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Developing care for a changing population: Patient engagement and health information technology

Discussion paper

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About this report

This report was originally prepared as a working paper for the Nuffield Trust and The Commonwealth Fund's 15th international meeting on improving the quality and efficiency of health care. The meeting, which took place in July 2015, was designed to provoke and inform debate. The Commonwealth Fund is a private, non-partisan foundation that supports independent research on health and social issues. The 2015 meeting reflects a shared commitment to cross-national policy exchange and builds on a collaboration that began in 1999.

The meeting brought together leading medical professionals and senior policy-makers from the United Kingdom and the United States to compare front-line delivery system models and policy approaches aimed at improving care for high-cost and high-need patients. This paper is one of three UK papers commissioned for the meeting and subsequently published by the Nuffield Trust. It looks at patient engagement and how health information technologies can help people to find health information, self-manage their complex health conditions and remain at home for as long as possible.

Contents

Key points

- Digital technologies can help patients access health information, self-manage long-term conditions, and maintain their independence at home

- Online access to these facilities has been slow to take off in the UK and many patients are unaware of their potential.

- Older people and their carers are increasingly familiar with the internet, so health information technologies could be used much more extensively to enhance their care and support.

- Patients and front-line staff should be actively involved in the design and implementation of these systems and tools.

- Future evaluations should focus on their impact on those with the most complex health needs.

1. Introduction

The NHS in England is facing a huge productivity challenge (Ham, 2015). Achieving the necessary improvements in efficiency to close the £22 billion funding gap by 2020 will require a transformation in the way care is delivered. To what extent could health information technology help to achieve this transformation?

The obvious starting point for tackling the productivity problem is to focus on those at highest risk of emergency hospital admission, but there is also potential to create value from better use of health information technology right across the spectrum of need.

'High-need, high-cost' patients – people with multiple or complex conditions – use a wide range of services, not just inpatient care (Hong and others, 2014). Many are also heavy users of primary care, specialist outpatient services, community nursing, social care and informal (family) care.

Most, but not all, of those in this group are aged over 65, but the group also includes younger people, including those with disabilities who live at home. As people age they are likely to have more than one long-term health condition along with increasing frailty (Barnett and others, 2012). Many are dependent to a degree on their families, who often require support themselves in order to perform their caring tasks effectively. A substantial subgroup is poor and living in disadvantaged circumstances, sometimes having to deal with inadequate living conditions and social isolation on top of their illness (Marmot and others, 2012).

While these people are often seen as the group least likely to be confident users of digital technologies, the situation is changing fast. In 2014, 22 million households in the United Kingdom (UK) (84 per cent) had internet access and 38 million adults (76 per cent) accessed the internet every day, 21 million more than in 2006 (Office for National Statistics, 2014). Those aged over 65 still use the internet half as much as younger people, but even among this age group, the rate of increase has been formidable, from only 9 per cent in 2006 to 42 per cent in 2014 (Ofcom, 2014). More than half the population (58 per cent) owns a smartphone and 74 per cent of adults bought goods or services online in 2014 (Ofcom, 2014). People have become increasingly comfortable with online banking and in 2012 the government launched a 'digital by default' standard for interaction with public services. It estimated that online-only payment for services such as car tax discs would save between £1.7 billion and £1.8 billion per year (Cabinet Office, 2013). The 'digital divide' between those who are confident computer users and those who lack this experience is still apparent, but it has become more concentrated, with only 12 per cent of the population currently unable to access the internet and having no plans to do so in the near future.

There is undoubtedly scope to speed up the pace of digital technology adoption in health care, and in this paper we outline a number of UK initiatives that are aiming to do just that. Meanwhile, almost all households in the UK own a telephone – a fixed landline, a mobile phone or both. The telephone remains an important and still under-

used technology for delivering health care advice and support, so we make no apology for including telephonic examples in this paper alongside those from e-health.

We have structured this review around three of the main applications of health information technology for people with complex health conditions – for self-care advice and routine transactions, for support in self-managing long-term conditions and for remote monitoring to help them to be cared for at home.

