

**The contribution of Internet use in personal networks of support for long-term condition self-management.**

**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.

## Introduction

The internet has long been recognised as a means through which lay health knowledge can be obtained<sup>1</sup> and it has become an increasingly utilised resource for health-information<sup>2, 3</sup>. 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<sup>4</sup>. 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<sup>3, 5</sup>. Whilst it is anticipated that digital access will in the longer term reduce social divisions<sup>6</sup>, empirical evidence supporting such assertions remains limited<sup>7, 8</sup> and there are indications that technologies may accentuate inequalities<sup>3, 8, 9</sup>. In marginalized communities, digital inequalities persist not through lack of access, which has been shown to poorly predict the utilisation of digital health resources<sup>3, 10</sup>, but through differentiated use and failure to draw upon online resources<sup>3, 10, 11</sup>. 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<sup>9, 11</sup>. People with access to the internet might lack the necessary skills and knowledge to be able to use it successfully<sup>3, 8</sup> 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<sup>5</sup>. 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, 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<sup>8, 13</sup> 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<sup>8, 14</sup>. Less attention has been given to the role that networks may have in compensating for unequal access and differentiated use, particularly in marginalized 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<sup>3, 15</sup>. Thus, network resources might support engagement with digital self-management in a way that has not previously been recognised. Personal networks<sup>1</sup> 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<sup>16, 17</sup>. '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

---

<sup>1</sup> 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.

housekeeping and occupational labour. 'Emotional work' relates to providing comfort when worried or anxious<sup>16, 17</sup>.

Research has pointed to the relevance of online communities as a form of social compensation in replacing or supplementing offline interpersonal relationships<sup>18</sup>. 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, marginalized community. In order to study the participation divide, it was relevant to explore the social, cultural and economic context of digital engagement<sup>11</sup> in relation to general internet use and internet use for condition management.

**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?

**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.

## **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<sup>17</sup>. The data set has been used for secondary analysis with successful publication, for example in Forbes et al<sup>19</sup>. Full details of the original studies design, sampling and data collection are detailed in Rogers et al<sup>16</sup> and Vassilev et al<sup>17</sup> 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<sup>17</sup>.

300 participants were recruited to the study between April 2010 and January 2011<sup>17</sup>. In this present study, 4 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<sup>17</sup>. 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 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, healthcare professionals, neighbours etc)<sup>17</sup>.

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.

### **Ethics Statement**

Ethical approval for the original study was obtained from the Greater Manchester Research Ethics Committee in February 2010 (ref:10/H1008/1).

### **Measures**

#### **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.

### **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<sup>17</sup>).

### **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 8 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.

### **Personal Network Participation and Resources**

A resource generator was used as a measure of access to network resources offered by members of the network<sup>20</sup> (**figure 1**); such as being able to access someone who knows how to fix computer problems, which has been used separately in the analysis. The resource generator has been used in previous research to measure the availability of social resources within personal communities of support<sup>20</sup>. It has been validated for use in English settings<sup>20</sup>

**Figure 1: Questions in the resource generator**

<b>Do you currently have access to someone who?</b>	
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
<b>Do you currently know anyone who would...?</b>	
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.

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.

**Measuring the availability of illness work**

The survey questionnaire was devised to quantify the contribution made by each network member<sup>17</sup>. This questionnaire consisted of 13 items addressing different aspects of the illness, everyday practical and emotional domains of illness work<sup>17</sup> (**figure 2**).

**Figure 2: Types of chronic illness work and questions used in the study**

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

Emotional work	<p>This person makes me feel good about myself.</p> <p>This person helps me value and enjoy life.</p> <p>This person helps me achieve personal goals.</p>
----------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------

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<sup>17</sup>, 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.

### **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-value of  $\leq 0.05$ .

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.

## **Results**

### **Sample ego level socio-demographic characteristics**

Most of the participants were men (64%, n=193). The mean age of the participants was 65 years old, with participant's ages ranging from 20 years to 93 years old. 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 1** demonstrates the sample characteristics of the participants.

