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RESEARCH PAPER

Continuity, but at what cost? The impact of telemonitoring COPD on continuities of care: a qualitative study

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Abstract

Background: Continuity of care is widely regarded as an important marker of quality in the management of patients with long-term conditions. New services that integrate telemonitoring into care pathways have potential to change aspects of continuity in both positive and negative ways.

Aims: A telemonitoring service for patients with chronic obstructive pulmonary disease (COPD) was introduced in Lothian, Scotland, in 2009. A qualitative study, nested within the TELESCOT COPD randomised control trial, was undertaken to explore the views of patients and professionals on telemonitoring. The perceived impact of telemonitoring on continuity of care was investigated as part of the research.

Methods: Semi-structured interviews were undertaken with 38 patients (47% male, mean age 67.5 years). A maximum variation sample in relation to age, sex, socio-economic background, disease severity, and compliance with telemonitoring was recruited. Thirty-two stakeholders (healthcare professionals and managers) were interviewed. Transcribed coded data were analysed thematically using the framework approach. Interpretation was supported by multidisciplinary discussion.

Results: Patients and healthcare professionals considered that relationship-based continuity of care was important in the delivery of telemonitoring services. Managers placed emphasis on improved continuity of clinical management as a means of reducing healthcare costs. However, professionals described many operational challenges arising from the 'bolting-on' of telemonitoring provision to existing usual care provision which, they considered, resulted in the proliferation of additional managerial discontinuities.

Conclusions: Managers and healthcare professionals face major challenges in meeting demands for both relationship continuity and continuity of clinical management in the development of telemonitoring services.

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Introduction

Policy makers and healthcare professionals have emphasised the importance of continuity of care, although precisely what is meant by this term is open to interpretation.[1,2] Increasingly, discussion has centred on two types of continuity of care: 'relationship continuity', a continuous caring relationship with a clinician, and 'continuity of clinical management' including providing and sharing information, care planning, and coordination of care.[3]

Sustained continuity of care improves quality of life and reduces hospitalisations for patients with long-term conditions.[4] There is, however, growing concern over the cost of continuity, both in terms of sustaining long-term patient-practitioner relationships and of providing 'seamless care'. Of particular concern is the future sustainability of current clinician-centred models of care management for patients with long-term conditions.[5]

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Patient self-management is increasingly promoted as a means of redistributing both the responsibility and cost of healthcare provision for people living with long-term health conditions. Policy makers and healthcare planners are adopting telemonitoring technologies* to support patient self-management as a means of both 'minimising unnecessary face-to-face contact with health services' and cutting costs.[6,7] However, there are concerns regarding how telemonitoring fits with existing practice and services.[8] Implementation of 'stand-alone' telemetric systems may challenge continuity of clinical management which, in turn, undermines continuity within patient-practitioner relationships.

In 2009, NHS Lothian set up a telemonitoring service for people with chronic obstructive pulmonary disease (COPD) with three aims: (1) to prevent hospital admissions resulting from delayed management of exacerbations; (2) to foster increased patient self-management of their condition; and (3) as a result of both these objectives to reduce healthcare costs.

The telemonitoring service used the Intel Health Guide (IHG)[9] which enabled patients to assess their symptoms using an online touch-screen questionnaire. Linked pulse oximeter, peak flow meter and electronic weighing scales transmitted physiological measurements to the device either directly or using Bluetooth® technology. Patients were instructed to complete the questionnaire and measure oxygen saturation daily, and to use the peak flow device and scales on a weekly basis. Broadband Internet, installed in patients' homes, transmitted data from the device to remote monitoring centres.

The four geographical regions of Lothian adopted different models of monitoring incoming data for patients in their catchment area. The majority of patients were looked after by community respiratory physiotherapists or by community nurses providing anticipatory care services, with the remainder monitored by practice administrative staff who referred to a general practitioner (GP) for advice on management if necessary. Some patients were monitored by practitioners known to them prior to telemonitoring (e.g. their own GP) while others were monitored by professionals with whom they had no prior clinical relationship (e.g. physiotherapy and nursing teams).

All patients were monitored on weekdays. Professionals telephoned patients to address any matters arising from the transmitted data. Telemonitoring was additional to existing professional roles and responsibilities.

The ongoing TELESCOT randomised controlled trial which aims to investigate the impact of the service on hospital admissions[10] contained a nested qualitative study to explore the views of patients and professionals on the implementation of telemonitoring. As part of the qualitative study, respondents were asked to discuss their views on the impact (if any) of telemonitoring on continuities of care.

Methods

Ethical approval

This study had ethical approval from the Lothian Research Ethics Committee (reference 08/S1101/60).