2. Technologies for self-care advice and routine transactions

Self-care is the most prevalent form of health care and most minor illnesses and accidents are treated at home without recourse to professional advice. When help is needed, there is a range of digital and telephone advice services available to British people, including state-funded services such as the NHS Choices website (www.nhs.uk/pages/home.aspx) and the NHS 111 telephone advice service. These services are soon to be combined into a multi-channel information system, accessible through a single portal, allowing people to:

- book appointments

- find information about health and conditions

- compare the quality of local services

- download self-care apps and tools (National Information Board, 2014).

The government hopes that this more coordinated approach will strengthen support for people to take more control of their health and care, interacting with care providers more effectively. But how confident can we be that these initiatives will really empower those in the high-need, high-cost group?

Finding health information and services

The NHS's main patient-facing central website – NHS Choices (www.nhs.uk/pages/home.aspx) – contains an enormous amount of information including a health encyclopaedia, medicines information, how to find services, indicators of the quality and performance of these, and much more. The site, which receives 40 million visits per month, includes an interactive symptom checker based on an algorithm to provide appropriate advice. People using the service are asked to enter answers to a series of questions before being directed to relevant information. Similarly, those who call the NHS 111 telephone number speak to a trained adviser who asks questions based on a similar computer algorithm to ascertain the recommended course of action. From its inception in August 2010 to February 2015, NHS 111 handled more than 24 million calls, 22 per cent of which were transferred to a clinical adviser, leaving 78 per cent directed by the algorithm. Just under 10 per cent of calls resulted in an ambulance being dispatched, while 6 per cent of callers were advised to go to their local emergency department and 53 per cent were told to make an appointment with their general practitioner (GP). The remaining 28 per cent of callers required no other service (NHS England, 2015). The extent to which NHS 111 impacts positively or negatively on the demand for other health services has been the subject of considerable debate. Many GPs complain that it increases their workload because patients are redirected to them unnecessarily and the British Medical Association has recently called for its abolition (Rimmer, 2015).

Searching for health information is a common activity, but less so than some other regular uses of the internet. In 2013, 43 per cent of all adults had used the internet to find health information, while 72 per cent had used it for other goods and services (Office for National Statistics, 2013). NHS Choices received 23.4 million unique visitors in 2014, the vast majority of whom were looking for information about diseases and symptoms (NHS Choices, 2015). However, usage patterns were characterised by a sharp drop among the oldest age group: those aged 65 and over were much less likely to use the internet for any purpose, with only 21 per cent using it to access health information (see Figure 2.1).

Figure 2.1: Internet activities by age group, 2013
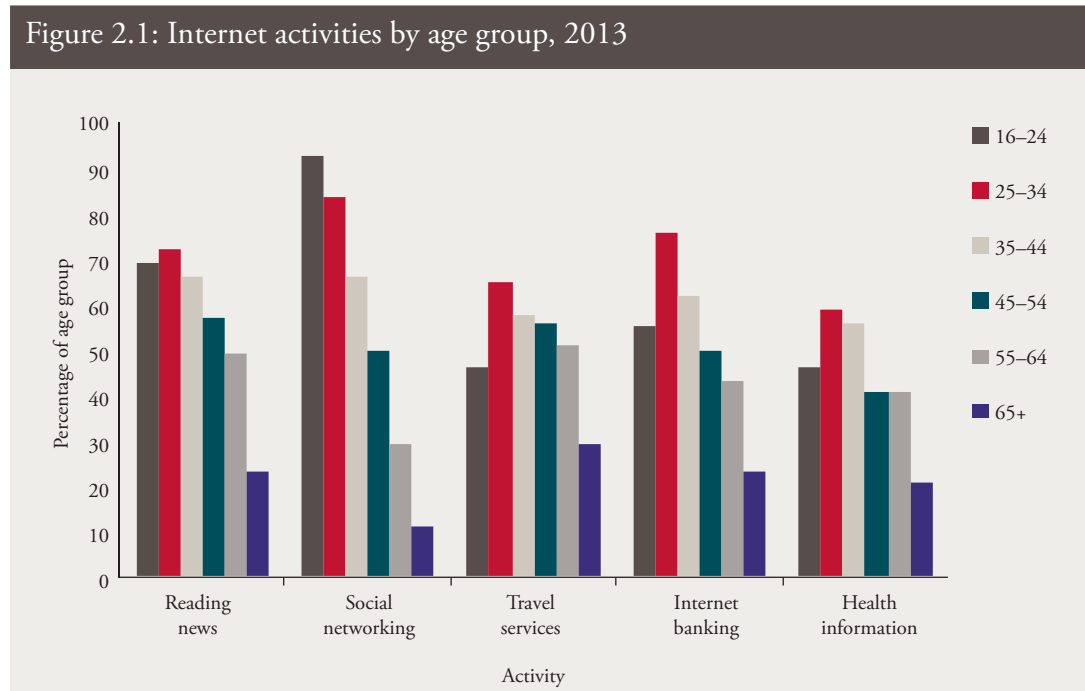
Source: Office for National Statistics (2013)

