E-health stakeholder consultation and policy context review

Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO) Programme of Research on E-health

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Contents

Appendices (separate documents)

Executive Summary

Background

The use of information and communication technology (ICT) may radically affect health services organisation and health. We aimed to assess the scope of e-health and to construct a research agenda. For the purposes of this study e-health meant the health services organisation and societal approach to health and health services which result from the introduction of, and increasing access to, new digital technologies, including the Internet, other computerised networks and tele- or distant health care assisted by new technologies. The critical phrase in this definition is the health services organisation and societal approach. For example, research into how computers might analyse ECGs was not within the scope of the study but the impact of being able to do such investigations remotely or at home was.

Aim

To explore the concerns of professional and lay stakeholders and to review relevant policy to produce recommendations for future e-health research.

Method

Stakeholders' views were sought in a two-stage process. First, 37 professionals representing 12 groups were contacted in telephone focus groups, telephone interviews, videoconference focus groups or face-to-face interviews. Discussion was prompted by e-health 'scenarios' and analysed using thematic content analysis. Second, 17 lay participants, in three face-to-face and videoconference focus groups, discussed and prioritised the themes arising from stage one.

A parallel, two-stage process was used to review the policy context. First, 26 policy-makers were interviewed and 95 policy documents were identified and reviewed. The contents of documents and interview notes were categorised under (a) English policies on ICT specific to health, (b) English health policies that may drive or constrain e-health, (c) non-health policies that may drive or constrain e-health and (d) EU policies which may drive or constrain e-health. Issues arising from the first stage were reviewed first in a conference workshop by 60 participants and second by further discussion among the research team.

Lastly, the themes and research questions arising from the stakeholder consultation and policy context review were compared and recommendations from policy context were adapted to take more account of stakeholder concerns. Two diagrams were developed to bring together stakeholder and policy-maker views of the required range of e-health research. A website to disseminate the findings and to invite further discussion has been set up.

Results

Stakeholders identified 15 areas of research at three levels, giving highest priority to whether use of information technology (IT) improved health and was cost-beneficial. Issues of responsibility, reliability, regulation, accessibility, confidentiality, security and ownership of information were next most important. Lastly, they identified the need for research into the processes that support effective e-health, namely professional training, patient training, patient control, integration of data, presentation of information, push and pull of information, location of information, patient expectations and choice, and using patient knowledge.

Recommendations from the policy context review were made for research in five areas, namely decision support, identification of best practice and barriers to implementation, sharing data and cross-sector working, involving the public, and multi-site working. A conceptual map was developed and a merged list of research recommendations made using six headings.

Research recommendations

Improved health and quality of life

While it may be an unstated assumption of policy documents, the overriding concern of stakeholders was that spending money on e-health should be worthwhile and should lead to improved health and quality of life.

1.1 To review the costs and benefits of a range of recent e-health applications, including the modelling of new forms of care made possible by ICT support.

1.2 To present those examples of e-health applications shown to have a demonstrable effect on improved health and quality of life to professional and public stakeholders to obtain their views as to the nature of the most appropriate investment in e-health.

Using information

Information is used either to make a decision, for operational purposes in organising services, or for reassurance (for either a professional or for patients or their families).

2.1 To explore attitudes of clinicians and their patients among those clinicians who do and those who do not use decision-support tools. In particular, to examine their perceptions of the benefits and barriers to use.

2.2 To assess the quality of information available from repositories of health data, how it can be legally, ethically and cost-effectively aggregated for public health policy and decision support.

2.3 To explore the costs and potential benefits of birth-to-death records to decision-making and other aspects of health care, and to identify policy changes required to achieve them.

2.4 To review decision support and expert systems used in the NHS to ascertain their impact on patient services.

Sharing information

This was a major concern in particular for research arising from the policy context review, relating to how information should be shared across site, across sector or professional groups, or with patients.

3.1 To examine how the NHS can work with other information and education providers to facilitate patient involvement in e-health.

