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**Self Management and Telehealth; Lessons learnt from the evaluation of a Dorset telehealth programme.**

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## **Self Management and Telehealth**

### **Abstract**

#### Background.

Telehealth is one of the ways that the UK health service is seeking to improve the care for people living with a long term condition. One of the aims of its 3 Million Lives programme is to achieve more effective self care.

A lot of the research into telehealth has focused on cost effectiveness, effective working practices and barriers to adoption. Patient experience is frequently discussed in terms of the reassurance experienced from the support offered through telehealth systems.

#### Objective.

This study reports the qualitative findings of an evaluation of a local telehealth programme introduced by the Dorset Clinical Commissioning Group for patients with COPD or CHF.

#### Methods,

29 patients participated in telephone interviews, held at the start of their telehealth experience and after they had been using the system for 3 months. Interviewees included people who had graduated from the telehealth system, or had asked to come off it. Healthcare professionals, mainly nurses, involved in the management of patients using the system were also interviewed.

#### Results.

The evaluation found that patients were using the telehealth equipment, often beyond the parameters of the formal telehealth scheme, to develop effective self management techniques.

#### Conclusions.

These results have implications for policy makers as removing the equipment when patients graduate as being self managing may mean removing the very tools that make that self management possible.

### **Key Points for Decision Makers**

Patients make use of telehealth equipment outside of healthcare professionals programmes to develop their own self management strategies.

Removing telehealth equipment from patients can remove essential elements of patients self management.

## **Self Management and Telehealth**

### **Background**

In the UK around 15 million people live with a long term health condition of one type or another, usually adversely affecting the person's quality of life DH (1), The UK Department of Health has tasked NHS England, through the NHS Outcomes Framework(2), to 'Enhance the quality of life for people with long term conditions'.

One of the ways the UK National Health Service (NHS) hopes to achieve this aim is through telehealth and telecare, and therefore the Whole System Demonstrator (WSD) programme was set up in 2008(3). This was a large scale randomised control trial to assess the benefits of telehealth and involved 3,030 patients living with either Chronic Heart Failure (CHF) or Chronic Obstructive Pulmonary Disease (COPD) or both, across three geographical areas, and 238 primary care providers (GP practices)

Telehealth is being delivered through the 3millionlives programme, launched in January 2012. The Minister of State for Care Services explained that the programme aimed to 'transform service delivery for people with long term conditions ... by utilising telehealth and telecare within (UK) health and social care services'(4).

Benefits of telehealth claimed by the 3millionlives programme(3) include 'more effective self care' and 'increased confidence to manage own health'. Benefits for healthcare professionals include being better informed about a patient's health status through the provision of regular data, and that people with long term conditions will become more involved in managing their own healthcare and therefore less dependent on the HCP.

The terms self management and self care tend to be used interchangeably in the literature, and much of the research carried out has focused on the role of the clinician in instigating or supporting self management. According to The Health Foundation 'self-management or self-care includes eating well, exercising, taking medicines, keeping in good mental health, watching for changes, coping if symptoms worsen and knowing when to seek professional help'(5). Whilst there is much discussion about the opportunities telehealth affords for improving patient empowerment as Klecun-Dabrowska(6) identifies assessing this is challenging and often not done.

As part of the 3millionlives National Health Service initiative Dorset Clinical Commissioning Group (CCG) set up its own telehealth service for people with Chronic Obstructive Pulmonary Disease (COPD), and requested an evaluation be carried out. This paper discusses the findings

of that evaluation that may be of interest to a wider audience. Usual research ethics principles of good practice such as informed consent and confidentiality were applied to the study in relation to the study participants even though this was a service evaluation.

## **Methods**

The telehealth system chosen involved a telehealth engineer installing equipment in the patient's home, comprising of monitoring equipment for blood pressure, weight, temperature and oxygen saturation levels and a tablet style computer that recorded readings from the monitoring equipment. The software took the patient through a set process which included carrying out monitoring using the equipment and answering questions about how they were feeling, and relayed the results to the patient's keyworker, a healthcare professional (HCP) generally a nurse or other clinician. The HCP could send text-based messages to the patient through the system, but patients could not communicate with, or contact, their HCP through the telehealth system. The readings and answers were available to the HCP through their work computer. The HCP and patient were expected to agree goals and monitoring frequency as part of the setting up of the telehealth monitoring.

