence (to do good), non-maleficence (an obligation to not inflict harm intentionally) and justice (distributive justice- equitable distribution of resources, rights based justice- respect for peoples rights, and legal justice- respect for morally acceptable laws) (Gillon, 1994). The issues below have been identified as most pertinent to this study.

Stage 2: Qualitative Interviews and concentric circle exercise of peoples experience with online and offline networks of support.

Consent: The participant will have access to detailed written information and will have a clear verbal explanation of the study. The participants will be made aware of the purpose and scope of the study, the type of questions that they are likely to be asked, what will be done with the results, and how their data will be anonymised and kept confidentially. The participant will have the opportunity to ask questions and have these answered satisfactorily.

The participant will be given time (at least 48hrs) to read all the information, ask questions and have them answered satisfactorily and consider whether they would like to participate, before consent to join the study can be completed. Consent will be completed and witnessed by the researcher before the interview commences. All participation is voluntary and participants will be able to withdraw at any time, without reason and will not be affected in anyway by their decision to do so.

The consent form will also ask participants if they are happy for their data to be retained and used for future research. They are under no obligation to do this and this will be explained prior to giving consent.

Support for participants: Because qualitative research aims at an in-depth understanding of a phenomena, the methods of data collection are often designed to be probeing in nature (Richards and Schwartz, 2002).

It is appreciated that talking about experiences of managing a long-term condition might not always be comfortable for the participants. There is a potential that some participants undertaking the interviews may feel upset when talking about how they self-manage their condition or about their personal networks of support. It is important to note that the upsetting questions cannot always be predicted, because they will often be dependent on the personal biographies and experiences of each individual participant, which will not be known to the researcher prior to conducting the interview (Richards and Schwartz, 2002).

However, every effort will be made to support participants during the interview. Prior to the interview participants will be encouraged to identify a supportive friend or family member to be available to them after the interview. Participants will also be signposted to the services offered by The Samaritans, who can be contacted should they experience distress after the interview and feel they cannot talk to their nominated contact.

Should a participant feel uncomfortable or distressed during the interview there is the opportunity to move onto a different question, take a break in the interview, or terminate the interview altogether- patients are advised this in the participant information sheet and will be reminded prior to starting the interview.

Inconvenience and opportunity cost: The inconvenience and opportunity cost associated with participation in qualitative research is often underestimated (Richards and Schwartz, 2002). As discussed this stage of the research will involve a interview which will last approximately 1 hour. To reduce the response burden to participants, these will normally be held in their homes or a place that is convenient to them, but this will still involve the participant being willing to allow a researcher in their home. In order to compensate people for their time and to thank participants for participating in the research, each participant will be given a £10 Amazon voucher on completion of the interview.

Support for researcher: The PhD candidate will have regular supervision with three academic supervisors (who all have extensive research experience in this research area) will be provided during this time. As an employee at the University Hospitals Southampton NHS Foundation Trust I also have access to the employee assistance service and counselling services through my professional union membership (Royal College of Nursing (RCN)).

Safety: University of Southampton, Faculty of Health Sciences lone interviewing policy will be followed when interviewing participants in their homes or in the public. This includes interviewing in daylight, carrying a charged mobile phone and notifying the and candidate notifying their academic supervisors of their whereabouts prior to visits. An agreed person within the NIHR CLAHRC Wessex will be phoned on the completion of the interview to report that the PhD candidate is safe; but this will not be in the presence of the participant. If the call is not received and the PhD candidate cannot be contacted within 3 hours, the police will be notified.

Data protection and anonymity: Participants will be guaranteed linked anonymity. This means that although all participants are linked to their data in the first instance, the data will be coded so that participants and members of their support network cannot be identified. All data that is collected will be anonymised. All participants will be given a unique ID for all generated data from the interviews- this will be saved on the J drive where we store data for all of the studies in the patient work theme. Signed consent forms and contact details will be stored in a separate locked filling cabinet in Professor Anne Kennedy's office. As such the consent forms and the contact details which contain personal identifiable information (linked data) will be kept separate from the anonymised interview data. This will be made clear to participants in the Participant Information Sheet.

All data that is collected will be anonymised and will remain confidential, in compliance with the Data Protection Act (1998) and the University of Southampton's Data Management Policy.

All data will be held on a secure, password protected computer that only the PhD candidate (CA) will have access to, in line with the data protection policy of the University of Southampton and in accordance with the data protection act (1998).

This will initially be stored on a password protected laptop- but will be backed up and stored on a desktop on the UOS network, where it will be saved on the J drive where we store the data from all the studies in the patient work theme.

Once the study is closed, data will be retained for 10 years as per the University of Southamptons research data management policy. Hard copies of consent forms and contact details will be retained in a locked filling cabinet in Professor Kennedy's office. Data will be stored on the J drive. The data will however not be available for future analysis.

Stage 3: Secondary analysis of data from the Understanding Networks of Care and Information Needs of People with Diabetes, Heart Disease and Kidney Disease (UNET) research project.

The initial study had full ethical approval from Greater Manchester Research Ethics Committee in February 2010 (ref:10/H1008/1)(Vassilev et al, 2013; Reeves et al, 2014; Forbes et al, 2016).

The participants of this study consented to their data being used for future analysis and the data is open for research purposes. All the participants' identities are confidential, and each participant has a unique participant identification number, rather than their name being attached to the data.