This drop-off in usage is striking when you consider that those aged 65 and over are the group most likely to be in need of health advice. Furthermore, these people do not appear to be using the telephone as an alternative to going online. Detailed usage data for NHS 111 are not currently available, but calls to NHS Direct, the predecessor telephone service to NHS 111, occurred at a much lower rate among the over 65s than among younger age groups (Cook and others, 2011).

The reason for the low use of remote health information services among older people is not entirely clear. It may be due to:

- a lack of computing skills

- a lack of smartphone ownership

- a lack of trust in the information or

- a general preference for face-to-face advice.

In 2009 the government introduced a health information certification scheme to tackle the trust issue: the Information Standard certifies websites if they can demonstrate that they provide health information that is 'clear, accurate, impartial, evidence-based and up-to-date' (NHS England, no date).

Successful accreditation entitles them to display a logo guaranteeing the quality of their information. The Information Standard processes were revised and streamlined in 2014, making it easier and cheaper to run, but it does not have a high public profile at present and its name does not convey brand recognition. Renaming it the NHS Information Standard would be an easy way to remedy this problem. Meanwhile, the deficit in computing skills is being addressed by developing digital health hubs in public libraries and community centres where people can access training and support to find the information they need (Cabinet Office, 2014).

Online transactions

The NHS has lagged a long way behind the commercial sector and other public services in relation to online transactions, including the ability to book appointments and order repeat prescriptions online. Most general practice patients still use the telephone to book appointments, despite the fact that many experience difficulties in doing so, with problems reported by one in four respondents to the national 2014 GP Patient Survey (25 per cent) (Ipsos MORI, 2015). In 2014 only 10 per cent had ordered prescriptions online, 6 per cent had booked their appointment online and hardly anyone (0.5 per cent) had accessed their medical record online.

Availability of these online services and/or awareness of their existence was low, with more than half of respondents to the survey saying they were unsure whether or not they were available in their practice. The government has tackled this issue by making it a contractual obligation for GPs to enable online access and by publicising it to patients. In May 2015 the Health and Social Care Information Centre announced that the number of GPs offering appointment bookings, repeat prescription requests and access to summary information in medical records online had tripled, with almost every GP surgery in England (97 per cent) now offering the service – a huge increase from only 32 per cent in April 2014 (NHS England, 2015b).

Use of telephone consultations with GPs has also been increasing, but once again from a very low base. Findings from the national GP Patient Survey suggest that there is little demand for this type of consultation, with only 6 per cent of patients indicating that they would prefer to speak to their doctor on the telephone. This may simply reflect low awareness that this is a possibility, perhaps due to reluctance on the part of GPs to publicise it to their patients. Despite this, about 12 per cent of GP consultations are currently carried out over the telephone, an increase from a few years ago. Meanwhile, a proportion of patients who cannot get a GP appointment when they want it (about 10 per cent) go to a hospital A&E department instead (Ipsos MORI, 2015). It is not certain that offering telephone consultations is an effective way to manage demand. Some practices have introduced nurse-led telephone triage systems to reduce the burden on GPs, but a randomised controlled trial of telephone triage in general practice found that it led to more consultations overall and an increase in GPs' workloads compared with usual care (Campbell and others, 2014). However, many practices are now encouraging more telephone consultations and there are many good reasons for doing so, not least patients' convenience.

