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Let's get digital – patient perspectives on using digital technologies in health management

Jae-Llane Ditchburn & Alison Marshall

Cumbria Research and Enterprise 2015

3rd July 2015

Background

Purpose: The study was carried out to fulfil one of the key tasks of the [Cumbria Strategy](#) for Digital Technologies in Health and Social Care which was to analyse the potential use or implementation of digital technologies in health needs.

Research involved two viewpoints – general practitioners (GPs) and patients.

“How can digital technologies help you in managing your health?”

AIM: To understand how people with long term health conditions perceive the use of digital technologies in supporting their health management

Design: Qualitative study with semi-structured interviews

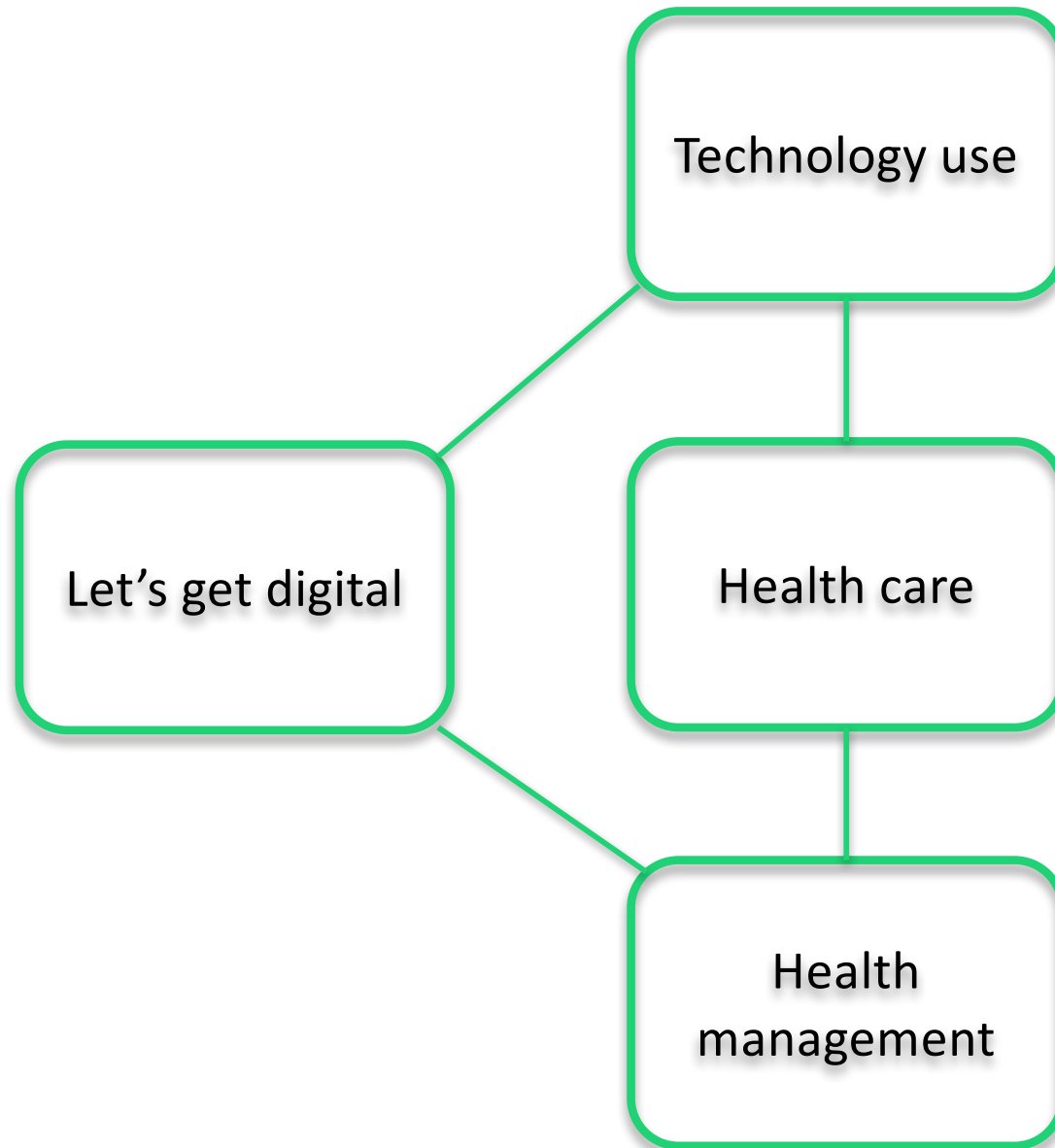
Data analysis: Qualitative content analysis

Time-line

DEC 2014: Ethics approval granted by UoC

JAN 2014: Recruitment of study subjects, data collection

May 2014: Study complete



- Social Media?
- Types of use?
- Commercial ?
- Communication?

