Bridging two translation gaps: A new informatics research agenda for telemonitoring of chronic disease

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\textbf{Abstract}

Objective: To propose a research agenda that addresses technological and other knowledge gaps in developing telemonitoring solutions for patients with chronic diseases, with particular focus on detecting deterioration early enough to intervene effectively.

Design: A mixed methods approach incorporating literature review, key informant, and focus group interviews to gain an in-depth, multidisciplinary understanding of current approaches, and a roadmapping process to synthesise a research agenda.

Results: Counter to intuition, the research agenda for early detection of deterioration in patients with chronic diseases is not only primarily about advances in sensor technology but also much more about the problems of clinical specification, translation, and interfacing. The ultimate aim of telemonitoring is not fully agreed between the actors (patients, clinicians, technologists, and service providers). This leads to unresolved issues such as:

1. How are sensors used by patients as part of daily routines?
2. What are the indicators of early deterioration and how might they be used to trigger alerts?
3. How should alerts lead to appropriate levels of responses across different agencies and sectors?

Conclusion: Attempts to use telemonitoring to improve the care of patients with chronic diseases over the last two decades have so far failed to lead to systems that are embedded in routine clinical practice. Attempts at implementation have paid insufficient attention to understanding patient and clinical needs and the complex dynamics and accountabilities that arise at the level of service models. A suggested way ahead is to co-design technology and services collaboratively with all stakeholders.

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1. Introduction

Telecare and telehealth initiatives have seen large investments in many countries in an effort to deliver better care. This includes home telemonitoring, where there is a significant potential gain from using informatics to detect deteriorations in chronic diseases in order to avoid serious illness and admissions to hospitals. However, efforts so far have not led to convincing evidence that informatics interventions are cost-effective [1–4], particularly so for specific conditions such as heart failure (HF) [5], chronic obstructive pulmonary disease (COPD) [6,7], and diabetes [8,9]. There is also no real evidence that monitoring technologies are capable of being implemented and sustained in routine clinical settings [4,10,11]. Why is this the case? What are the obstacles to the effective use of telemonitoring? We set out to identify the research gaps and define an agenda to address the shortcomings of existing home telemonitoring solutions for patients who have chronic diseases. By home telemonitoring we mean “an automated process for the transmission of data on a patient's health status from home to the respective health care setting” [3]. In particular, we have tried to address the inadequacy of approaches to detecting deterioration early enough to intervene effectively.

2. Background

In HF, prevalence in the western world is around 1–2% [12] and accounted for approximately 57,500 emergency admissions in England and Wales in 2007–8 [13,14]. COPD is the fourth largest cause of death worldwide [15] and accounted for nearly 110,000 emergency admissions in England and Wales in 2007–8 [13,14]. The prevalence of diabetes in the UK is around 4% and accounts for approximately 10% of the National Health Service (NHS) budget [16].

Numerous publications have outlined research agendas for e-health [17–27] yet only Ahern et al. [18,28] and Bath [17] have specifically considered the management of chronic disease. Ahern et al. argued the need for informatics-based interventions to demonstrate cost-effectiveness and improved clinical efficacy. Bath considered the potential of information and communication technologies (ICTs) to reduce hospital admissions by assisting early detection of deteriorations occurring in chronic disease, but his analysis lacked detail, saying only that they “have an important role to play”. A review by Gaikwad and Warren [4] concluded that: “home-based ICTs can facilitate timely identification of changes in chronic disease patients' functional and physiological status” and noted that such benefits are more consistently observed in pulmonary and cardiac studies than in other areas, although the evidence base for these claims is not substantiated.

Those who have delineated informatics research agendas for chronic diseases have not specifically regarded early detection of deterioration as an area requiring further work. Work by Koch [20] and our earlier exploration of the field [29] suggest that there may be a lack of coordination between clinical and technology expertise in this area and that the concept we refer to as early detection has significant implications for how organisations respond to alerts and for how professionals might have to restructure their working practices as a result. The aim of our study was to examine the field of telemonitoring with respect to early detection in specific chronic diseases, to assess the nature of the unresolved issues, and to set a research agenda that would identify the gaps in an effort to move the field forward.

3. Method

3.1. Mixed methods approach

We used a mixed methods approach (Fig. 1) to understand the current systems, practices and issues, combined with strategic roadmapping to explore and synthesise a research agenda. Ethical approval for the study was obtained from the South East Wales Research Ethics Committee.