Electronic health records

Since April 2015, all GPs in England have been required to offer patients online access to their summary care record. Up to now, most GPs have been reluctant to encourage their patients to review their medical records and few patients have pushed for it. A small number of general practices have bucked the trend, however. A study in two pioneering practices in England revealed a range of benefits for patients who accessed their electronic records, including better preparation for consultations, enhanced understanding and greater confidence (Shah and others, 2015). Even in these practices, the proportion of patients requesting such access was fairly small, but NHS England has committed to enabling patient access to 'fully interoperable electronic health records', with capacity for patients to write into them (NHS England, 2014). The target date for achieving comprehensive interactive access is 2018 (National Information Board, 2014).

An earlier government initiative to make online clinical summaries available to patients via a system known as HealthSpace eventually had to be abandoned due to lack of interest among patients and clinicians (Greenhalgh and others, 2010). Very few patients bothered to sign up (only 0.13 per cent of those invited to do so) and those who did were critical of the system, finding it difficult to use. An evaluation of the project concluded that its functionality aligned poorly with patients' self-management practices. The design had failed to take account of their attitudes, expectations, information needs and the wider health care context, rendering it largely irrelevant to them. Hopefully, the suppliers of general practice software have learnt from this experience and developed more user-friendly systems.

Online feedback

An important way to engage people in their health care is to ask for feedback on services. The NHS national survey programme was launched in 2002 and now covers virtually all NHS facilities (Coulter and others, 2014). The Friends and Family Test is the latest addition to the programme, designed to gather near real-time feedback via electronic means. Low response rates and non-rigorous sampling mean that this is an unreliable means of gaining performance information, but patients' free-text comments have proven useful as a stimulus for quality improvement (Sizmur and others, 2015).

Independent websites gathering unstructured real-time feedback, including Patient Opinion (https://www.patientopinion.org.uk/) and iWantGreatCare (https://www.iwantgreatcare.org/), are becoming more popular. Their primary purpose is to collect feedback on people's experiences to improve quality, but they have also been used by patients, their families and care providers to quickly solve problems and adapt care plans. Patient Opinion's case studies show how this type of real-time personal feedback can be used to help high-need patients. In one example, a daughter's online report of her mother's distress due to her delayed discharge led to immediate action, with a hospital consultant visiting to offer support within an hour of the complaint being posted (Patient Opinion, no date a). Another patient's son was upset about a lack of clarity and support regarding his father's medication and a chief pharmacist was able to effect a change quickly, with a positive result (Patient Opinion, no date b). A third example involved a daughter upset about her mother's care in a hospital ward, leading to a positive response from ward staff and better care for the patient (Patient Opinion, no date c).

These responses were only possible because senior staff were listening to the feedback in real time and were able to act quickly. The websites do not claim to offer this level of response routinely, but it is clear from these examples that instant communication to senior decision-makers using simple technology can be very useful. They also illustrate the important role played by family members in the care of their relatives and the benefits of engaging with them.

3. Technologies to help people self-manage long-term conditions

Improving care for the 15 million people with long-term conditions is arguably the most important challenge facing the NHS in England. They use at least 50 per cent of all GP appointments, 64 per cent of hospital outpatient appointments and 70 per cent of inpatient bed days, accounting for £7 out of every £10 of health care expenditure (Department of Health, 2012). The growing number of people with more than one long-term condition – projected to rise from 1.9 million in 2008 to 2.9 million in 2018 – poses a particular challenge (Barnett and others, 2012). The Department of Health in England has calculated that this could add a further £5 billion to NHS costs unless better ways can be found to organise services for these people. The main hope for improving health outcomes while balancing the books is to shift from a reactive system that treats people when they become ill to a proactive one that coordinates care and supports people to stay well. The Wanless report said as much in 2002 (Wanless, 2002), but progress towards the 'fully engaged' model has been painfully slow.