The evaluation ran over a 12 month period, and consisted of a questionnaire distributed via the telehealth system to patients, and telephone interviews with a purposive sample of patients who had given prior consent to being approached for feedback. The questionnaires mainly collected demographic information and satisfaction with the telehealth service. Focus groups and 1-1 interviews were also held with HCPs who were implementing the telehealth service to explore how they were managing the service and how it affected their care planning. Because of work commitments only one focus group with 4 participants could be arranged, and a further 6 telephone interviews were conducted.

This paper discusses some of the key findings of the qualitative element of the evaluation, especially in relation to the evaluation criteria that explored the extent to which the telehealth service supported patient empowerment. Although the authors make no claim that the feedback obtained in this service evaluation are transferable to other telehealth programmes some issues have arisen that we feel may be of interest to patients, HCPs and telehealth service commissioners and providers.

At the start of the evaluation period (July 2012) there were 77 patients already using the telehealth system. By the end (June 2013) this had increased to 335. A further 6 patients who had agreed to use telehealth monitoring, changed their minds and withdrew before starting.

Information was provided to the evaluation team in a pseudoanonymised format. The NHS(7) defines pseudonymisation as 'the process of replacing person identifiers in a dataset with other values (pseudonyms) available to the data user, from which the identities of individuals cannot be intrinsically inferred'. A reversible method was used so that the researchers could identify which patients they wished to contact to the CCG.

Consent to be contacted by the evaluation team was recorded by the HCP who initially set the patient up on telehealth. The evaluation team selected patients who had given their consent to be contacted to achieve a spread of geographical location, gender and age. The CCG was then asked to provide the name and telephone number for the selected participants. An initial phone call was made to the selected participants to explain the evaluation, and a convenient time agreed to call back to conduct the telephone interview. This allowed the participants' time to consider their decision about taking part in the evaluation. At the start of the telephone interview a consent script was used to obtain and record informed consent. No initial consent information was provided for 15% of telehealth users. A further 44% were recording as not giving consent, and 41% as consenting.

Interviews with participants took place in 2 phases. Phase 1 was ideally within 2 weeks of starting however for patients already using the equipment at the start of the period this was longer. Phase 2 was a follow up interview held about three months later. Some interviews were also undertaken with those who had not continued with telehealth; had graduated from telehealth or who had refused installation of telehealth equipment. In total 29 participants were interviewed in phase 1 with each interview talking an average of 10 minutes (range 4-22). Of these 24 were able to give a follow up interview. Of the other 5 three died before a follow up interview could be held, one had been admitted to hospital and one declined a further interview. Phase 2 interviews also lasted an average of 10 minutes (range 4-24). A semi structured approach was adopted, ensuring the same area were explored with each participant, but allowing the flexibility to follow up comments made, allow the participant to say what mattered to them, and to be responsive to each interviewee's individual circumstances and experiences. The interview brief is enclosed at appendix A.

The individual interviews and focus group interviews were recorded and transcribed before being analysed thematically with the support of NVivo10 qualitative data analysis software. Initially the data was analysed to identify information that explored the evaluation questions. It was then re-analysed using an inductive approach, to ensure that the richness of interview data obtained was not lost, and that important issues raised by

the participants were not overlooked. Rigour was established based on the principle of credibility, conformability and dependability(8, 9). The project assistant [LW] read each transcript and coded the data. These codes were then reviewed by the project manager [CB] and agreed. Further coding and re-coding led to the development of themes. Verbatim quotations were selected to support each of the themes identified, and random initials allocated as identifiers.

## Results

Patient interviewees were evenly split between men (n=16) and women (n=15).