Semi-structured interviews

Semi-structured interviews were undertaken to explore the views of patients and professionals involved or associated with the trial telemonitoring service in Lothian. Data were collected between March 2010 and February 2011.

Sampling and recruitment

Patients

The patient sample was derived from those who agreed to participate in the TELESCOT trial.[11] A maximum variation sample in relation to age, sex, socio-economic background (determined using the Scottish Index of Multiple Deprivation[12]), disease severity (using the MRC dyspnoea scale[13]) and compliance with telemonitoring (as identified by monitoring professionals) was undertaken to secure a diverse representation of the trial population.

Patients were invited by post to interview midway during their participation year in the trial. This enabled the collection of data from patients who had gained some familiarity with the technology and the monitoring service (earlier pilot work had acquired the perspectives of patients at entry point to the telemonitoring service[14]). Patients from the control group of the trial were also interviewed for comparative purposes. Reminder letters were sent to non-respondents one month after the dispatch of the first invitation.

Patient interviews occurred face-to-face within the person's home or by telephone. Interviews were conducted by a male postgraduate trained social researcher. The positioning of the researcher as investigator at 'arms' length' to primary care and the telemetric intervention helped facilitate open discussion. The researcher had family experience of COPD and his knowledge of the condition supported dialogue and understanding with respondents. The researcher had no prior contact with the patients involved in this study before invitation to interview.

Some patient participants requested that their partner/family member be present and contribute to the interview. Interview dyads were undertaken in those circumstances.

Professionals

Healthcare professionals with several months experience of delivering the service were interviewed. In addition to interviewing professionals with monitoring responsibilities, interviews were conducted with service managers, information technology suppliers, support staff (with training or administrative functions in relation to the telemonitoring service), nurses (those in primary and secondary care involved with COPD trial participants, COPD trial research nurses) as well as GPs who declined trial involvement in order to acquire a wide range of views. Healthcare professionals were interviewed either in their workplace or by telephone.

Interviews were undertaken until it was considered that data saturation had been reached.

Interview guides

Interview guides were used to frame discussion. The initial guides were based on themes identified from the literature and from earlier pilot work undertaken within the TELESCOT programme.[15] The guides were reviewed and refined iteratively during the process of data collection and analysis. The interviews explored patients' experiences of telemonitoring and their views on how

telemonitoring compared with 'usual care'. Professionals were asked their views on telemonitoring, how it affected practice or management (if at all), and the relationship between telemonitoring and usual care provision. (The interview guides are presented in appendices 1 & 2, available online at www.thepcrj.org)

Data collection

All interviews were audio recorded. Interviews were transcribed verbatim. Transcriptions were checked against the audio recordings.

Data analysis

Qualitative research is exploratory rather than confirmatory and conditional rather than conclusive. It is a means of providing answers to open research questions about phenomena that may be hard to predict and measure. Findings identified through qualitative study are not proof, but provide a description and an interpretation of social phenomena.[16] In order to ensure that the results of qualitative research are meaningful and potentially transferable, it is important that the context in which the study took place is adequately described.

In this study the 'Framework' approach[17] to data analysis was employed, given its applicability for applied or policy-relevant qualitative research. This approach involved researchers becoming immersed in the data and identifying a thematic framework based partly on the research questions, as well as data from the respondents. The data were then indexed by applying the framework to the whole dataset. The themes were subsequently charted into overarching themes and used to define concepts. Explanations of the data were considered by drawing on the original research objectives as well as the themes. Constant comparison (checking experiences against those of others in the sample) was undertaken to ensure that the thematic analysis represented all perspectives.

NVivo 7 software was used to assist with initial coding of the transcripts. Interpretation was supported by feedback from interview respondents, a coding review meeting involving TELESCOT colleagues, and multidisciplinary discussion. (The initial coding frames developed for this study are presented in appendices 3 & 4, available online at www.thepcrj.org.)

Results

A total of 38 patients (67% of the 49 patients invited, 47% male, mean age 67.5 years) and 32 healthcare professionals provided 70 interviews. Partners/family members of patients were present and contributed to eight of the interviews. The demographic characteristics of the patient participants are presented in Table 1. The average interview duration was 30 mins.

The findings are presented within the context of four main themes relating to continuity of care: (1) reassurance, accessibility and trust; (2) knowing the patient; (3) discontinuities; and (4) issues of cost and continuity.

Reassurance, accessibility and trust

For many, the telemonitoring service was seen as an improvement to standard care owing to its greater accessibility, the friendly manner in which it was provided, and its responsiveness to individual needs. The service was extremely popular with patients who reported a sense of reassurance in having someone 'watching over them'.