3.2 To explore patient attitudes towards initiatives to exploring patient involvement in e-health.

3.3 To identify the extent to which implanted or wearable technology removes the patient’s own control of their condition and to identify how ICT may best be used to encourage and facilitate patients to take responsibility for their health.

3.4 To investigate the extent to which recently introduced IT-based systems (such as e-booking) escalate patient expectations and consequently decrease satisfaction if those expectations are not met.

3.5 To investigate the efficacy of developing a code of collaboration under which organisations can explicitly share data and input to health records consistently, unambiguously and sensitively.

3.6 To determine how we can best deal with combining multiple sources of data, dealing with apparently conflicting information from different sources, with minimum patient risk, minimum cost, and patient consent and confidence.

3.7 To examine the costs and benefits of cross-sectoral records and patient safety issues associated with cross-sectoral working.

3.8 To investigate how ICT can best contribute to pharmacy clinic services sharing data with the NHS and patient.

3.9 To investigate the potential of e-health to enable effective interfaces, for example between health and social care, local specialists and specialist services, carers and professionals.

3.10 To investigate the costs and benefits of using different technologies to support community-based staff (for example notepad computers, electronic links to supporting organisations, teleconferencing in cancer services).

3.11 To explore the changes in work patterns, potential for patient involvement and legal issues in home care (for example, for older people).

3.12 To investigate ICT use in multi-site working in relation to such issues as culture change, governance, health professional training, patient expectations and changes to health outcomes.

3.13 To determine the costs and benefits of the use of health data cards.

Controlling information

Research into the reliability of information, if or how it should be regulated, how it can be accessible while maintaining security and confidentiality, and who is the responsible owner of information, particularly if there is considerable sharing.

4.1 To investigate how health professionals and patients discriminate between reliable and unreliable information.

4.2 To examine the circumstances in which regulation of information provision and use is necessary and further when education and empowerment of professionals is a more effective option. Additionally, what are health professional and patient attitudes towards the regulation of health information?

4.3 To investigate the extent to which health professionals advise patients as to reliable sources of information on the Internet, television and other media. Further, to examine the level of preparation and support health professionals require to provide such advice, and, additionally, patients' expectations of this advice.

4.4 To determine the subject of responsibility if health-care errors are made as a result of information transfer.

4.5 To explore how social organisation and different technologies can be used to help prevent inequity of access to information for both patients and professionals. Further, to identify initiatives where groups traditionally considered to have restricted access have successfully achieved training and access to new technologies.

4.6 To explore health professional and patient attitudes towards ownership and sharing of data.

4.7 To develop and test guidance on regulation and responsibility.

4.8 To examine the costs and benefits of different ways of addressing equity to inform citizens.

4.9 To investigate ways (quality marks, portals, patient and health professional training) to assist the public in obtaining quality information from the Internet.

4.10 To investigate patients' knowledge and views on confidentiality and their attitudes as to how their data should be used in terms of potential benefits to health and quality of life (for example in research).

Processing information

The way information is presented, tailored and filtered, or where it is presented (that is, should it be 'pushed' to the user or should it wait until the user 'pulls' it?, and should it be in hospital or the home?), can be described as processing information.

5.1 To what extent should health information be tailored to the needs of certain groups of patients and professionals, or further individualised?

5.2 To examine the costs and benefits of providing information in different locations (for example, mobile versus static for professionals; NHS versus home for patients).

5.3 To investigate how information can be better integrated so that patients can, for example, access their own medical record on the Internet, obtain relevant and validated information about it and order a prescription.

5.4 To identify instances or circumstances when patients want to enquire via known professionals and when from an anonymous source.

5.5 To investigate what services patients desire for electronic ordering and home delivery of medicine and how they can be delivered safely, equitably and cost-effectively.

5.6 To identify how e-health technologies can enable or improve family support for seriously ill children and provide just-in-time information tailored to individuals.

5.7 To examine the costs, benefits and attitudes towards and the use of ICT support for patients with severe chronic disease in their homes, such as video links to NHS and voluntary services, smart cards with patient records, etc.