**Table 1: Ego Level Descriptive Analysis**

Ego characteristic	N (%)*
<b>Gender</b>	
Male	193 (64.3%)
Female	107 (35.7%)
<b>Age</b>	Mean= 65.3 (SD=12.7)

<b>IMD Score</b>	Mean= 37.5 (SD=19.3)
<b>Income</b>	
Low income (up to £20,799 pa)	189 (75.3%)
High income (more than £20,800 pa)	62 (24.7%)
<b>Condition</b>	
Diabetes (type 1 and 2)	180 (60%)
CHD including high blood pressure	242 (80.7%)
Kidney disease	31 (10.3%)
<b>Highest qualification</b>	
No qualifications	63 (28.6%)
Qualifications up to A level	94 (42.7%)
Degree or higher	63 (28.6%)
<b>Marital status</b>	
Married	165 (55.0%)
Not married	135 (45.0%)
<b>Ethnicity</b>	
White	259 (86.3%)
Non-white	41 (13.7%)
<b>Employment status</b>	
In paid work, education or training	60 (20.3%)
Not in paid work, education or training	236 (79.7%)
<b>Number of conditions</b>	Mean= 2.8 (SD=1.3)
<b>Number of years with main condition</b>	Mean=10.2 (SD=8.5)
<b>General Health</b>	
Good	149 (49.7%)
Fair	101 (33.7%)
Poor	49 (16.3%)
<b>Time spent each day managing condition</b>	
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%)
<b>Happiness (scaled 0-100)</b>	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 2**.

**Table 2: Ego level Internet access and use descriptive analysis**

Internet use	N (%)
<b>Access to the internet at home?</b>	
Yes	157 (52.3)
No	143 (47.7)
<b>If you don't have access at home, do you have access to the internet elsewhere?</b>	
Yes	8 (5.6)
No	135 (94.4)
<b>Uses the internet?</b>	
Yes	131 (43.7)
No	165 (55.0)
<b>Used the internet in the last 6 months to help manage a condition?</b>	
Yes	76 (25.7)
No	220 (74.3)
<b>If not using the internet in the last 6 months for health, would you like to use the internet in the future for health?</b>	
Yes	22 (10.0)
No	198 (90.0)
<b>If not using the internet, would you like to use the internet in the future for health?</b>	
Yes	12 (7.3)
No	153 (92.7)
<b>Access to someone in network (whole) who knows how to fix computer problems?</b>	
Yes	158 (52.7)
No	142 (47.3)
<b>Access to an immediate family member who knows how to fix computer problems?</b>	
Yes	76 (25.3)
No	224 (74.7)
<b>Access to a wider family member who knows how to fix computer problems?</b>	
Yes	12 (4.0)
No	288 (96.0)
<b>Access to a friend who knows how to fix computer problems?</b>	
Yes	42 (14.0)
No	258 (86.0)
<b>Access to a neighbour who knows how to fix computer problems?</b>	
Yes	5 (1.7)
No	295 (98.3)
<b>Access to an acquaintance who knows how to fix computer problems?</b>	
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=.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).

### **Internet Use in General: Univariate Logistic Regression Analysis**

At the univariate level examining internet use, men more frequently used the internet than woman (OR 0.63, 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 and formal qualifications were positively associated (OR 5.833, p=0.00, 95% CI 3.031-11.226).

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 3**.

**Table 3: Internet Use in General: Univariate Logistic Regression Analysis**

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

Poor	0.625	0.321	1.217	0.16
<b>Time spent each day managing condition (reference up to 30 minutes per day)</b>				
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
<b>Network characteristics</b>				
<b>Access to people in network with the same condition (reference no access)</b>				
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
<b>Number of network members</b>	1.058	0.999	1.121	0.06
<b>Number of frequent contacts</b>	1.071	0.084	0.991	1.16
<b>Number of local neighbourhood support</b>	1.056	0.950	1.172	0.31
<b>Number of different agents in the network</b>	.989	0.825	1.185	0.90
<b>Local or dispersed network (reference local)</b>				
Dispersed network	1.201	0.745	1.937	0.45
<b>Total number of resources available</b>	1.112	1.069	1.157	0.00
<b>Does the participant have access to someone who knows how to fix computer problem? (reference does not have access to someone)</b>				
Has access to someone	3.822	2.354	6.205	0.00
<b>Total number of hobbies and social involvements (reference none)</b>				
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
<b>Illness work in network</b>				
<b>Illness work</b>	0.995	0.974	1.015	0.62
<b>Everyday practical work</b>	1.035	1.009	1.063	0.01
<b>Emotional work</b>	1.002	0.991	1.013	0.74
<b>Negative illness work in the network? (reference no)</b>				
Yes	2.368	1.418	3.953	0.00