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Appendix 1: Qualitative Interview Schedule

Information to the interviewee about the interview (notes in red are prompts for the interviewer, this is not an exhaustive list and is for reference only- it is expected that additional probes will be given in response to the participants answers)

We are interested in the lives of people with a long-term condition and particularly their experiences of support for their condition using both online and offline contacts.

Thank you for taking part in this research. There are three parts to this interview.

The first part starts out with a few broad questions about your condition and how you use the internet for support. The intention with these questions is to make you talk freely about how you use online communities to help you manage your condition.

The second part looks at the support that you have available in both your online and your offline networks. In this stage we will complete a diagram to illustrate who helps you, who you turn to for help, what they help you with, and how that impacts on your condition. We will also look at how this has changed over time, and how it changes when things are going well, and when things are not going so well.

The final part we will look at how the internet and online communities fit into your daily life; and how having access to the internet has shaped your overall social network and the support that is available to you. We will also run through a typical day, looking at how, when and why you use the internet during the day when things are going well, as well as when things are not going well.

I would like to use a recorder if that is OK with you? If you feel upset at anytime, please let me know. We can take a break, skip the question or if you need to, we can stop the interview altogether.

Do you have any questions before we start?

Experience of long-term condition at diagnosis and first experiences of using online communities to support long-term condition self-management in daily life

This section will ask some broad questions about your condition, how you manage it and where the internet and online communities fits into your overall management strategy. Please take all the time you need. I will listen to all you say and will take some notes to be able to ask you later to elaborate of clarify some details concerning your experiences. I would like you to feel that you can speak freely, with minimal interuptions from me. If you are ready, we will begin.

1	I would like to start by talking generally about your health and your condition. How does your condition affect you? What different about your life from someone who does not have this condition? What are the most challenging aspects of managing your condition in daily life? What role does the internet have in meeting these specific challenges (if it does).
2	Looking back, (if you can remember) could you please tell me about the first time you connected with others online to help you manage your condition and what was your motivation for connecting with these people? (How was your management of your condition at this time? Did anyone support you with this?)
2	Initially, who were the people you spoke to online? (Were they mostly people known to you already offline or did you try to connect with new people with similar experiences? - if so, why was this important?) (additional probe if they have never interacted, but only followed conversations as to why and what might prompt them to be more interactive).
3	Why do you think you choose to speak to these people? Why was this important to you at this stage in your illness? (additional probe depending on response- if mostly people already known- why? did they have a good understanding of the condition- or have the condition themselves?, why did you choose to speak to them online vs offline; if not known already offline- why was this important?- was it important to not be known etc.)
4	How was your first experience of using these online communities for this and what was the initial impact on your life and more specifically your ability to

	manage your condition? (What was your experience like of managing your condition at the time and how did this change once you started using online communities; did anyone support you with this?)
5	What do you see are the main points in change of how you manage your condition since using online communities? Does it help you, how important is it to managing your condition when things are going well? Does it become more or less important when things are not going so well?
6	I'm interested in understanding how communicating with people on the internet (both people you know offline and people you only know online) helps you manage your condition. What specific aspects of managing your condition does this make easier and how does it compare to the support that you receive offline?

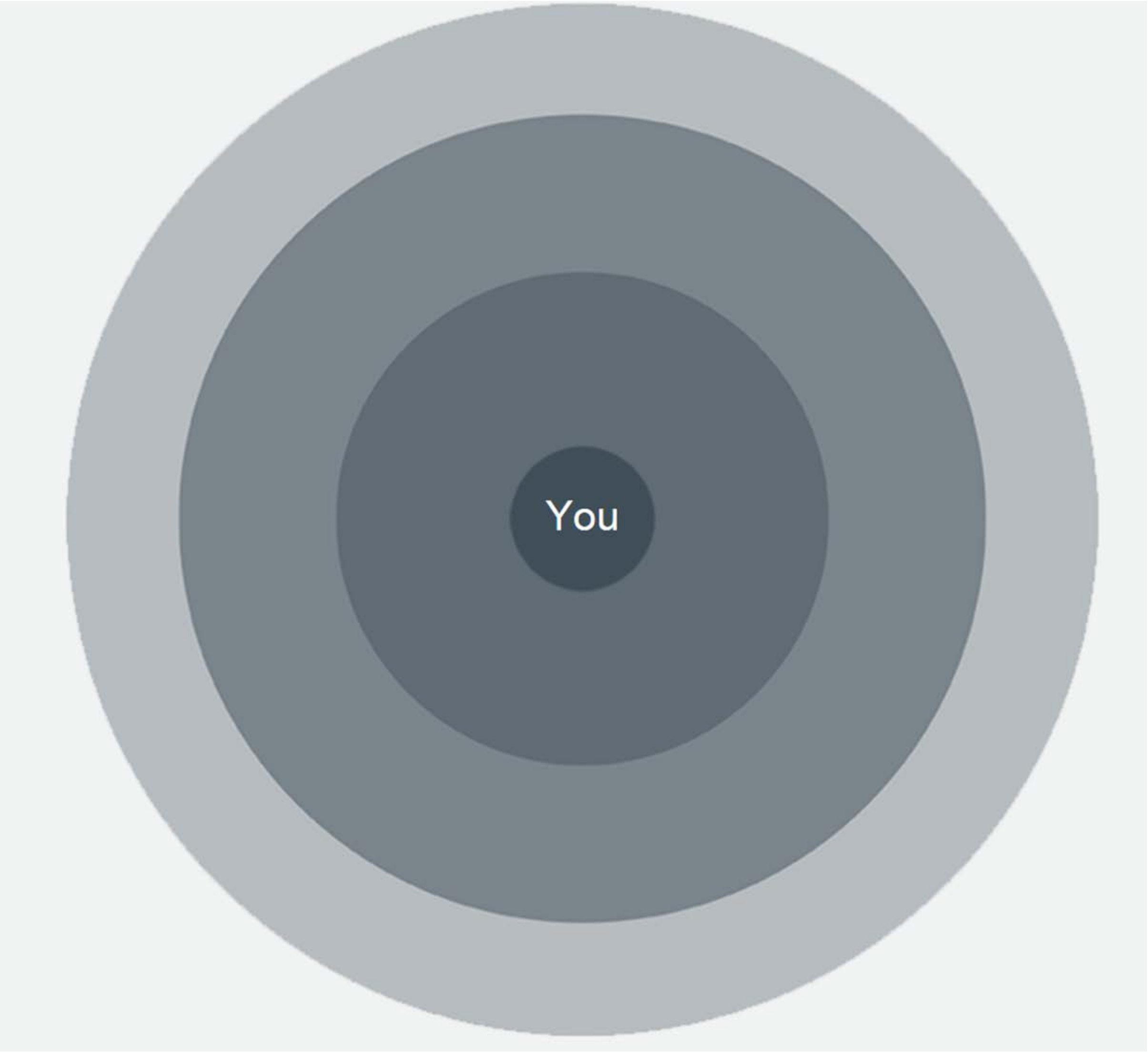
Types of work and involvement of different network members, the personal communities' network diagram.

