Abstract

Neoliberalism, austerity and health responsibilisation are increasingly informing policies and practices designed to encourage older patients to take responsibility for the management of their own healthcare. Combined with an ageing population, novel ways to address the increasing healthcare needs of older people have become a priority, with the emergence in recent years of new models of integrated care enhanced by combinatorial health technologies (CHTs). This paper presents qualitative findings from the evaluation of one programme, the Lancashire and Cumbria Innovation Alliance (LCIA) Test Bed, a programme funded by NHS England and conducted in England between 2016 and 2018.

Drawing on data from patients, family carers, and staff members involved in the programme, this paper explores the extent to which CHTs, as part of the LCIA Test Bed programme, contributed to health responsibilisation amongst older people with complex health conditions. Through this programme, we find that relationships between patients, family carers and healthcare professionals combined to create a sense of reassurance and shared responsibility for all parties. Our findings suggest the need for a more nuanced approach to responsibilisation and self-management for older people living with complex health conditions. By focusing on co-management – and recognising the potential of CHTs to facilitate this approach – there is potential to increase patient confidence in managing their health condition, reduce carer burden, and enhance clinician satisfaction in their work roles. While neoliberal agendas are focused on self-management and self-responsibility of one’s own health care, with technology as a facilitator of this, our findings suggest that the successful use of CHTs for older people with complex health conditions may instead be rooted
in co-management. This paper argues that co-management may be a more successful model of care for patients, carers and clinicians.

**Word count: 8877**

**Key words**

Ageing; Co-management; Healthcare; Health technologies; Neoliberalism;

Responsibilisation; Self-management
Introduction

Individualism is a key tenet of neoliberalist ideology, with the ideal neoliberal self being autonomous, individualised, self-responsible, self-acting, self-directing, and decision-making (Bondi, 2005; Cradock, 2007; Liebenberg et al. 2015). Within healthcare, individualism has informed an agenda of responsibilisation in which patients are required to take responsibility for their own health, behaviours, and healthcare (Brown and Baker, 2012). From this standpoint, it is no longer the responsibility of a welfare state to take care of people’s health, but is instead the responsibility of individuals (O’Malley, 2009). This shift in the conceptualisation of health responsibility highlights a central theme of neoliberalism: ‘the portrayal of personal choice and autonomy as the means through which responsibility is enacted’ (Trnka and Trundle, 2014, p.138).

Recent austerity measures in the UK have reinforced discourses of health responsibilisation. Public services are under increasing pressure to meet the demands of the population’s healthcare needs; there is a shortage of available hospital beds (The King’s Fund, 2019) and social care provision is increasingly limited as a result of reduced funding to local authorities (LGA, 2017). Further reinforcing discourses of health responsibilisation are concerns about policy and budgetary pressures ‘from the growing elderly population’ (Meldgaard Hansen, 2016, p.1093), and the perception that older people are placing a disproportionate strain on the healthcare system and economy more broadly (Hughes, 2017). We know that, globally, people are living longer lives. Recent figures show that 8.5% of the world’s population is now aged 65 years and over (Cire, 2016), with this projected to rise to nearly 17% by the year 2050 (He, Goodkind and Kowal, 2016). The UK is seeing a similar growth in its older population with the over 65s accounting for 18% of the population, and this figure expected to rise to 26% by
2066 (ONS, 2018). We also know that an ageing population brings with it some challenges, including increasing healthcare needs. As people are living longer, they are often living with one or more long-term health condition (LTC). In the UK, recent figures for adults aged over 65 years suggest that thirty percent are living with one LTC, twenty percent have two LTCs, and ten percent have three LTCs (Age UK, 2017). Rich et al. (2019) explain how within recent English health policy discourse, ‘investments in digital health care are justified on the basis of their ability to deliver greater efficiency of overburdened healthcare systems’ (p.38). The dominant discourse of an ageing population, and the increasing healthcare needs it brings, are therefore informing the health responsibilisation agenda.

Within a landscape of neoliberalism, austerity and an ageing population, the responsibilisation agenda is continuing to strengthen, with ‘the responsibility for the prevention and management of health shift[ing] increasingly onto patients (as consumers) and to technological systems’ (Rich et al. 2019, p.34). In the UK, for example, one of the aims of the ‘Personalised Health and Care 2020’ strategy (NHS Digital, 2020a) is to ‘to help people better manage their health and care’ and ‘take greater control of their health’ (NHS Digital, 2020b). Ways to address the increasing healthcare needs of older people have also become a priority, with a focus on facilitating older people’s ability to better self-manage their health care needs at home. One strategy developed by NHS England has been a focus on the potential of health technologies to support the provision of new models of care (NHS England, 2020). The NHS England Test Bed programme has been designed to encourage the trialling of combinatorial health technologies (CHTs), in which new models of care are supported by digital health technologies across a number of areas in the UK. This paper presents findings from the qualitative evaluation of one such programme, the Lancashire and Cumbria
Innovation Alliance (LCIA) Test Bed (hereafter referred to as ‘the programme’). Drawing on data from patients, family carers, and staff members, this paper explores the extent to which CHTs, as part of the programme, contributed to health responsibilisation amongst older people with complex health conditions. In doing so, this work contributes to the conversation regarding the responsibilisation agenda within healthcare and suggests the need for a more nuanced approach to responsibilisation and self-management for older people living with complex health conditions.