Care planning

The case for change rests on evidence that people who are more informed, more involved in decisions about their care and more 'activated' (willing, able and confident to self-manage their condition(s)) (Hibbard and others, 2004), generally experience better health and quality of life than those who are less informed, involved and activated (Michie and others, 2003; Schmittdiel and others, 2008). Both people with long-term conditions themselves, and the clinicians who seek to support them, can have various aims in terms of managing their health. These may include:

- minimising negative symptoms

- reducing health risks by improving health-related behaviours

- strengthening capabilities for self-managing and living well

- minimising dependence on resource-intensive, costly health services.

Personalised care planning is designed to help them achieve these goals. This is a process in which people with long-term conditions are encouraged to play an active part in determining their own care and support needs (Coulter and others, 2013). In pre-arranged appointments they engage in collaborative conversations, identifying priorities, discussing care and support options, agreeing goals that they can achieve for themselves, and co-producing a single holistic care plan with a shared record that is used to review progress on a regular basis. Instead of focusing on a standard set of disease management processes, the aim is to ensure that patients' values and concerns shape the professionals' response. There is evidence that this process can lead to better health outcomes and improvements in patients' self-management capabilities (Coulter and others, 2015). It requires clinicians to rethink the way they work, recognising

that the knowledge and experience that the patient brings to the care planning process is as important as the clinical information in the medical record. Various computer programs and apps have been developed to support the process, including templates to enable patients to record their behavioural goals and monitor progress, sharing this with clinicians where appropriate. One problem is that electronic medical records and clinical coding systems are not designed to enable patients to record their own goals so these can be shared with clinicians.

Clever use of 'big data' and predictive algorithms can enable more precise targeting of those at risk, identifying individuals who may benefit from care planning and intensive support, preventing progression to further ill-health (Bardsley and Dixon, 2011). This is already happening in health care to some extent, but it is nowhere near as sophisticated as in commercial advertising, where personal data are used for ever-more precise targeting of individuals (MashableUK, 2015). Predictive risk analysis could help clinicians to focus their efforts on those who can benefit most from proactive support, perhaps reducing the need for emergency interventions and hospitalisations. But, as recent experience with NHS England's care.data initiative indicates, the public will be suspicious of attempts to use their data in this way if the process is not completely open and transparent and if the reasons for the use of the data are not well explained.

Personalised care planning has major implications for commissioners too. Ideally, individual needs and choices identified during the care planning process would be aggregated to provide a local commissioning plan. This may need to go beyond the type of services normally provided by the NHS. Community and self-help groups can often provide the type of support to people with long-term conditions that statutory services tend to ignore, for example:

- cookery classes to help those struggling to eat a healthy diet

- gardening projects to encourage physical exercise

- volunteer befriending schemes to combat social isolation and loneliness

- advice centres

- peer-led self-help groups (Year of Care Partnerships, 2011).

Mapping local community groups and services into electronic health directories to facilitate signposting and referral is an important component, but local commissioners must be willing to support these non-traditional services. Even more fundamentally, they will need to embrace this bottom-up approach to determining health needs. Few have done so as yet.

Aggregating the support needs identified by individuals into a commissioning plan for a locality will require robust electronic records and systems for data sharing. Yet many local projects are hampered by inflexible electronic medical record systems that allow no space for recording patients' goals (Diabetes UK, 2011). And of course people's care needs may span multiple organisations and service boundaries, so professional silos and fragmented budgetary responsibility add even greater complexity. Success will depend on building effective local partnerships between NHS, social care, public health and community organisations, supported by effective record sharing and good use of digital technologies.

Decision aids and smartphone apps

Meanwhile, the production of online tools and apps to help patients with chronic disease management is growing exponentially. Shared decision-making is now being widely promoted and in 2012 the Department of Health invested in the production of a suite of evidence-based patient decision aids designed to help people make informed choices about tests and treatments (see http://sdm.rightcare.nhs.uk/). A large body of decision aids are also available internationally and standards have been developed to assure their quality (Elwyn and others, 2009; https://decisionaid.ohri.ca/azinvent. php). Good evidence of beneficial impact from the use of patient decision aids has been demonstrated in a large number of clinical trials (Stacey and others, 2014). The government's intention was to encourage wider uptake of these tools, but mainstream uptake must await a more concerted effort to train NHS staff in how to use them with their patients (Coulter and Collins, 2011). Progress has been slow to date.