Present experience of long-term condition self-management, and experiences of using online communities to support long-term condition self-management

I would now like us to discuss your present day situation. I'm interested in understanding the support you get to help you self-manage your illness both online and offline. I'm interested in understanding a bit more about how you use the internet (and specifically online communities) and about how that fits in with your overall network of support (both formal- such as health care professionals, and informal- such as friends and family) to help you manage your condition. I am interested in who you get help from, for what, and how you make decisions about to turn to for specific types of support. I am also interested understanding how this might change over time, when you face different situations. I am hoping we can talk about this in some greater detail.

Show the interviewee the circle diagram:

When it comes to handling your condition, we are interested in finding out about the importance of different types of support. The circle diagram is made to visualise what persons you think are important to you in managing your health situation and illness, this can include contacts or groups you know online and offline (as well as those that are known both online and offline) if you feel they are important to you in managing your condition.



You can see the diagram that you are in the middle of the circle. First, we are going to talk about when things are going well. We are going to think about people who are important to you, such as friends, family, and anyone at all who is really important to the management of your condition, they will be written in the centre of the circle.

After this, we will write anyone who is still important to you in managing your condition, but a bit less so in the next circle along, and then anyone who is a bit less important than that, will go in the next circle along.

There is a list of examples of people that you may find important to you in the table below, this is just an example, and you can write people or groups that are not shown in the table.

Let us start with whoever is most important for you in managing your condition.

<u>Types of Support</u>

Relationships	Spouse/Partner Son/Daughter Grandchildren Mother/Father Brothers/Sisters Relatives Friends (types of friends, be specific) Online friends Acquaintances Online acquaintances Accidental acquaintances with similar problems Pets Neighbours Colleagues/ University friends/ Classmates
Groups	Support group Lunch/Tea club Internet communities and social media (please be specific) Religious group Ethnic group Sports groups
Alternative medical	Traditional healers (faith healers, spiritualists, herbalists)
Non-medical professionals	Social workers

	Legal agents (police, lawyers) Religious or spiritual leaders Supervisors (bosses, teachers) Carers Volunteer (individuals)
Modern medical	GP Nurse Specialists Pharmacist

While filling in the diagram the interviewer should stimulate the interview to elaborate on:

- Why is the person in this circle and not in the other one? Why are both these people in the same circle? What is similar or different between them?

- What are the sorts of things you would never ask this person to do? Why? Who could/would you ask to do these sorts of things (e.g. related to practical tasks, illness related, emotional?) Why?

- Were there other people in your diagram in the past? How has this changed over time? Has the role of the people changed over time? How? Why?

How does your network change over time?

Looking at this diagram and thinking about the time when you were first diagnosed with this condition, and up to a year after diagnosis, can you tell me in what ways was this diagram different? Can you tell me:

Q1. First, who among these people/groups/services that are currently on the diagram were:

A) More important than they are at present? Why is this?

B) Less important than they are at present? Why is this?
C) Remain the same? Why is this?

Q2. How does the position of people on this diagram change when things are not going quite so well, who among these people/groups/services that are currently on the diagram do you feel become:

A) More important than they are at present? Why is this?
B) Less important than they are at present? Why is this?
C) Remain the same? Why is this?

(For those who become more important when things are not going so well, the participant is instructed to draw an arrow going towards the area of the circle where the person would be, as with those who would become less important, but with the arrow facing the other direction).

Who supports you with what in your network?

I would like to discuss the specific types of support that you get from people in your network, how you decide who to reach out to for help, what type of help this is, and the reasons behind why you use this person or group vs using other people in your network.

(Note to researcher: some of the items may be repeating areas discussed in the last section, if this is the case, these questions should not be asked again)

1	I'd like to know a bit more about how you get information relating to your condition. Can you please tell me where or who you go to find out more about your illness? Is this typically online or offline, or a mixture of online and offline contacts? (I'm interested to know why you go to that person for this- as supposed to other people on your diagram who you wouldn't do to- can you please give examples.)