Principles of research and development

A number of recommendations illustrated the general principles which should underpin any research and development in e-health, namely that as well as innovating in new forms of service delivery and organisation we should first identify best practice and the barriers to implementation, and that stakeholders (both professional and public) should be involved in research and development. Some of the areas to be reviewed are listed below.

6.1 Informatics training for health professionals, and to identify and explore examples of best practice to see how these can be disseminated to achieve improved health care. Further, to explore the attitudes of health professionals towards such training and use of the skills acquired in practice.

6.2 Working practices in other sectors (such as e-business) to identify best practice and barriers to similar uses of ICT in the health sector.

6.3 Web-based services for citizens in other sectors to see what lessons can be learnt on when to implement e-health solutions for patients.

6.4 Research on telemedicine (for example using coronary heart disease or cancer services) and barriers to its implementation.

6.5 The costs and benefits (including improved patient safety) of hospital systems that combine e-prescribing, order entry, decision support, bar-coding for medication management and robotic dispensing.

6.6 NHS procedures that aim to safeguard confidentiality of patient data and disseminate best practice.

6.7 The experience of UK citizens accessing health care in other countries (and vice versa), and to identify where health and other outcomes could be improved through the use of ICT.

The Report

Section 1 Aims

The aim of this study was to explore the concerns of professional and lay stakeholders in e-health, and to review the policy context for e-health to produce recommendations for e-health research. For the purposes of this study e-health meant the health services organisation and societal approach to health and health services which result from the introduction of, and increasing access to, new digital technologies, including the Internet, other computerised networks and tele- or distant health care assisted by new technologies. The critical phrase in this definition is the health services organisation and societal approach. For example, research into how computers might analyse ECGs was not within the scope of the study but the impact of being able to do such investigations remotely or at home was.

Section 2 Method

2.1 Research team and project management

The overall project was led by RJ, Professor of Health Informatics. There were two sub-projects. The *stakeholder consultation team* included an NHS health informatics lead (NG), a Professor of Epidemiology (MT), a Professor of Primary Care (JC), two academic nurses (GW and CH), a research fellow with experience of qualitative research (LC) and a research assistant (LL). The *policy context team* comprised two independent contractors (RR and JR) and a Professor of Nursing Informatics (GW), all of whom have extensive experience and contacts – both in the UK and internationally – in e-health and have been involved previously in similar scoping exercises.

The £80 000 funding was divided equally between the stakeholder consultation and policy context review. The stakeholder consultation was carried out by the University of Plymouth. Funding paid for:

- the marginal costs plus university overheads for a research fellow (LC; from mid-November 2004 to the end of August 2005) and a half-time research assistant (LL; for the same period);
- consumables and services, in particular telephone conference fees (to BT), and travel.

Time spent by the grant holders was not a cost to the project but was subsidised by the host institutions. The policy context review was carried out by two of the grant holders (RR and JR), who are independent contractors acting through the Centre for Health

Informatics Research and Development. The grant paid their fees and expenses and input from GW.

2.2 Overall design

The stakeholder consultation and policy context review proceeded in parallel (see Figure 1), coming together to review findings and develop a conceptual map. Discussion about the overall method took place between principal investigators of this project (EH2) and the parallel systematic review (EH1) – RJ and Claudia Pagliari – at the start. During the project we communicated about those people being contacted for expert review. For reasons internal to EH1 a further face-to-face meeting was cancelled. Due to time pressures on both projects this has not been rescheduled but it is our intention to review results from both projects in the near future.

