

Reconfiguring Care for Chronic Disease with Home Monitoring

A Pilot Study Report on Telemetry-Supported Care for COPD in Lothian Region

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EXECUTIVE SUMMARY

USER PERCEPTIONS

1. Patients and carers were very positive about the telecare system, even where there were operational problems. They consistently echoed a range of benefits cited in other studies
 - a. More rapid access to a GP / intervention when required
 - b. Reduced anxiety and reassurance that they were 'being monitored'
 - c. Relief that the difficulties they cited in knowing whether they were ill enough to call a doctor were to some extent handled by the system
 - d. Objective evidence from scores to inform their own or a carers' decision to call a doctor
 - e. Earlier recognition and acknowledgement of symptoms by patients, and greater awareness of symptoms by practice staff improved the quality of care
2. Patients typically identified avoidable delay as an important cause of previous hospital admissions
 - a. Delay in calling surgery due to unwillingness to bother a GP
 - b. Delay getting a timely appointment when they call
 - c. Difficulty getting to the surgery
 - d. (For some practices) Delay in getting antibiotics
3. Carers were crucial in helping patients to learn to use the system, as well as in supporting other aspects of compliance, liaison and feedback to the team. More account could be taken of this in recruitment, consultation and planning.
4. Both GPs and patients perceived that the quality of care had improved for these patients. This was balanced by a perception of a moderate but manageable increase in workload.
5. The potential impact on electricity/phone bills was a concern for a few people.
6. The alarm, and the unreliability of the process for switching it off when away was a recurring concern that should be addressed
7. A number of patients and GPs provided examples of promptly treated exacerbations that they felt would not have been reported, or which would have resulted in a hospital admission
8. Confidentiality was not an issue for patients

EMERGING CHALLENGES AND OPPORTUNITIES

9. During the pilot, the vision of telemetry-assisted care at home changed emphasis from protocol-led monitoring of patients symptom scores against standard benchmarks to longer term monitoring against personal benchmarks developed with additional patient and context specific information
10. The pilot appeared to act as a catalyst for change, providing a focus for reviewing practice, such as the provision of an emergency supply of antibiotics at home, to reduce delays between recognition of an exacerbation and treatment
11. Symptom scores alone were insufficient as a basis for either diagnosis or intervention, and further patient and context specific information was required to interpret or act on them. This was perceived as creating some additional work, but enhancing the quality of individual care
12. Symptom score recordings were shaped by a range of factors other than the disease:
 - a. Patient factors such as variation in the experience /management of the condition
 - b. The usability of the FEV₁ meter)
 - c. over or under-scoring on the self-administered questionnaire

- d. The impact of co-morbid conditions
 - e. Activity prior to testing
 - f. Use of oxygen, or other medication, before testing.
 - g. Environmental factors such as the weather, temperature or damp
 - h. Technological factors (e.g. transmission problems, battery failure, connectivity).
13. Physiotherapists, nurse managers, practice nurses and other health professionals identified opportunities for synergy in supporting home-based care, including using the system for:
- a. Sharing current information on patients, or tailored information for patients
 - b. Coordinating disparate care services around individual needs
 - c. Using video-consultation to contact or reassure patients, and prioritise visits
14. Nurses and nurse managers identified four key challenges for home based care telecare:
- a. Communication of the right information to the right person at the right time
 - b. Training to ensure that community nurses and others providing home-based care know what to do, particularly given the severity of some conditions now being managed at home, and the need for urgent action in some cases
 - c. Partnership working with other services
 - d. Pressure on community and social care resources

RECRUITMENT, IMPLEMENTATION AND USE

15. Training was seen by most patients as sufficient, however some, particularly older female patients were very anxious about using the system initially, and would have preferred an additional session.
16. Cognitively able, moderately severe COPD patients were seen by GPs and physiotherapists as the group most likely to both comply with and benefit from tele-monitoring.
17. GPs perceived their success in recruiting patients as requiring time and personal engagement that might be a barrier to recruitment for wider clinical implementation, or for a larger clinical trial.
18. Patients commented on the friendliness, responsiveness and accessibility of the installation and management team
19. Small patient numbers and a small team working directly with patients during installation provided one-to-one support with issues (technical and personal) that might have assisted recruitment and retention, but which would not be sustainable on a larger scale. Wider implementation is likely to require a very different mechanism for responding to issues that might affect retention.
20. The system and the peripherals were seen as easy to use by patients, (with the exception of the FEV₁ meter which was complicated to use, often failed to transmit, and had features making it difficult for some of the elderly patients)
21. Battery failure in the oximeter was a frequent problem, causing stress and inconvenience for patients and support staff, and with implications for data collection.
22. Transmission failure was a common problem, particularly with the FEV₁ peripheral, raising concerns for patients as to whether readings had been received or not, and confusion about the nature (or cause) of problems that arose. A software modification enabling a transparent feedback mechanism for users indicating the progress of the transmission, and giving pointers where this failed would be a useful design feature.
23. Although the patient interface was easy to use, the usability of the backend interface was laborious and cumbersome for GPs, practice staff and Careline staff. Professionals perceived the encryption process as laborious and time consuming and that it should be streamlined
24. Call centre staff felt that greater inclusion in development meetings would help coordination and communication.

1. INTRODUCTION

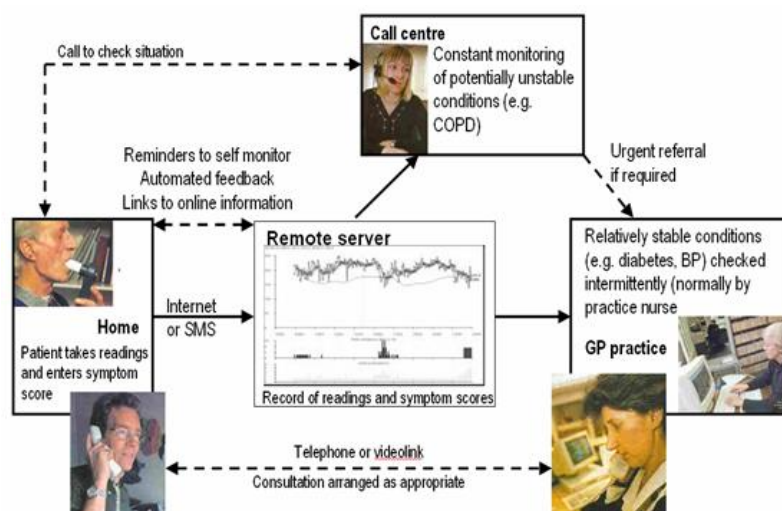


Fig. 1 Coordinating data, information and care services across an extended network

BACKGROUND

The need for telecare solutions has been driven by the anticipated challenges of providing care for an increasingly aging population in the UK where 17.5 million adults in the UK have chronic illnesses set to rise to 35 million by 2030. (Dept. of Health, 2004) There is currently renewed interest in the potential (and implications) of using assistive technology to enhance home-based care of long-term conditions and minimise hospital admissions, building on different visions of digitally mediated healthcare, from the extension of existing clinical services through to the reconfiguring of the disparate clinical, social and community care services. Wanless (2006) in an influential report in 2005 suggested these could be complementary, though the vehicle for renegotiating roles and resources to achieve this was not yet evident. The equally influential Whole System Demonstrator Network has adopted a more evolutionary approach, highlighting the experiences of innovative pilots in different regions (DH:CSIP 2009). The Scottish Government's care Development Board strategy document (Donnelly, 2008) sets out a vision for the use of telecare technology to support long term goals in this context, including the aspiration that 'remote long-term condition monitoring undertaken from home will be the norm' by 2015. What is clear from emerging research is the extent to which technical innovation can be a catalyst for rethinking practice, and the need for reconfiguration of policy, practice and governance around these changes in provision (Mort et al 2009; Callon 2003) The comments of those involved in the pilot project highlight the impact of such studies on the process itself, in facilitating collaboration and review of new ways of working across communities involved in providing care services.

While many of the studies of IT-supported management of COPD underline the potential for enabling patients to rethink their own management of their condition, Casas (2006), Wilkinson (2004) and Koff (2009) suggest that it can also prompt care teams to review their integrated management of COPD. Casas et al (2006) actively leverage this in facilitating more strategic alignment of shared-care arrangements between primary care teams and hospital teams, to avoid duplication and to generate synergies among different levels of the healthcare system. They suggest that 'the potential impact of the intervention on enhanced management of co-morbid conditions and social problems cannot be neglected,' and that 'the interventional impact may have prompted early detection and better management of exacerbations in the programme'. Koff et al (2009) in a similar study, attributed the positive impact of the programme to a combination of factors including disease-specific education, increased ability to self-manage, heightened contact with care providers, and remote monitoring resulting in early warning and early treatment.

Pilot projects provide an opportunity to explore patient and context specific factors which contribute to the (often contradictory) results in different studies about which Gaikwad (2009) comments. As such, they provide a living laboratory for developing or reconfiguring strategy in the design and implementation of telemetry-assisted care.

A LABORATORY FOR STRATEGY

The digital mediation of traditional care services reconfigures the nature of care, costs, risks and benefits for different stakeholders in ways which have not been fully evaluated. In many senses it implies a re-constitution of the traditional social contract between doctor, patient and care services. These reflect new dependencies, new axes of control, and emerging risks and uncertainties that have only been partially understood, and for which agreed processes have not yet been established. The criteria and strategies used by different stakeholders to generate, repair or re-constitute trust have implications for the usability, sustainability, governance and the quality of care in this new social contract.

There appear to be open questions however, concerning the sorts of benefits telecare might be expected to deliver, and about the patterns of demand on resources and workload that might be felt in different parts of the NHS and in other social and community care services. A number of overarching studies are now emerging, such as Constantinides et al, (2006) which share a similar focus, and identify recurring problem: solution scenarios in the implementation of such technologies. In a recent review of the benefits of home telecare for older people with long term conditions, Barlow et al (2007) and Hendy et al (2008) highlighted the lack of large scale in depth studies, the inconclusive evidence of either cost-effectiveness or patient satisfaction, and the need for more rigorous qualitative and quantitative study to inform investment in new services. They note the difficulty of evaluating a rapidly evolving technology such as telecare using conventional approaches. The introduction of new technology in collaborative contexts typically initiates a process of change and reconfiguration that requires ongoing monitoring and evaluation from different perspectives, and using qualitative and quantitative measures.

Following a programme of collaborative working in Lothian some of which was recently reported by Bowes and McColgan (2006), system supplier Tunstall, in conjunction with Intel set up a project using the Intel® personal health system (PHS) as the first phase in identifying issues and opportunities that might inform a larger trial. The PHS provides the patient with a home-based interface for delivery of a range of services to measure symptoms and vital parameters such as BP, blood glucose, pulse-oximetry and FEV₁ using linked monitoring devices. It incorporates a system for prompting patients to take their medications and record their symptoms (aided by blue-tooth connectivity to monitoring devices), and includes the potential for video-consultation. Data submitted to the system are transmitted to a central call centre manned by trained support staff, who may contact the patient or their health care providers if readings are out of range. While the system has the potential to manage patients with a number of chronic conditions, it was initially applied and tested in the context of Chronic Obstructive Pulmonary Disease (COPD).

THE PILOT STUDY

This pilot study provided a laboratory for mapping some of the emerging issues (technical, organisational, economic, managerial and ethical) that might inform the process of scaling up for wider implementation. It aimed to document a range of issues relevant to the implementation and evaluation of a large scale controlled trial of patients with COPD whose condition requires frequent hospital admissions that are both costly and stressful. The pilot will gather a) qualitative evidence of the experience of patients and care professionals in to inform a wider trial across Lothian region (McKinstry et al, 2009, Pinnock et al 2009), and (b) quantitative evidence to inform a trial to test the hypothesis that monitoring and early intervention can reduce the number of exacerbations requiring hospital admissions.

This qualitative report aims to provide an overview of stakeholder perceptions of the costs, risk, benefits and implementation issues in different context, including perceived benefits, issues, barriers and context and person specific factors likely to impact on successful implementation. This involved semi-structured interviews, ethnographic field work, focus groups/workshops with different user groups over the period of the study. The quantitative strand is reported separately, and evaluates the feasibility and appropriateness of the proposed outcome measures, and to gain an estimate of the impact of the systems on these outcome measures as the basis for designing a large scale controlled trial. These observations will be combined with other sources of information from logged use, a literature review and online feedback form In order to draw conclusions.

OBJECTIVES OF THE STUDY

The primary purpose of the qualitative strand of the study is to gather data which will inform the development of an intervention for a controlled trial along the lines of the newly revised MRC guidance framework¹ for complex interventions (Anderson, 2008).

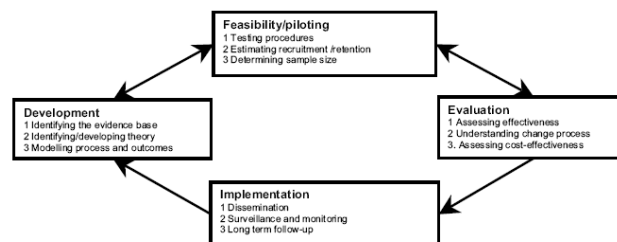


Fig. 2 The development and evaluation process (Reproduced from the MRC (2008) Guidance Framework 'Developing and evaluating complex interventions: new guidance.'

In particular, the intention was to understand the contextual and person-specific factors likely to affect the successful implementation of the system, the perceptions and experiences of patients and care professionals using it, and to identify issues in recruitment, installation and training as well as ethical issues that would have implications for the trial. The quantitative study on the other hand assesses the appropriateness and feasibility of collecting a range of outcome measures, including objective clinical indicators (such as admissions, use of healthcare resources), self-report questionnaires, and process measures, and provides an estimate of the extent of influence of the intervention on a range of outcome measures to inform sample size calculations.

The availability of new ways of monitoring , by both patients and doctors, ,also invokes new models of care, requiring changes in the roles of those involved. Pilots such as these provide an arena for exploring the evolution of different kinds of collaboration.

¹ www.mrc.ac.uk/complexinterventionsguidance

In COPD patients often have difficulty distinguishing the onset of an exacerbation from a 'bad day' and one possible mode of action is that tele-monitoring will define exacerbations more clearly and increase patient's confidence to commence treatment promptly. Glasziou (2005) for example, outlines how responsibility could be shared between patient and professional, moving from an initial process of stabilisation by a professional and a subsequent phase of maintenance and self-management led largely by the patient in the community.

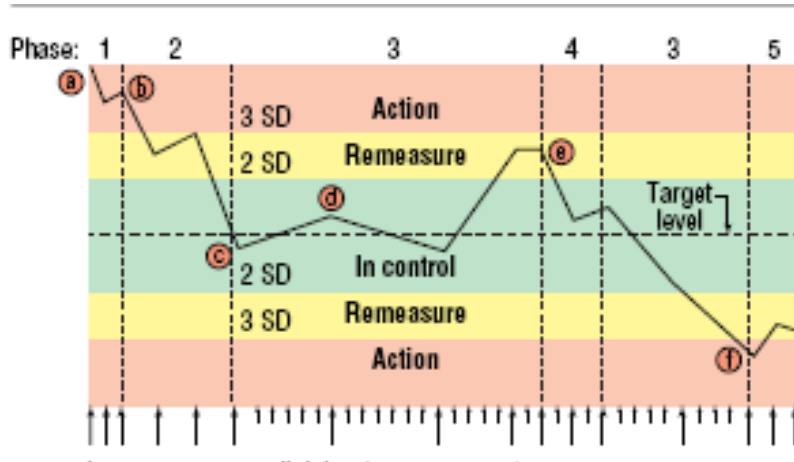


Fig. 3 The five phases of monitoring (From Glasziou et al 2005). Large arrows are clinicians' measurements and small arrows are patients' measurements.

Large arrows are

Within this new landscape, there is an interest in the possibilities of new and more tailored pathways for care arising from the alignment of technical, organisational, professional and community systems.

2. QUALITATIVE EVALUATION

RESEARCH METHODS

The research combined qualitative and quantitative methods. The qualitative strand focused on exploration of the perceptions of the different stakeholders with regard to the use of this technology, and the perceived benefits, barriers/ facilitators to implementation at different stages. We take a view of the implementation of new technology as a complex, socio-technical process aligning people, processes and technology from initial set up (e.g. support issues, stakeholder expectations and recruitment concerns) through to projected use and implementation issues and scenarios together with quantitative measures of key criteria such as hospital admissions, discharge rates and opportunities for facilitating home-based disease management.

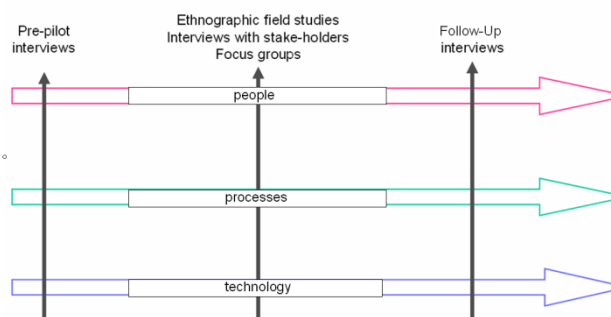


Fig. 4 The research process

We sought to draw on the perceptions of stakeholders and their knowledge of practices in their context as a basis for informing new developments. Complex healthcare interventions involve social process that may be difficult to explore using quantitative methods alone as Levin et al (2009) point out in a very recent review of methodology in randomised controlled trials of complex healthcare interventions.

Collaborative action research and grounded theory lends itself to the evaluation of new technologies that do not always build directly on existing practice, but require a reconfiguration of the process itself by the stake-holding participants. Pawson and Tilley (2001) and Plsek and Greenhalgh (2001, 2006) use this approach in realistic evaluation for teasing out what works in different contexts, as a means of informing development. The behaviour of complex socio-technical systems emerges from the interaction among the agents, and is inherently hard to predict. As challenges arise beyond existing frames of reference, roles, resources and processes are reconfigured, reconstructed or realigned to maximise perceived benefits and minimise perceived costs and risks (Kennedy et al 2007). The representation of stake-holding groups in the process of identifying and considering possible solutions, is an important aspect of the research. Bar Yam (2006) highlights the value of research methods that allow for observation of evolving and often unexpected possibilities as distributed user groups deal adaptively with challenges 'at the edge of chaos', where existing knowledge and process must be reconfigured.

Trials of complex interventions are of increasing importance because of the drive to provide the most cost effective health care and the value of including exploratory studies to inform the design of larger controlled trials is increasingly recommended, The MRC Framework for development and evaluation of Complex Interventions (Anderson 2008; MRC 2008) outlines the features of each stage in this model. This study bridges Phases 1 and 2, looking at readiness and exploring the issues. There is no control group in this exploratory phase but this is introduced in the next phase as the intervention is trialled.

ETHICAL APPROVAL AND GOVERNANCE

Ethical approval for the study was obtained from the Lothian Research Ethics Committee (07/S1104/45). The study was jointly sponsored by NHS Lothian and the University of Edinburgh.

INTERVIEWS

Patients were invited to participate by letter from their GP enclosing information about the trial and the consent process. Those who returned consent forms for interview were then contacted by the researchers for an initial unstructured interview on their expectations of the system, and their experience of the recruitment and installation process. They were contacted again after an average of two months of use and interviewed about their experiences of using the equipment.

We attempted to contact and interview all those who gave consent in the window between return of the consent forms and notification. Those who were not interviewed were either in hospital, unwell or not contactable.

Table 1. Interviews with Patients, GPs and Practice Nurses in Four Practices

Patients	18	Patients (11 males and 7 females) from 4 practices were interviewed in the period between consent and installation of the equipment and again after an average of 2 months of use. Two patients, both male, died during the trial and only the first interview is available. Average age was 68.9 with SD of 9.11 Patients typically had moderate COPD
GPs	4	GPs from all 4 practices (two male and two female)
Practice Nurses	4	1 from each of the four practices

Carers were generally present with patients we interviewed, and generally participated actively in the interviews, often answering on their behalf if the patient became breathless.

The practices were mainly in relatively deprived areas of Lothian in keeping with the recognised demographic of COPD. Care was provided by their registered GP, supported in some practices by a practice nurse.

Other healthcare staff in NHS Lothian who would be involved in the wider clinical trial were also interviewed about their perceptions of potential benefits, concerns, risks, costs, or impact of the intervention on roles, relationships and work practices.