**Health technologies**

A number of terms are used to describe healthcare technologies, which often have ‘no one universally accepted definition’ (Murphy et al., 2017, p.282) and can be confusing (Chalfont, Mateus, Varey et al., 2020). The term telecare tends to be used to encompass technologies which ‘fill the temporal gaps usually involved in the provision of hands on care’ (Roberts, Mort & Milligan, 2012, p.492) and promote ageing in place (Correa & Domènech, 2013). Telemedicine applications are often defined as ‘devices that can monitor, diagnose or treat people at a distance from a clinician’ (Oudshoorn, 2008, p.272). The broad definition within which we locate this paper is that of telehealth, which has been defined as ‘health-based IT-based care’ (Murphy et al., 2017, p.282). However, while the broad definition we work within is telehealth, the focus of the programme was on combinations of different forms of health technologies tailored to an individual’s primary health condition; hence throughout the paper we use the term ‘combinatorial health technologies’ or CHTs.
The combination of technologies received by patients was dependent on their individual health conditions and level of risk of hospital admission. Within this CHT approach, it is not only the combination of technologies used with patients that is important, but also the new models of care within which they are located and implemented. The Test Bed involved a programme of work in which CHTs were introduced as part of a package of care that involved new forms of integrated care delivery. The programme was delivered through two neighbouring Vanguard sites located in Lancashire and South Cumbria, in the northwest of England: the Fylde Coast Local Health Economy; and Morecambe Bay Health Community (Better Care Together). Both Vanguards were focused on population-based new models of care that were central to delivering the vision of the NHS Five Year Forward View: integrated primary and acute care systems (PACSs) and multispecialty community providers (MCPs) whose focus was on integration (NHS, 2014). The Fylde Coast Local Health Economy was a MCP Vanguard, with this model designed to dissolve the historical divide between health and social care and involving the redesign of care around the health of the population, irrespective of existing institutional arrangements. Better Care Together was a PACS Vanguard, with the general practice at the core of this model and the aim of joining up services, facilitating more sustainable use of resources, thereby enabling a greater focus on prevention and integrated community-based care, and less reliance on hospital care.

While the technology was an important part of the programme, the focus of our evaluation was on the effectiveness of these CHTs as a facilitative part of the new integrated care programmes, rather than solely on the roles of the CHTs. The evaluation sought to understand the impact of this combinatorial approach on the lives of older people with LTCs.
All patients discussed in this paper received the Motiva system, developed by Philips, and accessed either through a handheld tablet device or through their television. Using Motiva, patients were able to take their own vital signs using wireless (Bluetooth) enabled weighing scales and blood pressure cuffs. Where appropriate, these were supplemented by manually entered readings from pulse oximeters and tympanic thermometers. Clinical teams leading the programme decided which CHTs a patient would receive based on the primary health condition. While all patients discussed in this paper received Motiva, the combination of technologies differed depending on the LTC. A patient with COPD, for example, received a pulse oximeter and thermometer; in addition to these items, a patient with heart failure also received weighing scales. The technology protocol also differed according to the patient’s primary health condition. Participants were asked to submit their daily readings each weekday morning before 11am. These readings were collected through the handheld tablet or television set top box and forwarded immediately to the clinical team looking after that patient.

The Motiva Clinical system used risk profiling algorithms to prioritise patients whose vital signs indicated that an intervention was required. The clinical team were also able to schedule messages (hints, tips and reminders), educational video content (how to take your blood pressure, eating well), and surveys (traffic light, validated measures) for the patients to complete. Motiva was used to measure one or more of weight, blood pressure, pulse and SPO2 depending on the patient’s long-term condition. Figure 1 presents an image of the Motiva system and accompanying technology accessories used in the programme (Philips, 2020).
Full details of the programme evaluation design and the technologies used across the different patient cohorts are available in the evaluation protocol (Varey et al. 2018) and the final report (Milligan, Mateus, Palmer et. al. 2018).