2.3 Stakeholder consultation

2.3.1 Design

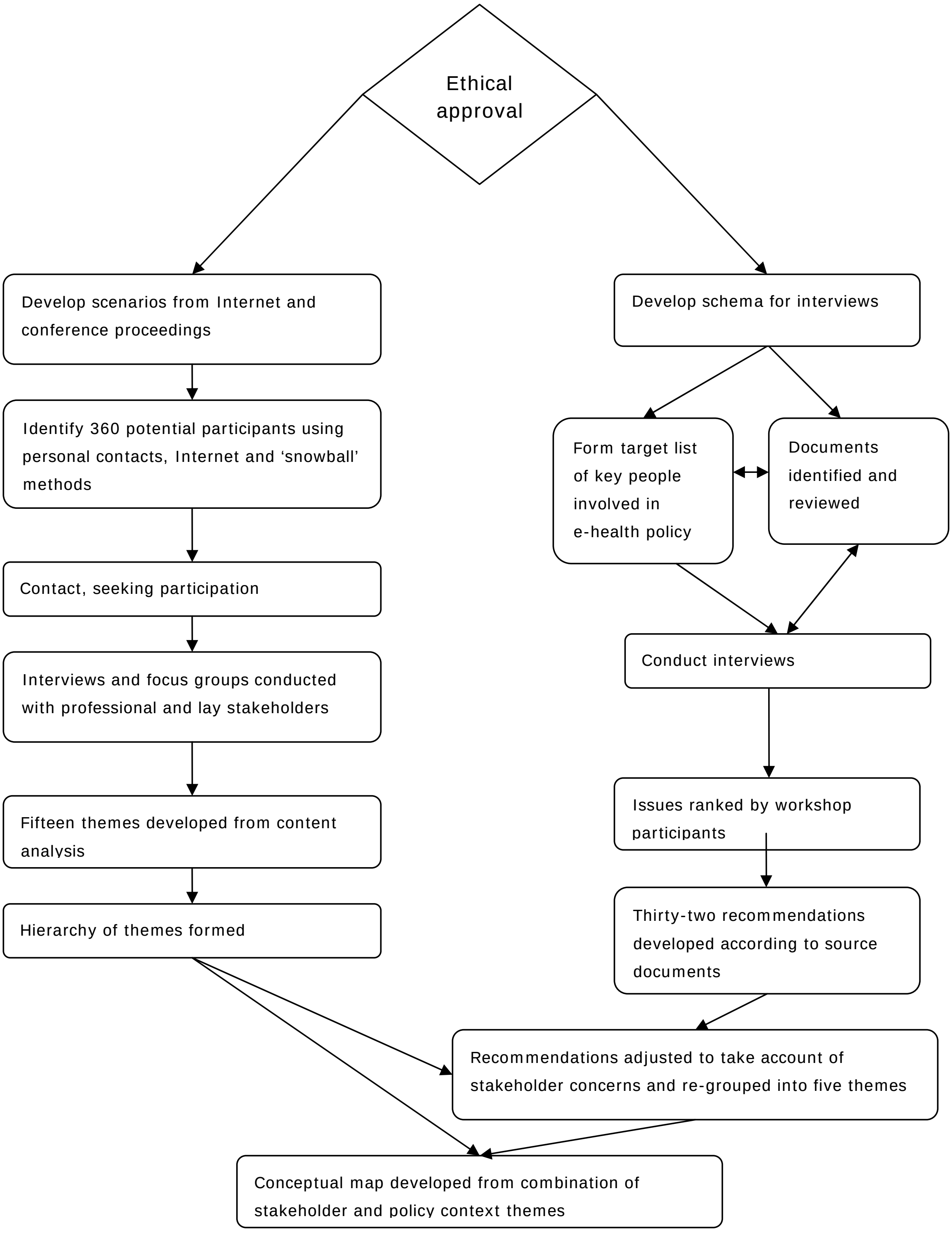
The study was reviewed and contacts with NHS staff were approved by the south-west Multi-centre Research Ethics Committee. Consultation with lay stakeholders was reviewed and approved by the University of Plymouth Faculty of Health and Social Work Ethics Committee. Stakeholders' views were sought in a two-stage process. First, 12 groups of health professionals were contacted and views sought. Second, the views of lay people were sought on the themes arising from the professional stakeholder consultation. Full details of the stakeholder consultation are given in Appendix 1.