Age range	60 or under	61-70	71-80	Over 80
No of patients	4	9	10	8
Primary diagnosis				
COPD	2	4	3	2
CHF	2	3	6	5
Co-morbidities				
0	3	2	5	3
1	1	4	4	3
2	2	2	1	1

Table 1. Overview of interviewees

Most people found the telehealth system easy to use, even if they did not have much prior experience with computers:

*"they came and installed it, the gentleman installed it, showed me what the what the set up was and I used it fine, it's so easy to use, y'know it's just straightforward."*[SH]

*"I'm not into computers or anything but I find it very easy".*[BK]

Not all the users were hesitant about computers, one patient in his 80s saying:

*"I'm quite a bit of a computer nut anyway so it isn't any um hardship for me to use a screen or anything".* [SL]

Some patients were reassured by knowing that their health was being monitored.

*"Well they're keeping an eye on me y'know, somebody's, I know somebody's watching all the time" [BB]*

*"I can talk to the ... y'know talk to it and tell them how ill I am, how I'm feeling and everything and they get back to me" [JK]*

Health care professionals were wary of medicalising patients, and one patient did comment on being disempowered by passively sending information through the system.

*"I just do the results and then I press send but that's all I was told to do. Well I go back on to the history and see what I was the week before most of the time it seems about the same .... my blood pressure goes up and down a bit but not by great leaps only sort of a few. I don't know what the readings should be anyway." [PK]*

Some patients however decided to take a more active role, using their readings, and the history from the telehealth system, to understand more about how they felt, and to support their decision making and self management strategies.

*"I like to know what's going on so the fact that I can look back at my readings and make comparisons is brilliant. And in a way that gives me confidence to move forward." [JT]*

Patients were working out how to maximise the benefits for themselves.

*"I've been using it once a week, and transfer the details to the community matron and my doctor but if I've felt unwell in the meantime then I've used it for my own sort of, to know what my sats are and how to deal with them, 'cos I'm quite up on the conditions that I've got at the moment so and regulate the medication if I have to so" [SR]*

*"if I do feel ill, I can go on that and I can look at my own readings rather than to start what you would call having what you would call going into a panic mode where your breathing would get um very very difficult and you would you start to panic so then you would be ringing an ambulance and now I can go on the machine and I can look at the readings and say well this is OK, this isn't that bad, I don't need to phone an ambulance, I just need to calm myself down" [SH]*

The educational opportunities afforded by the equipment were identified by some patients.

*"I mean every day is can be different unfortunately but um you get two days which are pretty good then you might get two days that are not so good but you know the pattern, you know that it's not going to stay awful all the time because of this machine teaches you that really. I was a very independent person before and I think this has given me back my independence because I can check my own blood pressure, my own temperature, and I know how to react if it's not right" [BK]*

*"the more you look into and the more you go along with your condition the more you feel comfortable about what works and what doesn't for you. And certainly [the telehealth system] has been part of that" [JT]*

Patient's didn't report they were being educated by their HCPs, although HCPs thought they were educating their patients . HCPs thought they were setting goals with patients, however most patients did not think they had been involved.

One HCP explained joint goal setting as:

*"I explain to them the reasons why they're going on it ... and I say it's for early detection of deterioration or to help us to increase the medication and get the, make sure the medication is suiting you and things like that so it's, the goals are set together" [HCP1]*

Others felt it was their role to set the goals:

*"it's knowing your patient really 'cos it's the nurse that will normally set the parameters and then go through them with the patient" [HCP2]*

Whilst the HCPs did talk about telehealth empowering patients, and their education role, how this was achieved was unclear.

*"I think generally if they're being monitored and you're doing visits anyway you do a lot of education with them and the whole point is empowering them to look after themselves, isn't it and know their condition" [HCP3]*

One explained that even before telehealth her practice had always promoted self-management:

*"I think with our patients we were always giving out self-management plans" [HCP4]*

Another commented:

*"I think some [patients] seem to be getting more used to what their observations should be for them" [HCP2]*

Most HCPs did not discuss how long patients would be 'on telehealth' although one did explain that:

*"I don't give them a time, I do obviously if they've got any concerns then I'll say to them this is our property in a nice sort of way and it could come out at any sort of time" [HCP5]*

## **Discussion**

Much previous the research into telehealth has focused on operational issues such as cost effectiveness (2, 10), effective working practices(11, 12) and barriers to adoption(13). Where patients' experiences were considered the focus was often on the reassurance afforded by using telehealth (14).