Table 1. Demographic characteristics of patient respondents

Characteristic	Respondents (N=38)
Sex	
Female	20
Male	18
Age (in years)	
44-54	2
55-64	9
65-74	22
75+	5
(Youngest = 44, oldest = 85, mean = 67.5)	
Scottish Index of Multiple Deprivation	
0-20% (high)	14
21-100%	24
MRC Dyspnoea Scale	
1	0
2	7
3	10
4	9
5	12
Usage	
Patients with telemonitoring compliance issues (as identified by telemonitoring professionals)	4
Patients who had withdrawn from telemonitoring service at time of interview	3 (2 due to technical problem with equipment, 1 due to ill health)
Patients who had telemonitoring service withdrawn at time of interview	1 (due to service viability issues)

> *I think it's very good. It makes you feel like somebody's looking after you. If anything goes wrong, you can get in touch with them any time you want ... you've got the confidence that they're going to get something done. I can't fault them anyway.* (Male, 79 years)

Relationship continuities between patient and professional within telemetric provision underpinned patient satisfaction. Patients commented favourably on the approachability of the telemonitoring professionals. The frequency of interaction between professional and patient, often triggered by the transmission of telemonitoring data, enabled many patients to get to know their designated telemonitoring professional and form bonds of trust with them. The majority of patients expressed gratitude for the personalised help, advice and support provided by telemonitoring professionals.

> *I mean these girls [telemonitoring professionals] can't [be] more on the ball ... if I need anything at all I've just to phone up ... it's a good service ... really good, first class. The highlight is I've got somebody feeding back and talking to me.* (Male, 69 years)

Patients described the role of the telemonitoring professional as a helpful intermediary between themselves and their GP. Relationship

continuities formed between patients and telemonitoring professionals often bridged barriers perceived to exist in usual care. For example, many patients spoke of the involvement of telemonitoring professionals in liaising with GPs to arrange timely appointments, home visits, renegotiation of existing medication regimes, and the provision of anticipatory medicine at home.

> *I'd say you get better [service] because if [telemonitoring professional's first name] comes on the phone and she'll say "I think you're needing to speak to the doctor", she's just giving me a warning that she's going to get the doctor to phone me. And they'll either say "Well, I think you're needing to have some antibiotics" or "I think maybe we should pop over and just see you."* (Female, 69 years)

Knowing the patient

Relationship continuities were also important to the professionals. For many practitioners, effective telemonitoring could only be accomplished by 'getting to know' the patient.

> *I think it's probably best if [telemonitoring is done by] people that are dealing with the patients every single day and have that bit of a relationship with them ... people are more trusting and it is something a bit more personable for the patient.* (Telemonitoring physiotherapist, ID29)

Practitioners considered clinical expertise important in interpreting and contextualising telemonitoring data relative to the individual's 'normal' readings over time.

> *… it's about putting everything into perspective with a COPD patient. It's knowing that somebody may normally have sats [oxygen saturation] of 85, … I think somebody who is an administrator may look at that and panic … It's knowing the baseline and a bit more about the disease ...* (Nurse, secondary care, ID22)

Discontinuities

While patients and professionals both identified benefits arising from relationship-based continuity of care in telemonitoring, many discontinuities in clinical management relating to telemonitoring provision were also identified.

Coordination and team work

Professionals reported operational difficulties concerning coordination and team work, citing lack of communication between procurement, installation and IT support functions. Practitioners indicated that there was little information sharing between the telemonitoring teams and little awareness of the practices of other telemonitoring colleagues in the management of patients.

> *[The problem is with] the communication between all the different parties who are involved, because you have IT involved in the installation and you have the company that install it. Then you've got a different person from a totally different background, who works in a totally different area, going in to do the training, and then you have another person monitoring ...* (Practice administrator involved in telemonitoring, ID7)

Records management and data interoperability

A major problem for many telemonitoring professionals was the lack of interoperability between the (stand-alone) telemonitoring system and existing patient information systems used in primary and secondary care. Many indicated frustration with the limited functionality of the telemetric information systems and the compartmentalisation of data between telemetric and usual care records which prevented information sharing with colleagues in related services. Professionals also commented on the volume of paperwork arising from the case management of telemonitored patients. Some described triplicate data entry in different information systems resulting from 'non-joined up' systems.

> *You spend a lot of time filling in forms to show that you're actually doing something. You're saving time [through telemonitoring] and, by filling the form, you're wasting time.* (Telemonitoring professional, ID15)

Cross-boundary working and differences in practice

Professionals were divided on the effectiveness of cross-boundary working between telemonitoring and normal primary care services. While some felt that telemonitoring shifted pressure from hard-pressed GP and hospital services, for others interaction between services proved problematic because clinical roles and responsibilities were not delineated. While some GPs appreciated sharing communication about patients and working in partnership with telemonitoring professionals, others found the involvement of non-medical community-based telemonitoring professionals intrusive, unwelcome and unhelpful.