Table 2. Interviews with other Health Practitioners in NHS Lothian

Respiratory Nurses	2	Two female, hospital-based specialists following up emergency COPD admissions before discharge, and briefly at home before handing back to the GP and community health nurse. These nurses will be part of the planned IMPACT team who will provide specialist support at home, supported by community health nurses in the full trial.
Nurse Managers (AHP)	2	Senior NHS Lothian staff heavily involved in the streamlining of allied health practitioners' services around the needs of chronically ill patients at home.
Community Nurse Managers	6	Community nurse case managers who will have a greater role in looking after chronically ill patients at home in collaboration with other specialists such as respiratory nurses, and others such as dieticians and social care workers. (Group Interview/Focus Group)
Physiotherapy Managers	2	One male working across two regions and with an interest in telecare as a means of outreach. One female involved in the wider trial of telecare in the second phase of the study
Physiotherapists	3	Two female physiotherapists and one male

Interviews were also carried out with members of the project management team, and those involved in recruitment, installation and training to identify issues such as ease of recruitment; selection bias; broadband availability; reasons for declining to participate, IT readiness of different practices.

ANALYSIS

Coding of interviews was iteratively refined using paired analysis of transcripts by two researchers and further refined in collaboration with the wider group. These issues, together with the outcomes of recorded observation studies provided a basis for feedback to the wider team, and in the context of the workshop, to stimulate discussion in order to refine the emerging issues.

FOCUS GROUPS / WORKSHOPS WITH HEALTH PROFESSIONALS

Focus groups provide a means of validating, refining and taking forward the issues arising from interviews or ethnographic observation. Stakeholder analysis (Robinson et al 2007) can also be facilitated through these activities. They can also help refine and tease out the context or community specific issues within and between communities which may underpin costs and benefits (e.g. socio-economic status, home support, compliance with traditional care plans, and attitude to personal health.) Three focus groups were held with clinical staff including nurse managers, community nurses and physiotherapists though much of this was used to clarify the nature of the trial itself, and the impact on nursing roles. A workshop was also carried out with a wider group of project managers, system providers, nurses, GPs, research nurses and health researchers to explore criteria for trust in telecare.

OBSERVATION IN CONTEXT

Ethnographic observation of installation, training and use in nine of the households provided useful insights into practicalities of use in the home context, and of the difficulties with particular aspects associated with location and use that give a much more visual indication of the issues.

OTHER SOURCES OF DATA

Data logs of usage were available. Email circulars also provided a valuable longitudinal record of how issues were perceived and dealt with at different stages in the pilot, particularly where these were circulated widely. Observations and minutes of formal and informal meetings and training sessions also provided occasional opportunities to track changing constructions of the issues as they were perceived and addressed at different points. A project wiki was also set up as a means of sharing or commenting on material available from the research and from community nurses and physiotherapists, particularly prior to workshops.

A number of more general focus groups were also organized in the early stages to provide a forum for demonstration of the equipment to community nurses and others and a general exchange of information. These were recorded and provided some generic background for interpreting possible issues, though not included in the data. Attendance and observation at regional meetings of COPD and telecare strategy groups, as well as training workshops and team management meetings also provided context.

PATIENT EXPECTATIONS



Fig. 5 Patient Expectations © Hulton Getty. Licensor www.scran.ac.uk

The baseline project interviews provided a benchmark for more in depth analysis post experience, and to elicit the needs and requirements against which patients were likely to match their experiences after installation of the equipment. Almost all patients and carers expected the principal benefit of the system to be a reduction in the different causes of delay in the management of an exacerbation.

Much of the initial conversation initiated by interviewees was given over to descriptions of how the disease impacted on their daily life, the anxiety precipitated by their earlier experiences of exacerbations sometimes involving hospital admission, and the different factors which they felt had contributed to this. The quotes in this section were selected from interviews recorded at the start of the trial unless indicated.

REDUCTION OF DELAY IN MANAGEMENT OF AN EXACERBATION

Patients and carers identified a clear set of barriers to timely access to care, from knowing when to seek help, to making an appointment, going to the surgery, and getting antibiotics or other medication to start treatment. It was clear from the initial interviews that the value of the system for patients and carers would hinge on the extent to which the system addressed this. They provided a range of reasons, each of which provides useful information for design of a system intended to minimise delay in diagnosis or treatment, or to meet the requirements of potential users in this group.

DELAY OCCASIONED BY NOT WISHING TO BOTHER THE DOCTOR

I mean I was like days into an attack and it was only when I was really desperate that I thought maybe I should call out the doctor. That was me. I canna go to the doctor. It's just....I'm gonna get over it. I'm not going to bother the doctor until I'm really bad.
(Female patient, 66, pre-installation)

Patients clearly felt unwilling to bother practice staff unless they were sure they were ill for a number of reasons.

I think it's the thought in case you're..you know... mistaken, you know? And it doesn't come to anything.
Female patient, 77, pre-installation)

The onset of an exacerbation was often difficult to distinguish from the frequent, self-limiting increases in symptoms on 'bad days', and doctors were perceived as being very busy, so patients often took a 'wait and see' approach before phoning the surgery.

Clinicians in the study commented on this reluctance to bother doctors as typical of older patients, even when they had been strongly urged to contact the surgery promptly.

The frequency with which patients experienced such symptoms during the pilot study underlined the difficulty patients had in balancing the risk of delaying treatment for an exacerbation, against concerns with bothering staff at the surgery unnecessarily.

Although in the minority, two of the women in the pilot also volunteered the fact that concerns about taking medication especially the side-effects of steroids were also been a factor in delaying seeking help.

DELAY THROUGH DIFFICULTY GETTING AN APPOINTMENT

This was perceived as a significant cause of delay by the majority of the interviewees, and one which provoked anxiety and occasionally anger. For these respondents, the primary anticipated benefit of the telecare system was the perception that this would provide faster access to medical assistance when required.

You cannae get a doctor so therefore it's no my fault that (get breathless) and I get angry. And I can't get a doctor. And it could have been prevented from getting to the stage that it is. (Partner interjects - It's easier getting an appointment with the undertaker). But that's truthful. There's some times you just cannot get a doctor. I've seen me having to wait days, you know.

(Female patient, 69, pre-installation)

To let you understand, just say I got up this morning and was awful bad, say I had a right bad lung infection, or whatever, and I phoned the surgery right now – no chance of an appointment the day. That's the truth. I'd be lucky, maybe, to get one next week. I'd be very lucky.

(Male patient, smoker, 49, pre-installation)

Many patients highlighted the difficulties they experienced in getting timely access as being the principal factor in choosing to use this technology, and the anxiety this generated.

Best thing? .On the average I would think that the machine...it would get attention a lot quicker than you would normally. I'm just going on what you hear...where you wait 3 days for an appointment. Some people even said they had a week to wait. And I said – 'Is that for a specific doctor?' 'No, no, for a doctor. From that point of view, the machine's a great asset. It would throw up to somebody right away that you need attention. You're no getting blocked off by a receptionist.

(Female Patient, 69, pre-installation)

DELAY DUE TO DIFFICULTY IDENTIFYING OR ACKNOWLEDGING EXACERBATIONS

Patients reported often having symptoms such as breathlessness that could be the start of an exacerbation, but which could also be transient effects of exercise, anxiety, weather or allergy for example. Often patients preferred to wait until it was clear that this was not just a 'bad day' before acknowledging the need to act. The speed with which symptoms could worsen, and the timing of this (for example over night or at weekends) were also seen as contributory factors in delay, particularly where this might involve treatment by out of hours or NHS24 staff unfamiliar with their personal history.

Patients anticipated that tele-monitoring equipment might remove this burden of doubt and anxiety both through the transfer of responsibility to an external arbiter, and through the provision of some tangible evidence (in the form of a score) as a basis for action. This anticipated benefit was also cited as a principal reason for participating in the study.

The provision of more tangible criteria for seeking help was seen as very helpful, particularly where some patients expressed a significant degree of anxiety about bothering a doctor, and when the symptoms could also be occasioned by a number of other factors.

You'd think you would find it easy to tell when you're ill but it's only afterwards that you know you are not well. But this technology is really brilliant.

The difference between no feeling well and being ill - she (practice nurse) said 'It's when you start no feeling well. . . no when you're ill that you should come down.' But I need to get the knowledge to separate the two. There's a big difference - ken what I mean? Feeling unwell and being ill - it's two different things.

*I said 'Well I'm really quite breathless but I don't know if I'm bad enough to go and see the doctor'. Because if I have to clean my windows I can be breathless, but it doesn't mean ...
(Female Patient, 66, post-installation).*

I'm usually two days into it - an infection - before I go to the hospital - unless I have a cough and then I know. You wait and see if you get worse or not. It can get worse very fast though.

(Male patient, 77, pre-installation)

DELAY THROUGH FEAR OF BEING ADMITTED TO HOSPITAL

Practice nurses following up reported threshold scores with some of the more severely ill patients they regularly saw and assessed, believed that some routinely underplayed symptoms when answering the online questionnaire to avoid triggering an alert and all the stress and disruption of yet another hospital admission. Many patients commented on their fear of exacerbation and a consequent admission to hospital.

*I knew if I went to the surgery I would be in hospital. So I said 'No.'. Ken what I mean?.' I'll just fight.' But I was really bad.
(Male patient, 76, post-installation)*

This contributed to reluctance in some case to being referred to out of hours staff (LUCS), when scores triggered an alert, in case this resulted in hospital admission by a GP who was not familiar with their 'normal' levels of breathlessness and blood oxygen. This is discussed further in the section on GPs perspectives. Practice nurses on occasion commented on the perception that some patients routinely under-scored on the online self-assessment questionnaires to avoid triggering an alert for this reason. For some more severe

patients there was the perspective that there was little point in being referred to hospital. One carer explained it succinctly.

I feel that quite often he leaves it a long timeAnd I understand that because he says ' what else can they give me?' He feels that he's done everything, so what's the point in going down?'
(Wife of patient, 72, pre-installation)

DELAY WHERE HIGH TOLERANCE LEVELS MASK PROBLEMS

Some patients (and their GPs and practice nurses) reported that they had learnt to tolerate/manage their conditions even where scores were well outwith thresholds that would normally necessitate hospital admission. Nurse managers expressed concern (see also the section on GP and nurse perspectives) about the risks of home-monitoring if non specialists and patients underestimated the severity of the condition, and the speed with which intervention (such as oxygen therapy) would be required. There were concerns about the potential risks if severe cases of COPD were increasingly monitored at home by non-specialist community care staff.

I think the main thing is that when these people are picked up by the care team or the primary care team, that nurses know what to do with them - that they're trained and they're competent. That's an area that we're trying to develop.

*It is about being **absolutely** clear what these people need in the way of support, and of what **exactly** will help. For **some** of these people who...(pauses briefly)...the only thing that will help **some** people is more perfusion – **getting their body on oxygen.***

Manager of distributed care services for patients at home

The risks implicit in monitoring patients with severe COPD, (together with the likelihood of frequent hospital admissions, and the limited scope for minimising the speed of deterioration of lung function), were suggested as reasons for focussing the service on patients with moderate COPD.

DELAYS IN GETTING TO THE SURGERY OR THE CHEMIST

For a number of patients, transport to the surgery and to a chemist was at some distance. There was quite a lot of variation across practices with some patients having to travel to collect prescriptions, some having them delivered, and other practices routinely providing these to be kept at home.

Because it's quite a wee bit of work getting to the doctor's - it's about 15 minutes walk - if we want to go to the doctor we've got to take two buses...You've got to wait, and then you come off, and then you've got the rest of the way to walk. It's no problem walking if you're OK, but if I'm having an attack there's no way.
Female Patient, 66.)

Given the speed with which symptoms could worsen, this accounted for a potentially significant delay that could be reduced through more widespread adoption of the practice of allowing patients to keep prescription medication at home to cut the delay between diagnosis and intervention. The availability of tele-monitoring scores in this context provides the GP with a basis for recommending use of medication at home as well as for patients seeking medical advice from the a doctor.

PATIENT EXPERIENCE



Fig. 6 The Personal Health System (PHS)

After an average of two months using the technology, patients' experience of the benefits seems to have largely matched their expectations, and most were delighted that it addressed the needs they felt they had, particularly with regard to access to appointments. In the few cases where patients were disappointed in the outcomes they made it clear that they were supportive of the concept in principle, but felt that there were concerns with the reliability of the technology or the organisation of the monitoring and clinical support processes in the exploratory pilot. All quotes here are post installation unless otherwise indicated,

You know if something was wrong I'd get a phone call from the surgery –saying- you know - tra la la - whatever it was. The way I look at it, if there was something wrong they'd write a prescription, and I'd get it sent to the chemist...and then I'd get it delivered direct.because if I'm unwell that's one thing I have to face is that long walk to X, because there's no bus direct from here an you know, when I'm unwell, um, so I'm delighted with it, yeah.

(Female patient, 66, post-installation)

The bulk of the comments in pre and post interviews related to the benefits they hoped for initially, and satisfaction with this where these were achieved in practice. Most of the issues emerged (sometimes unexpectedly) in response to open questions about their experiences of using the system. The issues raised are consonant with other reviews where patients are typically very positive about home telecare. Recent reviews by Gaikwad (2009), Botsis et al (2008) and Whitten and Mickus (2007) report similar positive experiences of the use of telecare by COPD patients, such as enhanced reassurance through being monitored. This positive experience is tempered by the lack of evidence that the measures themselves helped diagnosis of an exacerbation (Whitten and Mickus, 2007), and by the difficulties in evaluating the outcomes of studies typically carried out on small samples, in different contexts, and without a common framework for evaluation (Botsis et al, 2008).

REDUCTION OF DELAY IN DIAGNOSIS AND INTERVENTION

Oh you were waiting weeks, and he was suffering all that time. And (now) any time the machine takes his reading and it's not up to scratch, they're on the phone right away. He's (husband) fair pleased because he says at least it takes, you ken, the worry. Whenever you're no well you can get them right away. Get on antibiotics and that. Cos he will say 'you always leave it a wee bit too late. You wait till you're gone and bad, you ken'.

You must admit there was a big improvement, because it saves you begging for an appointment and things like that.

Carer for 69 year old male patient

Patients expressed great satisfaction and relief at the ease of access they now felt they had to early medical attention, and in some cases at the extent to which the fraught decision on bothering a doctor, possibly unnecessarily, was managed in part by proxy.

All the interviewees identified the advantages of a system that triggered intervention before patients were likely to have sought help – even though in practice there were occasional delays in the initial organisation of the monitoring process.

The lady said to me "You've got some very bad readings. Have you got the doctor? I said "No I'm feeling rough" I said, "but I've been like this many a time" I said, "so" I says "I don't think there's any need for it now. "Well we do, so do you mind if I phone?" I says "You can do what you like dear". She says "Well I'll phone the doctor". OK, the decision had been made for me – but nothing transpired from it. (Male Patient, 78, post-installation)

Patients did provide some examples of exacerbations which they felt had been avoided by having this system in place, and a number volunteered the view that they had been in hospital less frequently than usual.

*Yes, a couple of times **the doctors** have caught it before it goes into an exacerbation. ..There's a couple of times we've caught it before it got bad (Carer for female patient, 87, post-installation)*

*P I've been in t he hospital once since this started and I was in for a week'
I: And typically before you got this would you have been in more or less?
P: I would have been in more. Usually, sometimes, about 3 or 4 times a year (Female Patient)*

In addition to expediting access to appointments, it also, facilitated the delivery, or the home-based holding of prescriptions (e.g. for antibiotics) for rapid intervention.

P: So I don't need to have an appointment

C: He just goes on to it straight away. They write a prescription and it goes straight to the chemist

I: Did he have that before?

C: No he didn't used to have that before.~

I: Do you see that as an advantage?

C: Oh yeah, because normally..to get an appointment down here ..it's murder

It would be useful because if it happens at the weekends you're at the behest of NHS24 which is all very well..but they don't know the individual patients. If we had antibiotics or steroids, we could start them, and then see on the Monday morning, you know..to assess what we had done

(Carer for female patient)

All the interviewees were very positive about the concept.

Oh no – it's a great help. There's no two ways about it – it's a good thing. Well I think it's a good thing anyway, and the two boys that were there for Intel – they asked that- and I said "I thought you were come to take it away!" And I said – "You're no goin to take it away! You'll need to get the FBI!"

(Male Patient)

Even the interviewee who admitted to having had considerable anxiety in initial use of the equipment was vehement in the belief that this was 'one hundred percent right' for her. While other interviewees experienced technical issues they were very positive about the quality of both the clinical and the IT support. Comments suggest they balanced the benefits against the costs or inconveniences of breakdown and found the benefits and the sense of security significantly outweighed other considerations.

Only one interviewee found the balance had tipped the other way, through a combination of both recurring technical failures and compounded by a delay between transmission, triage and communication to the surgery in the first iteration of the protocol, where transmissions in the late afternoon would not reach the surgery until the next morning.

(The fan) was keeping her awake at night with the machine going.....but if what was being discussed was being fulfilled, and caring for my health, then the wife said "You know its worth putting up with". But when she seen the reaction we got with the doctor not coming and the pulsometer not...and I mean I would imagine, (.and I'm not a medical man), .but I would imagine that is one of the most important parts of the system to make sure your pulse is right. And then when no action was taken with that I thought "What kind of a set up is this, like?"

(Male patient, 78, post-installation)?"

REDUCTION IN ANXIETY FOR PATIENTS (AND CARERS)

This was one of the other almost universal themes in patients' and carers' comments, and one that is reflected in many comparable studies. For some, this reassurance appeared to stem from a sense that they were being watched, that access to help would be expedited, and they might avoid hospital admission, of which many had previously had particularly bad experiences.

It's actually quite comforting to know that they can see that every day, because before that I was getting rushed into hospital. Now with that they're seeing it - they're monitoring it.

(Male patient/smoker 59, post-installation)

For some, the pressure of deciding whether or not to bother a doctor was reported as a source of real stress, given that previous delays had resulted in hospital admission, yet symptoms were often transient or ambiguous, and there was real fear of bother busy GPs.

Actually it made me more assured. In a way it was a relief thinking that I should ignore my own thoughts on getting a doctor or something like that. This organisation was going to get hold of a doctor if their readings showed I needed a doctor. They were going to get hold of a doctor and get one here.

(Female patient, 47 with asthma and COPD, post-installation)

There are suggestions that for some, the system reduced the pressure of making the difficult decision to bother the doctor, transferred responsibility for that difficult decision to a trusted professional or proxy.

Makes you a wee bit confident you know....not wondering if you should contact the doctor. Most of the time it's my daughter that says 'you have to phone the doctor. Like most people I'm inclined to say 'I'll see how I am tomorrow'.

(Female patient, 87, post-installation)

This decision had clearly been a very fraught one in the past, occasioning panic in some patients, and compounding the problem.

C: Since he's been on that machine he's never had anything like that.

I: You've not had any attacks since you've had that machine?

C: Oh no. Because you're seen to right away now

I: So you think you've been catching things earlier then

P: Oh Aye

C: He'd have been carted away in an ambulance because he hyperventilates at the start. Just before the machine went in. He panics.

P: Ah panic... I was bad, and they took me into hospital on oxygen (Carer and patient with severe COPD, post-installation)

Patients and carers also highlighted the value of having hard evidence as the basis for deciding whether to call the surgery rather than delay.

And the readings are helpful for me, and I can physically see if her oxygen saturation is OK...and stuff like that so that's reassuring for me. So I must say I like it... I think its a good thing for a carer to have.

(Carer, female patient, 87)

ENHANCED AWARENESS/ ACKNOWLEDGEMENT OF SYMPTOMS

There was an expectation that this system might help patients recognise the onset of symptoms but most comments suggested this only happened to some extent. A number, however, reported that they were more likely to acknowledge their symptoms and thus act earlier.

*You know I can tell quicker than the machine if T's chest is getting worse.... I think the machine does help you **acknowledge** that there's something. Whereas before you just say 'Och...' You just go into denial. It gives you something concrete.*

(Carer, male patient, post-installation)

Oh I like it (as a carer) because I think it makes her think a little bit quicker and makes her realise and she'll maybe call the doctor in two days rather than three days if she's answered the 'Yes' prompts along to think like that.

(Carer, female patient, post-installation)

A number felt that they were already aware of the symptoms, but delayed for a range of other reasons. Here the external intervention was seen as crucial in reducing delay in starting treatment.

I know myself if that wasn't there I'd just keep puffin about.

(Male patient 77)

Well before I might have left it off for a week or two because I don't like taking them (steroids).I don't like the side effects. But I know when I have to take them now.

(Female patient with / COPD and asthma, 47)

Goodacre (2008) points to the economic and clinical benefits of better targeting of intervention around individual needs which telehealth monitoring can facilitate, and suggests this should also be taken into account when evaluating cost:benefits. A number of patients and carers reported that the use of tele-monitoring raised awareness of their condition amongst clinical and administrative staff at their surgery, thus improving the quality of care which they received.(e.g. facilitating reviews of treatment and access to antibiotics) The work of Gore (2000) suggests the diagnosis and treatment of COPD is very variable across practices, and there is some indication that the introduction of telecare can foster the exchange of good practice through the opening of new opportunities for communication, engagement and review across groups and practices.