**Digital health technologies, older adults and health responsibilisation**

There is a sizeable body of work to suggest the potential of digital health technologies to contribute to and transform healthcare for older adults, ranging from mobile health applications, to smart monitoring and telecare solutions (see for example Helbostad et al. 2017; Longhi et al. 2017; Milligan, Roberts & Mort, 2011). There is evidence that mobile technology has the power to transform healthcare in ageing societies (Chiarini et al. 2013) and empower patients to self-manage their healthcare, so improving self-efficacy and health outcomes (Gaikwad and Warren, 2009). Much research has focused on the role of digital health technologies for adults with chronic diseases, with suggested benefits including ‘improved support, better knowledge and improved health outcomes’ (Ekeland et al. 2010, p.741). And, while ‘evidence about the clinical benefits of ICTs for managing chronic disease is limited’, such technologies have been found to improve ‘patient self-control’ (Garcia-Lizana and Sarria, 2007, p.p.62-64).
In line with the health responsibilisation agenda, many of these discourses focus on the self (self-healthcare, self-management, self-efficacy, self-control) and on the responsibility of patients to change their own behaviours and take better care of their own health. In relation to older adults living with complex health conditions, the health responsibilisation agenda with its focus on the self may be problematic in that it downplays the importance of social conditions, context, and the practicalities and complexities of everyday life (Maller, 2015). Weicht (2011) highlights how, within discourses of care, independence and self-sufficiency are ‘constructed as ideals of human existence’ while being dependent ‘is seen as the expression of an inferior state of life’ (p.205). However, to self-manage their healthcare, older adults may be using health technologies in collaboration with other people, challenging such ideals and raising questions about the social context and relationships involved in their use. Previous studies have highlighted the importance of social context in relation to health (Wiltshire et al. 2018), asserting that ‘context is created by relationships with people’ (Frohlich et al. 2001, p.776) and have stressed the need to focus not only on the older people using the technologies, but also the experiences of others, including family members (Lindberg et al. 2013; Magnusson et al. 2004; Reeder et al. 2013).

There is evidence to suggest that relationships between patients, family carers and healthcare professionals are fundamental to the successful use of healthcare technologies, and that these technologies may establish or facilitate relations with others (Pols and Moser, 2009, p.174). Oudshoorn’s (2008) work, for example, highlights the ‘invisible work’ of carers and healthcare professionals which enable patients to play an active role in their healthcare through the use of technologies (p.272). In other work, Correa and Domènech (2013) argue that ‘family life changes once technology is introduced’ into the home and that health
technologies ‘play an active role in sustaining family relationships’ and that (p.p.3072-3082).

In addition to patients and family carers, Segrelles-Calvo et al. (2016) found that the advantages of healthcare technologies extended to healthcare professionals. In this paper, we contribute to this growing body of work by exploring the importance of relationships and interactions between patients, family carers and healthcare professionals in the use of CHTs to support older people with LTCs living at home within the programme. In doing so, we suggest the need for a more nuanced approach to responsibilisation and self-management for older people living with complex health conditions.

The LCIA Test Bed programme

Over a 30 month period from 2016 to 2018, the LCIA Test Bed implemented and evaluated a combination of innovative technologies and practices aimed at supporting older people (defined here as those aged 55+) with long-term conditions to remain well in the community, avoiding unnecessary hospital admissions (Milligan, et. al. 2018). With an aim of reducing pressure on primary and tertiary care, the CHTs used in the programme were designed to improve patient activation and better enable older adults with LTCs to self-manage their healthcare at home. Older people with a range of LTCs were recruited into one of three cohorts dependent on their level of risk of hospital admission.

As explained above, the programme was delivered through two neighbouring sites in the northwest of England. It offered an opportunity for local organisations working within the two sites to work together to address current healthcare challenges in the area by supporting
older people to better manage their own care at home. There are a number of healthcare challenges specific to the geographical area of the programme, including:

- A higher percentage of older people compared with the average across England (ONS, 2016);
- Lower life expectancy than in the rest of the country, with more people than the national average with three or more Long Term Conditions (LTCs) (Bradshaw, 2017);
- A significant dispersed and rural population.

While the overall programme evaluation took a two-phased approach, in this paper we are focusing only on the qualitative findings from one cohort of patients (those most at risk of hospital admission) and how they helped us to understand the impact of this combinatorial approach on the lives of older people with LTCs. The data consists of transcripts and researcher field notes from qualitative interviews with one of the four patient cohorts involved in the evaluation (see below), along with staff interviews and focus groups.

**Methods**

The data discussed in this paper was collected between December 2016 and March 2018. The evaluation received ethics approval from Lancaster University’s Faculty of Health and Medicine Research Ethics Committee (Reference: FHMREC16025) and the Health Research Authority (IRAS Project ID: 208395).

*Patient observational interviews*
Two sequential observational interviews were undertaken with each patient participating in the qualitative phase of the evaluation, taking place over the six-month period of the intervention: a) in the first month of participating in the programme; and b) during the final month (month six). Observational interviews entailed observation of participants’ homes, how the CHTs were organised within the home, and the ways in which participants engaged with the technologies. This interview approach and home-based setting facilitated: a detailed understanding of participants’ health status, health knowledge and activation prior to their participation in the programme; how they engaged with the service and used the technology within their own homes; and whether this changed over time.