> *People have really liked our service ... Yes, we've crossed a few boundaries and a few people have thrown their toys out the cot. "I do that, why are you coming and doing that?" I think we've managed it quite well by going "We can all work together".* (Telemonitoring physiotherapist, ID18)
>
> *… where community teams are involved with our COPD patients, we get a lot more contact, a lot more calls, a lot of those are not appropriate in our eyes. A lot of buck passing. I think potentially that's quite damaging to patient care.* ('Usual care' GP, ID9)

A number of professionals described sharp contrasts in practice. For example, some GPs and nurses expressed concern over use of anticipatory medication by non-medical telemonitoring professionals. Of particular concern was the perceived over-medication of telemonitored patients. This issue was also reflected by one of the practice-based professionals involved in telemonitoring.

> *Patients often have two standby courses of treatment in their home … My concern is they then get [repeat] prescriptions for further standby medication. Are professionals aware of how many courses of treatments that individuals are [taking]?* (Telemonitoring professional, ID8)

Issues of cost and continuity

While professionals expressed concern about management discontinuities relating to the development and implementation of telemonitoring services, healthcare managers focused on the potential economic benefits of using telemonitoring as a means of driving down service costs. Some considered telemonitoring to be a solution to problems caused by diminishing budgets.

> *… we're probably going to be operating with 20% less*

> *revenue within about four years from now so if ever there was a need to look to technology to support more remote delivery and patient self-management, then [now] is the time … cost efficiency … is crucial …* (Manager, ID14)

Managers considered that telemonitoring could deliver cost savings through workload management efficiencies. This was based on the supposition that the cost of the telemonitoring technologies would reduce over time and that service re-engineering would bring considerable cost savings through the centralisation of telemonitoring provision. Managers considered that the development of regional 'call centre' hubs would eventually reduce levels of clinician involvement in 'front line' service provision.

> *… how do we minimise some of the heavy clinician input that was put into the service model that we have ended up with? You can send initial triaging of information to a [centralised] non-clinical body who can do that in a much more cost effective way and release the clinician resource to do other things, the things they're meant to do.* (Manager, ID23)

Professionals and patients both opposed the vision of centralised regional models of telemonitoring provision. They considered integration of telemetric provision with local practitioner services preferable to centralised 'call centre'-type provision, emphasising the value of relational continuity over cost benefits associated with centralisation.

> *I don't know what to make of the fact that people consider sending it to call centres for monitoring … I find that quite extraordinary really because you need to know the patients as a professional to be able to do the monitoring effectively …* (Telemonitoring physiotherapist, ID19)

The proposition of the development of some form of regional 'call centre'-type service reinforced one GP's concerns about telemonitoring. The respondent, from a practice not participating in the trial, considered that the remote telemonitoring of patient data, undertaken outwith the parameters of established practice, compromised patient care.

> *I think [it's important that] the whole, holistic approach towards patients is not given away … singling out a few values … many kilometres away … in a control room with various remote criteria … but we are not quite sure what that means in the clinical context and how it is perceived by the patient.* ('Usual care' GP, ID11)

Patients related their experiences of the national telephone healthcare service, NHS24, when asked for their views on the proposition of a centralised model of telemonitoring provision. They spoke of poor service provision and experiences of alleged misdiagnosis. One carer related her hesitancy in seeking assistance from the service at the weekend, outside practice hours:

> *You're on the phone [to NHS24] for about an hour. Really, it's a joke … I mean at weekends usually if he's taken ill he tried to hang off to the Monday.* (Carer, ID1)

Discussion

Main findings

Patients and healthcare professionals considered that relationship-based continuity of care was important in the delivery of telemonitoring services. Managers placed emphasis on improved continuity of clinical management as a means of reducing healthcare costs. However, professionals described many operational challenges arising from the 'bolting-on' of telemetric provision to unreconstructed usual care provision which, they claimed, resulted in the proliferation of additional managerial discontinuities.

Strengths and limitations of this study

This research was undertaken as part of a randomised controlled trial evaluating a 'live' clinical service as a complex intervention.[18] This presented the opportunity to collect the views of patients and professionals at the point of service delivery. A pragmatic approach was taken to data collection and analysis. We strived to obtain a maximum variation sample from the patients and professionals involved in or associated with the telemonitoring service so that the widest range of views could be represented in the research. However, we acknowledge that we may not have encompassed all relevant views.

Similarly, data analysis meetings involving local researchers and healthcare professionals with an interest or involvement in telemonitoring were held to acquire multidisciplinary feedback. Again, we strived for inclusivity of relevant participants at these meetings. Subsequent data recoding and analysis was undertaken to support a balanced interpretation of the data.