	(if they are giving mostly online contacts- why is this? Is there someone available offline who they could turn to if they needed to get information? - if so what factors stop them from using these people in their offline networks?- can they give examples as to why they prefer using these online contacts?) (if they ask for information online how do they do this- is it directed at the group or board as a whole- or do they ask a specific person who they think might know the answer) (Are there circumstances where you would look for information from people online vs people you know offline? Are there circumstances where you would ask for information offline, and not online? - what factors are important in determining this). (Are there issues of access, i.e. is this person always available- who would you turn to if they were not available and you needed the information before they would be available? Does this have an impact on who you turn to at certain times of the day, or in certain circumstances?)

2	When you need advice about, or help with, medications or a specific aspect of self-management, who would you turn to? Is this typically online or offline, or a mixture of online and offline contacts? (Note for the interviewer- this can included: noticing or managing symptoms, help/advice about performing difficult, inconvenient and painful tests, being prescribed new medication and wanting to find out advise, wanting to try out a new self-management strategy- and wanting advise from people who have done the same- have specific experience with doing this) (I'm interested to know why you go to that person for this- as supposed to the other people on your diagram, can you please give examples.) (if they are giving mostly online contacts- why is this? Is there someone available offline who they could turn to if they needed to get information? - if so what factors stop them from using there people in their offline networks?- can they give examples as to why they prefer using these online contacts?) (if they ask for information online how do they do this- is it directed at the group or board as a whole (economy of effort- resource mobilisation)- or do they ask a specific person who they think might know the answer) (Are there circumstances where you would look for information from people online vs people you know offline? Are there circumstances where you would ask for information offline, and not online? - what factors are important in determining this).
4	Which people or groups on your diagram can you speak to/find out information about sensitive aspects relating to your condition? Why do you think you can speak to them about these aspects, but not to the other people on your diagram?

	(Im interested to know why you go to that person for this- as supposed to the other people on your diagram, can you please give examples.) (if they are giving mostly online contacts- why is this? Is there someone available offline who they could turn to if they needed to get information? - if so what factors stop them from using there people in their offline networks? - can they give examples as to why they prefer using these online contacts?) (Are there circumstances where you would look for information from people online vs people you know offline? Are there circumstances where you would ask for information offline, and not online? - what factors are important in determining this).
3	Is there anyone on your diagram who might be able to help explain something to you that you do not understand, such as medical terminology, units of measurement, how to do something? Are there people in your diagram who can help you find information if they do not have it themselves? (I'm interested to know why you go to that person for this- as supposed to other people in your diagram, can you please give examples.) (if they are giving mostly online contacts- why is this? Is there someone available offline who they could turn to if they needed to get information? - if so what factors stop them from using there people in their offline networks?- can they give examples as to why they prefer using these online contacts?) (if they ask for information online how do they do this- is it directed at the group or board as a whole (economy of effort- resource mobilisation)- or do they ask a specific person who they think might know the answer) (Are there circumstances where you would look for information from people online vs people you know offline? Are there circumstances where you would

	ask for information offline, and not online? - what factors are important in determining this).
4	Who in your diagram helps you with practical everyday work, that is not necessarily related to managing your condition, but might be made difficult due to being unwell. These can involve mundane tasks and activities that when we are well we can take for granted, however those living with a long-term condition, may not be able to do these things all the time, particularly when things are not going so well. These tasks might include housekeeping, shopping and personal care. (I'm interested to know why you go to that person for this- can you please give examples.) (Why do you turn to them instead of the other people on your diagram, how do they help, what specific support do they provide?)
4	Where would you go, or who would you go to, for advice or help with relieving stress? Or if you are worried about your condition? Is this typically online or offline, or a mixture of online and offline contacts? (why do you turn to them instead of the other people on your diagram, how do they help, what support do they provide?) (I'm interested to know why you go to that person or group for this- can you please give examples) (if they are giving mostly online contacts- why is this? Is there someone available offline who they could turn to if they feel low? - if so what factors stop them from using these people in their offline networks?) (If they look for

	emotional support online- how do they normally get it- is it through a post to the group as a whole- or to a specific person etc.?)
5	Who or what in your diagram gives you emotional support and encouragement? Can you think of examples? Are they mostly online or offline contacts? (How does this affect the management of your condition?) (why do you turn to them instead of the other people on your diagram, how do they help, what support do they provide?) (I'm interested to know why you go to that person or group for this- can you please give examples) (if they are giving mostly online contacts- why is this? Is there someone available offline who they could turn to if they feel low? - if so what factors stop them from using these people in their offline networks?) (If they look for emotional support online- how do they normally get it- is it through a post to the group as a whole- or to a specific person etc.?)
6	Who in your diagram would step in/ stand up for you when you do not feel well enough to stand up for yourself? [Note to interviewer: Sometimes people around you may not understand how you feel due to your condition and you may not always feel comfortable explaining and defending yourself.]
8	Looking at your diagram who do you think you would like to be more involved in helping you with your illness than they are at present? (What factors prevent them from being more involved? - why do you think this is?- does this affect who you turn to for support?)
9	What and who helps or hinders your care (related to diet/exercise/medication)? Can you think of examples?

	Are there people in your diagram who make it difficult to manage your health? (Why do you think this is? Have you found any strategies for overcoming this?- Do you think they have difficulty understanding your condition? Do they encourage behaviours which are not good for your condition? Does this person upset you?)

Mobilisation of online and offline support

I'm interested in understanding a bit more about where the internet (and specifically online communities) fit into your daily support in different situations.