In this paper, we focus on findings from Cohort 1, which included patients with a risk of hospital admission greater than 25% and who experienced the long-term conditions COPD or heart failure. We focus here on this group of patients because these participants were the most frail of the group and therefore those who were most likely, should the programme be successful, to benefit from the ability to self-manage their health. As a result of their complex health care needs, this is also the cohort for whom the programme was likely to be most challenging. Findings from this cohort suggest the need for a more nuanced approach to responsibilisation and self-management for older people living with complex health conditions.

Patients meeting the Cohort 1 criteria were invited to participate in the programme by their healthcare providers. Where possible, purposive sampling was applied to consider gender,
age, LTC, living status, and the CHTs being used. An overview of patient participant demographics is presented in Table 1.

The patient data referred to in this paper draw on 45 observational interview transcripts conducted with twenty-four patients, and accompanying researcher field notes. These data comprised 24 initial interviews and 21 follow-up interviews. Three patients who took part in the initial interview subsequently withdrew from the programme before the follow-up interview could be conducted.

Staff member interviews and focus groups

Members of staff across the two sites completed regular diaries throughout the programme, and were later invited to take part in either an interview or focus group to explore the impact of the programme on daily working practices. For all activities, participant information sheets were provided and informed consent was gained. The staff data referred to in this paper draw on one interview and two focus group transcripts conducted with eight staff members across the two Test Bed sites, including: two advanced nurse practitioners; a clinical care coordinator; a GP; a practice nurse; a primary care assistant; and a project lead and a team leader (non-clinical).

Data analysis

All qualitative data were audio recorded using an encrypting digital voice recorder. In the process of transcription, names of participants were anonymized and any identifying features
removed or coded. Pseudonyms are used in this paper for the patient participants. All qualitative data were analysed thematically with the aid of Atlas.ti qualitative software. Identification of emerging themes and initial coding was undertaken by the field researcher (SV) then shared and agreed during evaluation team data analysis workshops. The coding framework was also shared with the Evaluation advisory board. The major codes emerging from the data were presented in two deliberative panels comprising key stakeholders including older patients, family carers, clinicians and other healthcare staff and technology providers, for fine-tuning and final verification.

Table 1. Patient participant demographics

All participants in this cohort except one were retired, with all identifying as White British; this lack of ethnic diversity reflects the characteristic of the population of the sites where, in 2011, 99% of people aged 55 years or over defined their ethnicity as White (ONS, 2017). This inevitably biases the results of the programme evaluation to a specific demographic.

Findings

Health responsibilisation and self-management

The use of CHTs in the programme encouraged health responsibilisation and improved the management of health among patients with the most complex healthcare needs and highest risk of hospital admission (Cohort 1). The provision and availability of health-related
information through the CHTs was a valuable factor in this. The CHTs offered to patients in this cohort featured information in the form of LTC-specific tips and videos built into the technology protocol. The CHTs provided patients with access to their readings, and they valued being able to look back at this data. A limitation of the CHTs was that they only provided access to the previous 28 days’ data, and some participants began to keep their own additional paper records, which often continued beyond their participation in the programme (see Figure 2). Other data received by patients included automated survey results and traffic-light colour-coded messages, which many participants found to be useful and reassuring:

Just the other day I had a [...] traffic-light system [message] – red, amber and green – and it came back I’m on green, I’m okay, my heart failure’s, you know, in control, the medication’s working, so... that was the best bit, you know, knowing that things are all right. I mean there are days you feel a bit, you know, a bit off and you’re wondering are things okay, but it’s nice to have this telling you that [you are OK].

(Robert, patient interview 1)

Figure 2. Example of a patient’s own additional paper records

The use of CHTs resulted in patients learning about their own particular LTCs and, as a result, many developed better knowledge about and understanding of their health condition, resulting in their feeling better able to manage their LTC. Patients described learning about their blood pressure, including what is a good reading and how to better control it. Other learning valued by participants related to diet and exercise, as well as the importance of drinking plenty of fluids. Margaret, for example, noted how the technology provided
information about ‘how much exercise you can do, what you can eat [and] they cooked a meal that’s good for you when you’ve had heart problems’, all of which she found very useful.

Barbara, who suffered from anxiety and COPD explained that the technology helped her to understand why she often feels the way she does, alleviating her anxiety: ‘If I’m feeling funny, I know the reason why – I didn’t before’.

Healthcare staff involved in the programme explained that patients ‘like learning about their own health and they recognise when things aren’t right’ (HCP focus group). While some people required higher levels of support, HCPs felt that the vast majority of patients and carers got on well with the CHTs, citing examples of patients and family carers developing knowledge, skills and confidence to better manage their health conditions:

The technology was a visual reminder and patients could see what they were doing right.

[One patient] was bad at taking her inhalers and things like that but when she took them correctly and then did her sats [oxygen saturation levels] she could see the benefits and how much better she had got, purely from the graphs […] [Patients with COPD] could see the signs and feel the signs and knew when to start their rescue medication.