REINFORCING LIFESTYLE CHANGES IN PULMONARY REHABILITATION

One of the unexpected benefits was the potential for monitoring and reinforcing the impact of lifestyle changes such as smoking cessation

When I stopped smoking I could see the difference in the scores. I've noticed, even my peak flow. My peak flow will never be really high. There it was 105. Well, it's usually about 80 or 90, ken? But since I've stopped smoking, I'm putting the weight on. I notice it on that scale.

(Female Patient)

Parallel pilot projects are underway in other clinical areas in which a focus on supporting self-care and lifestyle changes in diet and exercise are crucial. These studies are further exploring the potential of such systems as a means of facilitating tailored advice, providing feedback and reinforcement and coordinating services around individual needs. (Hanley et al 2009). It is hypothesised that the impact will be on three levels – the information will assist and encourage the patient to improve their own self-care, it will facilitate clinical decision making, and both will be enhanced by the new channels of communication between patients and health care providers along the lines of self-care models described by Glasziou et al (2005).

EXTENDING PHYSIOTHERAPY SERVICES TO PATIENTS AT HOME

Patients in two practices where pulmonary rehabilitation services were available in community centres often commented on the value they had experienced from such services and in addition, carers appeared to benefit from the support of the community carer networks, and from being able to do something constructive.

They feel a lot better. They can do things again that they couldn't do when they first went.... If it is the diet and exercises, then that one (points to pulmonary rehab. booklet) some of that could be on the machine.

(Carer for male patient with severe COPD and depression)

One GP pointed to the combination of telemetry assisted self-care with associated pulmonary rehabilitation as a potentially winning combination.

I think they (moderate to severe) get the most out of it. Depends on how bad their acute exacerbations are, In combination with pulmonary rehab. That would sell it. A combination, combined approach would be brilliant. I think if that was – if people who had COPD were offered this for monitoring their progress – just the fact that they are mentoring their progress every day

(GP)

Suggestions included putting tailored material on the system, using the updated symptom scores as a basis for prioritising visits, using the planned video-conferencing system to assess or reassure patients as a cost-effective alternative to home visits, or including some limited physiotherapy exercises on the system, along the lines trialled by Burkow et al (2008), with the caveat that these need to be tailored to the needs of individual patients!

I: Do you think putting something like those breathing exercises on, or maybe video clips, would be worthwhile?

C: Yeah

P: Well, it's not really because unless somebody shows you what you're on about.

C: It needs to be personal

P: Like when she says to me "Breathe through your nose".

C: Breathe through your nose.

P: Uh huh, they're watching you to see what you are doing to see if you're doing it right. Unfortunately, I don't

I: No, I can't either

P: I don't because I was a diver and you don't breathe through your nose as a diver because you've a bloody big nose clip on it

(Male patient, severe COPD and depression)

GREATER AWARENESS OF SYMPTOMS AS A BASIS FOR IMPROVING CARE

In the course of evaluating daily scores, a great deal more detailed and current information was accessible to a the healthcare team than previously, and there was a perception that this contributed to more individualised and informed care. Patients indicated in some case that they had never felt so well looked after.

Possibly the doctors were more...they all seemed to know what was going on...whichever doctor phoned or came from the practice..the regular doctors all seemed to know what was happening.

(Daughter of female patient, 87, post-installation)

A number of patients commented on the heightened awareness of their condition at the surgery, and the quality of care they received.

Oh aye, there's a lot of awareness. Ah cannae complain about the backup, let's say. S and that at the care centre. And L. down there and the doctors....I mean that medical staff down there -I mean Dr M has been on the phone himself a couple of times, and L. He's some man. He's very dedicated...

(Male patient, post-installation)

Casas et al, (2006) and Koff et al (2009) also point to the potential benefits of shared-care arrangements between primary care teams and hospital teams where information is well managed across teams.. A greater awareness of 'normal' levels of breathlessness for individual patients, and a more collaborative approach to intervention also contributed to avoiding unnecessary and unwanted trips to hospital. Scoring benchmarks were set quite low however, and there was concern by patients that when being dealt with by the out of hours LUCS service, this could result in unnecessary hospitalisation.

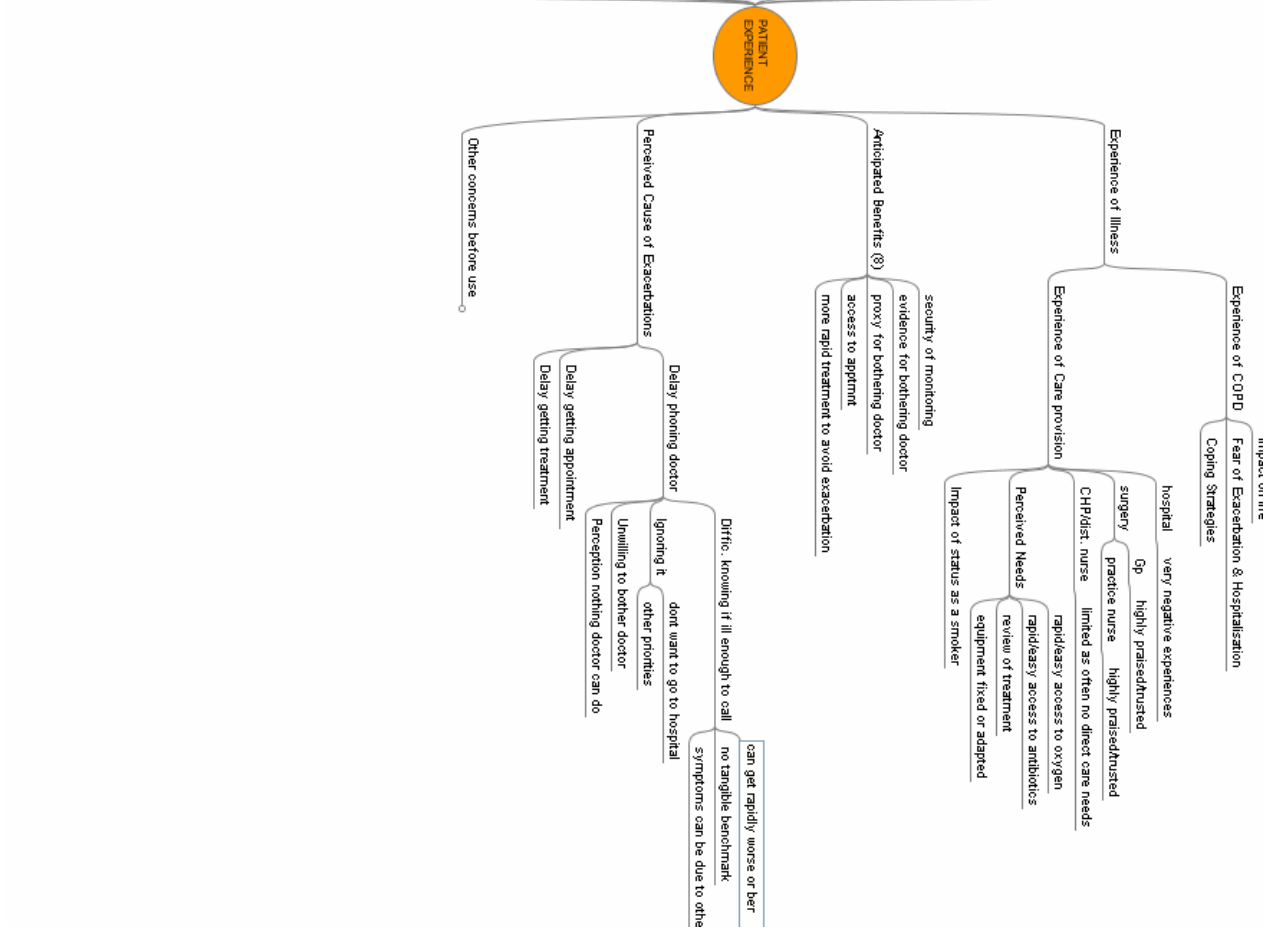
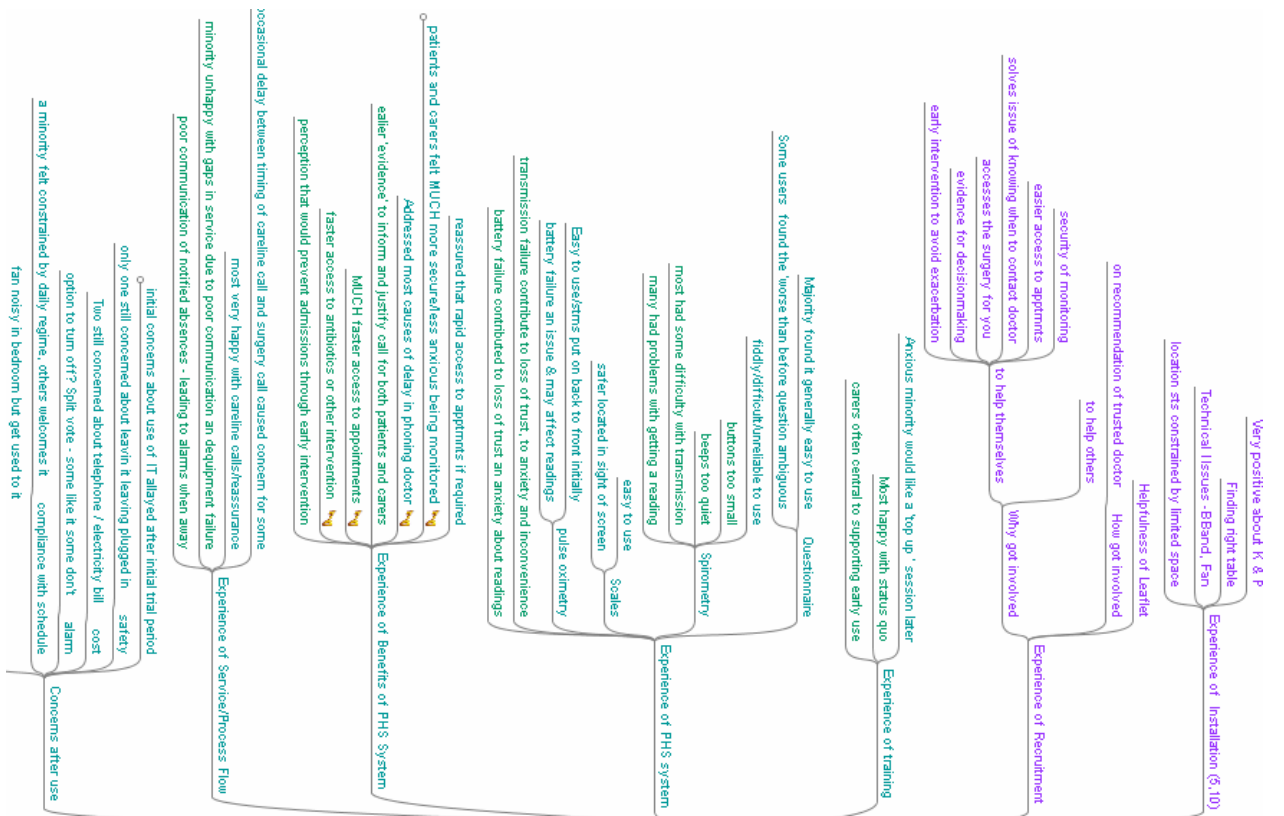


Fig. 7. An early overview of the issues raised by patients from initial interviews..

TRAINING



Fig. 8 Home installation of the PHS

RECRUITMENT

Patients were happy with the recruitment process. Most agreed to participate on the basis of very positive and trusted relationships with a GP. The ongoing input from the GP, the installation team, and the project manager were instrumental in supporting users over the initial teething problems, and there were concerns voiced by one GP that this might be less sustainable when implemented on a larger scale.

The patient leaflets and other documentation were seen as helpful and clear, although often read by a carer or partner rather than the patient. We established that patients had been told this was a pilot, and to call the GP directly if they had a worsening of symptoms however it was evident that this advice – like much of the information in the leaflet - was sometimes forgotten. It was recommended by more than one patient that key information including numbers to call could be made available on the machine as well as on the leaflet. Almost all patients accepted the invitation to take part, partly on the basis of encouragement by the doctor, something that cannot be assumed in larger scale implementation.

Two GPs highlighted the potential difficulties for a wider rollout where this kind of personalised engagement from GPs could not be assumed given the need to follow up invitation letters with phone-calls to encourage and maintain engagement.

I thought you know if we just send letters they'll just bin them, because that's what the majority of patients do – so I had to phone them all and - so it's quite time consuming – even for a small number – to do that. We were left with quite a lot of stuff to do.

GP

They will do that if you enthuse them in the first place – not just sending out a letter saying would you like to be part of this study. I think our patients feel they were individually handpicked by their GP because they could benefit from it – that's what enthuses them

.(GP)

First lesson learned was that if you want people to agree to it a letter isn't enough. You have to go round (to) folk and explain what's involved. That takes the best part of the morning. Problem is, for getting people signed up to it there's no substitute for doctors persuading the patient. And I mean it worked. It made it very personal for them. It certainly made a difference, because they all signed up there and then. So I can understand why practices have been reluctant to volunteer because it's extra work.

(GP)

Cognitively able moderate to severe patients were seen by physiotherapists as most likely to benefit from both monitoring to support early intervention and reduction of inappropriate hospital admission, and also support in identifying, acknowledging and acting on symptoms as well as self-care advice.

One of the GP practices had patients who were significantly more ill, and older, and although they were perceived as having benefited, there were frequent interruptions as a result of hospital admission and other complications. It was also clear from this cohort, that patients who were less cognitively able, (e.g. with early signs of dementia), would not be suitable.

INSTALLATION AND IT SUPPORT

The installation team was very well regarded by interviewees, and their availability and accessibility ensured that unanticipated problems and technical failures were prevented from impacting more seriously on retention of patients .

You have a bit of banter wi them. K's a nice lad – cannae do enough for you. So's that P - the boy fae the (unclear). Nice folk – can't do enough for you.

P. did a wonderful job. You need a dedicated project manager. One point of contact. And certainly what our patients want – there was only ever one telephone number and that was the main person. I think that's really important He had the respect of the patients and he got things done when he said. If he said people were coming at two, people pitched up as promised. It's so important for people who do not like seeing strangers. You want a single point of contact. You want the patient always to be notified before somebody turns up so there are no surprises. It's about managing expectations. I think one of the reasons it did work so well was because patients did feel they got a responsive service

(GP)

The existence of an informal support system and small patient numbers may well have shielded the pilot from the impact of issues (technical and personal) that might otherwise have affected recruitment and retention. This has resource implications when the service is scaled up for wider implementation

The one patient who chose to leave the trial without other pressing medical or personal circumstances, did so where trust in both the technical system, and the human backup failed.

Technical support is planned on the basis of an estimation of the likely resource required, and balanced against other commitments. Unexpected failures arose that required significant extra resources, and the resulting service delay compounded the experience of technical failure. This led to a breakdown in confidence in the dependability of the system and the service as a whole.

INTEGRATING THE SYSTEM INTO DOMESTIC AND SELF-CARE ROUTINES

Usable systems need to be integrated into the space and the domestic routines of users. Assessing where to locate the equipment within the home involved a range of factors. Most patients found the use of the equipment fitted well into their daily care routines and was not seen as time-consuming. The high rates of compliance in data logs support this. Physiotherapists in particular saw scope for significant synergies here with the self-care and rehabilitation agenda.

In some houses, lack of space and appropriate telephone sockets made it difficult to ensure ease of use without, for example having to bend down to a low table, or sit at an awkward angle on the side of the bed, and in other cases prevented use of a second phone or a laptop requiring a phone line. Consideration also had to be given to easy access to other equipment in the same space, such as oxygen, where patients in some cases had low mobility.



Fig. 9 Location and safety issues

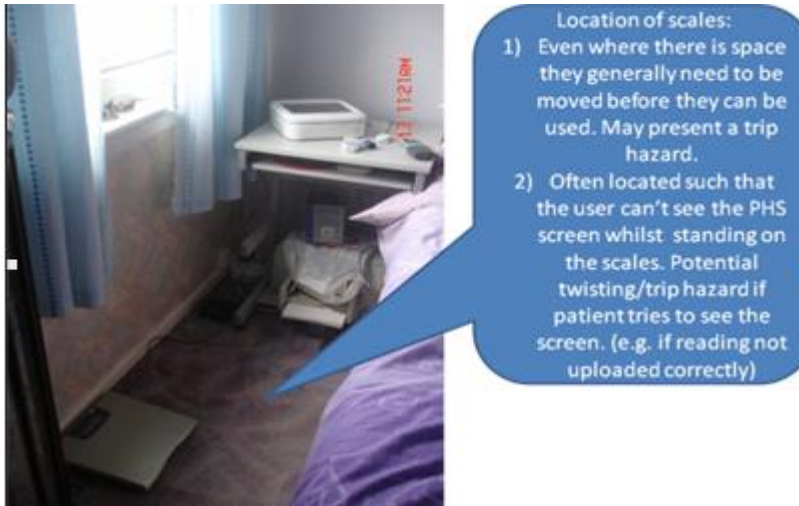


Fig. 10 Location and safety issues

Many households were not in a position to acquire a new table, even where space was available. One community nurse suggested use could be made of one of the Lothian repositories for provision of a table with the equipment if necessary.



Fig. 11 Location and aesthetic issues

Equipment was also seen by some female patients as intrusive in the home context. As one female patient said 'I hate it. Hate it. I think I told you the last time that it was when everybody went away and it was there, where the telephone is now, and I looked at all the cables and I thought 'What have I done in the living room? ...All the cables. They're just like spaghetti junction round here.' She also commented on the impact she felt it had on visitors as well. This is also found in other studies such as (Hensel and Demiris 2006).



Fig. 12 Location and visual impact

The noise of the fan was also an issue when equipment is located in bedroom environment, disrupting the sleeping (and often work) routines of the wider family. Installation of the system in a spare room was seen by a number of patients as constraining subsequent use of that room for visiting friends and family, largely because of the noise of the fan and the alarm, but also in the case of grandchildren through concerns they might play with the system.

CONCERNS ABOUT COST

Possible additional electricity and telephone bills were persistent concerns for a minority. A number of patients were initially worried with the risks of leaving the system plugged in, but by the second interview, only one still voiced some concern.

MISSING UNMONITORED SYMPTOMS

Tele-monitoring only monitors symptoms related to detecting exacerbations of COPD, and symptoms due to co-morbid conditions would be missed (for example perception of palpitation). Some patients were unclear what was/was not being monitored with a potential risk that neither patient nor professional takes responsibility for raising queries about other non-COPD related symptoms. The comments of one patient highlight this possibility.

You would have thought that they could have picked it up. With people of my age you would have thought that was one of the things they would have been looking for you know – if someone has a low pulse rate.

Male patient, 78, with cardiac problems

THE CONFIDENTIALITY OF PATIENT DATA

This was consistently **not** an issue for patients or carers in either pre or post interviews. This may reflect the trust in the care team as known individuals, the low level of data transferred, and the fact that these patients were much more concerned more that their data might **not** be transmitted and seen.

As care staff also pointed out, this was, largely because the nature of the data being shared, such as pulse oximetry, would be of very limited useful to others, and was in any case encrypted. If anything, patients were concerned to optimise the access to this data to the wider care team, rather than the reverse

TRANSMISSION OF CROSS INFECTION

This was an additional issue raised by the installation team. Patients were visited on repeated occasions by a team of installers, researchers and research nurses. Tunstall have a policy in place to reduce cross infection through use of wipes between patients. This reflects the fact that they are working with people who are frequently subject to respiratory infections transmitted by contact, and working with equipment requiring close contact with mouth and hands.

TRAINING ISSUES: EXPECTATIONS AND EXPERIENCE

For most people the training was sufficient, but many had found it helpful to have the support of a partner or carer. The fact that the system prompted next steps was seen as very useful. In practice almost all patients found it easy to get started after an initial training session, although problems arose where batteries failed and the system did not respond normally. For most patients it was just a part of a daily routine.

FEAR OF USING IT

Women often expressed concern about their abilities with technology, and were more anxious about 'doing it wrong'. They were also sometimes at pains to disguise the extent of the problems they had had, and the support that had been garnered from partners, carers, grandchildren and others. This has implications for support in the wider trial.