1	What role does the internet have in helping you strengthen and possibly maintain relationships that you already have offline? Could you please tell me a bit more about how you use the internet to reach out to people that you already know offline? (Does it help you stay in touch with people when your condition may make this difficult to?- does it help ask many for support- in a way that is more efficient than asking for help offline? Does it have a role in allowing you to keep in contact with people throughout the day?) (how important are online communities in helping you remain socially engaged when things are not going so well?
2	How do you use the internet and specifically online communities to help you manage your condition on a daily basis, when things are going well? (It might be best if we start at the beginning of your day and then ask you to reflect on the moments during the day that you would typically speak to people online, this can be people you know offline too, such as friends and family).
3	Can you please tell me if you think this typical day changes when things aren't going so well, such as when you are struggling to manage your condition (coping with symptoms, starting a new treatment, receiving bad news, a new diagnosis etc).

Socio-demographic data

Fill in an tick off but NB: some questions may have been answered in the interview and should not be asked again.

1. Are you:

Male	Female
☐	☐

2. What is your date of birth?

Please write here……………………

3. What is your marital status?

Never married or formed a civil partnership	Married or in a civil partnership	Separated	Divorced	Widowed
☐	☐	☐	☐	☐

4. Which ethnic group do you consider you belong to?

- **White**

British	☐
Irish	☐
Other white background Please specify	

- **Black or Black British**
-

Caribbean	☐
African	☐
Other black background Please specify	

- **Asian or Asian British**
-

Indian	☐
Pakistani	☐

Bangladeshi	☐
Other Asian background Please specify	

- **Chinese or other ethnic group**
-

Chinese	☐
Other ethnic background Please specify	

- **Mixed**
-

White and Black Caribbean	☐
White and Black African	☐
White and Asian	☐
Other mixed background Please specify	

5. Which of these qualifications do you have? Please tick all that apply

1 or more O levels/CSE/GCSE (any grade)	☐
1 of more A levels or AS levels	☐
Degree	☐
NVQ	☐
Other trade qualification	☐
A Professional qualification	☐
No qualifications	☐

Your neighbourhood

1. Please provide the first four characters of your postcode

………………………………..

Your work

1. Which of these best describes your current work situation?

	You
In paid work (full or part-time, including self-employed)	☐
Retired from paid work	☐
In full time education or training	☐
Voluntary work	☐
Looking after home/ family	☐
Long-term sick/ disabled	☐
None of the above	☐

2. The average income in the UK is £26,500. How would you describe your income?

Lower	Average	Higher
☐	☐	☐

Your health and day-to-day activities

1. What is your main long-term condition?

………………………………………………………………………………….

Appendix 2: Poster to be displayed in universities, libraries and community centres in region- with permission to post.

UNIVERSITY OF Southampton

CLAHRC Wessex

Do you have a long-term condition and use online communities to

We would like to find out about how people who live in Hampshire, Wiltshire or Dorset and who have a long-term condition use online communities for help and support.

If you are interested in finding out more about this study please contact Chris Allen at the University of Southampton.

Email : ca2v07@soton.ac.uk

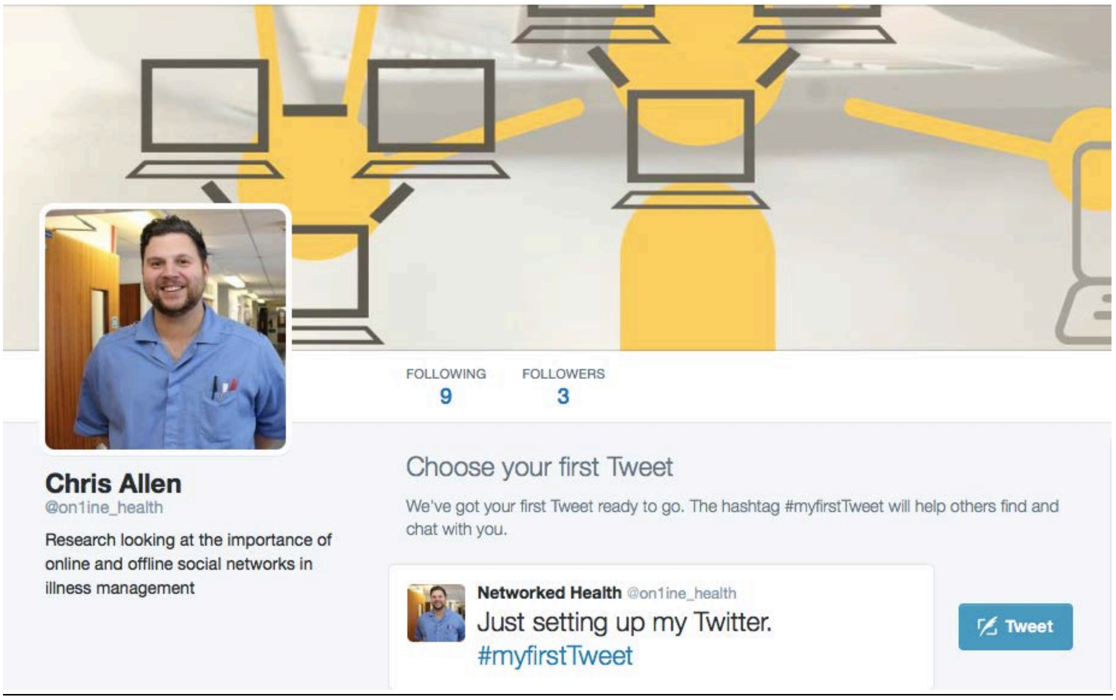
ca2v07@soton.ac.uk	ca2v07@soton.ac.uk	ca2v07@soton.ac.uk	ca2v07@soton.ac.uk	ca2v07@soton.ac.uk	ca2v07@soton.ac.uk	ca2v07@soton.ac.uk	ca2v07@soton.ac.uk	ca2v07@soton.ac.uk