The contribution that telehealth can make to patients' self-management is seldom the main purpose of studies, but is acknowledged in many of the papers. A study undertaken in Scotland(15) collected qualitative data from 38 patients. They found that *'participants found it helpful to know about their weight, blood pressure and oxygen saturation score and to have the facility to monitor data trends over time'*. The researchers coded this into a theme of information, support and reassurance.

A qualitative study undertaken in Wales(16) with 22 telehealth users found that patients felt more involved in their care. They also noted that some of the people in their study were making adhoc use of the equipment, outside of the agreed monitoring regime, which had led to improved recognition of changes in their condition.

One study that did specifically explore how telehealth impacted on self management(17), was carried out in Taipei with people with hypertension or diabetes or both. This used a qualitative approach comprising a focus group with 12 participants and a further 8 individual interviews. This found that most participants felt telehealth had improved their self care by giving them access to accurate and immediate information which allowed them to make changes to their lifestyle and eating habits in response.

In our study patients fell into two distinct groups. One group of patients were happy that the nurse could 'keep an eye' on them and intervene if necessary. The other group were proactively using the readings to improve their own understanding and to decide when they needed an intervention of some sort, either independently, for example to do their own breathing exercises, or to contact their HCP to ask for help.

The HCPs involved in our evaluation thought they had a role in educating patients, however the nature of this role was not clear. Patients who were improving their self-management skills all discussed how they were using the readings they took, but none mentioned that their HCP had a role in their development.

Our evaluation did not seek to explore the characteristics of the people in each group, although some mentioned that they had experience of living with their condition for a long time, and others had previously been proactive in buying their own monitoring equipment where it was available (e.g blood pressure monitors). One of the limitations of this service evaluation is that it had a limited remit. The findings reported here were not fully explained. This is an area that would benefit from research to better understand the process that is happening, and to explore ways that the health services can support more people to use telehealth to promote self management rather than promote HCP management.

This also has implications for the concept of people 'coming off telehealth'. In keeping with most telehealth programmes patients were expected to 'graduate' from the programme when they were effectively self managing. Graduation includes removing the equipment so that it can be used for a new patient. Paget et al(16) found that at the end of their 12 week telehealth intervention most people did not want to have the equipment taken out of their home again. One patient being quoted as saying "Telehealth has become a part of my everyday life". The authors acknowledge that majority of patients had become so dependent on the system that it had to be removed gradually.

## **Conclusion**

The process by which some people with long term conditions use telehealth to become effective self-managers is not clear, nor is the role of the HCP in that process. Better understanding of that process would enable HCPs to offer appropriate support to patients to improve their self-management ability.

If the monitoring equipment is what is supporting self management the concept of 'coming off' telehealth needs to be rethought. The HCP contact may well be able to be reduced or withdrawn however removing the monitoring element of the equipment will also remove the very tools essential to continued self management.

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Carol Bond was responsible for the design and management of the evaluation and for drafting the paper and is the guarantor for the study.

Louise Worswick was responsible for conducting interviews and data analysis, and contributed to the drafting of the paper.

### *Conflicts of Interest*

There were no conflicts of interest for either author.

The funder had no direct involvement in carrying out the evaluation or the preparation of the paper.

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Appendix A

Patient Interviews

Semi structured interview schedule

Confirm consent for recording

Check length of time on telehealth

Tell me about how you've been getting on with using telehealth  
(explore successes and problems)

How does it fit into your daily routine?  
(comfortable fit or disruptive)

What happens to your results?  
(explore feedback and communications)

How has your care changed since going onto telehealth?  
(explore satisfaction with changes?)

When you were discussing going onto telehealth were the reasons discussed with you?  
(explore how was goal setting was done)

Can you sum up how you feel about telehealth so far?