3.2. Literature reviews

We conducted a search for systematic reviews, meta-analyses and health technology assessments related to the use of ICT in managing patients with COPD, HF and diabetes in their homes. We searched EMBASE, CINAHL, EBM reviews, INSPEC and Ovid MEDLINE® databases from January 2003 to May 2008 using search terms such as ‘telemedicine’, ‘monitoring’ and ‘technology’ combined with each of the exemplar diseases. We also searched for randomised controlled trials of telemonitoring published after the end of the review search dates. Studies were reviewed to determine the evidence for the acceptability, clinical and cost-effectiveness of the technologies evaluated.

3.3. Key informant interviews

We used purposive sampling to select appropriate clinical professionals, medical and informatics academics and others with specific policy-level roles for healthcare IT or chronic disease. We used semi-structured interviews to explore: what are the best indicators (signs or symptoms) for early detection of deterioration; when to initiate monitoring; how to collect data, analyse and store it; how to act on detected events (alerts); what are the patient or clinical issues with the use of such technologies? We conducted thematic analysis on the transcripts using inductive coding and a constant comparison method [30]. Emerging themes were explored using concept maps [31] until the research team were confident that the results represented an accurate synthesis of the collected data.

3.4. Focus groups

We conducted focus groups of patients with the exemplar conditions and their carers. Each of the clinical colleagues in our research team identified 20 candidate patients who were invited to attend. Patients were also asked to invite their carers to separate focus groups. Three patient-oriented narratives (see examples for HF in Appendix 1) were developed using information gathered in the literature reviews and informant interviews. The first narrative (“Typical HF Today”) describes
the situation most patients experience today in the UK NHS, where telemonitoring does not feature and provision of care is fragmented. The second narrative ("eHealth 2010") describes an example of the current use of telemonitoring and the third ("eHealth 2020") describes an idealised futuristic situation.

The narratives were presented to the focus groups in turn and questions were posed to ascertain the acceptability and desirability of each approach. Summaries of the points elicited were confirmed with participants at the end of the discussions and thematic analysis was then conducted on the transcripts.

### 3.5 Strategic roadmapping

We used Multi-Path Mapping [32], a variant of roadmapping [33], to identify the lines of research required to support a future vision of early detection. Multi-Path Mapping has been developed specifically to address areas of emerging science, engineering and technology that are characterised by a high degree of uncertainty about how the future may unfold. A Multi-Path Map (MPM) combines understanding of the potential of technology with creative thinking about possible futures. It is a graphic illustration of the step-wise developmental pathways of technology over time [34], accounting for uncertainty about how the future may unfold. As illustrated in Fig. 2 and the completed MPM in Fig. 3, the developmental stages depicted by an MPM extend from fundamental laboratory research, to applied methods, product/service development, field testing, regulatory approval, in-use evaluations and potentially, widespread deployment. Arrows show the necessary activities for progressing between stages, from the present day to a time in the future (e.g., 10 years hence).

We see such pathways in the Medical Research Council’s framework for the development and evaluation of ‘complex interventions’ [35,36] and Cooksey’s ‘pathway for translation of health research into healthcare improvement’ [37].

We used MPM in an interactive interdisciplinary workshop. We used purposive sampling to select candidate participants from backgrounds similar to those used in the key informant interviews. We used scenario forecasting [38] to stimulate forward thinking during the mapping process. Scenario forecasting combines known facts with social, technical, environmental, economic and political trends (drivers) to produce plausible alternative “scenarios” of how the future may look. Working in groups, we asked participants to identify the challenges, opportunities and knowledge gaps involved in transitioning from the present day scenario ("Telemonitoring 2010", see Appendix 2) to one of two future scenarios of telemonitoring. In the first of these ("Ubiquitously networked patients") responses to monitoring data are fully integrated into the organisational service model; in the second ("It’s my medical data") patients hold their own data and are empowered consumers, creating new demands on healthcare providers.

After the workshop, we generated a single Multi-Path Map from the group results. We combined it with the other data...
Fig. 3 – Multi-Path Map for early detection of deteriorations in long-term conditions. Illustrates a vision of 3 evolving generations of early detection systems. Lines depict ‘paths’ of research needed to fulfil the vision for each generation. Items with arrows indicate barriers to adoption.