(HCP, focus group)

The learning facilitated through the use of CHTs had a positive impact on the daily activities of a number of participants, which in turn had a positive impact on their quality of life:

I mean I went into town on… yesterday we went into town. Now it was very cold, wind was blowing, and you felt cold and I had to sit down quite a few times, but I learnt that off one of the videos that was on the machine. If you feel out of breath, sit down. I mean
I did get to the stage – I’ll be honest with you – that I didn’t feel like going into town, I didn’t feel like going out of the house, but I said to my wife, ‘Right, we’re going in town, we’re going to get some stuff today.’

(John, patient interview 1)

John’s example illustrates how reassurance and increased health-related confidence can have a positive impact on the choices older people feel able to make regarding their daily activities. This reassurance saw patients engage with the CHT even when not required to. For example, participants were not required to submit their readings at the weekend; however, many chose to do so for their own information and peace of mind. In addition to the readings required at one time point on weekdays, patients often took additional readings at other times of day to check on their health and wellbeing. Robert explained he was attending an event at the weekend related to his hobby, and would use the healthcare technology to take additional readings before setting off on the long drive.

In fact I’m away this weekend […] going down on the Saturday and stopping overnight at [a hotel] […] I’m not exactly looking forward to the drive: you know, I don’t know how I’m gonna feel […] I’ll most likely take [my readings] on Saturday morning […] It won’t stop me going, put it that way whatever it says. But if they’re fairly normal, you know, then I might feel in a better frame of mind for the day like, you know.

(Robert, patient interview 2)

Examples within the data of participants choosing to monitor their own health status, even when not required to by the programme, illustrate how the CHTs encouraged participants to increase their own awareness and knowledge of their health conditions.
In addition to the information and feedback received through the CHTs, participants placed importance on the information and feedback received from healthcare professionals (HCPs). This was sometimes received during telephone conversations, and other times during face-to-face appointments:

When I went to see [my GP] he said, ‘Your readings on the blood pressure,’ he said, ‘I’m really, really impressed with them.’ That’s what he told me. He said, ‘They are brilliant for a bloke of your age. They’re well within the parameters’ [...] they used to be up in 170 over something, now they’re about… 120 [...] Bottom one’s usually between 60 and 70, you know, and he said for me that’s very good.

(Richard, patient interview 2)

It is therefore important to note that patients did not use the CHTs in isolation from other people. Family carers were often involved in the taking and submitting of patient readings each morning and healthcare staff explained that, for a lot of patients, ‘it’s the family members that are actually doing it’ (Staff focus group). In the early stages of participation in the programme, the majority of patients living with a family member worked together to use the CHTs. For some patients, support from a family carer was essential to their participation in the programme. Dorothy, for example, explained that in the early days of the programme, it was important that her son was able to help her because, on her own, she was not sure she
would ‘do it right’. Similarly, Gary said ‘it wouldn’t have been so easy for me to do it’ without the help and support of his wife.

Patients and family carers used CHTs alongside HCPs, and these relationships were fundamental to the successful use of the CHTs in the programme. The CHTs enabled HCPs to have more contact and connections with their patients, with many welcoming the added diversity to their role as a result of the programme:

I’ve enjoyed the contact with patients and the feeling that you’re actually helping them, aren’t you, to manage their illness? [...] It’s actually nice to talk to people about how they’re managing on a day to day basis.

(HCP, focus group)

The Test Bed programme brought with it changing working practices for HCPs, with tasks including: monitoring patient data and looking for trends; addressing alerts when patient data is outside of normal parameters; ongoing revision of individual patient settings, so system parameters reflect what is normal for an individual; providing support and reassurance to patients and family carers about their data and using the technologies; checking patient data against patient records (on a different system); and following up missing patient data where expected readings are not received. Staff were often required to make numerous telephone calls each day to ensure the appropriate and safe monitoring of patients taking part in the programme. An important part of the working day during the programme was therefore talking with patients and family carers and HCPs explained that acquiring ‘personal
knowledge’ about patients and family carers was crucial for understanding the circumstances in which people were using the CHTs.

For many patients, the programme reinforced the importance of key healthcare staff in the management of their long-term conditions. Key members of staff cited by patients included community matrons, consultants, GPs, pulmonary rehabilitation teams and respiratory nurses. Relationships with key members of staff were particularly important when patients first began to use the technologies and their individual data parameters were being established. Charles and his wife explained the importance of their GP’s reassurance when, in the first few days of the programme, they received messages about his low pulse:

Family carer  I think it was an automated [message]. Yeah, ‘Your pulse is low, please ring your surgery’ […]

Interviewer  How do you feel about the fact, you know, you’ve got a reading and it’s quite low? Does it make you feel anxious or are you okay about that?

Patient  Well, it didn’t... it didn’t because we got this message back from [the nurse] saying [our GP] had told us not to panic. Or told me not to panic.

Interviewer  And so did you find that quite reassuring?

Patient  Yes.