At one stage I was almost crying. If they put a 14 year old kid into a room and handed it that I'm sure they would be capable. '(looks upset).

I do think you should have a longer time / even an hour, or half an hour, or maybe a few days with someone you can call.

(Female patient, 66, post-installation)

Some of this group would also have liked further top up sessions for this reason. Many patients therefore valued the second visit by the research nurses who provided training. Ostensibly this visit was to capture baseline measurements; but it also enabled the patient to ask more questions, and the nurses to assess and support patients' understanding of the equipment. Despite this, these women all indicated that the benefits they felt were so significant that it far outweighed other issues. As the first of these interviewees put it -

You don't know what questions to ask the first time"

It was good to have a second visit (from the training nurse). I needed extra help with the puffer (peak flow), that one was baffling me".

Men appeared more confident in their abilities, and generally didn't express these concerns to the same extent.

Fine. I'm a sparkie, and, well, I am electricity trained, so it didn't frighten me, let's put it that way, and, I mean, I don't have no trouble with it whatsoever. It asks the same questions every morning.

(Male patient)

ROLE OF CARERS AND OTHERS IN THE EARLY STAGES

The role of the carer, partner, computer-literate children and grandchildren or even neighbours as back up was an intrinsic part of the viability of the process. This has implications for training and support in wider implementation. The role of the carer, or the existence of a support network should be taken into account in the facilitation of support or additional training for this group.

Drawing on wider social and community resources is increasingly a feature of other regional studies evident from the Whole Systems Demonstrator Network, and recent reports of regional pilots by the Care Services Improvement Partnership² (CSIP Networks) commissioned by the Department of Health to provide support for local authorities and their partners in health, housing and social care (DH: CSIP 2009). The Kent telecare pilot is one of a growing number using the resources of the wider community, including volunteer groups, and Age Concern, to help people without a carer to take their measurements, trouble-shooting and answering general queries. The shortage of existing resources is a recurrent theme in a range of report, and is also a feature of the new Scottish Government Telecare Strategy Report (Donnelly, 2008), the NHSS eHealth Strategy 2009-11³, and the recent US Telecare Strategy document 2008-2012⁴ which highlights the need for greater representation as well as collaboration with patients and carers and other stakeholders.

Almost all the users had depended to some extent on the support of family, carers or friends who reduced anxiety by providing a back up at critical points in the initial process of developing confidence with the system.

At first I had to have her watching me because I would do 'DONE' or I would take the thing out of the nest. So I had to watch and just stick to the rules...I was a bit hasty at the beginning.. So E...she supervised for about a week or so.
(Male Patient, 77)

Although very occasionally, carers were anxious **not** to have this additional responsibility!

Ah never use it. It's himself. Because I feel if I go through, one of these days it'll be "Go on you just do it."
(Wife/Carer)

This shared management of the condition may be seen to be beneficial and empowering. Further exploration of ways in which this might be leveraged or extended would be useful, from both a patient and a trial perspective, such as the patient support network described in other studies such as the Intel Global Aging Experience Project (Roberts et al 2006)⁵ and Whittenberg et al (2008). Wider implementation could consider routinely ensuring that suitable support was available at the recruitment stage, and that a friend or supporter was also able to attend the training session. The Care 21 Framework⁶ supporting carers in Scotland provides a vehicle for liaison given the importance of their role in facilitating effective telecare, and the additional pressures this places on them.

² <http://networks.csip.org.uk/IndependentLivingChoices/Telecare/TelecareOutcomes>

³ <http://www.show.scot.nhs.uk/eHealth%20Strategy%202008-11%20final.pdf>

⁴ <http://www.hhs.gov/healthit> <http://www.hhs.gov/healthit/resources/reports.html>

⁵ <http://download.intel.com/healthcare/telehealth/gaebrochure.pdf>

⁶ www.carersscotland.org

USABILITY ISSUES



Fig. 13 Nurse manager trying out the PHS at a training workshop

Patients and care staff were asked to comment on their experiences of using the system, including the peripherals for spirometry, pulse oximetry and the navigation of the front and back end screens they were required to use.

PATIENT PERCEPTIONS

Second interviews, after some time spent using the machine, highlighted recurrent IT issues, particularly with battery failure leading to unexpected difficulties with connectivity, transmission of reliable scores. We discuss patients perception and experiences of use in this section, but also include a section on the experience of Care staff with the monitoring screens.

IT FAILURE

Battery failure in one of the peripherals was an issue for many patients, after some weeks of use. A small group had problems where screens had gone blank, and reported that they had been told was due to a virus on the server where the data are received before relay to the telecare call centre. Two also reported breakdowns when the monitoring system had to be collected for repair.

In the pilot, many of the calls reporting were fielded by Careline or by the project team, and the number of technical problems experienced by users was mitigated by the accessibility of rapid face-to-face or phone based support from known and trusted individuals. These experiences have implications for the success of the wider rollout. Some of the issues emerging from comments were related to specific features of the peripherals, but there were also general comments of relevance to the design of the system and the software. Patients expressed concern at the difficulty of knowing why readings were not transmitting. This was stressful for some people concerned to know if their scores had been received.

NEED FOR FEEDBACK ABOUT WHAT IS HAPPENING/ WHAT USER SHOULD DO

The activity of the system was not very transparent to users, with problems compounded by lack of feedback for users in particular with regard to transmission. This meant that the nature of the problem (principally battery failure) was not clear, prompting unnecessary concerns and delays, as well as raising anxieties about the arrival or the accuracy of the reading. Unexpected battery failure in established technologies such as laptops is made visible by a flashing icon, alerting the user to impending problems, and instructing them what action can be taken. Reddy et al (2003), in other studies of the usability of health and business technology, are at pains to point out the benefits of making the activities of the system more visible to users, either visually, or through appropriate error messages or instructions for seeking help. This has clear implications for designers.

It's easy enough to use, but it's not working. We tried changing the batteries and that. But it's still not working. When you press the button the light's no coming on. Whatever it is there's something wrong with the wee control unit. I only had the one - with the pulse oximeter. The chap came out and it was the batteries. (They) just stopped working. (It) kept coming up 'Your reading has not been accepted'. So after a few days I phoned Careline and they said 'Switch it off and on'.

Patient trust in the systems and the service delivery as a whole was eroded where expectations of reliable technology or reliable systems was not met. One patient left the trial because of serious technical failures compounded by subsequent delays in responding to this.

*And then it broke down and it took about ten days to get it back, right? And then after that the pulsometer went down so a lady phoned me two days later and she said 'Im not getting no recordings on your pulsometer'. I said 'No it's not working. I says 'It's not coming up. its not working'. So she says 'I'll get somebody to see to that straight away.'. Well it was about **8 or 9 days** before they come.*
(Male patient)

Well we were thinking of getting rid of it. There were a couple of times when you were thinking...it's more trouble than its worth. Sometimes you feel like that.
(Carer for female patient, post-installation)

Trying to establish whether readings had been transmitted was time-consuming, and caused anxiety for some patients. Some were unsure if they had gone through the process correctly, if the system had transmitted correctly or if the readings had been received. This could (as indicated earlier) be made more transparent to the user, as is routinely the case for example in the tracking of online orders or by receipt of a text message or email.

*Sometimes it doesn't register. I took the readings this morning -three readings. And I think those are just the same as normal. It's missed it before. It's taken the reading sent - like 'transmitting reading'. And then it's said 'No transmission found' or something at the top. But that was two transmissions in the one day and they didn't get either of them. So **that's** slightly annoying...so **that's** a bit scary...if you're relying on it.... Because if that had been a bad set of readings, and it was full rollout they'd be sitting there waiting on the doctor getting in touch or whatever.*

(Carer for patient, 87, post-installation)

BATTERY FAILURE

Problems with batteries were appearing as connectivity problems, with long delays in transmission. Batteries were also designed to be fitted differently from normal batteries i.e. not intuitive for patients fitting the spare batteries themselves. This generated a second set of enquiries.

One patient felt that the failing batteries had impacted on the readings themselves, for example.

P: Well, I didn't know anything about batteries and the warning light kept coming on, and I kept saying "There's something wrong with it"....And what happens with this one is, when it first comes up.. when it did come up.. it wasn't giving you a very high reading and I was getting my doctor saying "what's wrong with you?" and I said "It's not me, it's the machine".

This morning it's the best it's been. It started off at 93, no 91, and went up to 95. Well, if you're in between the 90s, 90 - 95, you're alright. I was getting readings of 70 and 80 on the blood oxygen and he was phoning me up. Just as well he was phoning me up, because the last time, last month, twice because the readings were there, I was sent to the hospital in a bloody ambulance.

I: So, just because the battery was low, you were getting low readings?

*P: Ah, because the battery was low, it was not kind of a proper reading
(Male patient)*

The lack of interface support/helpful error messages or pointers for users is also apparent here. By contrast, with one exception, the distributed team were seen as (Careline, the project manager, the GP and installation team) very helpful where readings had not come through, or there were other failures.

This is less likely to be possible in a wider roll-out. Likely failure scenarios need to be anticipated and practical support planned.

PULSE OXIMETRY

Pulse oximetry was seen as very easy to use by patients although battery problems and movement of the finger during readings were both perceived as impacting on readings. GPs and respiratory nurses were more convinced of the reliability of the readings from this peripheral, given its ease of use. Unlike they FEV₁ for example, where difficulties of using it correctly at home were well known. The number of problems reported in the trial compounded this view.

SPIROMETRY / FEV₁

Transmission frequently failed, or appeared to work but was not received. Patients worried if the readings had been received, and often concluded that they had 'done it wrong'. Blowing three times was also a significant effort for users: in one case particularly so as the user thought he was supposed to do it with the same breath!

The thing I found was - you pressed it the first time then there's nothing. Ah'd to press it a second time and then it would beep, and then you hear a sort of echo bleep. And I don't know if that counts two but I always press it twice - press it and get a sort o beep, and then ah press it again and ah get the same - seems to have gone through - so I assume that's right.

(Male Patient. 77)

One 74 year old female patient describes the difficulties of using the spirometry equipment

I think it was the peak flow I wasnae doing it right. I wasnae going through the whole procedur. I would forget to press that button thing. And then that holder, and I would knock it off. It took me a few days and that before I got used to it.

SYMPTOM QUESTIONNAIRE

Approximately half the respondents found the questionnaire difficult to complete to their satisfaction, and would have liked more guidance on those aspects they found ambiguous or unclear. A number suggested they would like to add additional explanatory information to support interpretation of scores – for example if they had taken readings after activity, where the questions did not correspond to the symptoms they experienced, or the difficulty of interpreting phrases such as 'more breathless', where the benchmark for comparison was not obvious.

Ambiguous

*It asks is it higher than normal .I dinnae know what the normal's supposed to be. And you're saying "Do you have a cough? Do you have a runny nose?" Well I've got a cough. I've got hay **fever**. **Of course** I've got a runny nose. So I don't know what...Sometimes it's not all black and white (Male patient / severe COPD)*

Subject to under or over-scoring

I think I've under-scored a few times...I think the danger of the machine is that you tend to underscore. If you're a bit hippy you'll over-score (!) I would think the average person would be more inclined to over-score. Sometimes you don't like to say yes in case it comes up with other questions .(Male patient)

VIDEOS

Patients found these generally interesting, though many were unwilling to risk exploring the resources for fear of doing something to the system or not getting back to the original page or settings. Both patients and practice nurses suggested that more tailored material could be added to the system that might also improve self-care and use of nebulisers, for example, or provide information of lifestyle changes such as smoking cessation, exercise, stress management or diet.

Well that lady was saying that it's really good like. They're starting off, and after their 9 weeks they're fitter. They feel a lot better. They can do things again that they couldnae do when they first went.... If it is the diet and exercises, then that one (points to pulmonary rehab. booklet) some of that could be on the machine. (Carer)

FRONT END AND NAVIGATION

Users seemed to find it very intuitive once shown how to start it, although most patients were reluctant to explore the other functionality in case they accidentally did something, or couldn't return to a familiar page. One GP summarised the difficulties and suggested possible changes to make the interface more transparent for users.

One of the things was the patient never knew if it had been sent successfully.

You know one of the things that would be really useful – you know this thing when you're on the computer and you get these ten tasks that all have to be done – and it goes 'tick tick tick' as it does them (for example in virus scans) . Having that you know, after your FEV₁. These have been collected and worked These have been successful. Checking reading' This would create communication with the person doing it. Because they're really in a loop and they can't get out of [it]. It wouldn't be difficult to put something like this into the programme. But it would actually reassure the person doing this. So they don't spent time waiting to hear from someone did it work or didn't it.

The peripherals were generally seen as requiring some redesign for older users with poor sight, hearing and dexterity. The sequence of steps for patients did not allow for going back to the beginning if an error was made which was seen as unhelpful .

WEB CAM

When the use of the web cam was explained as a means of allowing a GP or nurse to see the patient to provide further information for a diagnosis, patients were cautiously welcoming of the idea. Privacy seemed to be an issue for some, but was balanced by the perception of benefit afforded by an extra channel of communication. This is consonant with the outcomes of a study by Demeris (2009). Being told explicitly that the web cam was only switched on during a consultation and can easily be switched off, changed initial reactions from negative to positive in most cases.

C: You're definitely needing a system whereby X (patient) can add information

P: That's where the webcams come in. You can say 'Look I've got a runny nose but I don't think it's anything to do with...' (Carer)

Interestingly, one patient suggested that it might give them more information about the clinician dealing with their condition, reflecting the concern of many patients to be seen by someone who was familiar with the issues in COPD in general, and with their case in particular. Out of hours services dealt with by LUCS, where unfamiliar doctors were on call, were rarely accessed for this reason.

ALARM

Some patients found it a useful reminder, though rather more found it stressful or disruptive, particularly where requests for it to be turned off while on holiday were not always actioned

The worst thing is this alarm. It's sometimes not convenient. If you want a long lie - so by the time you get to the machine you're bloody out of breath anyways and then you've to use the puffer.

(Female Patient)

Well it's all right for the two little kids. You know they sleep through it, but when our daughter comes across, we can't put her in that bedroom, so what'll happen, we'll have to put her in our own

(Male Patient)

Patients pointed out that it would be particularly helpful if the design of the system was changed to allow them to turn the alarm off themselves without unplugging the machine

*The left hand didn't seem to know what the right hand was doing in the organization. Let's say I'll not be here tomorrow. And when we come back the alarm's blaring away. **An it's been going aw day!** I've never had that problem since then but thank goodness we werenae away for a week.*

(Male Patient)

USABILITY OF INTERFACE FOR GPs, NURSES, CARELINE STAFF

GPs, practice nurses and the call centre staff felt the back end interface significantly slowed and complicated their work because of the design. For all of these groups, time and accuracy were at a premium. They required the key elements highlighted on one screen, for reference in a 10 minute appointment, without the need to flick through several screens. One GP summarised the issues particularly clearly.

Back end?

Cumbersome and unfriendly. You end up going through multiple screens to get the information you want. Maybe it could default to information over the last 7 days, and you could colour code this as to how often it was outwith the parameter - scoring more than 4. I found it a very awkward back end. In fact I can't think of a worse one. The system for BP is so much better. Your time – pulling up these things. Hardest bit was doing the daily look through, and it was a pain in the neck to click there and look at what their score was. It would have been so easy if I just clicked on the ones who were red.

(GP)

I looked at the oximetry for the last five days, the peak flow for the last five days, and then looked at the questions. I want to be able to see the information for my patients for my 20 patients, and be able to glance at it and not ...I mean to look at one person's results must be – what 8 different screens? It looked as if it had been designed by a computer programmer with a minimum of user input.

(GP)

I think it's very clumsy. Despite asking people scoring high to be highlighted they've never done that so you have to open up every record. It's not a simple click. It would be nice to have a nice little navigable record.

(Female staff member. Careline)

Despite this, the system was still seen as very viable. As one critical GP put it 'At the end of the day it works, some teething problems but - can the patients do it? 'Yes.' Has the structure and the technology worked reliably? and the answer is 'Yes'

CARE TEAM PERSPECTIVES



Fig.14 Doctor and nurses at Royal infirmary of Edinburgh, 1910 , Copyright Scran

TELECARE AS A VEHICLE FOR CHANGE

Technology cannot deliver care, but can enable the redeployment of care time, manage risk by providing security and provide alerts.

Wanless Report on Social Care (2006)

The introduction of new technology in the context of care is increasingly recognised as requiring the reconfiguration of roles, risks, resources, costs and benefits – or as one member of the team put it – ‘reconfiguring the care mountain around the needs of patients at home’. The pilot team were fortunate in coinciding with a national review of the roles of nurses in the community where responsibilities and resources were already being reviewed and realigned around the needs of home-based patients (Scottish Executive Report 2006). As numerous recent papers such as Hendy et al (2008) suggest, the introduction of telemetric support for home based care is about change management, rather than an add-on to an existing service. The experience on the pilot suggest the process has been a catalyst for change, and for rethinking the basic shape that services should take in an era where the requirements of long-term conditions and cost effectiveness may favour alternative models of provision. A range of issues emerge in the process of rethinking the provision of care at home. These range from changes in assumptions about how the system would be used to support coordinated care around the needs of patients at home or in the community, to the consideration of how information would be communicated, how services would be coordinated around that, and what the technical and clinical risks and opportunities might be. The discussion workshops led by the Whole Systems Demonstrator Network WSDAN⁷ provide a useful insight into the problem scenarios recurring across regional implementations in the UK. Many of these issues are echoed in the comments of nurses, nurse managers and other health professionals in our study.

⁷ The WSDAN is run by the Kings Fund and CSIP http://www.wsdactionnetwork.org.uk/news/human_factors_in.html

GPS AND GP PRACTICE NURSES

A total of eighteen health care professionals were interviewed, including those involved directly in the practice, but also others whose work is, or will be affected by the wider implementation of home based care in the wider rollout of this initiative, and by the rapid expansion of telemetry-supported home based care in the community generally. These included respiratory specialist nurses following up patients after hospital admission, community nurses (previously district nurses) and physiotherapists providing pulmonary rehabilitation at home or in local surgeries. GPs and practice nurses were in the frontline of use of the piloted service, so their comments reflect the experience of the pilot implementation. The home based COPD specialist service, however, was in the process of development, so many of the comments of respiratory nurses, physiotherapists and nurse managers reflect their perceptions and expectations of a system that had been demonstrated and in which they expected to be involved later in the year.

The views of GPs and practice nurses in the frontline of use of the new service coincided with those of their patients with regard to the quality of care provided using the monitoring system. They felt it supported the targeting of care on agreed needs, and enabled patients to recognise their symptoms as a basis for early treatment. They also commented on how much patients appeared to have enjoyed it. The general view of the system was positive, even although this had involved them in some additional workload, particularly at the outset, in incorporating new ways of monitoring, following up and documenting this activity in the records. This reflected the lack of dedicated community support teams, which were still being adapted and integrated during the pilot, to support the wider rollout.

PATIENT BENEFIT

The patients have actually enjoyed it very much – and we have actually one chap who is missing it so much he phones us every day anyway!!

From the point of view of patient education I think they're a bit more au fait with... 'Oh I'm more breathless than usual and maybe I need to call the doctor'. Sometimes we'll get 3 out of 10 phone us, but I guess it's sometimes going to be 'Oh for goodness sake not another one.' But often it's quite appropriate and sometimes very exciting.

(GP)

Although doctors and nurses mentioned some additional work in the absence of the dedicated support team, they felt this was manageable, and was balanced by the perception (strongly underlined by patients) that this improved the quality of care in a number of ways, from mutual awareness, to reviews of treatment, and earlier and more individualized negotiation of intervention. This was echoed by the comments of those involved in project management and implementation. The arrangements being developed in part of the Lothians support this aspect of provision (whereby the system monitoring is undertaken by a specialist respiratory nurse/physiotherapy service) was seen as a good model.

MOVE FROM STANDARD TO INDIVIDUAL BENCHMARKS

The initial vision of a straightforward monitoring process, based on a standard benchmark, and with little additional input from GPs in supporting and monitoring patients was challenged in practice.

I thought it would be more clear-cut. It didn't occur to me it would be so difficult to work to a standard baseline. It's a lot more complex than I thought it was going to be.

(GP)

GPs, respiratory specialists, physios and practice nurses emphasised the limitations of numbers-based decision-making. The potential of the video-conference facility was seen as one way of complementing/validating the objective data.

Scores are only part of the picture. You need to see the person as well (Comments about effect of conditions at home, drugs taken/not taken, anxiety, use of nebuliser in assessing and responding to scores).

(Community nurse)

The variability across patients and context suggested the need for both individual benchmarks and also the need for further information not conveyed by scores alone.