- Experiences in primary care
- Accessing health care
- Health records

- Health monitoring
- How can technology help (in coping with condition, daily activities etc)?

Participant demographics : 22 people with long term health conditions (3 males, 19 females), mean age 47 years, age range 25 – 66 years

Major health condition	Number of people
Fibromyalgia	5
Myalgic encephalomyelitis (ME)	5
Fibromyalgia and ME	9
Acquired brain injury	2
Chronic regional pain syndrome	1
TOTAL	22

Other health conditions: hypermobility syndrome (4), chronic pain (12), arthritis (4), diabetes (3), irritable bowel syndrome (3), periodical depression (2), osteoporosis (2), spinal stenosis (1), chronic cough (2), sleep apnoea (1), Vitamin D deficiency (1), dystonia (1), pernicious anaemia (1), Barret's oesophagus (1), Bipolar disorder (1)

Results

Most were active on Social Media and used the Internet for utility purposes, accessing information, networking and entertainment.

“helps me feel I’m not alone”

“Internet gives me the chance to participate in so many things, and contact people, which due to my condition I wouldn’t be able to do without it ”

Half of our participants use health apps and health monitoring devices.

Use of mobile apps tended to be higher in younger participants.

On email:

None have used email communications with their GPs but most were in favour of using email or secure messaging, if there was an opportunity for it.

On viewing their health records: none have viewed their health records online, only one participant reported having paper copies of her health records, most were unaware of the option to view their health records, most agreed that sharing their health records online would be beneficial, one did not agree to sharing health data and four people were unsure.

On current experiences with their GP, our data showed/indicated:

High and low degrees of satisfaction

Long waiting times for referrals

Poor doctor-patient communication

Doctor-patient mistrust

Insufficient time during consultations to ask questions

“Seeing a doctor these days is a nightmare, firstly trying to get an appointment, then trying to get a doctor who believes in M.E. and Fibro, or not blame everything you go to see him about on Fibro, I think it takes far to long for a diagnosis of M.E. & Fibro and then you get no help or support, I have no faith in doctors anymore they don't care!”

Only one participant was familiar with NHS e-Referral (previously known as NHS Choose and Book).

On time spent to see their health care provider (from getting dressed, traveling, waiting and on the way home):

Responses were variable and dependent on other factors
Responses ranged from 45 minutes to 3.5 hours.

Examples of estimated time spent and anecdotal comparison with telephone and remote consultation

	Face to face		Telephone	Remote
	Participant 1	Participant 2	audio	audio & visual
Getting dressed	60 min	60 min	0 min	0 min
Travel	10 min	10 min	0 min	0 min
Waiting to see GP	15 min	45 min	?	?
Appointment with GP	10 min	10 min	10 min	10 min
Chemist	10 min	15 min	10 min	10 min
Total	1 hr 46 min	2 hrs 20 min	20 min	20 min

Overall positive attitudes towards technology in health and social care, although there were mixed responses about remote consultations.

“Good idea!”

*“I have never used Skype, but if it meant getting appointments or consultations **quicker** then I would give it a try.”*

“I would hate it! I already hate telephone appointments. In common with face to face appointments it does not give me unpressured space to think what I want to say and take in what is being said to me.”

Areas in health management raised by the evidence for which could be improved using technology:

Role in general practice

Interface between primary and secondary care

Continuity and coordination of care

Role in general practice



Enable hassle-free access to GPs



Have allotted time for telephone appointments or callback



Offer email communication for patients

“If I call in the morning I could be waiting until end of surgery 3 or 4 o’clock for a call. I’d prefer a set time where the Dr’s made telephone appointments then u could make sure u were available and undisturbed.”

“often when I have struggled to an appointment I am in a lot of pain and suffering cognitive problems which mean I cannot concentrate or express myself properly. If I could email, I could put things in writing in my own pace.”

Interface between primary and secondary care

“If I could access my own records pre my GP appointment, I could read my consultant’s letter and attend my GP appointment more prepared.”