(Charles, patient interview 1)

Data suggest that the use of CHTs underlines the importance of the relationships between patients, family carers and HCPs. For the vast majority of patients and family carers, access to healthcare and continuity of care were concerns, with many having experienced difficulties securing a GP appointment:
We never see [our own GP] because he only works two half-days a week and we can
never get in. They just won’t give you an appointment for him. The only way I can get an
appointment with [him] is to ask for a telephone appointment with [him]. And then he
rings me and he’ll make me an appointment [...] Nobody on the desk will give me an
appointment with him.

(Larry, patient interview 2)

Many discussions with patients and family carers were dominated by this topic, with
participants expressing anxiety and discussing the various strategies they use to negotiate
issues of waiting lists for appointments, gatekeeping receptionists, and a lack of continuity of
care. It is particularly interesting that these experiences appear to have motivated some
patients and family carers to take part in the programme, increasing their motivation to use
CHTs.

Participants liked that the technologies brought them closer to healthcare professionals.
Edward’s wife explained that the programme ‘has been great ... brilliant [because of] the
different callers and the different interaction’. Similarly, for Gary and his wife, the programme
increased their contact with healthcare professionals, which was important to them because
they had very little family support and Gary’s wife was suffering from depression and
struggling to cope with his complex needs. Gary believed the programme had given them
‘some security’, while his wife described ‘having this feeling that you’re not on your own ... that you’re only a telephone call away to somebody’.
Shared health responsibilisation

The encouragement of health responsibilisation and self-management was not achieved solely through the individual patient’s use of the CHTs. Instead, our findings suggest that the CHTs encouraged and enabled a shared responsibilisation between patients, family carers and HCPs. Many patients and family carers described feeling cared for and cared about because of their participation in the programme. Participant comments included that it was ‘Nice to know someone is at the other end’ (Nancy), gaining peace of mind because the staff ‘genuinely cared’ about them (Gary), and how ‘Every day someone is not just looking at the data but is thinking about me’ (Linda). Kathleen discussed how this care was particularly important to her because of her heart condition and the fact she lives alone:

> It’s like you know there’s somebody gonna be at the other end of the phone and, even if they’re shut, you get through to that and they get you through and they see those walk-in places. They connect you with them. There’s always a connection there, you see. And without [the technology] you’re not [connected] because you can never get hold of your GP. And with me, with it being my heart, it makes me feel secure...just knowing that the care is at the other end, you know?

(Kathleen, patient interview 2)

Despite feeling cared for and looked after, patients and family carers adopted active, as opposed to passive, roles in their use of the CHTs. This included the monitoring of data specific to the patient’s health condition, for example blood oxygen levels, blood pressure, temperature and weight. Patients did not take their daily healthcare readings for the sole
purpose of remote monitoring by HCPs; instead they were active agents in this monitoring. Participants were aware that HCPs had access to the data arising from their daily readings and would be monitoring these readings; indeed, for many patients, the knowledge they would be monitored by HCPs was an important factor in their decision to take part in the programme. However, patients also referred to monitoring their own data for information, patterns and peace of mind:

[The programme has] helped me focus on my health really because you just kind of... blood pressure was just a number that you got when you turned up at the doctor’s, and it’s quite interesting to see a sort of... a daily sort of figure. Yeah, I think actually what [the programme] has done is prompted me into starting this diary [see Figure 3] and that, for me, is incredibly useful.

(Joyce, patient interview 2)

Figure 3: Excerpt from Joyce’s diary records

Importantly, our findings suggest that confidence and peace of mind were also important to the HCPs involved in the delivery of the programme. The monitoring of patient data and addressing alerts increased levels of job satisfaction for many as a result of knowing that patients were stable and future issues were being prevented:

It’s not just patient reassurance, it’s ours as well, because we do have very poorly patients and it has given us the confidence to know that what we’re doing is right, and if something isn’t working, like medication, we can change it.

(HCP, focus group)
A significant majority of Cohort 1 patients felt more confident about their health condition by the end of their participation in the programme. This increase in health-related confidence was attributable to the relationships and social interactions facilitated by the CHTs, which enabled patients, family carers and HCPs to each adopt active roles in the management of patient healthcare.

Patients did not feel solely responsible for managing their health condition; instead, the programme resulted in patients and their family carers feeling better connected to HCPs, and part of a shared approach to managing the patient’s LTC. The dynamics between patients, family carers and HCPs combined to create a sense of reassurance and shared responsibility, which resulted in increased health-related confidence in this cohort. When asked in the final interview to sum up their experience of the programme, the majority of patients and family carers referred to ‘reassurance’ and ‘confidence’ (see quote below). For many participants, living with a LTC created daily anxieties about their health which informed what they felt able to do. Patients and family carers noted how shared responsibility for their health alleviated these anxieties, often referring to the CHTs as ‘an early warning system’ that was able to inform them if anything was wrong with their health. Participant comments included ‘knowing that things were alright’ as a result of the programme (Gary) and the importance of ‘know[ing] if something was wrong’ (Richard). Margaret, who has heart failure, explained that as a result of the programme she felt able to be more active:

Patient [The programme] gave me peace of mind in a sense in most things [...] It’s like a back-up on your health. You don’t think of your health, but if
you’ve had a bad op, then you start doing if you’re getting older, it starts to come into your mind more, doesn’t it? [...] 