### **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-.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 4**.

**Table 4: Internet Use in General: Multivariate Logistic Regression Analysis**

	Odds Ratio	95% confidence interval		P
		Lower	Upper	
Age	0.924	0.896	0.953	0.00
IMD score	0.979	0.961	0.997	0.02
<b>Highest Qualification (reference no qualifications)</b>				
Qualifications up to A level	4.273	1.822	10.020	0.00
Degree or higher	5.041	1.935	13.134	0.00
<b>Access to someone who knows how to fix computer problems (reference no access to someone who knows how to fix computer problems)</b>				
Has access to someone who knows how to fix computer problems.	4.213	2.140	8.294	0.00

**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 5**.

**Table 5: Internet Use for Condition Management: Univariate Logistic Regression Analysis**

	Odds Ratio	95% confidence interval		P
		Lower	Upper	
<b>Ego level characteristics</b>				
<b>Gender (reference male)</b>				
Female	0.734	0.343	1.570	0.43
<b>Age</b>	0.998	0.969	1.028	0.91
<b>IMD Score (based on Nov 2007 ratings)</b>	0.990	0.972	1.008	0.29
<b>Income (reference low income; up to £399 pw or £20,799)</b>				
High Income (£400 or more pw or £20,800 or more pa)	1.562	0.728	3.351	0.25
<b>Highest qualification (reference no qualifications)</b>				
Qualifications up to A level	1.478	0.457	4.781	0.51
Degree or Higher	1.437	0.422	4.902	0.56
<b>Marital Status (reference married)</b>				
Not married	0.794	0.385	1.638	0.53
<b>Ethnicity (reference white)</b>				
Non-white	0.774	0.292	2.055	0.61
<b>Employment (reference in paid work, education or training)</b>				
Not in paid work, education or training	0.799	0.384	1.664	0.55
<b>Number of conditions</b>	0.928	0.717	1.200	0.57
<b>Length of time (in years) with main condition</b>	0.977	0.936	1.019	0.27
<b>General health (reference good)</b>				
Fair	1.186	0.540	2.606	0.67
Poor	1.650	0.559	4.873	0.37
<b>Time spent each day managing condition (reference up to 30 minutes per day)</b>				
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
<b>Network characteristics</b>				
<b>Access to people in network with the same condition (reference no access)</b>				
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
<b>Number of network members</b>	1.041	0.959	1.130	0.34
<b>Number of frequent contacts</b>	1.082	0.968	1.211	0.17
<b>Number of local neighbourhood support</b>	0.958	0.829	1.106	0.56
<b>Number of different agents in the network</b>	1.441	1.060	1.959	0.02
<b>Local or dispersed network (reference local)</b>				
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
<b>Illness work in network</b>				
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

### **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,  $p=.006$ , 95% CI 1.009-1.052); but were less happy (OR 0.810,  $p=.014$ , 95% CI .686-.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 6**.

**Table 6: Internet Use for Condition Management: Multivariate Logistic Regression Analysis**

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

### **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<sup>2</sup>. Prior research has found associations between online and offline network engagement<sup>21</sup> 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<sup>18</sup>. 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,

---

<sup>2</sup> 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.

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<sup>22</sup>. 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<sup>22</sup> through the extension of offline support, for example lifestyle change or the adoption of new activities related to condition management<sup>23</sup>. 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<sup>24 3</sup>. Therefore, access to online support might be an indication of the avoidance or absence of offline support, thus acting as a substitute.

### **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 generalizable to the wider population. The response rate in the initial study was low and is possibly due to its focus on a marginalized 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.

### **Conclusion**

---

<sup>3</sup> 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

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<sup>3,9</sup>, 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.