Enable email communication and/or faster receipt of letters to the patient

share health records between different points of care (with patient’s consent)

Make available health records online to patients and support them on how to access their medical data

Continuity and coordination of care

*“I would be very pleased if I could **email someone to clarify** my understanding of what’s happened in consultant appointments. Or just to get general answers about particular conditions.”*

*I am unable to know until the day **whether or not I can attend** as on average I am only well enough to leave the house a couple of days a week.”*



Improve communication



Offer remote consultations



Offer
telehealth
monitoring
to patients



Support
patients in
looking after
themselves

*“I have a blood sugar meter and a blood pressure machine that I bought but am too poorly and stressed to get into the routine of either as I am chronically ill and also a carer. I think it would help incentivise me to try harder if I could upload these results and communicate with health care professionals about them **online**, rather than having to struggle in to the surgery.”*

Conclusion

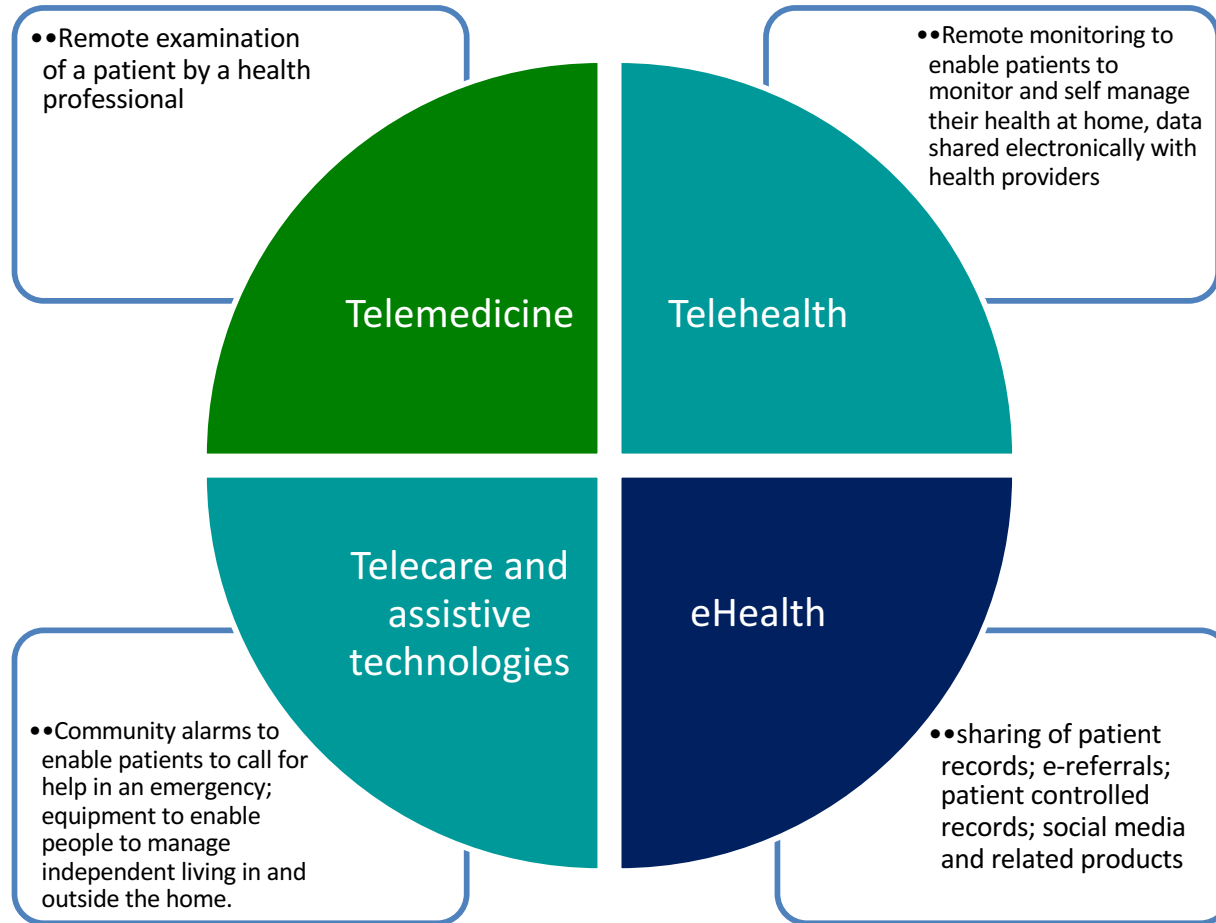
There *is* a need for digital technologies in managing health for people with long term conditions, particularly in health monitoring, maintaining access to health care and patient support.

Addressing these issues by integrating digital technologies in a variety of clinical and social settings may help improve their quality of life.