4. Results

4.1. Literature review

Our reviews of telemonitoring for HF and COPD reveal that there is a tendency for implementation of telemonitoring to race ahead of an agreed clinical need and to assume that monitoring per se adds value. This pattern seems particularly clear in the context of managing patients with Type 2 diabetes, where there is an unresolved debate about the value of glucose monitoring – to the extent that it is not part of current clinical guidelines.

4.1.1. Telemonitoring in HF

We found six systematic reviews, covering 100+ separately identifiable trials of telemonitoring for HF. We did not find evidence of a consistent effect on mortality or on hospital admission. The evidence base is weak: trials feature small sample sizes, short follow-up durations, and outcome measures that are overly simplistic (hospital admissions) or too complex to allow comparisons (combined outcomes). Three reviews presented significant reporting bias [10,39,40] and there is insufficient evidence of cost-effectiveness due partly to a lack of rigorous economic evaluations. Most studies lack detailed description of the data collected and how it was analysed in order to achieve clinical decisions [5,10,39–42]. However, the weight of evidence indicates that telemonitoring can produce clinical benefit for HF patients at an equivalent or reduced cost to usual care, although the nature of the benefit is not consistent.

4.1.2. Telemonitoring in chronic obstructive pulmonary disease (COPD)

To date, there is one systematic review of the evidence for telemonitoring in COPD [43]. This review shows that few randomised controlled trials have been conducted and those completed have limitations. Typically, the 6 studies meeting the review criteria [44–49] are characterised by small sample sizes, poor reporting and short term follow-up periods. Notwithstanding these limitations, authors of these studies report positive trends. They report that telemonitoring is associated with a reduction in the number of exacerbations [45,47], emergency department visits, and hospital admissions [45–48]; and that physiological monitoring devices are acceptable – although few of the studies required patients to...
actively use these devices. In most studies [44–46,48] the telemonitoring technology is conceived to give patients ‘access’ to a nurse-led call centre. The studies did not rigorously examine cost-effectiveness but where it was looked at, some savings were noted [44–46,48]. In summary, our review concluded that the evidence in support of home telemonitoring for COPD is limited in volume and quality.

4.1.3. Telemonitoring in diabetes
Unlike COPD and HF, diabetes represents a chronic disease with an established history of self-monitoring. Patients with Type 1 diabetes routinely self-monitor and there have been several attempts to utilise communication technologies to support a younger and more mobile patient population [50,51]. However, the evidence base to support regular self-monitoring of blood glucose for patients with Type 2 diabetes is weak [52–54]. Small improvements in glucose control have been found in some studies but the clinical impacts of these changes over the long term are not known. Trials have often been small-scale and of short duration.

It is not clear that the use of telemonitoring technologies improves matters. The evidence suffers from the same limitations as for COPD and HF: small samples, short durations and heterogeneous and complex interventions that are poorly characterised and examined [8,9,55]. The impact of introducing technology has been generally small, with greater impact on patients’ quality of life than on their glucose control and clinical outcomes. Economic evaluations have been particularly lacking in this area.

4.2. Key informant interviews
Twenty-six informants were interviewed [56] from a variety of backgrounds: academic and non-academic, clinical (specialist, generalist, consultant, and nursing), UK NHS policy-making, telehealth, and medical technology development. Informants were positive about the potential use of telemonitoring technologies, but noted that home telemonitoring approaches are currently seen as a “bolt on” to current models of health and social care provision, which are themselves fragmented.

There was a consensus that the main driver for telemonitoring should be clinical need. A consistent view was that data were often collected without a clear aim or consideration of its relevance and that the questions that were important to clinicians were not sufficiently addressed. Without this it is difficult to establish clinical acceptability of a system.

Sensors for physiological parameters in use today are relatively cumbersome, but an emerging generation of sensors will be insensible and invisible, requiring very low power or being self-powering, and capable of collecting mobile data rather than at a fixed location.

Informants suggested better indicators to improve early detection but noted that these may vary in usefulness between patients. They stressed the need for individual baselines and for using trends and multiple signals. Clinical informants valued qualitative parameters, such as changes in activity levels or appearance as sensitive indicators of deterioration.

Most current telemonitoring systems use simple thresholds as the basis for triggering an alert (e.g., by a nurse inspecting the data) and there is little automated analysis of data. Some informants expressed the view that medico-legal issues were a significant concern: who takes responsibility (e.g., patient, carer, case manager, community nurse, GP, consultant or a commercial provider) for the accuracy of the detection system and for taking the correct clinical response is a key question. Informants suggested the development of protocols with hierarchies of responses and responders related to the severity of the alert.