I: Do you think an individual benchmark would be more useful?

D: I think so. I think that would be more appropriate because people do have very different symptoms obviously.

Sometimes we have phoned patients when their scores have been high and one woman said – well actually my husband's out cycling so, em, I think the levels at which are symptomatic according to themselves is very variable.

(GP)

GPs and practice nurses also commented on the score in the context of what is 'normal' for the patient, and whether anxiety or other factors were implicated, that would have a bearing on the nature of the intervention required.

And some people are just quite stoical and bash on despite being quite puffy and breathless, and carry on with their exercise and their COPD rehab themselves, and others are quite anxious and - you know - a set of readings is

(GP- female)

Setting a threshold appropriate for all patients was something of an impossible task, given the apparent poor correlation of scores with actual symptoms in some cases. There was considerable variance between individuals in their tolerance, and management of low oxygen levels and breathlessness, and the range of patient and context specific factors that impacted on these readings.

Frequently GPs commented on the difficulty of interpreting data in relation to standard benchmarks. As one GP pointed out – ‘Having a threshold of 95 isn’t that useful if you have 99 most of the time. (It’s) not the threshold so much as change itself’. Variation around an individual benchmark was seen as the most appropriate way forward. This would also be consonant with the intention of developing individual care plans in the wider rollout.

D: Yes there is no doubt. Somebody – a doctor or a nurse - has to make a decision. It will be important to see where the mapping is over- and under-sensitive.
(GP)

Some of the difficulties appeared to derive from over and underscoring on the online symptom questionnaire. Patients found it difficult to be clear about the question at times. By the same token, doctors found it frustrating that the questions were being misinterpreted. Patients, nurses and GPs were clear that additional patient and context specific data were required, and while this was acquired by phone in most cases, those interviewed latterly were already aware of or starting to use web-cam for video-consultations., though not all GPs felt this was ideal.

I don't think that would be very great in a busy general practice. I think it would be difficult to get some patients off the line. I think with a phone call you have a little bit more control, and I suspect I would probably grimace too much.
(GP)

COMPLEMENTING SCORES WITH PATIENT AND CONTEXT-SPECIFIC DATA

Scores alone were seen as providing a very limited indication of risk in many cases, and there was some emphasis on eliciting further information through a telephone or video consultation, or by face to face assessment by the GP or a specialist nurses. One practice nurse described her approach as using the system to derive a shortlist and then using her knowledge of the patients supplemented by a phone call or a video-consultation to interpret the figures, and decide on how to prioritise visits in agreement with the patients.

This provided the working model that was adopted in practice, balancing the risk indicated by benchmark scores against more patient and context specific information. GPs in other surgeries, and physiotherapists felt the visual, interactive possibilities of the video-conferencing facility in the larger clinical trial would help bridge much of that gap, and allow them to exercise the more holistic assessment facilitated by seeing and interacting with patients.

Two things – one is just being able to look at people, two is being able to tell how quickly...how many words they can say in a breath. I'm quite optimistic about that [as] a combination
(GP)

The threshold of 3 for the weighted scores was seen as a little low, but increasing this to 4 raised concerns that some patients requiring intervention would be missed. There were some false alarms based on high scores and sensitive benchmarks, but GPs were all aware of at least one case which had been picked up by the system, but who had not self-reported, potentially avoiding a hospital admission.

In addition to the need for local or patient specific information to make sense of de-contextualised data, there was a need to be reassured that the data reflected real physiological effects rather than artefactual ones as a result of technical issues, battery failure, design factors, and the use or usability of equipment by patients.

RELIABILITY AND CLINICAL VALUE OF HOME BASED SPIROMETRY

The reliability of spirometry measures done at home was questioned by the professionals involved, and particularly by those specialising in respiratory conditions.

It's difficult to do, It doesn't tell you anything. It doesn't change your management of them. It's a total waste of time. Patients don't like doing it and you're not going to get them to do it properly and unless you're standing there anyway
(Respiratory Nurse)

Having unanimously highlighted the lack of reliability, and also lack of clinical value in deciding on treatment, there was a minority view that even if patients used it inappropriately, it could provide some indication of change over time, but that other measures, such as pulse oximetry, were more reliable, and of more use in decisions about clinical care.

LONG TERM MONITORING AND INDIVIDUAL PATTERNS

An emerging theme from interviews with different groups was the perceived potential for using long term monitoring of individual patterns, particularly in oxygen saturation, not only as a useful predictive index for exacerbations, but also as a basis for decision making in treatment – such as provision of oxygen at home, or when commencing a new medication. This resonates with the growing literature which looks at the potential of tele-monitoring systems as a vehicle for more individually tailored care, and the availability of new approaches to modelling and managing rich distributed data over time in contexts such as telecare (Masis et al 2006)

WORKLOAD

In some cases there was an increase in workload reflecting the low level of the threshold, but there was also a perception, that the frequency with which patients experienced clinical symptoms was higher than had been realized in the past.

Patients were scoring much higher than we thought they would – or more frequently than we thought they would – for two reasons – one that we've underestimated the number of exacerbations that patients have had in the past--I'm sure that that's true-- but the other reason is that the instrument I think was a little too sensitive. And initially we thought we would only have to be contacted and these patients looked after when they became ill, and that Careline would look after them most of the time

(GP)

Some GPs and nurses had concerns from the outset that this might add to workload, or change the balance of work from face-to-face consultations to remote monitoring and administration. This was perceived by implementation team interviewees as having important resource implications for the wider rollout. At the level of individual work roles, in GP practices, with small groups of patients, practice nurses and GPs felt this was doable, but involved some initial reorganisation.

Has it increased the workload?

I don't think it does increase the workload. As soon as you ask anyone to do something extra....BAD...but it is actually quite easy to speak to someone and assess whether they are the same as normal.

So it's doable?

Yes – on the numbers we've got just now. Initially for the first week or two it probably increased the workload. You need to make time of the day for looking at communications and the backend

Has this been a useful way forward?

*I can't think of anything else that would have been so useful
(GP female)*

GPs interviewed were very positive, after the initial few weeks. Practice nurses and GPs had to adjust their working practices to accommodate this, and also to elicit more information to supplement the score data. There was a concern, however, that this might not be so manageable with larger numbers following wider implementation.

Both suggested a higher threshold, or an individualised one would help, as would more usable screens. They felt that much of the time spent dealing with the system was due to the design of the backend interface, which was seen as poorly aligned with their requirements. One practice nurse highlights some of these issues in the following quotes.

I look at it before Careline have looked at it. How am I going to build this into my day? But I've done it

*I do find it difficult to diagnose....They're scoring 9 but their chests are clear. Questions need to be a bit deeper. If a patient answers 'yes' you need to know why.
(Practice Nurse)*

We didn't realize how much input was needed for it. They do need a bit of time set aside for that. It's not been a lot of time. The doctors were a bit up in arms about it 'Oh is this going to be even more work'. Last time it was over the weekend as well. Two patients scored two 3s and a four. When the doctor phoned one was fine - though saying that the other needed antibiotics.

(Practice Nurse)

Interviews at the start and at the end highlighted the extent to which very positive patient feedback underscored the perceived value of this approach, despite the additional workload of dealing with alerts and calls to patients. This was beginning to be seen more as a reorganisation of existing routines around patient care at home, rather than additional work per se. Patients also expressed some concern that they might be providing extra work for practice nurses in particular.

USING TELECARE DATA TO MANAGE CARE

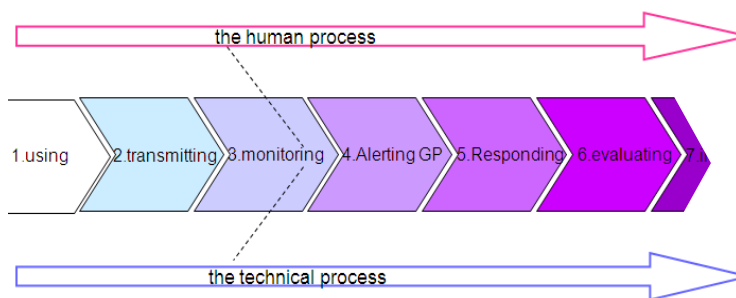


Fig. 15 Aligning technical and care processes.

In the context of eHealth and other digitally mediated systems, the quality of data is subject to loss, distortion, transformation or de-contextualisation that can make it unreliable or insufficient for use. (Ure et al, 2006; Bowker and Star, 2000; Brown and Duguid 2000). Data quality can be compromised at a number of critical interfaces.

The quality, reliability and thus safe usability of that data is dependent on minimization of possible issues at each of these stages. The so-called 'social life of information' is familiar in other eHealth and eBusiness applications with implications for data quality, and decision support where data is assessed independently of context.

MAKING SENSE OF TELECARE DATA

Interpreting data from a screen without sufficient person or context specific information was a recurring theme. It highlighted the limitations of a vision based on protocols and standards applied to diverse populations. Practice nurses, with a wealth of background knowledge about their patients were quick to highlight the need for supplementary knowledge of patient and context, as were GPs, physios and the patients.

There's one lady that says 'No' (on the questionnaire) every day. But she's probably the worst patient on it. Her chest is terrible. I know she'll be struggling but she answers 'No.' She says 'I don't like to bother anyone'.

(It's) hugely variable. I sent Dr X out to see them and he came out and said all their tests are clear but why are they scoring 9?. It just doesn't make any sense. If you phone they'll explain. 'I went out and it was cold, I'll be fine again tomorrow'.

(Practice Nurse)

A second step was seen as essential in making sense of scores, and agreeing appropriate intervention with patients or their carers.

They'll be scoring 9 and you'll phone them up and they'll give you a reason WHY they're scoring 9 .

(Practice Nurse)

There was a widespread awareness of the limitations of assuming that the score alone was sufficient to facilitate either diagnosis or treatment without further information.

One thing I'd be worried about is that it's all general, and not individualized. I treat each COPD (case) the way it needs to be treated.

(Physiotherapist)

Based on threshold protocols, reflecting standards generally used as criteria for treatment and hospital admission, many of these patients would have been on antibiotics much more frequently. This presented a dilemma for practices.

You can't just continually prescribe antibiotics for these people. I'm worried now that I prescribe millions of antibiotics. But then if you're scoring 9 - and some of these people can go down SO quickly.

(Practice Nurse)

MAKING DIAGNOSTIC TOOLS MORE SENSITIVE AND MEANINGFUL

Additional information /tests

The difficulty of interpretation without additional information led to suggestions such as a Chart for breathlessness on a 5 point line (as one patient suggested) and a colour chart for phlegm. One practice nurse would have liked occasional sputum tests to provide additional information, and a protocol for patients to take the initiative based on their own scores and perhaps other tests.

Additional channels for communication information

Patients were anxious to provide additional information, as they were aware at times that their scores were abnormal due to other activities, and likely to be misinterpreted without this contextual input, and the proposed web cam/video conferencing system was seen as a way of addressing this.

Patients often had other routines done just before or just after using the telecare system, such as taking oxygen, which impacted on results. One GP pointed to the need to include a means of making this evident.

You also need some indicator to show – 'Have you been on your oxygen or not? It makes a material difference to the value

(GP)

More helpful display/representation of information

GPs and physiotherapists suggested making it possible to see symptoms and possibly treatment over time as a graph, rather than having to revisit multiple screens to get this information. Highlighting and colour-coding was also suggested as an aid to interpretation and rapid analysis in busy surgeries and call centres.

Can you see drug treatments as well on system - to see how often they've been treated and how many exacerbations? So you can see what's really going on, so there might be a variation – a reason for that elsewhere – there might be a factor in their exacerbation (e.g. damp at home) .

Physiotherapist)

Some of the comments related more to the usability of the tools, (See Usability Section) which also impacted on the quality and reliability of scores.

BALANCING RISKS

The same score could be interpreted and acted on very differently in different patients and in different contexts. Patients, perhaps for this reason, were often anxious to speak to their own GP (even where this involved delay) rather than contact an out-of-hour's doctor, and risk being admitted to hospital on the basis of readings which were poor in relation to standard thresholds, but 'normal' and manageable for them. Balancing risks was a recurring theme.

My concern is more the other way, that a doctor who doesn't know them, for example in Lothian Unscheduled Case System (LUCS), seeing some of those scores will look at that score and call an ambulance, and they've always been like that. And of course that might INCREASE hospital admissions (as a result of this monitoring!)

(GP)

Cornwall Primary Care Trust have responded to this concern by providing a 'COPD passport' for patients, with information which may be important if they are seen by other clinical or paramedical staff, in addition to advice to help cope with the debilitating fear, evident in many interviewees, of having an exacerbation.

The high proportion of patients presenting with symptoms at threshold level significantly increased the normal level of prescription of antibiotics and steroids.

What we do know comparing this year and last is that the number of uses of antibiotics has doubled, steroids has doubled, the number of times....people have been given these prescriptions has doubled, and the number of times that the electronic record has opened has doubled..so there has been a workload implication for this

But quite what effect all these antibiotics are going to have at the end of the line is a different story. It may be good if it keeps them out of hospital or if it makes them feel better generally, but I think.....you, these drugs are not without side effects...whether we're going to give folk cataracts with these drugs....put on weight...it 's a concern.

(GP)

Two of the four GPs commented on hospital admission as possibly 'more appropriate' than before, and all voiced a perception that the quality of care was better than before.

There was some evidence of less hospital admission, lower scores, less deterioration – but that this came at the cost of an increased workload (but not extraordinarily)

(GP)

This was balanced against a perception of a moderate but manageable increase in workload at the outset, much of which would be offset by the support services of the specialist respiratory team in the wider implementation

A CATALYST FOR REVIEWING CARE

Koff (2009) and Casas (2006) highlight the role of such studies as a catalysts for rethinking care, and attribute many of the positive outcomes to reviews and new synergies between players in the care 'supply chain'. (Similar effects have been documented in other contexts such as eLearning and eBusiness which have prompted reviews of practice in general. (Laurillard 2002), where new technologies prompt a rethinking of how the service can best be delivered, and how different possible configurations may impact on different parties)

Consideration of possible points of delay between the onset of symptoms, access to a care professional and access to antibiotics or other medication seemed to stimulate rethinking of the possibilities available for such patients, and the sharing of ideas and practices that could contribute to that, such as keeping emergency supplies of antibiotics at home .

And the other thing it's made us aware of is the need to give these patients antibiotics to keep at home. And I suspect in that respect our patients are being better looked after than other patients we see.

(GP)

A CATALYST FOR RETHINKING MODELS OF DIAGNOSIS⁸ AND CARE

Recognition of an exacerbation was increasingly identified as a consultative process without clear cut defining features that could provide the basis for an unequivocal benchmark, given the apparent variation in symptoms, and tolerance of them. The role of patient and context specific information was seen as crucial in informing these judgements.

Without a doubt this telemetry intervention has changed the way we treat it, you know? We're treating people more frequently, and that may or may not be a good thing. I'm probably a bit more inclined to prescribe antibiotics. Having said that I'm probably a wee bit more sceptical about symptoms, you know? Because people say they've got all these symptoms, and you know that doesn't always mean they've got an exacerbation. I mean to start with we were definite that if they scored more than 4 we would put them on antibiotics and we suddenly realised they would ALWAYS be on antibiotics.

It would have been quite nice if there WERE some physiological method, or better method for identifying exacerbations than there is at the moment, cos its still a bit hit or miss but there's no doubt, definitely no doubt about the fact that we are identifying MORE.

(GP)

The number of exacerbations being reported was also identified as being higher than anticipated, with some of this being attributed to the low benchmark criteria for triggering an alert, but there was also a view that

⁸ We refer here only to the diagnosis of an exacerbation rather than the condition / COPD

the frequency of these events in patients lives was under-reported, and in addition to presenting additional workload, had an impact on the perception of the patient experience of the condition.

The role of video-consultations in facilitating additional support for this towards the end of the pilot was very consonant with this, and highlights acknowledgement of the more constructed and collaborative aspects of diagnosis that can also be facilitated.

I think if I had someone who was scoring high it would be quite nice to be able to see how they were and speak to them and see if they thought they needed antibiotics or steroids...and just LOOK at them. Because I mean GPs do make very, very important judgments on this sort of global 'What does he or she look like.'
GP)

The increase in reporting of exacerbations as a result of monitoring surprised some GPs and comments suggest it may have provoked some review of the frequency of exacerbations patients experienced but didn't report, and the means by which these might be best identified. In practice, the model of diagnosis and intervention in clinical practice is not easily aligned with the abstractions used to support decision support in tele-monitoring applications and other eHealth applications for analysis of distributed data. Bodenreider et al, (2004) highlighted similar problems in the design of software to integrate and analyse patient and imaging data associated with different disease domains. Bar Yam (2006) points to the existence of different approaches to health monitoring, with different costs and benefits in practice. He takes the view that public health can be viewed as a complex systems where there is scope for both models of population based intervention as defined by a standard symptom score or defining criteria, but also models based on individualised, long term monitoring of complex individual conditions that are more cost-effective for those with complex needs. The emergence of wearable or ingestible sensors as a means of providing this kind of individualised monitoring and prevention invites consideration of how this can be incorporated into current models of practice, of policy and of funding. (Cleland (2009)

WEBCAM / VIDEO-CONSULTING TO COMPLEMENT DATA ON SCORES

Those patients at the end of the pilot who were given updated machines provided a brief opportunity to explore opinions about the possible benefits and disadvantages of using these. Initial opinions suggest that it would provide a vehicle for addressing concerns about the using scores alone, allowing nurses and GPs to:

- build on a more familiar approach to assessing patients visually as well as talking with them
- allow visual clues (e.g.skin colour, rate of breathing, expression and cognitive and social interaction) to be taken in to account
- facilitate reassurance of patients.
- allow patients to provide supplementary information about their symptoms
- provide opportunities for facilitating remote consulting by physiotherapists and others

USING TELE-MONITORING DATA TO COORDINATE CARE

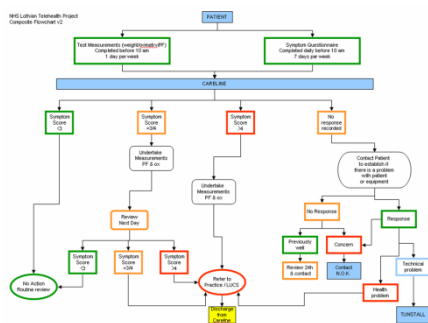


Fig. 16 Early version of the protocol for data triage and intervention

The initial vision for the pilot was based on a standard threshold for all patients. Measurements were sent from the patient to a database accessed by the call centre, and where scores exceeded the threshold, to the GP. In this scenario, the benefits of early intervention for patients reductions in hospital admissions was expected to be achieved with minimal additional workload for practices. This was changed in the light of (a) the limited value of standard threshold scores in recognising exacerbations or care, and the potential for delays at different stages in the information ‘supply chain’ between patient, call centre and GP.

The second iteration was based on use of the threshold as an initial ‘at risk’ list, and further information was collected by phone. This required some re-organisation of practice work roles and routines, but once done, was seen as providing a better quality of care for patients with a greater but manageable level of additional work.

A third possibility was discussed with some of the interviewees toward the end of the pilot, whereby patients would monitor their own scores and phone the surgery based on the variation around an individual benchmark. Patients split into different camps here.

PATIENT VIEWS

As it became apparent that the initial scenario for triage through Careline was likely to institute delays in the process, patients were asked if, as an alternative, they would feel happy using the readings to phone the surgery themselves. There was a mixed response.

A few took the pragmatic view that it might expedite the process (Some saw this as a practical way of minimising the potential for delay, facilitated by the fact they would have some evidence to overcome a reluctance to bother the doctor). Having the evidence gave some patients a basis for overcoming reluctance to bother the GP. Some patients felt that if they knew clearly they ‘had to’ phone if they hit a certain threshold, they would feel able to phone a doctor without delay.

*That would be brilliant. Yeah that would be brilliant...Well I would know that they're saying that if it's like that you **have** to phone.*

(Female patient, 87)

I think that would probably be better because it would be quick. You could have that option at least, because with it going through the call centre it can be at least a day.

(Carer)

Some however felt they would once again be faced with delays getting appointments, or delays deciding whether to phone the doctor. Interestingly, a number of patients felt this scenario was only viable in practices where it was possible to get a prompt appointment, and referred to friends they knew who would face delays in accessing treatment if required to go through the surgery route again. Deshpande et al (2009) comment in a recent review of asynchronous telecare applications, that ‘the satisfaction ratings seemed to be influenced by wait times for obtaining traditional in-person care’.