In 2013 NHS England developed a health apps library, a database of apps covering a wide range of conditions, treatments and self-management strategies (http://apps.nhs. uk/). App developers were encouraged to submit their products for inclusion. These were reviewed to ensure they were clinically safe, relevant to people living in England, based on information from verifiable sources and compliant with the Data Protection Act 1998. Part of the government's strategy to transform digital care, the aim is to empower people to take charge of their own health (National Information Board, 2014). Examples include:

- Coordinate My Care (http://coordinatemycare.co.uk/) to enable people to record an advance care plan

- Big White Wall (https://wwwbigwhitewall.com) for people with mental health problems

- Health Mapper (www.healthmapperapp.com) for tracking health conditions, receiving reminders and sharing information with clinicians

- iReminisce (http://ireminisce.co.uk/) for people with dementia.

In contrast to the solid body of evidence on the effects of using patient decision aids, the explosion of health apps has not been accompanied by rigorous evaluation of their effects on any comparable scale. A few randomised controlled trials and systematic reviews have appeared, giving mixed results. For example, a Cochrane review of computer-based self-management interventions for people with diabetes found evidence of a small beneficial impact on blood sugar control, but no effect on any other outcomes (Pal and others, 2013). Another Cochrane review of smartphone and tablet apps for asthma management found inconclusive results (Marcano Belisario and others, 2013). On the other hand, an earlier review reported that the use of interactive computer apps for people with a range of chronic conditions resulted in improved knowledge, social support and health behaviours, as well as better clinical outcomes (Murray and others, 2005); and some apps have been found helpful for people with mental health problems (Donker and others, 2013). The critical question – whether use of these technologies can reduce demand for health services and save money – has not yet been answered conclusively. However, it is probably unrealistic to expect every app to undergo rigorous evaluation in a randomised controlled trial. A 'horses for courses' approach may suffice, with users – both clinicians and patients

– being encouraged to pick those that best meet their individual needs. The National Information Board (2014) has announced its intention to introduce a national certification scheme for health apps, which will make it easier to find good-quality information tools.

Telephone coaching

A more basic technology – the telephone – is being used to provide structured self-management support to people with long-term conditions. Health coaching, as it is commonly termed, was introduced into the UK a number of years after its widespread uptake in the United States and there are now a number of British companies offering telephone health coaching services. Supported by electronic conversation guides or protocols, health coaches provide remote support to patients in their own homes.

Birmingham OwnHealth was an early UK example of telephone coaching. Established by a primary care trust in 2006, this aimed to improve self-care strategies, improve clinical indicators and reduce health service use (Steventon and others, 2013a). Enrolled patients were assigned a care manager who phoned them on a monthly basis to provide personalised guidance and motivational support and helped them to coordinate service inputs. Initial evaluation of the service found high levels of user satisfaction and improved clinical outcomes among a subset of patients with poorly controlled diabetes (Jordan and others, 2011). However, a separate evaluation found no reduction in hospital admissions or outpatient attendances – indeed, these increased more quickly among those who were coached than among a matched group of controls who did not receive telephone coaching (Steventon and others, 2013a). Birmingham OwnHealth was decommissioned following this disappointing assessment.

Should we conclude from this that telephone coaching offers no benefit to patients or the health system? Not necessarily. Health coaching is used widely in the United States, apparently with positive results. Telephone coaching can provide effective self-management support, motivating people to adopt healthy behaviours and boosting their confidence, but it may not lead to cost reductions (The Evidence Centre, 2014). Some evidence from the United States suggests that it could do so (Wennberg and others, 2010), and this optimistic conclusion has been supported by a Cochrane review of its use with heart failure patients (Inglis and others, 2010), although another study in the United States found more negative results (Lin and others, 2012). Whether these contrasting results are due to differences in the design of the interventions, the implementation strategies or the study designs is not known. In the meantime, wider experimentation with health coaching in all its various forms is indicated, looking in particular at the impact on patients' self-management capabilities.