Thank you

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Digital health – definitions and scope





CUMBRIA STRATEGY FOR DIGITAL TECHNOLOGIES IN HEALTH AND SOCIAL CARE

The Strategy project is a hands on, practical study, led by the University of Cumbria and completing by the end of March 2015. Preliminary results will be presented at a series of workshops in autumn 2014, to develop the Roadmap for Implementation of Digital Technologies in Health and Social Care. The work is funded by the Academic Health Science Network for North East and North Cumbria.



SCOPE AND DEFINITIONS

The strategy covers the population of Cumbria and their health and social care requirements. Services involved may include organisations within Cumbria, or those based outside but serving the needs of those in Cumbria.

The term 'digital technologies' is defined broadly to include the use of information and communications technologies to replace, augment or complement conventional face to face health and social care delivery. Specifically, we include:



Telehealth, telemedicine and telecoaching

- Remote consultations between patients and health professionals, or between health professionals (telemedicine);
- Remote monitoring providing equipment to enable patients to monitor and self manage their health at home, shared electronically with health providers (telehealth);
- Providing equipment to support a remote examination of a patient by a health professional (supported telemedicine);
- Telecoaching to encourage healthy living and self care.

Telecare and Assistive Technology

- Community alarms to enable patients to call for help in an emergency;
- Telecare providing equipment to enable people to manage risks associated with independent living in and outside the home.

Other applications

Key tasks for the Cumbria Strategy for Digital Technologies in Health and Social care

Task 1: Mapping and scoping of existing best practice

Task 2: Gain understanding of issues specific to rural healthcare

Task 3: Digital technologies in health needs analysis

Task 4: Roadmap development

Task 5: Dissemination and influencing

Task 3: Digital technologies in health needs analysis

- Review existing published studies and tools available to analyse health needs and demand.
- Interrogate EMIS records held by Cumbria CCG to understand high level needs.
- Work with one or more GP practices to check and validate a case study on integrating digital technologies to routine services.
- Produce guidance on how GP practices can assess their own needs and implement digital technologies.

Time line: Cumbria Rural Health Forum

Sept 2013: Ideas on rural health

Dec 2013: Funding call, digital tech definition, known projects/ good practice, identify gaps

Feb 2014: outline of bid to submit, discuss Cumbria Strategy

March 2014: successful bid application from AHSN NE & N. Cumbria

JUL 2014: Work on tasks/initiatives, literature search

SEPT 2014: Workshop 1

- GP practices needs analysis
- Data from practice managers
- From there – studies on GP and LTCs
- Activity – categorise/cross link mapped items

DEC 2014: Workshop 2

- Described studies to Forum
- Activity – work on 3 themes
 - Improve health outcomes for those with LTCs, support more to self-manage
 - Explain, clarify, share good/bad practice, assess impact and value

FEB 2015: Workshop 3

- Update Forum – website, twitter
- Discuss plans for CRHF Phase 2
- Activity – implementation planning exercise – for the *Rurals*, how can we design digital services for them?

APR 2015: Networking meeting

- Discussion of Forum, benefits, what has worked well
- Plans for the Future year
- Activity – member survey

How can digital technology help you in managing your health?



“There is an important role for general practice in supporting people with multiple long-term conditions rather than transferring clinical responsibility to specialist teams. However, as many of these patients are likely to need specialist input at least some of the time, the interface between general practice and specialist care is also crucial” (Goodwin et al. 2010, p.58)

“There is a particularly strong case for case management for people with multiple long-term conditions, to provide the relational continuity and coordination of care that the evidence suggests is highly important to this group” (Goodwin et al. 2010, p.58)

Questions on technology use

- Can you tell us about how much technology you use for yourself? For example go on skype, or surf the Internet?
- As an example, do you use Phone banking? What if the same thing was made available except it is your GP or the clinic that helps manage your health? Would there be any difference in sharing of data related to health and other aspects of your life (e.g. finance, retail)?
- What kind of technologies do you use? (Computer, smartphone, gaming etc.)

Question on health management using technology

- Based on daily activities, where do you think technology would fit it?
- Do you think any of these activities could have been handled using remote technologies?
- Would you be willing to try it out if a certain technology could be used?

Question on health care

- How often do you see your GP or health care professional?
- How long does it take for you to get ready to see your GP or health care professional?
- Have you looked at your health records?
- How do you feel about sharing data that relates to your health? If you can see your health records and people like doctors and nurses can also see them, how would you feel about that?