The wider technological and service environment has significant bearing on the contextualisation of the research findings. This research has occurred against a backdrop of rapid advances in telemonitoring technology and corresponding NHS service developments. This study, undertaken in one health board region, presents an investigation of the views of patients and professionals on telemonitoring of COPD at an early stage in the development of both the technology and the application of the technology in an operational context. Indeed, the service evolved and changed significantly during the lifetime of the trial as it adapted to suit local services and preferences. This enabled the research to explore the views of a wide range of stakeholders involved in the development and provision of the service. Over time it is envisaged that the emergence of alternative technologies may open new avenues in telemonitoring service provision which may change the perceptions of those involved.

Interpretation of findings in relation to previously published work

Relationship continuity between patient and practitioner is often cited as an important factor affecting patient satisfaction in primary care.[19] Patients emphasise the importance of receiving care from a 'known and trusted' practitioner.[20] A key reason attributed to this preference is the assumed better medical knowledge and understanding by the 'known practitioner' of the patient's personal and family background.[21] Recent research has indicated that relationship continuity is also important for patients receiving home-based telecare.[22]

In this study, patients and professionals valued relationship continuity within telemonitoring provision. It is worth noting that many of the patients had no prior professional relationship with the

telemonitoring professionals engaged in their care (particularly among those telemonitored by the community respiratory physiotherapists and the community nursing team). However, both patients and professionals reported that trusted patient-practitioner relationships developed quickly over the course of the trial period. Professionals attributed this in part to telemonitoring: the regular checking of telemonitoring data enabled an understanding of the patient's condition which, many professionals considered, would have taken longer to acquire without access to such data. This was thought to support pre-existing professional practices that facilitated relationship continuity, such as home visits and telephone consultations.

Continuity of care is often viewed as 'seamless care' involving coordination, teamwork, cross-boundary working, good record systems, and the timely communication of relevant information between care providers and with patients and carers.[23] Within the context of the trial service, telemonitoring operated as compartmentalised care, in some cases developed and tested by new community-based teams operating as a supplement to, but outwith, established primary care provision. The role of some groups of telemonitoring professionals as 'go-between', facilitating service provision between patients and 'usual care' providers, proved something of a double-edged sword. On the one hand, patients greatly appreciated the efforts of telemonitoring professionals to bridge perceived service difficulties in established care provision. On the other, the addition of telemonitoring activities within an unreconstructed usual care arena highlighted many differences in practice. Sometimes this created conflict – not solely because of differences in care provision arising from telemetric versus usual care practices but also due to the contrasting philosophies and perspectives of the professionals operating the services, themselves from a variety of occupational groupings. Therefore, a key challenge faced by those involved in telemonitoring was the management of professional and organisational relationships. Many acknowledged that the decision to operate telemonitoring as an adjunct to usual care (in some cases) added complexity to efforts to achieve and maintain continuity of care.

The organisational approach to care management – notably the management of change – had a significant impact on the continuity of clinical management. In this trial service, change was not instigated by a 'guiding coalition'[24] of professionals wishing to instigate developments in practice or by patients lobbying for different/improved service. The decision to pilot telemonitoring was initiated at the managerial level. The impact of this was that professionals, regardless of the type of service they were providing, often felt that the introduction of telemonitoring was something 'done to them', not involving them. The disconnect between the aims and aspirations for the telemonitoring service as formulated by managers and the practical concerns of professionals further exacerbated discontinuities of clinical management. While professionals worked hard to provide a 'seamless' service to patients, discontinuities resulting from the initial organisational management of the service left many to query the longer term viability of the service set-up.

May *et al*. outlined the high failure rate of telemetric services to 'normalise' within clinical service provision, stating that many products and services do not last beyond the pilot stage.[25] Among the factors affecting implementation and take-up they note the importance of effective translation of technologies into practice by cohesive cooperative groups and stabilisation of telemetric systems through integration of professional knowledge and practice. The results of this study indicate that further work is required in the development of a shared vision of telemonitoring and continuity of care by stakeholder groups, and the integration of both into practice. To paraphrase Guthrie *et al.*, if managers and professionals are serious about the importance of continuity of care, as they claim to be, 'then they need to ensure that organisational change promotes it.'[26]

Implications for future research, policy and practice

Major questions challenge the development of both the telemonitoring and 'continuities' agendas in primary care. Should future implementation of telemonitoring provision place emphasis on the importance of relationship continuities in implementing safe and effective telemonitoring through localised practitioner-led services? Alternatively, should future development comprise centralised provision potentially enabling minimised practitioner involvement in order to realise economies of scale?

Conclusions

The contrasting views of patients and telemonitoring professionals versus those of healthcare managers, as presented in this research, represent the dichotomy at the heart of current healthcare policy regarding implementation of telemonitoring and its impact on continuities of care. Continuity, but at what cost?