4.3. Focus groups interviews (patients and carers)
Sixteen patients and seven carers attended focus group discussions. Patients with COPD were sceptical about using sensors – concerned that, from their perspective, the problem was not the identification of exacerbations but the lack of adequate responses by healthcare providers. In their view, early detection was not practical as they considered that exacerbations developed quickly (within hours). They expressed distrust of technology and lack of computer literacy as reasons for not using telemonitoring. Patients with HF also perceived deteriorations as rapid events without warning, but had higher levels of anxiety and were receptive to telemonitoring, especially as a means to contact health professionals when needed.

Patients and carers varied in their attitude to the benefits and feasibility of telemonitoring depending on their condition and their experience. There was a lack of awareness of the early warning signs of deterioration (prodromes), although carers were possibly more observant or objective than patients.

4.4. Strategic roadmapping
Twenty-four individuals with backgrounds in healthcare, technology development, health informatics, health policy and telehealth participated in a workshop held in May 2009 to undertake Multi-Path Mapping [32]. Working in groups, participants created four maps that we subsequently synthesised into one (Fig. 3). The component parts of the map (labelled 1–25) are explained below.

The MPM illustrates a vision for three generations of early detection telemonitoring systems. Firstly, there are proprietary and ad hoc systems (1), evolved largely from those available in the market today and based on collection of simple physiological data (e.g., pulse, blood pressure). Secondly, future multi-parameter condition-specific systems appear based on partially generic platforms (2) [57,58] using more versatile, durable and less obtrusive sensors (3). Thirdly, we foresee the emergence of more generic platforms (4) within 8–10 years, with applicability across a wider range of conditions and multiple morbidities (5) but requiring further research on specific and sensitive clinical indicator sets.

Technical interoperability (6) remains a challenge, although this is being addressed by industry efforts (e.g., Continua Health Alliance, Integrating the Healthcare Enterprise, and HL7). There was an agreed need for further research to enhance adaptiveness in such systems (7 and 8) and to
consider whether early detection might be more dependent on heuristic approaches (such as context-aware detection of changes in weight and walking speed performance) rather than on task-dependent data collection (9). There was consensus on the need for further research in the domains of knowledge representation (10), machine learning of variations in a patient’s ‘normal’ status (11), and data analysis methods (12). For clarity, Fig. 3 only illustrates selected technologies.

The MPM depicts non-technological barriers to adoption by the healthcare service (13–21). Some of these are being addressed by, for example, the UK’s Whole System Demonstrator trials [59] but many key questions remain unaddressed. Large organisations like the UK’s NHS find it hard to adapt to new ways of working demanded by the availability of new technologies (14). Barriers include uncertainty about the response protocols (13 and 16), payment systems (18) and prescribing protocols (17). There is a fundamental lack of clarity regarding the location of decision-making responsibility when the service is spread across multiple providers (13 and 19–21). This issue has not been addressed in work to date and may require changes in how services are designed and managed, impacting existing medico-legal frameworks (15). The usability of monitoring devices and sensors (especially for individuals with reduced mobility and/or cognitive impairment) (23) is a significant problem.

For simplicity, only three groups of paths (24–26) are illustrated in Fig. 3, but these are by no means the only possible pathways. In particular, we see paths of co-design (27), where multiple stakeholders engage in iterative creative interactions as an essential step in innovating technologies that are better fit to purpose and to the eventual creation of generic platforms (26) [60–63].

5. Structuring a research agenda

From early in the study, information provided by the interview informants clearly revealed four key questions around telemonitoring: (i) When is it appropriate to use telemonitoring? (ii) What should you monitor and look for? (iii) How do you find it? and (iv) When you have found it what do you do next?

The MPM highlights, in the lower left quadrant, issues relating to detection (ii) and (iii) and in the upper central area issues relating to service provisioning and delivery (i) and (iv). Thus, in order for telemonitoring technologies for early detection to become embedded in practice, it seems necessary to specify two interrelated areas of interaction: the detection model and the service model. We describe the detection model as being about “knowing what to monitor and what to look for” and “Knowing how to look for it”.