## References

1. Hardey M. Doctor in the House: the Internet as a source of lay health knowledge and the challenge to expertise. *Sociology of Health and Illness* 1999; 21: 820-835.
2. Thackeray R, Crookston B and West J. Correlates of Health-Related Social Media Use Among Adults. *Journal of Medical Internet Research* 2013; 15.
3. Zach L, Dalrymple PW, Rogers ML, et al. Assessing Internet access and use in a medically underserved population: implications for providing enhanced health information services. *Health Information & Libraries Journal* 2012; 29: 61-71. DOI: 10.1111/j.1471-1842.2011.00971.x.
4. Blickem C, Bower P, Protheroe J, et al. The role of information in supporting self-care in vascular conditions: a conceptual and empirical review. *Health and Social Care in the Community* 2011; 19: 449-459. DOI: 10.1111/j.1365-2524.2010.00975.x.
5. McAuley A. Digital health interventions: widening access or widening inequalities? *Public Health* 2014; 128: 1118-1120.
6. Andreassen H, Dyb, K. . Differences and Inequalities in Health. *Information, Communication & Society* 2010; 13: 956-975.
7. Chou W-yS, Prestin A, Lyons C, et al. Web 2.0 for Health Promotion: Reviewing the Current Evidence. *American Journal of Public Health* 2013; 103: e9-e18. DOI: 10.2105/AJPH.2012.301071.
8. Latulippe K, Hamel C and Giroux D. Social Health Inequalities and eHealth: A Literature Review With Qualitative Synthesis of Theoretical and Empirical Studies. *J Med Internet Res* 2017; 19: e136. Original Paper 27.04.2017. DOI: 10.2196/jmir.6731.
9. Rogers A and Mead N. More than technology and access: primary care patients' views on the use and non-use of health information in the Internet age. *Health & Social Care in the Community* 2004; 12: 102-110. DOI: 10.1111/j.0966-0410.2004.00473.x.
10. Sarkar U, Karter AJ, Liu JY, et al. Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access. *Journal of the American Medical Informatics Association : JAMIA* 2011; 18: 318-321. DOI: 10.1136/jamia.2010.006015.
11. Robinson L, Cotton S, Ono H, et al. Digital inequalities and why they matter. *Information, Communication & Society* 2015; 18: 569-582. DOI: 10.1080/1369118X.2015.1012532.
12. Wagner TH, Bundorf MK, Singer SJ, et al. Free Internet Access, the Digital Divide, and Health Information. *Medical Care* 2005; 43: 415-420.
13. Huxley CJ, Atherton H, Watkins JA, et al. Digital communication between clinician and patient and the impact on marginalised groups: a realist review in general practice. *British Journal of General Practice* 2015; 65: e813-e821. DOI: 10.3399/bjgp15X687853.
14. Choi NG and DiNitto DM. The Digital Divide Among Low-Income Homebound Older Adults: Internet Use Patterns, eHealth Literacy, and Attitudes Toward Computer/Internet Use. *J Med Internet Res* 2013; 15: e93. Original Paper 02.05.2013. DOI: 10.2196/jmir.2645.
15. Burnett G, Jaeger PT and Thompson KM. Normative behavior and information: The social aspects of information access. *Library & Information Science Research* 2008; 30: 56-66.
16. Rogers A, Vassilev I, Sanders C, 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. DOI: 10.1186/1748-5908-6-56.
17. Vassilev I, Rogers A, Blickem C, et al. Social Networks, the 'Work' and Work Force of Chronic Illness Self-Management: A Survey Analysis of Personal Communities. *PLOS ONE* 2013; 8: 61-69. DOI: 10.1371/journal.pone.0059723.
18. Collins JL and Wellman B. Small Town in the Internet Society: Chappleau Is No Longer an Island. *American Behavioral Scientist* 2010; 53: 1344-1366. DOI: 10.1177/0002764210361689.
19. Forbes H, Sutton, M., Richardson, G., Rogers, A. The determinants of time spent on self-care. *Chronic Illness* 2016; 12: 98-115.

20. Webber M, Huxley, PJ. . Measuring access to social capital: the validity and reliability of the resource generator- UK and its association with common mental disorders. . *Social Science & Medicine* 2007; 65: 487-492.
21. Hogeboom D, McDermott R, Perrin K, et al. Internet Use and Social Networking Among Middle Aged and Older Adults. *Educational Gerontology* 2010; 36: 93-111. DOI: 10.1080/03601270903058507.
22. Perry BL and Pescosolido BA. Social Network Dynamics and Biographical Disruption: The Case of "First-Timers" with Mental Illness. *American Journal of Sociology* 2012; 118: 134-175. DOI: 10.1086/666377.
23. Vassilev I, Rogers A, Kennedy A, et al. The influence of social networks on self-management support: a metasynthesis. *BMC Public Health* 2014; 14. DOI: 10.1186/1471-2458-14-719.
24. Allen C, Vassilev I, Kennedy A, et al. Long-term condition self-management in online communities: A meta-synthesis of qualitative studies *Journal of Medical Internet Research* 2016. DOI: 10.2196/jmir.5260.