New models of telemonitoring provision (and related practices) are required that both retain the benefits of relationship continuity, as valued by the respondents in this research, in addition to realising managerial and cost reduction benefits from the integration of telemetric technologies into 'normalised' practice within the current economic climate.

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from the wider team. The paper was written mainly by PF and HP with input from the other authors. BMcK is the study guarantor.

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* In this context, telemonitoring refers to the use of communication technology to enable healthcare professionals to remotely monitor patients' clinical status.

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Appendix 1.

Appendix 1: COPD RCT - patient interview schedule

COPD ID number/ initials / date

Statement of anonymity.

Would like to talk about:

- *your health before the project*
- *how you got involved in the project*
- *what it was like when you first got the system*
- *How you find using the system; what happens when your readings are high/ low; and if you or you family use the information on the system for yourselves*
- *Your health over the past …. Months since you got the system*
- *Anything else you think it may be helpful for us to know*

1. **Patient health:**

- What breathing problem do you have? When did you learn you had COPD?
- How do you feel your condition affects your daily life?

  PROBE - Before the project:
- How did you cope with your condition? Were family and friends involved?
- Do (did?) you have 'good days' and 'bad days'? What do you feel is the difference between a 'good day' and a 'bad day'? What is the difference between a 'bad day' and an exacerbation' Has the system helped you differentiate these?
- How often did you have to take antibiotics and steroids? Could you get them quickly if you needed them?
- Had you been admitted to hospital? How often? How was that?
- How easy was it to get an appointment with a GP when you felt ill?
- How was your condition managed by your practice? Did you feel 'you had a say' in the care provided? Was there anything you did to manage your condition?
- What role for family/ friends/ carers in the management of your condition?

2. **Recruitment:**

- How did it happen?
- Reason for participation?
- What were your expectations of involvement in this research? Have these expectations been met?
- Who do you think benefits most from your involvement in the research – you or doctors/ nurses?
- Was correspondence clear to understand?
- Did you read the leaflet? Did it make sense to you?

Appendix 1.

- Was it made clear that the service was not a replacement for normal practice?
- How could things be improved?

3. What it was like when you first got the equipment

- Could you tell me what it was like when you first got the equipment

Probe

Installation:

- How did it happen?
- How could things be improved?

Training:

- Did you receive training?
- Did you think the training was adequate/ long enough?
- How could things be improved?

Use of equipment:

- Talk through daily use. Impact on daily routine?
- Convenience of location & 'physicality' of the equipment (ask about noise, for example).
- Usability of interface.
- Views on online questionnaire. (Applicability/ relevance?)
- Ease of use of peripherals.
- Any technical difficulties? Was it clear what to do in case of technical problems?
- Any concerns about confidentiality of information?
- How could things be improved?

4. **Self-management & clinical care:**

Has using the system:

- helped you (or, in your opinion, doctors/ nurses) better understand your state of health?
- affected how you feel about your condition/ care?
- led to any changes in how you manage your condition?
- led to any changes in how you feel your care is managed?
- helped you (or the staff responsible for your care) in catching exacerbations earlier or not?
- improved access to doctors/ nurses/ services (such as access to appointments)?
- changed how you feel staff deal with you as patient?
- had any impact your quality of life?

5. How has your health been over the past X months since you got the system?

- **Probe:** Treatment, exacerbations, hospital admissions (if hasn't already been covered)

Appendix 1.

6. **Family/ friends/ carer interaction:**

- Have you told any other family/ friends about the equipment? What do you say about it?
- What do your family/ friends/ other practitioners think about it?
- Does anyone else help you use the technology on a daily basis?

7. **Service provision:**

- What about the number of visits from different people you've received during your involvement in the research... How do you feel about that?
- Overall how would be rate the telemonitoring service you've received? (Explore.)
- If given the choice would you continue to use the equipment after the research is over? Why (not)?

8. **What are the best and worst things about the telemonitoring system?**

9. **Any other comments/ concerns/ suggestions for improvement?**

Explain to patient happens next: transcription, analysis and draft report. Patients can request access to their own transcript and propose amendments re: any errors/ misrepresentations.

Appendix 2.

Appendix 2: COPD RCT - practitioner interview schedule

Staff name/ date. *Statement of anonymity.*

1. Can I ask what your role normally is?

- Usual job. (If it is a newly developed role/ service ask for explanation of function.)
- On project.

2. Vision:

- What were your initial expectations of the system?
- Were they met?
- Did your view of the utility/ application/ benefits of the technology change over time? If so, in what way?

3. Usage of technology:

- Talk through how you normally use the telemonitoring system (a typical day).
- Usability of the data display interface - strengths & weaknesses?
- Did you receive training in using the system? Views on the training received in using the system.
- Have you experienced any technical problems? Views on level/ quality of technical support.