4. Technologies to help people to remain at home for as long as possible

Telehealth (the remote exchange of data between a patient at home and health care professionals to assist in the management of an existing long-term condition) and telecare (the remote monitoring of an individual's health and safety in their home environment) hold out the hope of improved outcomes at lower cost, the holy grail of high-value health care. This type of remote monitoring and information exchange may help users feel more secure and more confident when going about their daily activities.

In 2006, the Department of Health in England decided to launch a series of demonstration projects to test these assumptions in a randomised controlled trial. With more than 6,000 participants recruited from 238 general practices in three regions in England (Cornwall, Kent and the London Borough of Newham), the Whole Systems Demonstrator was claimed to be the largest randomised controlled trial of telehealth and telecare in the world. The trial, which ran from 2009 to 2011 at a total cost of £3.7 million, involved: people with diabetes, chronic obstructive pulmonary disease (COPD) and heart failure, who were potential candidates for telehealth; and people with social care needs, who might be helped by telecare. Most participants were at the higher end of the risk spectrum, with a high likelihood that they would experience unplanned hospital admissions. The study was designed to test the impact of these remote technologies on service utilisation, clinical effectiveness, cost-effectiveness, patient and professional experience, service delivery and organisation, as compared with usual care (Bower and others, 2011).

The first details to emerge from the Whole Systems Demonstrator trial showed that telehealth use was associated with lower hospital admissions (odds ratio 0.82 [0.70 to 0.97]) and lower mortality (4.6 per cent v 8.3 per cent; odds ratio 0.54 [0.39 to 0.75]) (Steventon and others, 2012). This led the Department of Health to issue a triumphant press release. However, subsequent analyses were much more equivocal about the benefits to the wider system. The investigators found no reduction in GP consultations or social care use and no evidence that these forms of remote care were cost-effective. There was a suggestion of a beneficial impact on quality of life for telecare users, but not for those using telehealth services (Bardsley and others, 2013; Cartwright and others, 2013; Henderson and others, 2013; 2014; Hirani and others, 2014; Steventon and others, 2013b). The study also found no evidence that this form of remote monitoring strengthened people's self-management capabilities.

Despite these disappointing results, the Department of Health pressed ahead with the Three Million Lives campaign – a collaboration between industry, the NHS and social care partners – to promote the wider uptake of telecare and telehealth. Responsibility for this initiative has now been passed over to NHS England and

incorporated into its Technology Enabled Care Services (TECS) programme (see https://www.england.nhs.uk/ourwork/qual-clin-lead/tecs/). The programme is encouraging health care commissioners to consider investing in a variety of remote services, including wearable monitors, urine and blood analysers, blood pressure monitors, text messaging, telephone coaching, movement sensors, pendants, alarms and so on.

Various plausible reasons have been put forward to explain the largely negative results of the Whole Systems Demonstrator trial, some of which had to do with the design of the trial itself, the selection of sites, the top-down nature of its implementation and the relatively short intervention period (Hendy and others, 2012). In contrast to the trial's more pessimistic assessment, anecdotal reports on the TECS website detail various benefits resulting from the use of remote monitoring technologies, including cost reductions and improved patient satisfaction. These positive impressions are also supported by evidence from several systematic reviews (McLean and others, 2012; Pandor and others, 2013; Polisena and others, 2009), but the overall picture remains mixed, with some reviews finding no evidence of benefit (Wootton, 2012). A qualitative study involving patients and carers shed some useful light on the complexities of implementing these technologies in the context of people's daily lives (Wherton and others, 2015). This pointed strongly to the need to make them customisable and adaptable to fit in with how individuals live and manage their health issues, rather than expecting patients and their carers to conform to a standardised model.