There is a critical lack of understanding about the key issue for early detection: can we determine a combination of changes in agreed variables that detects what is abnormal for a particular patient in order to provide a predictive alert? In HF, patients repeatedly deteriorate (decompensate) and require urgent treatment. Monitoring weight gain (fluid retention) is the most commonly accepted detection parameter but recent research [64] has confirmed that it is not a sufficiently sensitive early indicator of impending decompensation. In COPD, the aim is to empower patients themselves to intervene in order to ameliorate exacerbations by, for example, calling for assessment, or self-managing by taking oral steroids or antibiotics. In both HF and COPD there is evidence from our interviews that existing monitoring approaches lack specificity and that insufficient consideration has been given to whether patients and their carers are willing and able to use the proposed technologies.

“Knowing how to look for it” is concerned with both emerging sensor technologies and issues of data quality, analysis and fusion. Although sophisticated approaches are emerging [65,66], most existing telemonitoring systems use simple thresholds for individual parameters that are barely adequate as the basis for reliable triggering. Recent developments in computer science research [67,68] make it easier to create flexible and extensible systems for data collection, processing, and visualisation. Diverse inputs from aerospace research [69,70]; research on pattern-matching [71]; and the representation of human expertise [72–75] suggest new approaches to the problem. Social science research contributes by eliciting patient, carer and response services’ narratives and formulating a more holistic view of an early detection model [76,77]. Thus, specifying the detection model is not purely a technical issue: it is also a social and organisational problem in which different kinds of knowledge and experience need to be combined and weighted in order to meet the needs of both clinicians and patients.

Looking now at the question of what constitutes a receptive service model [78,79], we see this as a pair of challenges, again with social and technical components: “Knowing when to use early detection monitoring” and “Knowing how to respond”.

The first of these requires new prescribing protocols. Telemonitoring is not suitable for all individuals nor is it appropriate under all medical circumstances. Knowing the aim of the intervention in relation to a specific patient (e.g., to reduce hospitalisations) is a key success factor. What is the model of provisioning, training and instigation? Are there barriers and obstacles to monitoring that vary across different patient groups by disease, age, gender, ethnicity, level of education, socio-economic status, etc.?

“Knowing how to respond” gives rise to two areas of inquiry. Firstly, there is a need to define and operationalise a response protocol. Who responds to a signal indicating that a patient has crossed the threshold from normal to abnormal and how do they mobilise action? Responses will need to be graduated to the degree of severity of the alerts. Does the protocol rely on initial feedback to the patient or to a call centre? Will this kind of response model, when scaled up to cover large populations, remain cost-effective?

Underpinning these unresolved issues is a concern about who is accountable for action or liable for the risk of taking no action, i.e. considerations of clinical and legal accountabilities [80].

The technical and organisational elements of new systems of practice mutually shape each other. Recent work in medical sociology has emphasised the ways in which assumptions about the identity and behaviour of professional [81] and patient [82] users are embedded in telemedicine and related systems [83–85]. Such assumptions are often hidden from people using the system and are revealed by the
breakdown in practice that occurs when such systems are deployed [76,86–88].

Appendix 3 lists research topics for early detection under each of the themes described above.

6. Discussion

6.1. Principal findings

The research agenda for early detection is less about sensors and technological advances and more about the translational problems associated with transitioning from basic research to routine practice [37] (Fig. 4). Our results confirm that there are problems both in putting prototypes to work in the setting of first use (‘first gap in translation’), and also in moving beyond efficacy in ideal settings to widespread implementation in routine practice (‘second gap in translation’).

The applied nature of informatics-based work means that users (patients and clinicians) play a more influential role and at much earlier stages than for, say, pharmaceutical interventions. An early detection system requires identifying indicators that clinicians trust and that draw on data that patients are able and willing to provide. Embedding an early detection model into a service model means recognising that new information leads to new responsibilities and accountabilities, with consequences for health professionals, managers and patients. The same actors are implicated in both activities but we do not see evidence of conjoined consideration of the second gap when attempting to bridge the first gap.

6.2. Strengths and weaknesses

The engagement of an inter-disciplinary team spanning medicine, healthcare, informatics, computer science, sociology and engineering to conduct the reported work has avoided the tendency to view the field chiefly from the perspective of creating new technologies. Mixed methods (literature reviews, patients groups and key informants (for both interviews and roadmapping)) have acted to reinforce each other through verification and cross-checking. For our roadmapping, we employed Multi-Path Mapping as it is specifically designed for areas of emerging technology characterised by uncertainty [32].