4. Workload and care management:

- How do you integrate usage of system into your work?
- How this compares with 'normal care'?
- Any new roles/ responsibilities which accompany your telemonitoring work? (Explore elements: e.g. training/ risk / prescribing, for example.)
- Has it changed the way you manage care? (Person contextual/ protocol driven?)
- Has it changed your perception of how care should/could be managed?
- Workload issues? (Do you think this would be an issue for others?)

5. Practitioner views on patient usage of the telemonitoring equipment:

- What do you think of the telemonitoring equipment used by patients – strengths & weaknesses?
- What are your impressions of what patients think of the system?
- Do you think it has affected on how patients perceive their disease and self-management?
- Do you think telemonitoring changes the way patients and practitioners relate to each other?

6. Impact on early detection/ prevention of hospital admission:

- What are your views on the protocol? (Is it useful/ any difficulties?)
- Has the system been helpful in early detection / prevention?
- Has the system impacted on patient hospitalisation? (Frequency/duration/appropriateness.)
- Has the system prompted more changes or reviews in medication or treatment?
- Any examples of interventions that wouldn't otherwise have happened?

continued >

Appendix 2.

7. Management issues:

Both in terms of service development & the trial:

- what things went well and what things didn't work well?
- what could have been done differently?
- what's your overall impression of how things have been managed?

8. How would you define success with regard a telemedicine project such as this?

9. Reflecting on your experience, what are the best and worst things about telemonitoring?

10. Do you think the system should be rolled out across Lothian? If so, what ways do you think that could be best done? And specifically which patients, under which circumstances?

11. Any other comments/ concerns/ suggestions for improvement??

What happens next: transcription, analysis and draft report. Practitioners can request access to their own transcript and propose amendments re: any errors/ misrepresentations.

Appendix 3.

TELESCOT QUALITATIVE STUDY – COPD PATIENTS – CODING FRAME

THEME 1: Living with COPD

Receiving diagnosis

Information provision at point of diagnosis

State of health

Impact on lifestyle

Identifying 'bad days'

Involvement of family & carers

Emotional & practical support

Feelings of helplessness

On my own

Smoking

Interaction with primary care

Difficulties getting GP appointments

Accessible service

Impersonal service

Lack of information provision

I don't like bothering my GP

Attitudes towards emergency services (inc. NHS24)

Treatment and Therapy

Hospital admission

Anticipatory medication at home

- **Too much/ too little? (as part of usual care)**

Use of oxygen

Pulmonary Rehabilitation

Interaction with CRT (as part of usual care)

Appendix 3.

THEME 2: Setting Up Service: in preparation for telemonitoring

Installation

Choosing where to site the technology

Problems associated with installation of broadband telephone line

No problems

Training & initial support

THEME 3: Researching Telemedicine: patient perspectives

Becoming involved

Reasons for participation

Helping others

Helping me

You don't turn anything down because it might be helpful

Helping us all!

Dealing with 'paperwork'

Dealing with the questionnaires

Too much paperwork

A bit confusing…

No problems

Clarity of information

Level of instrusiveness of the research process

On future use of telemetry (if offered – control patients)

Interested in use

Not interested in use

Appendix 3.

THEME 4: Receiving Tele-Service

Views of the service

Praise for the telemonitoring teams

- ∞ **A friendly service**
- ∞ **A responsive service**

Medication

Telemonitoring staff as 'gatekeepers' to antibiotics

Too much medication?

Changes to medication

Hospitalisation

Perceptions of Identification of need for admission resulting from telemonitoring

Perceptions of prevention of admission resulting from telemonitoring

Accessibility of tele-service compared to 'usual services'

Cost issues

Expensive equipment

Money-saving service

Waste of money

Not costing me much

Concerns over domestic electricity usage

Most positive thing about being tele-monitored

Reassurance (of being tele-monitored)

Negative things about being tele-monitored

Nothing I don't like

Reactions of family and friends to tele-service

Praise

Criticism

Indifference/ no comment

continued >

Appendix 3.

Reactions of GPs to tele-service (as described by the patient)

Engaging with data

No idea

Waste of money

Concerns over post-trial service provision

On the possibility of continuing/ after the trial period

Yes, please!

Not sure

Would wish to hand it back

Withdrawal

Due to technical problems

Temporary withdrawal due to ill-health

Cancellation of service

Appendix 3.