Appendix 3: Sample posts on Facebook and Twitter accounts set up specifically for promotion of this research

Both accounts will post every 2 days, postings can be shared by other accounts. It is anticipated that the post will be shared by other accounts, including that of the PhD candidate, but postings will always originate from the accounts set up specifically for this research. In addition, posts will also be made to known support groups- as well as groups that we become aware of on both platforms; this will be done once in the first instance, then again after a week, then every month after that for each group. This is to give all members of the group an opportunity to find out about the research, whilst at the same time giving new members the opportunity when they join the group later. This frequency will however avoid being annoying, or inconvenient to members of the group who do not wish to participate, by minimising their exposure to the posts beyond what is necessary to give others the opportunity to participate. Examples of how the accounts are set up and how they will post are given below.

Twitter

Example screen from Twitter page



Chris Allen
@on1ine_health

Research looking at the importance of online and offline social networks in illness management

Choose your first Tweet

We've got your first Tweet ready to go. The hashtag #myfirstTweet will help others find and chat with you.

Networked Health @on1ine_health
Just setting up my Twitter. #myfirstTweet

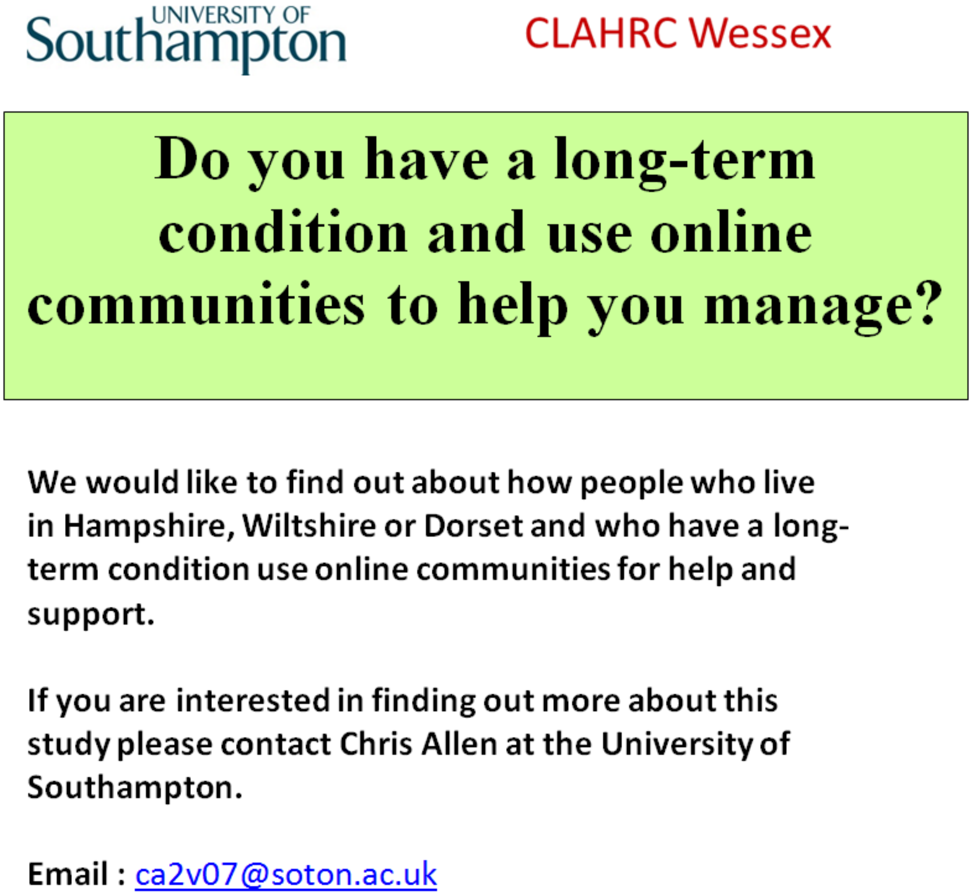
The Twitter handle is @on1ine_health. The bio, which can be seen by anyone using twitter and looking at the account will read:

PhD research from the University of Southampton Faculty of Health Sciences, looking at online communities and illness management.

The 140-character tweet will read:

If you have a long-term condition and use the internet to manage it, we are interested in speaking to you about your experiences. With every tweet will be the following picture- which gives more information than the charater limit allows including a contact email address to email for more details.

Image for every tweet



UNIVERSITY OF Southampton

CLAHRC Wessex

Do you have a long-term condition and use online communities to help you manage?