*I think it would be handy **mainly** because we’ve got a very good surgery and the doctors are **excellent**. If I phone in, in the morning, and they haven’t got an appointment they give me one over the phone and if they think you need an appointment they’ll say – ‘you better come up’*

(Male patient, 77)

GPs and patients both recognized risks in the potential for delay in the data ‘supply chain’ given that this was not done in real time.

Well some of them can go off so quickly. I mean yesterday someone scored a nine. I would want to know right away someone had scored a 9 rather than waiting 24hrs.

(GP)

Some became very anxious and breathless on being asked what they thought of this as a possibility

I think that sort of thing is best left to professional people. No. I would’ve gone “No I don’t feel that bad” and let it ride. (Becomes very agitated and breathless).

(Male Patient)

*I think I’d prefer it the way it is. I’d be imposing...I’d feel I’d be imposing....how could I put it....forcing ourselves on them. I don’t want to....(getting breathless)
..I want to leave it the way it is.*

(Female patient, 69)

On being asked if he would be happy to use the readings on the system as a basis for phoning a doctor one patient expressed both the reluctance many had about phoning a doctor, and the confidence they appeared to have in the monitoring system.

I think you’ve got to have some medical knowledge to be able to do that correctly. No, as I say, I will let it go to the very end before I get a doctor, so it wouldn’t be fair on the system, if, for instance, I pop my clogs because I didn’t phone in. Well it wouldn’t have been the system’s fault. It would have been my own fault.

(Male patient, 87)

Some patients seemed less than clear as to exactly what was being measured, by whom, how or when. They felt better looked after but may have been overestimating the scope of the monitoring provision. One, for example, assumed that because of his personal medical history, he would be being monitored for other heart related changes not associated directly with COPD. This misconception is a risk which should be further explored in the wider trial.

DIAGNOSING EXACERBATIONS WITH TELE-MONITORING DATA

Attempts to map diagnosis of exacerbations and care as a black and white, digitally-mediated processes was seen by some as an oversimplification of the much fuzzier and collaborative process that supports decision-making on the ground.

With telecare the door is open or not – it's clear cut and easily resolved. How do you define an exacerbation? The original way we'd have been always on the phone. That's problematical. Even with the patient in front of you it's hard to diagnose an exacerbation. How do you manage this? (GP)

In this context, the pilot considered and explored different options, from traditional data triage through Careline to direct reading from the surgery, to combining this initial risk assessment with phone or (latterly) web-cam consultations with the patient to contextualise the initial reading with other information from the patient, and to negotiate an appropriate response. Careline staff were also interviewed for feedback on their experience of the process, and their recommendations.

THE CALL CENTRE PERSPECTIVE

Two call centre staff members were at the interface between patients and GP practices, and were able to give useful feedback about the issues as they perceived them in the first iteration of the triage process, based on the protocol.

Technical issues and workload

Workload was higher than expected, as a function of technical issues being reported by patients, in addition to the level of the trigger threshold itself.

They (patients) have been phoning regarding faults mainly, and we are able to resolve most of them ourselves. Or they're phoning to say they're going away so to update their notes. We didn't think we'd have that kind of contact.

Process development

Careline had to be quite pro-active in helping establish new routines as situations arose

Very much we had a problem with LUCS (unscheduled care service) out of hours so B set up a protocol, so it works at the weekend. We had a problem with LUCS and said we're not getting the support to help the patient, and it worked.

Continuity

Patients commented on the friendly reassuring manner of the call centre staff and there was an appreciation of the personalized nature of the interaction with Careline, since the same two staff members managed the calls over the course of the pilot.

We acted on two calls, one got admitted to hospital. So it was quite good. One of the patients' wives phoned the next day just to thank us for what we'd done. They are very appreciative.

Delays associated with de-encryption and reporting tools

The need to de-encrypt data was seen as time consuming and prone to error, and possibly unnecessary.

I understand the importance of security..but it's very basic information... the GP reference number and the date and the trigger level so...even if you got into that there's nothing you can do, so I don't know why...

Well I mean, on Sat it took me about 30 -40 minutes to get this across. I had to de-encrypt them and it didn't give me the right date. So I'd to come all the way up and do them all individually, and S had to do that as well. So you've actually got the report and then you've got to go through them all and then see what the score is.

These unexpected aspects of the process were more problematic than initially expected

It's a lot more complicated than what they initially said. And that's the time consuming bit. The contacting patients and contacting doctors has been relatively OK, although there's been a couple of times that um X or the nurse has been on holidays to contact and nobody knows.

Handover: Managing information sharing

Careline staff felt it more appropriate to do a direct handover to a person. And on a number of occasions did follow up with patients to check that the surgery had been in contact with them.

I would have preferred to have phoned (not emailed) and passed it on to somebody because then you would have passed it on to somebody. So that we know they'll speak to the patient.

Call Centre recommendations

The two call centre operators made a number of recommendations based on the pilot experience, and echoing comments made by other groups, particularly in relation to the usability of the interfaces they were required to use.

- More usable backend screens and de-encryption and reporting tools. These were seen as central to reducing unnecessary time and effort, and a real source of delay. In this they concur with GPs experience for the backend system. Reddy (2003) highlights the importance of different interfaces to support different communities with different tasks
- More inclusion in general meetings and updates on issues with the performance of the system, as they acted as interfaces with patients reporting problems.
- More training. As they found they were answering many calls about faults, they felt they would have benefitted from more in depth explanation about aspects of the system that failed. Training was an issue with implications for a future rollout.
- Ensure all GPs are clear about the protocol, and their role
- More resources for a dedicated person to cover the telecare workload

THE PERSPECTIVE OF NURSES, NURSE MANAGERS, PHYSIOTHERAPISTS

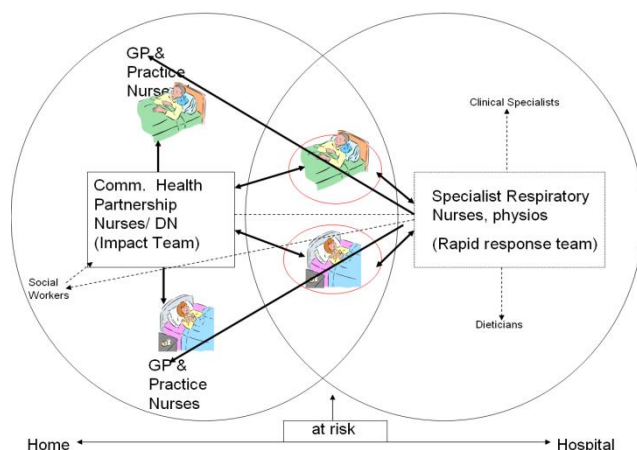


Fig. 17 The nexus of care across acute services, primary care and community services

In some respects, telecare provided a catalyst for rethinking how care services are delivered, by whom and on what basis. The current reconfiguration of allied health services around patient care at home has meant there have been opportunities for useful alignments of agendas and resources to common ends, and some of the literature associated with this is highlighted in the discussion section. During the pilot, the care community were involved in a number of dissemination and feedback workshops to gather opinions prior to the randomised trial and wider implementation, which would involve community nurses, and respiratory specialist physiotherapists and nurses in home-based care in new ways. The interviews here reflect their expectations and concerns about these future plans.

Nurses, nurse managers and physiotherapists were quick to identify synergies and opportunities for using the system as a vehicle for supporting, enhancing or extending their activities with home based patients, despite increasing financial restrictions. Many suggestions came from care staff, particularly physiotherapists visiting patients with this equipment installed. The presence of the equipment in the home, and the positive reception by patients became a focus for stimulating a range of useful discussions with patient, carers and researchers which have since generated other initiatives.

RETHINKING PRACTICE

The reconfiguration of roles, resources and risk across parties raises issues of representation and resourcing for different stakeholders in such contexts, including patients, and their carers, as well as other social, housing and community care groups whose resources are already stretched, but whose responsibilities will now be increased. How this new social compact will be negotiated, and how these groups will be represented is not yet clear. Kaplan (2008) discusses this in the US context, where collaborative representation is a central strand of the next US ONC-Coordinated Federal Health Information Technology Strategic Plan 2008-12⁹. We canvassed the views of practice nurses involved in the use of telecare, and also of those involved in the training and demonstration of this for the wider implementation. The comments of GPs nurses, nurse managers and other allied health professionals should be seen in the context of the ongoing review of community nursing, and current initiatives to coordinate disparate services around the needs of patients at home. There is an obvious synergy here with the aims of the telecare pilot in that rather than being seen as a source of disruption, it was seen by many as a potential vehicle for supporting that change – for sharing

⁹ <http://www.hhs.gov/healthit/resources/reports.html>

current information across teams, and supporting the coordination of those services at a time when care services, and nursing services were being reviewed as a national priority.¹⁰

The tele-monitoring system was used as part of an evolving nexus of co-dependent care services in the reconfiguration of services around more streamlined care at home for long term conditions. Issues raised by the extended care team have implications for the successful implementation of the system within the services which will be required to translate early detection into a rapid and effective response, sufficient to impact on hospital admissions. A wide range of professionals in the extended care team were interviewed. These included GPs, community health practitioners (CHPs) and their case managers, respiratory nurses and physiotherapists, practice nurses and rapid response team nurses, and hospital consultants. Some are directly involved in the pilot, and some are likely to be involved when the system is rolled-out more widely.

PERCEIVED OPPORTUNITIES FOR SYNERGIES AND OUTREACH

Nurse managers in particular perceived the telecare system as an **opportunity** and a **challenge** in that its value was dependent on the extent to which it was integrated effectively into the wider context of services provided for and by the extended care team, and available to the right people, at the right time. They were very positive about the potential for the system as a vehicle for supporting initiatives to streamline patient-centred care more effectively. They regarded this (and other telecare systems) as part of a wider nexus of inter-related services for COPD patients. They were equally clear that this was a tool that was only likely to add value as an integral part of a wider alignment of services and resources

Physiotherapists and practice nurses expressed particular interest in the potential of the web cam facility to extend the reach of information and services despite resource constraints, to improve the communication/coordination of current patient information across care teams, and to provide more visual and contextual evidence in clinical decision-making where threshold scores are insufficient.

You really need a sort of second layer (video-conferencing or phonecall) to make sense of the scores, and decide if they need a visit. M's scores are OK but I know..because I spoke to her that she's really bad. Others score high and they're fine.

I've been phoning but, You need to be able to see them.. you get a lot of information from that -how fast they're breathing -what colour they are
(Practice Nurse)

Practice nurses and physios both commented on the potential of including information on the system that would enhance care in other ways which might contribute to the aim of reduced hospitalization. Casas (2006) highlights this as a benefit in a similar European study with patients in Leuven and Barcelona. This suggested untapped potential for enhancing care through tailored provision of information for patients as well as care staff.

You'd make more difference to hospital admissions just getting them to use the equipment properly. Some of them have been using it wrong for years.
(Practice nurse)

¹⁰ Better eHealth: Better Care NHSS eHealth Strategy 2009-2011 <http://www.show.scot.nhs.uk/eHealth%20Strategy%202008-11%20final.pdf>

It's all down to education, Patient understanding of the disease. Knowledge of their anxiety. Managing in the right way.

(Physiotherapist)

A VEHICLE FOR COORDINATING INFORMATION AND CARE SERVICES

Physiotherapists, community nurses and nurse managers were quick to identify useful possibilities for using the system as a vehicle for enhancing or extending services, such as access to current patient information or care plans, and provision of support or information to patients.

They (physios) could pick up their information early...when they are doing their morning visits...because it's home based visits, and be able to prioritise those that need to be seen...also they could...without actually having to perform a visit..they could actually have a telephone interview

(Allied Health Practitioners Manager)

The comments of health professionals highlight the particular priorities of this group in communication of information and coordination of services around patient needs. The technology is seen as a vehicle for supporting this. Nurses' opportunities for action in this landscape are heavily dependent on the timely communication and sharing of information, and the timely coordination of service around that information to the appropriate people.

The recent literature highlights the need to align the roles of other health and social care partners, of carers, families and of local communities in shaping the nature, cost and quality of care. Horton (2008), and Botsis (2007) are among a growing range of studies which explore the extent to which partnership working has to be renegotiated around a range of new roles, risks and rewards. By implication, there must be a vehicle for this renegotiation of the current contract, as in other sectors being reshaped by digital media. In the US, the management of stakeholder representation and collaborative governance is a central strand of long term strategy, and there is greater emphasis on the creation of opportunities for this. (US ONC-Coordinated Federal Health Information Technology Strategic Plan 2008-12). Physiotherapists, practice nurses and, in some cases patients and carers, clearly saw potential for using the system both to share information and to extend services to patients at home.

CHALLENGES

The perception of health professionals reflected their concerns with communication and coordination across the system as a whole, and many of the challenges and opportunities they identified reflected this.

THE RIGHT INFORMATION, TO THE RIGHT PERSON, AT THE RIGHT TIME

Measures that were valid and meaningful, and good processes for sharing information and streamlining services were seen as one of the biggest challenges to enable a telehealth application successfully to support services around home-based patient care.

In avoiding delays experienced by patients:

I think anything that gives better information more quickly is a good thing. But that's the thing with information, if it's not passed on to somebody then it's NOT a good idea, so there have to be good procedures in place for making sure that the information goes to whoever needs it.....without that you can have all the technology you like but it's not going to be useful, and I think it would really destroy patients confidence if deteriorating results were coming in and nothing was happening.

(Nurse Manager)

In avoiding provision of information that was not available at the right time (or in a usable format):

If the community rehab team are going to be more involved then they're going to need to get information earlier in the day, so that sort of thing. There's no point in information coming in at mid-day

(Physio Manager)

TRAINING ISSUES

There were concerns about the reconfiguration of roles, risk and responsibilities in telehealth / home-based care where community health practitioners practice nurses and others would be dealing with specialised and/or severe cases of COPD at home, and might not have the specialist knowledge and information needed to respond promptly and appropriately.

I think the main thing is that when these people are picked up by the care team or the primary care team that nurses know what to do with them. That they're trained and they're competent...that's an area that we're trying to develop.

There were also some concerns (from a resource perspective) as to who would be responsible for training patients or following up initial training, as well as issues about troubleshooting problems when setting up or adding to the system in the wider rollout. This concern also figured in discussions with the project management team.

CHANGE IN CARE MODELS

The issues of over-medicalisation and increased anxiety that some nurses anticipated were not borne out in patients' interview, since this group of patients with moderate to severe COPD had lives already dominated by the disease. It might be more of an issue with a cohort in the early stages of the disease, with relatively normal lives. Nurses voiced some concerns about over-emphasis of the implications of individual readings and the need for either additional or longer term indices. The threshold scores were in fact often insufficient basis for identification of exacerbations or intervention without further information, and in practice they felt that long term monitoring of individuals might make more effective use of such facilities.

I think patients get hooked on readings too much. I think where we get the benefits is where we put them on long term assessment. We did that for two weeks with oxygen therapy and that was fabulous.

(Respiratory Nurse)

This was a view that emerged from discussions with GPs also, as individual patterns and trends over time became more apparent.

PROJECT MANAGEMENT PERSPECTIVES

Interviews with four of the project management team highlighted a perception of this as a process of change management, or 're-engineering the business' as one of the interviewees described it. This is very much in line with the finding of other recent reviews, and of the other regional pilots reported through the UK Whole System Demonstrator Network.

Most projects are sold initially on the basis of saving costs, but I don't think that is the case at this stage. It's more about reengineering the business. It's maybe about taking some of the savings you make on hospital admission and reinvesting those in getting an extra specialist nurses to deal with this.

(Member of Project Steering Group)

This evolving model of care, and the associated change process is echoed in studies across very different national contexts. Glasgow (2008) describes the provision of care for COPD in Australia as an incremental process of change 'from one of acute and episodic care orientation in both the private and the public sectors, to a system that deliver anticipatory chronic disease care as well. Horton (2008) points to the need to renegotiate roles, risks and rewards, and Valsecchi et al (2007) highlight the shaping role of context in this process, and the importance of taking account of local stakeholders needs and perceptions in managing the implementation.

Managers and implementation team members commented on the evolution of both the vision and the strategy for pursuing, from an initial, fairly clear-cut, data driven model to a model of 'protocol-managed support for long term conditions, supported by telecare' and finally to one that was more reflective of clinical diagnosis and intervention as a collaborative, constructed and often fuzzier process, reflecting the impact of multiple patient and context specific factors not evident from scores alone. The web camera in the second phase of the implementation addresses some of these issues. Riley and Cowie (2009) highlight the challenge this presents to traditional working and funding practices, and the extent to which it requires a more flexible rethinking of care services. Edwards et al (2008) review a number of studies requiring significant changes in care delivery practices and cultures, highlighting barriers such as the reconfiguring of staffing roles, risks, resources, technical and system interoperability, and ethical and legal issues (Kaplan 2008, Anderson 2007) delivering across jurisdictional boundaries. In particular, they highlight the problem of value models in that most healthcare systems do not reward clinicians for keeping patients well but rather reimburse care when patients are sick.

There was also a perception that savings in one area, such as care in hospital, transferred costs to other areas where more resources were then required, such as community nursing. The means by which such resources and responsibilities would be redistributed is one of the issues raised by the implementation of telehealth. The criteria for evaluating costs and benefits, such as quality of care, is still controversial. The recent Symposium on the Future of Telehealth organised in collaboration with the National Institute for Health in the US highlighted the difficulties inherent in doing this, or as one speaker put it 'deciding if the juice was worth the squeeze' and suggesting policymakers should not only judge costs and benefits in terms of cost reduction but also in terms of quality of care.

In terms of the diagnostic and care pathway, the pilot highlighted the evolution of the vision of digitally-mediated monitoring and care, from one of threshold based triage, to a two stage process refined by a negotiated individual process between GP/practice nurse and the patient. The opportunity to monitor

symptoms over time against individual norms generated outcomes that challenged more conventional views of the diagnosis of exacerbations in COPD, and of the nature, frequency and treatment of exacerbation. The intervention and the data produced by telemetry- assisted monitoring generated consideration of new clinical challenges and new ways of anticipating, diagnosing and intervening.

Both the change in clinical pathways, and the change in strategy and resourcing, point to the need to secure support for the renegotiation of roles, resources, risks and rewards across the distributed care team. In this regard, the pilot team were very fortunate in the timing of the study, coinciding with a wider review of home based care in general, (Kennedy et al 2009) and for COPD in particular.

OPPORTUNITIES FOR SYNERGIES AND STRATEGIC ALIGNMENT

Many studies in the literature highlight the need for collaborative involvement of care staff, patients and carers in reconfiguring new processes. Coulter (2007) and Bates (2008) highlight the need for involving patients, and Bradley (2003) stresses the value of active involvement of nurses in the design, development and implementation of any technology application. The timing of this study was therefore seen as helpful, coinciding with a wider review of care for home based care in general and COPD in particular and a one project investigator put it 'we were pushing at an open door'.

Two things intertwined – provision of service for COPD and provision of telehealth. COPD provision up till now has not been well managed. We hit at a time when they were reviewing primary care services who were hoping to manage those services more effectively. So we were very fortunate. So we were pushing at an open door.

(Research Manager / GP)

This allowed the pilot to avoid some of the issues reported in other studies, where new technology can be seen as disruptive of, or creating tension within normal care practices. (Hibbert et al (2004). The potential for collaboration with other groups such as rapid response Community Respiratory Team and the Edinburgh based IMPACT respiratory team¹¹ provided useful synergies in this respect as did work with other groups and networks with a remit or an interest in providing support for COPD patients at home.

Koff (2009), Casas (2006) and Wilkinson (2004) suggest that telecare studies can also prompt useful reviews of integrated care of COPD by healthcare teams. Casas et al, (2006) actively leveraged this in facilitating shared-care arrangements between primary care teams and hospital teams to avoid duplication and generate synergies between different levels of the healthcare system. They suggest the intervention also contributed to enhanced management of co-morbid conditions and social problems and that 'the interventional impact may have prompted an early detection and better management of exacerbations in the programme'.

3. QUANTITATIVE ISSUES FOR THE RCT

This strand of the pilot study explored the outcome measures to be used in the larger randomised, controlled trial or metrics of importance to health service implementation.