THEME 5: Using the technology

General Usability

Easy to use

Intel Health Guide

Taking readings

- **Easy to use**
- **Interpreting questions**

Video content

Using the web cam

- **Not working properly**
- **Reaction to potential future use of web cam**

Noise issues

Alarm issues

Illumination issues

Cables

Technical problems

Patient generated errors

Peak flow device

Taking readings

Technical problems

Patient generated errors

Pulse oximetry device

Taking readings

Technical problems

Patient generated errors

continued >

Appendix 3.

Electronic scales

Taking readings

- **Understanding metric measurements**
- **Watching weight**
- **Product comparison**

Technical problems

Patient generated errors

Technical support

Praise

Appendix 3.

THEME 6: Self-management

Attitudes to self care prior to telemonitoring

Leave it until it gets bad

Self-efficacy

Initial apprehensions

It's not for the shopping.

The daily routine

No hassle

Forgetting

Repetitive

Disruptive

Taking readings

Understanding 'normal'

Gauging condition

- **Recognising exacerbation**

Monitoring trends

Information & empowerment

Reacting to readings

Making decisions regarding lifestyle choices

Waiting for the call from the tele-service

Choosing to contact staff over health concerns

Choosing to' self treat'

continued>

Appendix 3.

Social interactions with the telemetric environment

With family & carers

- **'Interventionists'**
- **'Facilitators'**
- **'Observers'**
- **Family/ carer exclusion from technology by patient**
- **Role in anxiety reduction**

With telemonitoring staff

- **'Advisers'**
- **'Instructors & enforcers'**
- **'Surrogate practitioners'**

'Back-up'

Compiled by: Peter Fairbrother, Telescot

Date: 28 February 2011

Appendix 4.

TELESCOT QUALITATIVE STUDY – COPD STAKEHOLDERS – CODED DATA

THEME 1: Researching Telemedicine

Methodology

Asking the right questions?

Using the right methods?

Recruitment

Frustrations and disappointments

Explanations for recruitment difficulties

- **Unrealistic expectations**
- **Competing priorities/ workloads**
- **Eligibility criteria**
- **Poor communication**
- **Feeling misled by the Trial team**

Non-participating practices

- **Reasons**
- **Factors that would encourage participation**

Data collection

Baseline assessment questionnaire

Three monthly questionnaires

Trial administration

Trial-Tele-Service Interface [other elements]

Appendix 4.

THEME 2: Leadership & Management

Vision & ownership

Defining success

Reducing hospital admissions

Organisational development/ financial

Improved quality of life for patients

Dealing with change

Managing cultural transition

Factors affecting stakeholder engagement

Cost & finance

Funding development

Funding service provision

Planning & development

On the viability of future roll-out

Considering future tele-service models

- ***'Knowing the patient' & the importance of continuity of care***
- **Hybrid models**
  - **Remote call handling & multidisciplinary teams**
  - **Triage involving non-clinical staff**

Appendix 4.

THEME 3: Setting Up Service

Training

Telemonitoring training for staff

Telemonitoring training for patients

Installation

Delays

NHS Lothian E-Health team/ IT support

Issues of organisational development

On-the-ground service provision

Appendix 4.

THEME 4: Tele-Service Provision

Expectations

Perceptions of patient views

Perceptions of views from the healthcare community

Negative/ sceptical

Positive

Lack of awareness

impact on admissions

levels and usage of medication

The telemonitoring equipment [front-end/ devices used by patients]

Specification & functionality

Usability

- **Easy to use**
- **Perceived patient difficulties**

Technical malfunctions

Positive aspects of tele-service provision

Access to data

Practice development

Supporting workload management

Patient responsiveness to tele-service

- **See also: Tele-service Provision: perceptions of patient views**

Enhanced patient care

Supporting continued professional development

Negative aspects of tele-service provision

Appendix 4.

- See: Setting Up Service: installation
- See: Researching Telemedicine: trial management: recruitment
- See: Leadership & Management: issues of cost and finance
- See: Tele-service Provision: the telemonitoring equipment
- See: Undertaking Telemonitoring: workload
- See: Undertaking Telemonitoring: team working and lack of communication
- See: Self Management: towards greater dependency on NHS services

Appendix 4.

THEME 5: Undertaking Telemonitoring

Protocol-driven decision making

Using back-end telemonitoring software

Workload

Roles & responsibilities

No change

Conflicting with values/ practice

Increment to existing responsibilities

Shifting the balance of care

Team working & lack of communication

Tele-Service interaction with 'usual care'

Appendix 4.

THEME 6: Self-management

Definition

Medical compliance

Patient empowerment

The importance of patient education in supporting self-management

Perceived patient attitudes and behaviour

No connection to the concept of self-management

Towards greater dependency on NHS services

Towards greater independence

Fostering both independence and dependence

Reinforcing a sense of illness

Fuelling patient anxiety?

Towards a (realigned) patient-professional relationship

Compiled: Peter Fairbrother, Telescot

22 February 2011