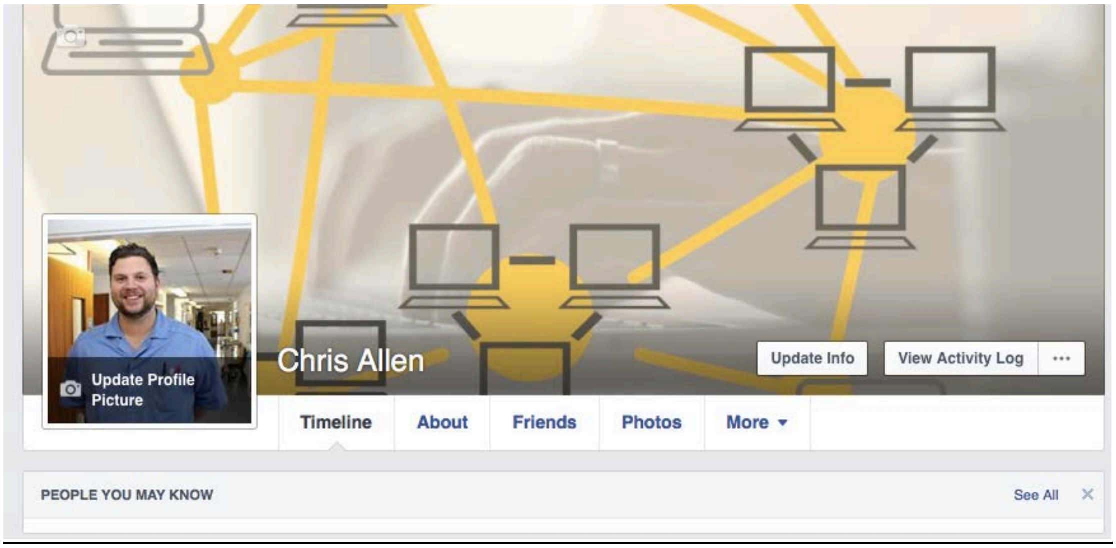
We would like to find out about how people who live in Hampshire, Wiltshire or Dorset and who have a long-term condition use online communities for help and support.

If you are interested in finding out more about this study please contact Chris Allen at the University of Southampton.

Email : ca2v07@soton.ac.uk

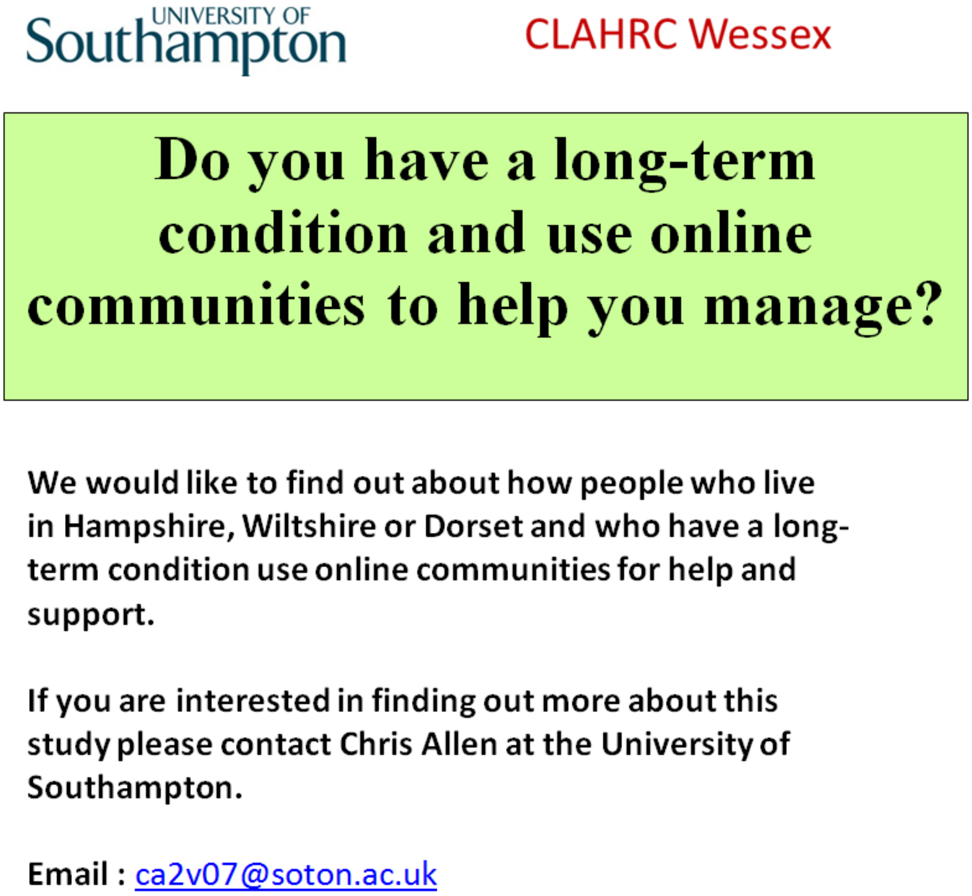
Facebook

Example screen from Facebook Page



Post: If you have a long-term condition and use the internet for support in managing it, we are interested in speaking to you about participation in research we are doing which is looking at people online and offline social network support and the impact this has on the management of their condition. If you would like to find out further information about what is involved and how you can take part, please email Chris Allen, a Clinical Academic Fellow at the University of Southampton, Faculty of Health Sciences on ca2v07@soton.ac.uk, who will send you further information, that you will need to read and consider before deciding if you would like to take part.

Image for every Facebook post



UNIVERSITY OF Southampton

CLAHRC Wessex

Do you have a long-term condition and use online communities to help you manage?

We would like to find out about how people who live in Hampshire, Wiltshire or Dorset and who have a long-term condition use online communities for help and support.

If you are interested in finding out more about this study please contact Chris Allen at the University of Southampton.

Email : ca2v07@soton.ac.uk

Appendix 2 Participant Information Sheet

Participant Information Sheet

Study Title: Exploring illness support in online and offline social networks for people who have a long-term condition.