Our study was restricted to three exemplar conditions (COPD, HF and diabetes). We observed differences between all three conditions; specific combinations of clinical indicators for the early detection of deterioration will be required in each. Other chronic diseases and combination of morbidities will also require detailed specification.

Our qualitative work has been limited to participants from the UK. However, none of the items in our research agenda are UK-specific and each can be interpreted in consideration of particular national circumstances.

We would have benefited from being able to observe ongoing telemonitoring projects, such as the “Whole System Demonstrator” projects (Department of Health, UK), although we were able to include data from participants working in these studies.

6.3. Results in context

We observe that many of the future directions for research, suggested in Koch’s 2006 review [20] remain unfulfilled. It is significant that the leading edge of research in this area does not seem to have advanced significantly since then.

Parallel work to our own by Paré et al. [89] updating earlier work [3] analyses the clinical effects associated with telemonitoring and discusses the conditions for success of telemonitoring interventions. The results of that review bear out our own findings that there is evidence to support clinical effectiveness of telemonitoring but it is equivocal. This is because many studies have not considered telemonitoring as a complex intervention and have thus insufficiently isolated how individual factors of the intervention contribute to effectiveness. Paré et al. confirm our view that further work is needed. The authors, in identifying patient selection, choice of device and its usability, and characteristics of the telemonitoring programme and work organisation as critical success factors, have reached broadly similar conclusions to our own four key ‘knowing’ questions of telemonitoring use.

Comparing our findings with the UK Assisted-Living (AL) roadmap [23], we find that both studies specifically highlight the need for further technology developments: sensor enhancements, more integrative data processing, and improved interaction between users and systems. The AL roadmap foresees integration and interoperability of component systems and processes, leading to the emergence of a standards-based infrastructure of monitoring centres and response providers, similar to our “platform” proposition. Our results add to this by recognising the translational obstacles of putting technology to work. The AL roadmap recognises the need to re-organise health services to support delivery of new services, but provides no detail for how this should happen.

Fig. 4 – Translational gaps in health research.
Adapted from Chart 7.1: Pathway for Translation of Health Research into Healthcare Improvement, The Cooksey Report [37].
Our work has clarified that the key issues here revolve around the sociology: knowing when to use monitoring; determining, on receipt of an ‘alert’ who should respond and when; and knowing who is accountable for outcomes.

6.4. Implications

Nearly two decades of effort to improve the care of chronic diseases with the use of ICT has failed to deliver systems that are both embedded in routine clinical practice and delivering significant benefit. Repeated attempts to implement technologies have paid insufficient attention to the clinical indicators of deteriorations, and to understanding the complex dynamics and accountabilities that arise at the service model level when interventions are delivered in response to alerts. Our study has shown that the future research agenda is not only technological but also clinical, social and translational and that these challenges must be addressed in an interdisciplinary manner.

We are convinced that the future lies with approaches that are both more generic in the technology sense and more sociologically informed than those currently available. One can see this as a move towards a platform-oriented approach, in which a technology exists as a basis around which third parties can build a range of capabilities and services [90,91]. We believe a breakthrough is possible in this area by using collaborative co-design processes [63,92,93] involving relevant stakeholders (clinicians, patients, carers, service providers and industry) from the start. Such a breakthrough would address the key issue of properly embedding the fundamental technologies for early detection into widespread use.

Authors’ contributions

The study was conceived and designed by Hardisty, Gray and Elwyn with assistance from Conley and Rana. Acquisition of data was undertaken principally by Hardisty and Peirce. All authors participated in the workshop to create the Multi-Path Map. Analysis and interpretation of data were undertaken by Hardisty, Peirce, Elwyn and Preece with assistance from all other authors. Drafting the paper was carried out by Hardisty with principal assistance from Peirce, Elwyn, and Preece. All other authors contributed to and/or critically reviewed the manuscript. All authors gave their final approval to it.

Conflict of interest statement

All authors declare that they have no personal and/or financial interests related to the subject matters discussed in the manuscript.

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Appendix A. Supplementary data


REFERENCES


[25] L. Catwell, A. Sheikh, Information technology (IT) system users must be allowed to decide on the future direction of major national IT initiatives. But the task of redistributing power equally amongst stakeholders will not be an easy one, Inform. Prim. Care 17 (1) (2009) 1–4.


neuroinformatics project, Neural Netw. 21 (October (8)) (2008) 1076–1084.