**Interviewer** And when you say that without the technology you think you’d have been more wary doing things, does that mean that, with the technology, you think you were more active?

**Patient** I do, yeah, because it gives you the confidence to carry on, because things are running normally.

**Interviewer** And how do you feel now? Do you feel like you’ve continued to keep that level of activity?

**Patient** Yes. Yeah, probably, because now things are feeling better and [heart failure] is not the first thing that I think of when I wake up in a morning. It’s not the first thing that’s in my head now sort of thing.

(Margaret, patient interview 2)

In addition to patient reassurance and confidence, our findings show that this is equally important for the health and wellbeing of the family carer, with evidence that the CHTs helped to alleviate carer burden. In their follow-up interview, Paul and his wife explained how they felt much more confident and less anxious about their situation as a result of their participation in the programme:

**Patient** To be checked every morn-... every day on that [device] and being able through the pad to compare it with the last seven days and then the last 28 days is very reassuring [...] You know that you’re sailing along on a decent wind.

**Family carer** And there’s somebody at the other end who are checking [...]
Patient We’ve been right royally treated [...] We really have. You see [my wife] had to go away because [she] was suffering from anxiety and depression.

Family carer Depression, and I needed a break [...] 

Patient We’ve felt supported [in the programme] ... all the time, yeah.

Family carer You know there’s somebody there

(Paul, patient interview 2)

Despite the additional tasks associated with the use of CHTs, HCPs cited examples of being able to better manage and prioritise workloads:

It has cut back on our home visits as well because we can see what we want to without going out to each person. We used to go out probably every two weeks [...] Now, if people are quite stable, we’ve cut that back to when they want us. We just keep an eye on them on Motiva [...] which can save a 25-minute drive each way.

(HCP, interview)

Our findings highlight the potential of CHTs to alleviate pressure on HCPs, including GPs, allowing them to focus on patients with the most pressing needs:

The Advanced Nurse Practitioners [at this surgery] are under a lot of pressure doing triage shifts and face to face, so I thought [the programme] is something a bit different [...] It could be a bit different for a number of clinicians, couldn’t it? [...] I see it for myself as a doctor thinking: rather than doing all the same things, telemedicine is a way forward to cope with the lack of clinicians, doctors and nurses.
Discussion

In recent years, research focusing on the use of health technologies has suggested their potential to contribute to and transform healthcare for older adults. Cited benefits have included improved self-healthcare (Chiarini et al. 2013) and self-control (Garcia-Lizana and Sarria, 2007), along with increased patient motivation for health self-management (Gaikwad and Warren, 2009). Our findings support and contribute to these previous findings, with the majority of patients feeling more confident about the management of their health condition as a result of the programme. However, many of these discourses focus on the self (self-healthcare, self-management, self-efficacy, self-control) and on the responsibility of patients to change their own behaviours and take better care of their own health. As discussed earlier, this focus on the self is problematic because it downplays the importance of social conditions, context, and the practicalities and complexities of everyday life (Maller, 2015) and the fact that older adults may be using health technologies in collaboration with other people, rather than alone.

Findings from our study show that the use of CHTs encouraged health responsibilisation and the improved management of patient health. However, importantly, patients did not use the CHTs in isolation from other people and our data show how relationships between patients, family carers and HCPs were fundamental to the successful use of the technologies, supporting the findings of previous work (Correa and Domènech, 2013; Oudshoorn, 2008; Pols and Moser, 2009). Patients felt more confident about their health condition by the end.
of their participation in the programme. The increase in health-related confidence can be understood in relation to the co-management of patient health facilitated by the CHTs. This co-management of patient health saw patients, family carers and HCPs adopt active roles in the management of patient healthcare. The distinction between self-management and co-management is an important one. Patients did not feel solely responsible for the task of managing their health condition, as the term self-management might suggest; instead, the programme resulted in patients and family carers feeling better connected to healthcare professionals, and part of a shared approach to managing the patient’s LTC. The CHTs enabled patients with more complex health needs to share responsibility for, and co-manage, their health with family carers and HCPs, something that they had not previously had the opportunity to do. Therefore, rather than self-management, the increase in health-related confidence in the participants was attributable to the co-management of patient health facilitated by the CHTs.