Researcher: Chris Allen **Ethics number**: 19132

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This project aims to understand how people use online communities to help them manage their condition. The PhD candidate is Chris Allen, a Clinical Academic Doctoral Research Fellow of the School of Health Sciences, of The University of Southampton. It will form part of a PhD thesis.

We are interested in how people self-manage their long-term condition and are particularly interested in speaking to people who use online communities to help them manage their condition. We want to know more about how people use these communities, what they use them for and how this helps them manage their condition. We are particularly interested in how this relates to offline support and how people make decisions about whether to find help online or offline during different situations (for example, a new diagnosis, flare up of symptoms, or change of medication)

Why have I been chosen?

After seeing a Tweet, Facebook post, poster, or after hearing about the research at a local support group, you have contacted the research team through email for further information. Please note: you will only be able to take part in this research if you live in the Wessex region of the United Kingdom (Hampshire, Wiltshire or Dorset).

What will happen to me if I take part?

If you decide to take part in this study, you will be asked to take part in a short face-to-face interview and an exercise that involves mapping the people who are important to you on a diagram. This will be done with a researcher in a place that is convenient to you. The whole interview and exercise will take approximately 1 hour, though this time may vary depending on your responses.

The interviewer will ask you about how you use people or groups online and offline in your social networks to help you manage your condition and who you reach out to for support in different situations. This interview will be digitally recorded to enhance the accuracy of reporting your experiences with online and offline support. During this time we will look at which individuals and groups are important to you with regards to managing your condition; we will use a diagram called a concentric circle as an exercise to help you discuss the support that you have, and how you make decisions about who to go to for help in certain situations, such as a change in your condition, or a flare up in your symptoms.

Once the interview is over, you will be asked if you would like to see the summary report and feedback any comments, this is voluntary, and you do not have to.

Are there any benefits in my taking part?

To compensate you for your time, each participant will receive a £10 Amazon voucher on completing the interview.

By taking part, participants might also benefit through a raised awareness of the importance of personal networks. The reflective nature of the interview may allow those taking part to use this experience to make better use of their existing social networks for self-management support as well as consider potential alternatives.

It is hoped that your participation will help us to build a better understanding of how people use the internet and more specifically online communities to help them manage their condition. Your responses may therefore benefit others, should the research inform future interventions.

Are there any risks involved?

Talking about your experiences might not always be comfortable. Some participants undertaking the interviews may feel upset when talking about their condition or about their support.

Should you feel upset, there is the opportunity to move onto a different question, take a break in the interview, or terminate the interview altogether.

Whilst it is not intended that the interview should upset you, it would be helpful to identify someone, with the researcher, who would be supportive to you should you need them following the interview.

Additionally, if feel you need to talk to someone after the interview you can phone the Samaritans group on **116 123**.

What happens when the research study stops?

Once the study has been completed the information obtained will be analysed and the findings will be written up (as part of the requirement of the PhD). A summary of the study and its findings will be made available to those who have participated. It is anticipated that the findings will be published in a relevant journal. You will not be identified in any report/publication that arises from this research.

Will my participation be confidential?

Although all participants are linked to their data initially, the data will be anonymised so that participants and members of their social network cannot be identified.

No identifying data will be released to anyone other than the investigators. Your data will be stored on a password protected computer. This research project is being conducted in accordance with the Data Protection Act (1998) and the University of Southampton's research data management policy which is available at: http://www.calender.soton.ac.uk/sectionIV/research-data-management.html.

What happens if I change my mind?

Participation in the study is voluntary. You have the right to withdraw from the study at any time, without providing a reason. This decision will not affect any services you or your relatives receive and will not affect your legal rights. You will need to inform the researcher of your intention to withdraw so that you are not contacted again in the future.

What happens if something goes wrong?

In the event that you need to raise a concern/ complaint please contact Isla-Kate Morris (02380 595058, rgoinfo@soton.ac.uk).

Alternatively you could contact the supervisors of this research project, Professor Anne Rogers, Professor of Health Systems Implementation (02380 596830, A.E.Rogers@soton.ac.uk) or Professor Anne Kennedy, Professor of Health Systems Implementation (02380 598956, A.Kennedy@soton.ac.uk) or Dr Ivaylo Vassilev, Senior Research Fellow (02380 598956, I.I.Vassilev@soton.ac.uk).

Who is organising and funding the research?

The organisation financially supporting the research is NIHR CLAHRC Wessex. The research sponsor is the University of Southampton as this is where the doctorate will be registered.

Where can I get more information?

For further information about the study, please contact the PhD candidate, Chris Allen (02380 598956, ca2v07@soton.ac.uk)

THANK YOU FOR TAKING THE TIME TO READ THIS INFORMATION SHEET

Appendix 3 Consent form

CONSENT FORM
(19/05/2016, Version 2.0)

Study title: Exploring illness support in online and offline social networks for people who have a long-term condition.

Researcher name: Chris Allen
Ethics reference: 19132

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet dated 19/05/2016 (version 2.0) and have had the opportunity to consider the information, ask questions about the study and have had these answered satisfactorily. ☐

I agree to take part in this research project and agree for my data to be used for the purpose of this study ☐

(i) I agree to being interviewed. ☐

(ii) I agree to this interview being taped ☐

I understand my participation is voluntary and I may withdraw at any time without my legal rights being affected ☐

I agree for information about me to be used in this study. ☐

I understand that the ‘validity’ of my consent is conditional upon the University complying with the Data Protection Act and I understand that I can request my details be removed from this database at any time. ☐

Data Protection
I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)…………………………………………………

Signature of participant……………………………………………………………..

Date………………………………………………………………………………

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