- The implementation of quantitative measures of change in patients' quality of life, mood and self efficacy and attitudes to telecare over the 6 months intervention
- Measures of change in, use of both primary and secondary healthcare resources and prescription costs during monitoring

MEASURES OF CHANGE

We used validated questionnaires at the beginning and end of the six month intervention

- Quality of Life - the St George's Respiratory Questionnaire or SGRQ (Jones et al 1991(SGRQ1), 1992 (SGRQ2), 2002 (SGRQ3). The SGRQ is a validated and widely used instrument which measures health impairment (symptoms, activities and impacts) in patients with COPD on a scale: 100 (greatest impairment) to 0, and is responsive to change (Jones 1991, 1992) with a minimum important difference (MID) of 4 (SGRQ3).
- Self-reported health status– the EQ-5D questionnaire, (Brooks 1996)
- Chronic Disease Self-efficacy scale (CDESES), (In Lorig et al 1996)
- Lung Information Needs Questionnaire (LINQ) (Hyland et al 2006). The LINQ measures the information needs of people with COPD on a scale of 0 (low needs) to 25 (high). Scores correlate with the healthcare services accessed.
- Anxiety and Depression – the Hospital Anxiety and Depression Score (HAD) (Zigmond et al 1983) The HADS is a validated questionnaire with independent scales for anxiety and for depression (scores ≥ 11 indicate significant anxiety (or depression); scores ≤ 7 are normal).⁴⁸
- Opinion of telemedicine – the Telemedicine Perception Questionnaire (TMPQ) (Demiris et al 2000)

MEASURES OF RESOURCE USE

This was measured by

- Number of medication prescriptions recorded in the patients primary care records
- Use of primary care resources including GP telephone contacts and appointments related to COPD
- Use of secondary care resources, namely the number of admissions to hospital with a primary diagnosis of exacerbation of COPD, and the length of hospital admission.

These data were collected from the patients' primary care records by a research nurse for the 6 months of the intervention (2008), and from the same 6 months of the previous year (2007).

ANALYSIS

In order not to over interpret the small dataset from this pilot work, we have limited our presentation of data to descriptive statistics and graphical representation of the use of healthcare resources and questionnaire data.

POPULATION

The 27 patients were spread across four practices, and with a predominance of ex-smokers, and slightly more men than women. All those approached agreed to participate and those who dropped out did so for medical reasons such as frequent or extended hospitalization that significantly complicated compliance. Before and after questionnaire responses were obtained from 24.

Table 3 The distribution of the population

TABLE 1: DESCRIPTION OF THE PARTICIPANTS (n=27)	
	Number of patients 27
Male n(%)	16 (59)
Median Age	69
Smoker n(%)	9 (33)
Ex-smoker	18

MEASURING CHANGES BEFORE AND AFTER MONITORING

There was no evidence of significant change in any of the questionnaires (see Figure 18) Given the sample size, however it is impossible to draw more detailed conclusions although changes were all in the desired direction, **IE**

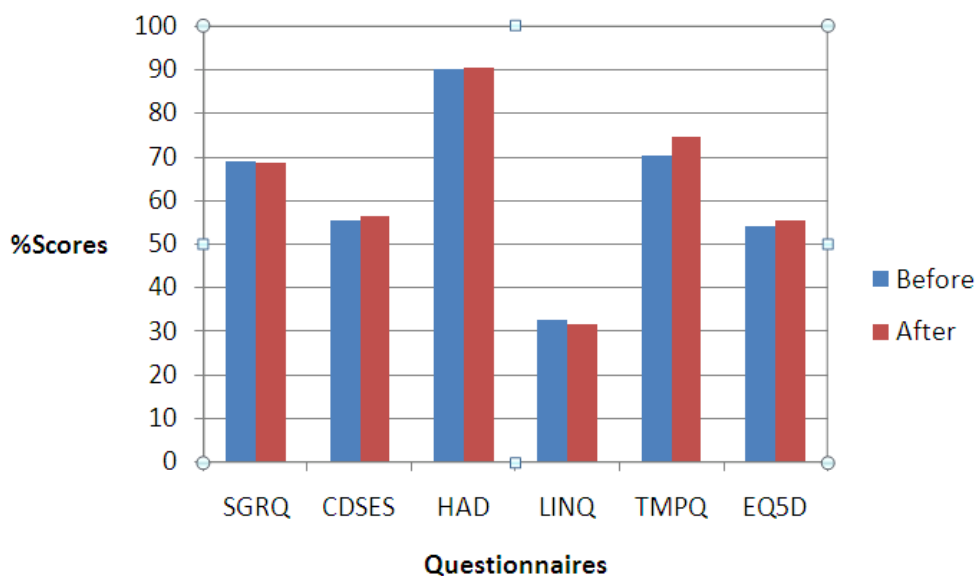


Figure 19 An overview of relative changes in scores on the questionnaires before and after the study

The questionnaires in Figure 19 use different scales and have different distributions, and are therefore not directly comparable, however rendering these as percentage scores gives an indicative view of changes before and after intervention,

The **SQRG** (St George's Respiratory Questionnaire) is on a scale from 0-100. Here 0 represents the best possible score, and 100 represents the worst. An improvement in the respiratory questionnaire is represented by a **reduction** in score.

The **CDSSES** (Chronic Disease Self-Efficacy Scale) is on a scale from 0-100. Here 0 represents the lowest level of self-efficacy, and 100 the highest. Improvement on this questionnaire is represented by an **increase** in scores.

The **HAD** (anxiety or depression questionnaire) has a non-ordinal structure, Scores of 0-7 are identified as non-cases of anxiety or depression, Scores of 8-10 indicate borderline cases. Scores of 11 or more indicate a case of depression. In this questionnaire, an improvement is represented by a **reduction** in score. We have mapped scores from the non clinical range of 0-10 as a percentage score here as an indicator of the direction of change, but this does not imply that these are analogous.

The **LINQ** (Lung Information Needs Questionnaire) measures the extent to which patients' need for information about the disease and its management have been met. The scores range from 0-25, with 0 implying needs have been met, and 25 implying that patients still require information in all the domains covered. In this context, an improvement is represented by a **reduction** in score.

TMPQ The **TMPQ** (Opinion of telemedicine) allows scores from 17 (lowest opinion) to 85 (highest opinion), so an improvement is represented by an **increase** in score.

The **EQ-5D** (Quality of Life Questionnaire) runs from 0-100, with 0 representing the worst imaginable health state, and 100 as the best. Improvement on this questionnaire is represented by an **increase** in score.

Patients found the questionnaires onerous to use, given that this was combined with additional paperwork associated with the other research activities and the installation and training process. The telehealth readiness (TMPQ) and self-efficacy (CDESES) questionnaires were particularly troublesome and we decided not to use these in the subsequent RCT. Although some effort was dedicated to supporting patients in completing these, they were considered excessively long, difficult to answer, and, from a patients' perspective somewhat irrelevant to their concerns and perceptions.

Concerns such as these have prompted the development of more usable, interoperable and flexible data collection tools for collecting and analysing self-report data from patients with common diseases. The US National Institute of Health Roadmap PROMIS study¹² is piloting what is claimed as a more usable, reliable and interoperable framework .

MEASURING CHANGES IN RESOURCE USE DURING MONITORING

Data were collected from GP records, and for hospital attendance and in-patient care, through ISD. This was extremely time-consuming as the records were often incomplete and it was not always clear if contact by patients was by phone, face to face or by home visit. Appointment systems, rather than the clinical record, often had to be accessed to determine service usage. Such a method would not be appropriate on a large scale and for the trial we therefore recommend service usage should be assessed by 3-monthly patient questionnaires with a proportion validated from the records.

To measure resource use we compared the number of medication prescriptions (figure 4), use of primary care (figure 5), and use of secondary care (figure 6) for the 6 month period during which the patients had the device with the same 6 month period the year. Despite the small numbers, the results indicate a highly significant increase in antibiotic and steroid prescribing resonating with the early and increased recognition of exacerbations perceived by both patients and clinicians. There were some differences between surgeries with one surgery increasing prescribing more than the others.

¹² PROMIS Research Programme 'Dynamic Assessment of Patient Reported Chronic Disease Outcomes, RFA Number: RFA-RM-04-011 (Reissued as RFA-RM-08-023) is supported by the Dept. Of Health and Human Services, and the National Institute of Health

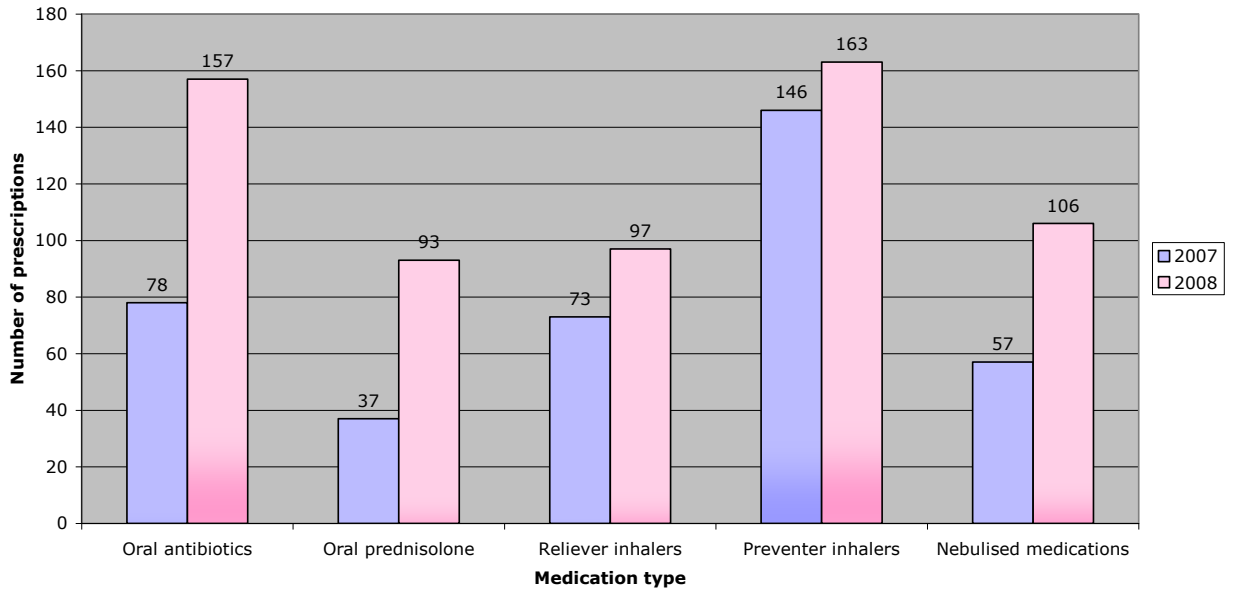


Figure 19 .Change in prescribing during the intervention 2008 and same six month period in 2007

Clinicians' perception of the workload was reflected in the increased primary care patient contacts, and the observation that this was manageable probably reflects the facts that most of these contacts were my telephone rather than clinic attendances or home visits (See figure 20).

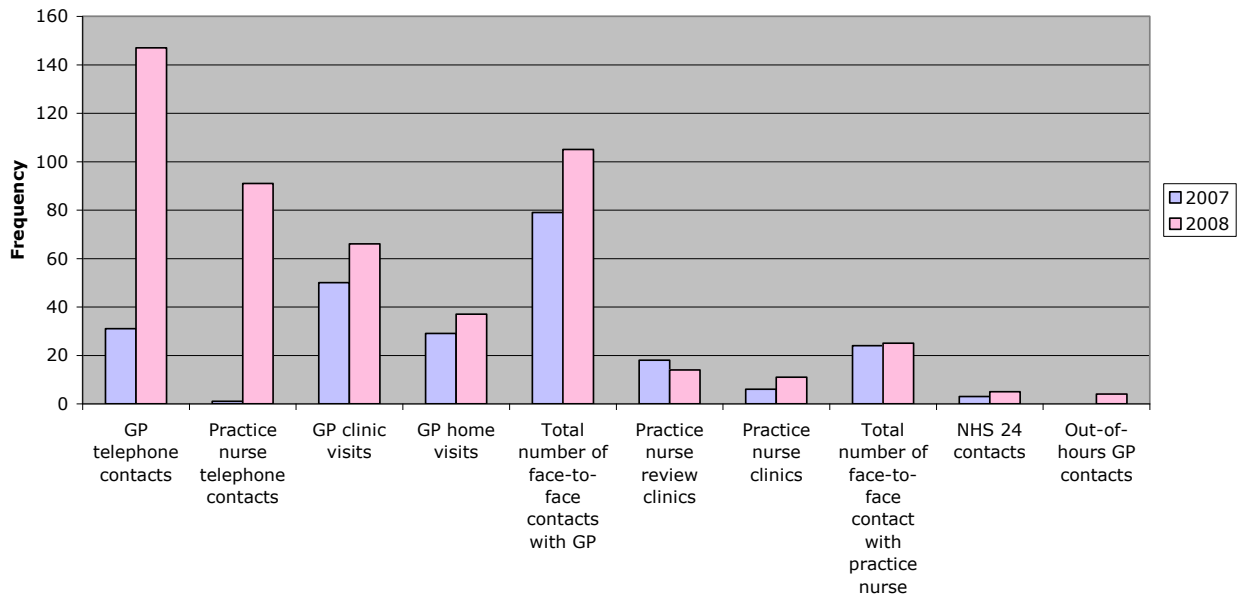


Figure 20 Primary care usage during intervention in 2008 and same 6 month period in 2007

CHANGE IN SECONDARY CARE USAGE

The large data relating to use of secondary care usage was strongly skewed by one very long admission (62 days). The number of patients was too small for us to draw any further conclusions about impact of the technology on admissions.

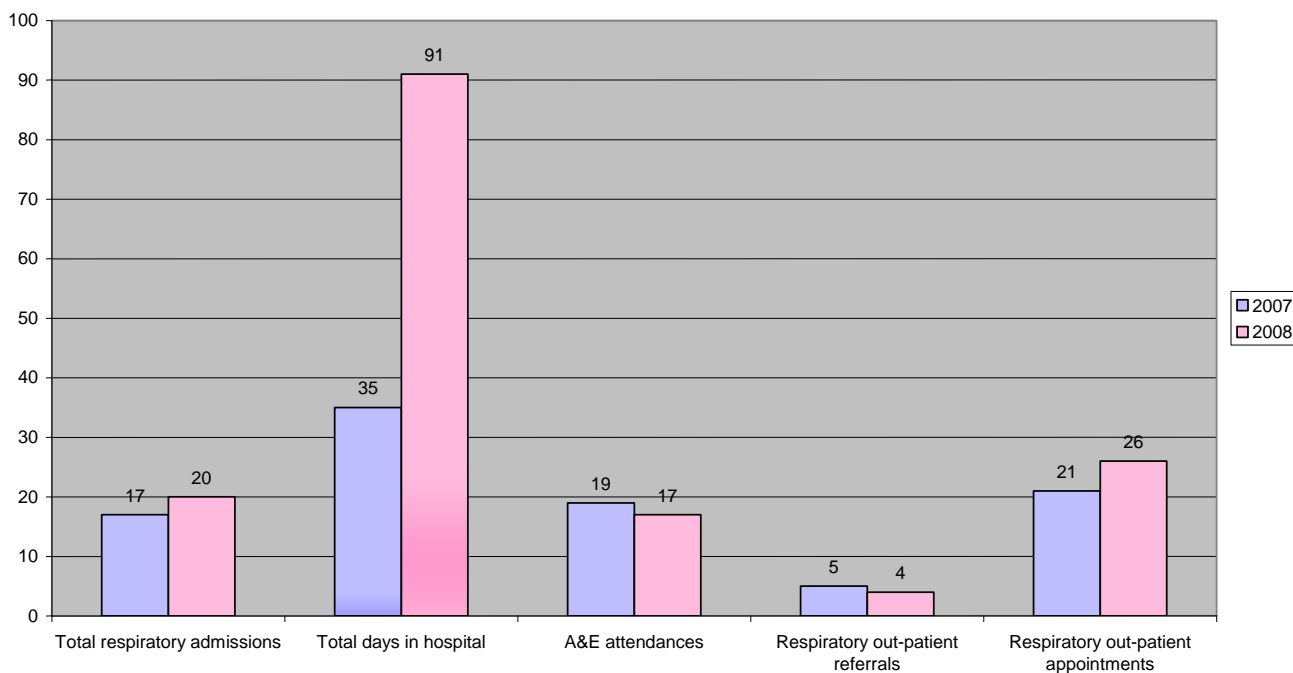


Figure 21 Clustered bar chart to show change in total usage of secondary care during the same six months in 2007 and 2008 (NB: 'Total respiratory admissions' and 'Total days in hospital' refer to those with a primary diagnosis of COPD.)

IMPLICATIONS

One of the most striking findings from the quantitative measures was the significant increase in prescribing of antibiotics and steroids. There may be a number of reasons for this.

It may reflect better diagnosis of previously unreported symptoms. This is supported by the qualitative data with both patients and doctors, which suggests that patients were unwell more often than had previously been realised, and many episodes previously unreported by patients were automatically picked up during tele-monitoring. Other initiatives have had similar experiences. The Telehealth Services Association Annual Report (Jones, TSA, 2009) for example, highlights an example from the introduction of tele-monitoring in ChorleyWood Health Centre, where GPs were 'surprised by the degree of clinical need amongst these patients' and suggest that the data had a profound effect on clinical decision-making and patient care. 'The clinical team was taken aback by the power of the data to effect change in their way of working; it proved hard to ignore poor treatment outcomes. It imposed a level of clinical responsibility not experienced before and engendered interest in other clinicians involved in the patient's care'.

A contributing factor may also be the fact that many of these patients were given emergency supplies of antibiotics and steroids to keep at home for the first time not all of which will have been taken during the six month study.

The technology that was also new to those participating and intervention levels were initially set very low, so patients were contacted at relatively low scores which may have resulted in increased prescribing, though our

qualitative work suggested that this tailed off with time. Confirmation of this finding, and the benefits, or otherwise, of this increased prescribing will therefore be one focus of the larger controlled trial..

Parallel to the increased prescribing is an increase in the contacts with primary care, though the fact that most of these contacts were by telephone meant that the impact on workload was not as great as might have been predicted. Modifications to the monitoring protocols may impact on these data when the service is rolled out: For example, initial monitoring by a respiratory specialist professional who knows the patient and their disease (as opposed to a call centre) may mean that they will be able to interpret the incoming data clinically obviating (or increasing) the need for some of the calls. Again the RCT will allow for exploration of the impact of different approaches on workload.

The questionnaire study highlighted a number of issues relevant for the larger study, and raise questions which require a larger more controlled study to answer. Patients found the questionnaires onerous to use, given that this was combined with additional paperwork associated with the other research activities and the installation and training process, The telehealth readiness (TMPQ) and self-efficacy (CDSSES) questionnaires were particularly troublesome and we decided not to use these in the subsequent RCT.

The questionnaire results for quality of life and anxiety did not reflect the comments made in qualitative interview. It would be useful to unpick this in more detail with a larger sample, looking more specifically at the aspects of quality of care which patients and GPs articulated in interview. Improvement in quality of care is frequently reported in the literature and was very consistently reported by interviewees. The difference between qualitative and quantitative measures here may reflect the sample size, but may also raise questions about the usability and the sensitivity of the questionnaire to particular aspects of the user experience. Two recent studies using the questionnaire as an indicator have found that telecare has had neither a positive nor negative effect on patient quality of life, with one study stating that 'the addition of telehealth to COPD patient care was not a significant predictor of well being' (and Mickus 2007). The 2008 study by Trappenburg, which also examined the effects of tele-monitoring in patients with COPD, also found no significant changes in health-related quality of life (Trappenburg 2008). The adequately powered RCT will allow this issue to be assessed more effectively, and look in more detail at the difference between quantitative and qualitative measures of quality of life. It is therefore of interest that the US National Institute of Health Roadmap PROMIS study¹³ is piloting a new set of questionnaire banks for collection, representation and reuse of self-report data in chronic diseases that will centrally manage analyses and generation of item banks and computerized adaptive testing systems. This was instituted as a means of addressing a number of the issues encountered in trials requiring the collection, tailoring and re-use of this kind of data.

¹³ PROMIS Research Programme 'Dynamic Assessment of Patient Reported Chronic Disease Outcomes, RFA Number: RFA-RM-04-011 (Reissued as RFA-RM-08-023) is supported by the Dept. Of Health and Human Services, and the National Institute of Health

4. DISCUSSION:

Aligning People Processes
and Technology

ALIGNING PEOPLE, PROCESSES & TECHNOLOGY



Fig. 22 Technology-assisted care.

We provide a brief overview of the issues raised by patients, care teams and project managers in the coordination of care using telemetry assisted monitoring at home.

PEOPLE

The system was very positively received by patients, carers and health professionals despite some concerns about workload,

PATIENTS

The very positive responses from patients was attributed to

- easier access to care
- reduced anxiety
- enhanced quality of care

The pilot highlighted the practical and the psychological difficulties that patients and their carers face in identifying when to access professional care, and in negotiating the process of getting an appointment. They mentioned anxieties about 'bothering' a doctor, the difficulty of differentiating between transient symptoms and the onset of an exacerbation that are reported by other authors such as Adams et al (2006).and the impact of difficulties and delays experienced in getting an early appointment in some practices. Shipman (2009 in press) also underlines these issues in a study of the factors influencing contact between advanced COPD patients and their surgeries. She highlights the potential for more pro-active contact by GPs or others in the practice, and raises the need to consider alternative approaches such as nurse led tele-monitoring.