The provision and availability of health-related information was a valuable factor in the co-management of patient health in the programme. This sharing of information and feedback took place in a variety of ways including directly through the CHTs, phone calls, and face-to-face meetings, involving patients, family carers and HCPs alike. For patients and family carers, the information and feedback enabled them to increase their knowledge of LTCs, having a positive impact on daily activities and quality of life. However, this exchange of information was not limited only to patients and family carers; it was a two-way exchange in which HCPs also learned and developed their knowledge about patients’ conditions and healthcare.
Existing research indicates that monitoring has an important role to play within telehealth (Barlow et al., 2007; Paré et al., 2007), and monitoring was an important aspect of our data. Again, however, our findings suggest an important distinction: between co-monitoring and monitoring. We found that patients, family carers and healthcare professionals engaged together in the co-monitoring of patient data, adopting active roles in the process, as opposed to patients being passively monitored by healthcare staff as the term monitoring might suggest. Although aware that HCPs had access to their daily readings, patients also monitored their own data for information, patterns and peace of mind.

This paper contributes to knowledge and understanding regarding the role of monitoring in relation to the management of older patients’ healthcare in the home, and explores ‘new questions beyond those of clinical and cost-effectiveness’ (Ekeland et al. 2010, p.741). Lindberg et al. (2013) found that digital health technologies are often used as a tool for ‘communication between patients, family members, and healthcare professionals’ (p.27). Our findings suggest that CHTs enable more than communication; rather, the dynamics of co-management and co-monitoring between patient, family carer and HCPs combine to create a sense of reassurance and shared responsibility, resulting in increased health-related confidence. This co-management and co-monitoring alleviated the anxieties of living with a LTC, by providing ‘an early warning system’ to patients, family carers and HCPs.

Existing literature identifies a need for research to focus not only on the patients using the technologies, but also their immediate family members (Lindberg et al. 2013; Magnusson et al. 2004; Reeder et al. 2013). Through our use of observational interviews with patients in their own homes, we have been able to explore the experiences of patients and family carers
using CHTs, as well as the perspective of HCPs involved in their use. It is evident that co-
management and co-monitoring were beneficial for family carers and HCPs, as well as
patients. With many family carers negotiating the demands of caring responsibilities and their
own health conditions, the reassurance and confidence extended to carers and helped to
alleviate carer burden. For HCPs, our data indicate that they also benefited from the social
interaction with patients and family carers facilitated by the CHTs. Our findings suggest that
HCPs felt better connected to their patients, and were able to better manage and prioritise
their workloads, resulting in the alleviation of pressure and the ability to focus on patients
with the most pressing needs.

Our findings suggest that, through the use of CHTs, older adults are able to take on some
responsibility for their own healthcare. However, as a result of frailty and complex LTCs, there
comes a point for some where shared input and support is needed from family carers and
healthcare professionals. Relationships between patients, family carers and healthcare
professionals are an important facilitator in the co-management of health for older adults
using digital health technologies. The use of such technologies reinforces the importance of
key healthcare staff in the management of patients’ long-term conditions, and underlines the
significance of these relationships. The technologies can be seen as bringing these parties
closer together with the shared goal of improving health management. The CHTs actively
enhanced the relationships between patients, family carers and healthcare professionals
providing an important foundation for co-management and co-monitoring, resulting in
patients and family carers feeling better cared for.
Conclusion

In the LCIA Test Bed programme, the relationships between patients, family carers and healthcare professionals, and the dynamics of co-management and co-monitoring, combined to create a sense of reassurance and shared responsibility for all parties. The use of CHTs in the programme encouraged health responsibilisation; however, this was not through individual healthcare responsibilisation, but through the encouragement of greater shared responsibilisation in which monitoring was shared between the patient, family carer and clinical staff. While there is an increasing focus on the use of CHTs to encourage the self-management of healthcare for older people, our findings suggest that co-management may be a more successful model of care for patients, carers and clinicians. By focusing on co-management – and recognising the potential of CHTs to facilitate this approach – there is potential to increase patient confidence in managing their health condition, reduce carer burden, and enhance clinician satisfaction in their work roles.

This paper demonstrates how integrated care supported by CHTs can encourage older adults to take responsibility for their own care through an enhanced form of shared responsibility. While neoliberal agendas are focused on self-management and self-responsibility of one’s own health care, with technology as a facilitator of this, our evidence suggests that the successful use of CHTs for older people with LTCs may instead be rooted in co-management. Our findings suggest that, for patients in this group, the successful use of CHTs requires shared input and support from healthcare professionals. While cost saving is therefore unlikely to be a benefit that can be claimed in the short term, further research is needed to understand the
longer term benefits and potential cost savings of using CHTs with older adults with the most complex health care needs.

Our work is an example of the need to take a more nuanced approach to health responsibilisation in which older adults with LTCs can take on some aspects of responsibilisation, within the context of co-management. Such an approach may also counter the binary approach to dependency and independence often present within discourses of care for older people, in which dependency ‘is seen as the expression of an inferior state of life’ (Weicht, 2011, p.205).

References


Table and Figure captions

Table 1. Patient participant demographics

Figure 1. The Motiva system and accompanying technology accessories used in the LCIA Test Bed

Figure 2. Example of a patient’s own additional paper records

Figure 3. Excerpt from Joyce’s diary records