The fact that older, frailer people at high risk of falls and fractures, and those with cognitive or physical disabilities, can access help quickly through remote monitoring technologies can be immensely reassuring to themselves, their family and the clinicians responsible for their health care. However, most of these technologies require only passive involvement. Users must be willing to follow the instructions or press the button to download the data, but control remains in the hands of professionals who monitor the results and make the decisions. Patients may welcome the fact that they do not have to travel to a clinic so often for blood or urine tests, but use of these machines alone may do little to enhance their capabilities for self-management. Indeed, there is a risk that telehealth could undermine people's sense of self-efficacy, encouraging dependency on the machines without providing the sense of control needed to boost people's confidence in their own self-care efforts (Sanders and others, 2012). If these technologies are to be truly empowering, patients and their carers need to be more actively involved, with an understanding of what is being monitored and why, and what actions they can take to maintain control of their health and independence.

5. Conclusions

The history of digital innovations in health care has been characterised by claims of transformational impact from enthusiasts (see for example http://themedicalfuturist.com/), followed by more sobering assessments from academic evaluators. Those introducing these technologies often hope that their introduction will lead to an immediate measurable impact on emergency hospital admissions, leading to cost savings, but this aspiration is probably naïve, at least in the short term. These systems may deliver efficiencies in the long term, but only if they are carefully designed to solve real problems and offer obvious benefits to staff, patients and carers. In the meantime, cost savings are not the only important outcome to measure; impact on patients' quality of life and clinicians' working practices are equally, if not more, important.

The British health system has been a laggard when it comes to the uptake of health information technologies, being slower to embrace digital opportunities than other sectors of the economy. After the failure of the over-ambitious attempt to introduce a single, centrally mandated electronic care record, the NHS adopted a much more cautious approach. Government bodies are now involved in a concerted attempt to encourage greater use of the health information technologies, but the complexities of health care systems, coupled with concerns about the protection of personal data and the fear of loss of control on the part of clinicians, have acted as a break on progress (Mudge and others, 2015; National Information Board, 2014). Focusing on relatively simple innovations first, rather than trying to digitalise the whole NHS in one go, seems sensible but it requires investment and effective support and it is not always clear where this will come from. Unrealistic goals and over-ambitious evaluations are not helpful. These interventions require time to bed in, and they often need further tweaking to ensure that they are fit for purpose. Studies have sometimes revealed a mismatch between the assumptions made by the developers of the technology and the reality of how people manage their health and care in the context of their daily lives. Developers who take the time to work closely with clinicians, patients and carers to make sure their innovations meet real needs in an appropriate way usually produce better products.

What, then, are the implications for high-risk, high-cost patients? Older people and their family carers are becoming increasingly familiar with the internet and all it can offer, so there is no reason why health information technologies could not be used much more extensively to enhance their care and support. We believe these technologies have the potential to be of great benefit to them and to the wider health system, but we would urge those promoting them to adhere to the following principles:

- **Build from the bottom up.** People at the coalface of health care have plenty of good ideas on how it could be improved through better use of health information technologies, but they often lack the technical knowhow to realise their ideas. They need support, perhaps in the form of a national software development team, to help turn innovative ideas into practical reality. Encouraging this type of bottom-up approach to development, supported by an innovation fund, coupled with realistic evaluation and testing, could potentially reap dividends.

- **Involve users in system design.** Digital tools, remote monitoring systems and telephone support services can be used to help people live independently for longer, but only if they are well designed with the end users – the patient, their family, carers and the professionals who support them – in mind. Too often, clever pieces of kit are designed without sufficient thought being given to the problem they aim to solve and without involving the intended users in determining when and how they should be used. Informal carers make a huge contribution to the health of those with the greatest health needs. Whether they live with the person they care for or at a distance, well-designed digital technologies have the potential to improve their knowledge, skills and peace of mind. Innovative technologies to help them perform their caring responsibilities effectively should be a priority for development.

- **Specify realistic goals and evaluate these.** In an increasingly financially challenged service budget-holders will require evidence of effectiveness before parting with their money. Many good ideas have floundered for lack of evidence that they will benefit both users and the wider system. Well-designed technologies have the potential to improve people's lives. They may also save money and time in the long run, but making that the overarching goal to be measured in evaluations before the innovation has had a chance to bed in is likely to result in overly pessimistic conclusions. The first priority should be to test their immediate impact on patients and the health care workforce, using this learning to improve the products and their implementation. Evaluation of the wider impact on service use and costs should then follow at a later stage.

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