The system played a positive role in highlighting the hurdles patients and carers experience in the process of acknowledging and accessing timely help. In addition, the intervention appeared to provide an opportunity for the review of care and the exchange of good practice. In other reviews also, patients were typically very positive about home telecare, and preferred a combination of home telecare with conventional health care delivery, with cost reductions particularly associated with time-saving and reduction in need to travel. Savolainen et al (2008), Botsis et al (2008) and Whitten and Mickus.)

ALLIED HEALTH PROFESSIONALS

Increased Quality of Care

Nurses, physiotherapists and GPs on the frontline were very positive about the approach, despite some reservations about scaling up without additional resource, citing very positive patient feedback and greater awareness of symptoms. As with patients, the perception of benefits greatly outweighed the initial re-arrangement of work practices to accommodate the monitoring.

There were some concerns about the increase in patient contact (mostly by phone) partly as a result of low trigger threshold levels. This was useful in consideration of appropriate baseline levels for the wider trial, and raised additional issues about the potential for negotiating individual patient benchmarks, and the implications of moving towards that.

Increased Workload

Practice nurses and GPs on the study pointed to a manageable increase in workload monitoring patients largely due to the need for a second stage following up the scores of at risk patients, and greater reporting of symptoms as a result of a low trigger threshold.

The workload reflected the finding that scores were insufficient for diagnosis without significant context and patient specific information, and required a phone call or a visit not anticipated in the design. This was a key finding for the design of the wider trial given the initial assumption that much of the work would be automated through triage.

There were also some concerns (from a resource perspective) as to who would be responsible for training patients or following up initial training, as well as issues about troubleshooting problems when setting up or adding to the system in the trial.

There was a concern that significant scaling of numbers might thus require additional resource, and clear protected time for nurses to monitor and follow up patients adequately.

Increased Medication

The number of exacerbations being reported was also identified as higher than anticipated, with some of this being attributed to the low benchmark criteria for triggering an alert, but there was also a view that the frequency of these events in patients lives was under-reported, and in addition to presenting additional workload, had an impact on the perception of the patient experience of the condition.

But quite what effect all these antibiotics are going to have at the end of the line is a different story. It may be good if it keeps them out of hospital or if it makes them feel better generally, but I think....you ..these drugs are not without side effects...whether we're going to give folk cataracts with these drugs..put on weight...it 's a concern."

(GP)

If tele-monitoring identifies more patients meeting the criteria for intervention than would self-report in usual care, this raises questions as to whether tele-monitoring studies can be fairly compared with usual care on cost criteria.

The literature on behaviour change (Ogden 2009) is relevant here, and the literature on nursing at different stages of transition in the acceptance and management of illness (Marineau 2006). These provide pointers for how telecare could be useful at different stages, for example in transition from hospital to home, or in reinforcing perceptions of improvement (as opposed to illness) through awareness of own scores. There appeared to be the potential for developing useful synergies with physiotherapists, respiratory and community nurses and COPD networks in this area in the longer term.

The criteria for success that managers cited had already moved from the baseline of reduction in hospital admission as the main arbiter, to quality of care for patients, based on greater synergies of disparate technical and human resources and this is increasingly echoed in recommendations based on national reviews. (Scheller-Kreisen et al 2009).

PROCESSES : USING DIGITAL DATA FOR DIAGNOSIS AND INTERVENTION

I thought it would be more clear-cut. It didn't occur to me it would be so difficult to work to a standard baseline. It's a lot more complex than I thought it was going to be.

GP)

The initial vision of a straightforward monitoring process, based on a standard benchmark, and with little additional input from GPs in supporting and monitoring patients was challenged in practice by the role of context and patient specific factors impacting on both symptoms, and interpretation of scores.

The pilot study provided a useful sandpit for exploring alternative scenarios, each of which had different resource implications, and different costs, risks and benefits.

INTERPRETING DIGITAL DATA

The access to long term individualised data appeared to prompt reviews of practice, with less reliance on a standard benchmark, and more use of a consultative process with patients, where context and patient specific issues, including co-morbidities impacted on intervention.

The intensive monitoring of individuals generated awareness of the degree of variation in symptoms, and tolerance of them, and the difficulty of translating this complexity on the ground into a clear-cut decision support system. This is a challenge that has hindered the implementation of decision support systems (such as ontologies) in other eHealth initiatives (Ure 2009)

The study suggests that initial assumptions about the diagnostic measures of most use in remote diagnosis may have been ambitious in the assumptions about the predictive value of benchmark scores as diagnostic indicators. the same score was seen have very different implications in different patients.. Some patients may have developed good management strategies for very low oxygen levels, but when they do present with problems these may be more urgent. Other patients may have manageable levels, but anxiety and difficulty managing this may lead to increased breathlessness and panic attacks. Some patients typically overscored on the online short questionnaire and others underscore the implications for intervention, and the associated risks are very different. ,

Generic threshold levels were of very limited value alone in gauging a patient's condition, and the need for/nature of intervention required. Individual benchmarks were seen as a more logical approach by GPs and nurses, as well as the option of supplementing the initial shortlist of at risk patients with telephone or video conference calls. This kind of monitoring actually provides an opportunity for this. The value of local knowledge of the patient was made more evident. It was required to both make sense of threshold measures, and as a basis for negotiating an appropriate intervention, by phone or by videophone.

Interoperability of Data

Barnsley Hospital in South Yorkshire is one of a number where this is becoming apparent. They currently provide home health monitoring systems for patients with chronic heart failure, where patients often have multiple and complex needs that require remote medical data to be placed in the context of an individual's health, care, and living arrangements. They found that obtaining such contextual information required greater connectivity between individual technologies and IT systems to fulfil its potential. This is something remarked on by community health nurse managers, if care staff are working across practices where data is in separate silos, and was central to the initial concerns expressed by managers of Allied Health Practitioners, that mediated tele-health services would only be effective if the information reached 'the right people, at the right place, at the right time.'

In other UK pilots this has also been an issue. Dr Mike Bainbridge, clinical architect for NHS Connecting for Health, the agency of the Department of Health responsible for delivering the National Programme for IT in the NHS has highlighted the lack of connectivity due to the absence of common standards, and a lack of integration into wider initiatives as a barriers to the exploitation of electronic assistive care if this is to be scaled up in real terms. While the Continua Alliance addresses some of those issues for the interoperability of standards used in the design of telecare systems, it does not address the fact that the patient data care teams will need is stored in many different sites, in different formats, and often across different practices, requiring different access rights.

SCENARIOS FOR DATA TRIAGE AND INTERVENTION

Without a doubt this telemetry intervention has changed the way we treat it, you know I mean to start with we were definite that if they scored more than 4 (threshold at which an exacerbation was considered likely) we would put them on antibiotics and we suddenly realised they would ALWAYS be on antibiotics

(GP)

The scenarios for managing the process of diagnosis and intervention cycled through three iterations in the course of the pilot

1. automated decision support based on data triage and a protocol
2. a two stage process combining automated decision support based on data triage, validated by local input from patients and nurses to valid or interpret scores and agree on care options
3. patients use their scores as a basis for an informed decision about accessing services, and as a basis for managing conditions

The very different scenarios invoked, and the different cost, risk and benefits associated with them, raises issues of representation in the process of shaping these new digital territories, such that they are both fair, and ultimately usable and acceptable in practice.

Kennedy et al (2007) have long argued for a whole systems approach to the provision of effective support for self-care that would leverage the potential of telecare systems to provide more flexible professional response

pathways, more flexible arrangements for access to care or advice, and more collaborative working in the design and dissemination of information and advice around patients' needs.

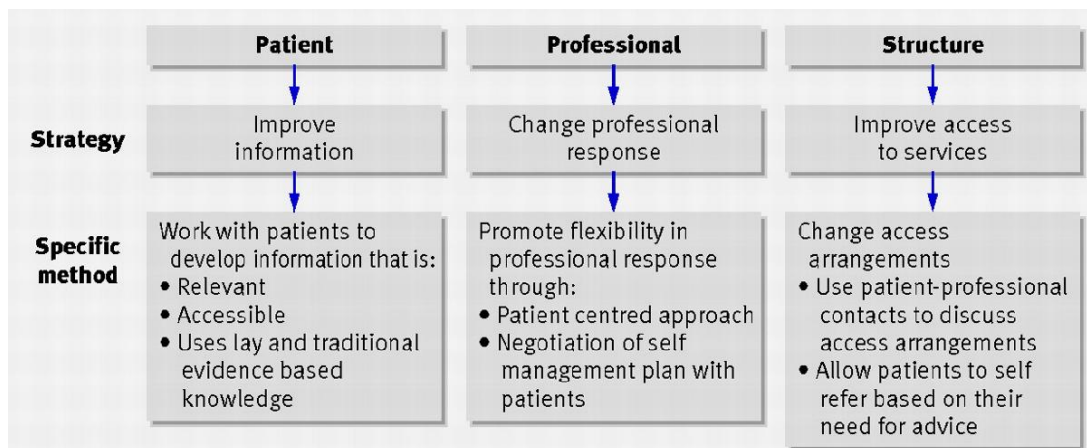


Figure 25 An intervention based on a whole systems view (From Kennedy et al (2007))

They highlight research into improving the quality of health care that indicates that multifaceted interventions are more effective than simpler ones and that enduring change requires a multilevel approach, where changes at different levels are interlinked to maximise the effect., as for example in the WISE14 model of chronic care model, which seeks to place self care in a wider context of professional behaviour change and community engagement.⁸

In the Technology Services Association Annual Report.(TSA, 2009), Stephen Johnstone, from the Department of Health (Long Term Conditions) outlines a view that barriers occur at three different levels: service user level, provider level and system level, and underlines the need to addressing barriers at each level for telecare to work in practice The mapping of that process in the Lothian pilot was a useful frame of reference for both communication and planning change in service delivery with or without telecare, and this may in itself have been a valuable outcome.

THE PILOT AS A LABORATORY FOR STRATEGY

The project management team highlighted a perception of the project as a process of change management, or 're-engineering the business' as one of the interviewees described it. In this, the pilot study provided a laboratory for strategy, rooted in the target context, and involving the stakeholding parties actively in the process. This is very much in line with the finding of other recent reviews, and of the other regional pilots reported through the UK Whole System Demonstrator Network earlier. This evolving model of care and the associated change process is echoed in studies across very different national contexts. Glasgow (2008) describes the provision of care for COPD in Australia as an incremental process of change 'from one of acute and episodic care orientation in both the private and the public sectors, to a system that deliver anticipatory chronic disease care as well'. Horton (2008) points to the need to renegotiate roles, risks and rewards, and Valsecchi et al (2007) highlight the shaping role of context in this process, and the importance of taking account of local stake-holders needs and perceptions in managing the implementation. .

RECONFIGURING CARE AROUND PATIENTS' NEEDS

¹⁴ National Primary Care Research and Development Centre. The WISE approach to self management. www.npcrdc.ac.uk/WISEApproachSelf-management.cfm

The Wanless Report (2006) identified the need to reconfigure and align the resources of different groups in primary and social care around patients needs in new ways, and this was evident in the different scenarios for triage and intervention that evolved through the pilot study, each configuring roles, risks and resource allocation in different ways. What is less clear is the process whereby particular choices of care pathway are to be made.

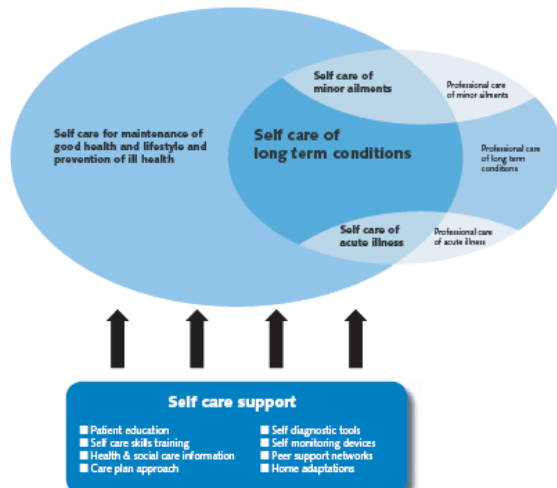


Figure 23 Supporting self care across the whole system (Adapted from WanlessReport , 2006)

A very wide range of pilot studies in the UK have been evaluating the use of telehealth systems with much of the discussion and dissemination being mediated by the Whole System Demonstrator Action Network 15 The Network is run by The King's Fund and CSIP Networks and is funded by the Department of Health., and provide reports and reviews of the large number of regional pilots throughout the UK, that resonate with the findings in the pilot reported here. Salient issues they report resonate with the findings in our own and others cited from the recent literature. The outcomes indicate that:

- a majority of older people express a preference for remaining in their own home
- technology that supports this is generally very positively regarded by patients
- successful telecare needs to involve the integration of a number of different players in new ways that require evaluation of the issues and risks in change management.
- people with low and medium level needs find greatest cost/ benefit, with hospital admissions being reduced, shortened or delayed in many studies.
- participants felt more empowered, more confident and independent
- as a result of that experienced less anxiety and thus interacted less with services
- when they did access services it was more appropriately and as a result of that the number of bed days for the group decrease
- emergency admissions decrease and where individuals have died, it has been at home not hospital
- staff were more aware of the needs and preferences of patients and carers

The Kent study included in the pilot other agencies such as Volunteer Groups and Age concern who support people who may not have a carer and need help with taking their measurements. More recently a group of service users from the Kent Pilot who've benefited from using the technology, have volunteered to support new and existing users by undertaking trouble shooting and answering general queries. The impact of telecare

¹⁵ <http://www.networks.nhs.uk/networks/page/1209>

on carers, and their role in making it work, are significant aspects of the West Lothian outcomes also, and could be given more consideration in the design and deployment of such systems.

Generally, design is patient centred, but for many of these patients, the decision making and the degree of dependence on carers suggests that fitting around carers who 'make it work' on the ground may be more important than is generally considered.

Among many pilot reports on self-care, a number identify the need to identify and address the needs patients themselves and their carers say they have in practice. The positive comments in the Lothian pilot reflected the good match between the needs patients identified at the outset, and those delivered by the tele-monitoring system. The research and the pilot process was a catalyst for a review of the patient experience in ways that made gaps, and requirements more transparent and auditable to the wider care team. This process itself generated benefits beyond those of tele-monitoring, as for example in the wider adoption of practices to minimise delays, such as providing antibiotics at home. The WSDAN pilot studies highlight other initiatives that arose out of other pilot studies which acted as a vehicle for patients and carers to identify and address particular needs or concerns in collaboration with their care teams.

- South Wiltshire PCT for example, organised a chronic obstructive pulmonary disease (COPD) process mapping event to establish the care currently being provided to COPD patients by mapping the key aspects of the 'patient journey', providing leaflets and using a carer/rehab. network to support self help. A number of pilots report on the extent to which such strategies enhanced self care and made staff more aware of the issues patients were dealing with.
- Newham Health Care and Newham PCT have jointly funded a project where, expert patients, the local 'breath easy' group and physicians, nurses and physiotherapists are working together to develop a seamless COPD pathway across primary and secondary care.
- Central Cornwall PCT has developed a COPD Passport for people living with COPD. It was created in response to reports that many people with COPD suffered from a debilitating fear of further exacerbation. It gives advice to help reduce the 'fear factor', and also provides paramedics and admitting staff with important information in the event of the patient exacerbating, thus allowing him or her to be fast-tracked into the Respiratory Unit. This will now rolled out to selected GP practices for a trial period then be made available across the county.

TELECARE AS A CATALYST FOR CHANGE

One recurring issue echoed in the study is the transformational potential of telecare and by the same token, the inherent risks of reconfiguring services in new ways. Hendy et al (2008) highlight the processes and difficulties of the organisational changes required by the introduction of what has been termed disruptive technology for this reason. As with other ICT-supported change processes such as the introduction of eLearning and virtual learning environments (Laurillard 2002) the process has been a catalyst for change, and for rethinking the basis shape that services should take in an era where the requirements and the cost base may favour alternative models of provision.

The role of other health and social care partners, of carers, families and of local communities is increasingly part of this re-evaluation. One of the more successful recent initiatives with community matrons playing a key role in catalysing and managing this process is reported by McHugh(2007), and highlights the role of local partnerships in reconfiguring the nature, cost and quality of care.

Horton 2008, and Botsis reiterate this in another recent study, pointing out that partnership working has to be negotiated as part of the reconfiguration of roles, risks and rewards, citing ethical, legal, design, usability and other issues, as these have become more evident in practice, and need to be considered in the design and deployment of such services. Technology innovation in other contexts suggests that often insufficient time

and resources are made available for this in the initial stages, and delays and problems typically arise from unpredicted issues later in the proceedings .

A number of reports including Barlow et al (2007, and Botsis et al (2008) suggest that the most effective telecare interventions appeared to combine the benefits of automated vital signs monitoring and telephone follow up by nurses to contextualise the evidence (had they been very active before a reading and over-scored for example), and to negotiate an acceptable interventions. This matches the approach that evolved in the pilot in response to early feedback on an approach that depended more on threshold scores based on patient self-monitoring.

TECHNOLOGY

The system and the peripherals were seen as easy to use by patients, (with the exception of the FEV₁ meter which was complicated to use, often failed to transmit, and had features making it difficult for some of the elderly patients)

Battery failure in the oximeter was a frequent problem, causing stress and inconvenience for patients and generating additional work for support teams. The potential to impact on the accuracy of readings was worrying to both patients and staff and needs to be addressed.

Transmission failure was a common problem, particularly with the FEV₁ peripheral, raising concerns for patients as to whether readings had been received or not, and confusion about the nature (or cause) of problems that arose. A software modification enabling a transparent feedback mechanism for users indicating the progress of the transmission, and giving pointers where this failed would be a useful design feature.

Although the patient interface was easy to use, the usability of the backend interface was laborious and cumbersome for GPs, practice staff and Careline staff. Professionals perceived the encryption process as laborious and time consuming and that it would need to be streamlined to be usable with larger numbers of patients in practice, and within the constraints of a ten minute appointment.

CONCLUSION

There is nothing more difficult to execute, nor more dubious of success, nor more dangerous to administer than to introduce a new system of things; for he who introduces it has all those who profit from the old system as his enemies, and has only lukewarm allies in those who might profit from the new system.

Niccolò Machiavelli, The Prince, Chapter VI.

Patients and carers were consistently very positive about their experiences of using the technology, despite the inevitable initial teething problems with the equipment. They found it reassuring, they felt the quality of their care had improved and that it addressed problems experienced in either getting appointments, or deciding whether it was appropriate to access a doctor.

Doctors, practice nurses and managers of allied health practitioners were more cautiously welcoming, particularly in view of the feedback they had received from patients, despite an initial increase in workload and concerns about the usability of the interface for different purposes. The rethinking of nursing and care services for patients with long-term conditions at home in the region meant that change was seen as inevitable, and the introduction of a home hub and a communication network was therefore seen as more of an opportunity to enhance, extend or sustain services in new ways.

There is already evidence that tele-monitoring systems opens up avenues for new realignments of the technical, human, and organisational systems that are involved in mediating care. The process of rethinking the delivery of care services across different stakeholder groups may well have been a useful process in itself. Barlow and Hendy (2009) suggest much of the potential for scaling up will depend on this kind of understanding of different scenarios for integrating new digital infrastructure with the distributed care infrastructure, and their implications on the ground, (Nicolini 2009).

Perhaps one of the less obvious benefits of such studies is the role they play in providing a vehicle for rethinking practice in a disease domain that has traditionally been neglected. While there is a real demand for evidence of cost-effectiveness to support policy change in this direction (Barlow 2009), the economics of traditional hospital-based care for an aging population may be moving the debate rapidly from 'Can we afford to do it?' to 'Can we afford not to do it?'

In a recent review of benefits of home telecare for older people with long term conditions Barlow et al (2007) and Hendy et al (2008) (and also Constantinides, 2006) highlight the lack of large scale in depth studies, the inconclusive evidence in many of these of either cost-effectiveness or patient satisfaction, and a lack of rigour. While the evidence is not yet conclusive that telecare will cut costs, it is clear that the impact of telecare in postponing and diverting people from hospital and residential care will redistribute costs and benefits across the system. In ways which will require significant renegotiation of rights, roles, risks and resources.

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