2.3.2 Recruitment

Twelve groups of professional stakeholders were contacted via e-mail. Potential participants were identified by Internet searches and by 'snowballing' from existing contacts. 360 (30 in each group) were sent an e-mail inviting them to take part in the study, with a consent form to return to the researcher via e-mail, or post if they agreed to take part in the study. Thirty-seven (10%) professional stakeholders consented to take part in the study and were consulted either via telephone focus group (25), telephone interview (six), videoconference (four) or face-to-face interview (two). The groups contacted were:

1 NHS e-health innovators and implementers;
2 academic researchers in e-health;
3 NHS staff in primary care;
4 NHS staff in secondary care;
5 NHS primary care trust managerial staff;
6 NHS acute trust managerial staff;

Figure 1 Parallel methods of stakeholder consultation and policy review



7 suppliers;
8 professional organisations and royal colleges;
9 informatics trainers;
10 governance and other regulators;
11 charities and other providers;
12 other NHS managers.

In addition, two groups of lay participants (older people and parents of young children) were recruited using snowballing techniques. Two groups of older people (consisting of eight and four participants respectively) and one group of parents (consisting of five participants) took part in the study. Potential participants were sent study information sheets and consent forms either via e-mail or by post (see Appendix 1, Annex 1).

2.3.3 Prompts for discussion

Scenarios depicting the current or future use of e-health technologies were constructed to prompt discussion among the professional groups of relevant themes regarding the use of e-health technologies. The subject matter of the scenarios was driven by news reports, informatics conference proceedings and general Internet searches. Both patient- and professional-centred scenarios were developed in order to achieve a balance of perspectives. A pool of 32 scenarios were constructed and discussed among the research team. Fifteen scenarios were omitted, seven were added and the remainder of the scenarios were reworded as a result of this discussion. Four of the 24 scenarios were allocated to each of the 12 professional groups using a balanced incomplete block design (Armitage and Berry, 1987; each scenario was therefore used twice). A semi-structured interview schedule incorporating the scenarios was constructed.

Lay participants were provided with a synopsis of each of the themes to have emerged from the professional stakeholder consultation in order to stimulate discussion. A semi-structured interview schedule was constructed around these themes which encouraged participants to discuss the themes and make judgements regarding those themes that were or were not important to them.

2.3.4 Procedure for professional groups

On consenting to take part in the study, professional stakeholders were sent a choice of dates and times to take part in a telephone focus group. If groups were unable to agree to a time that was convenient to all, individual telephone interviews were carried out. Upon the focus group or interview time being agreed, a telephone conference was booked and participants were sent the telephone number, security access code and the scenarios that were to be discussed during the interview. Prior to carrying out the first professional stakeholder interview, a pilot interview with five professionals was conducted in order to test the procedures and materials to be used. All participants successfully accessed the focus group, and the tape recording of the discussion was of good quality. However, some aspects of the schedule and the conduct of the focus group were changed for the future in order to aid discussion between the participants.

2.3.5 Analysis

Transcripts of the focus group and interview discussions were audio recorded, transcribed verbatim and analysed using thematic content analysis. A copy of the first transcript was scrutinised by three researchers to ensure reliability of analysis. Analysis revealed 15 themes relating to areas of concern to stakeholders regarding the future use and direction of research in e-health.

2.3.6 Procedure for lay groups

Lay groups were recruited using snowballing techniques and were contacted regarding participation via e-mail or telephone. Two groups of older people met in Plymouth and Surrey. Both groups completed a face-to-face focus group discussion with the aid of a facilitator. On completion of this discussion, the groups were linked via videoconferencing to continue the discussion. A convenience sample of parents recruited from a local nursery met in Plymouth and participated in a face-to-face focus group discussion. Focus groups and videoconference were audio recorded, transcribed and analysed using thematic content analysis.

2.4 Policy context review

Policy context was reviewed by contacting key policy-makers and identifying and reviewing policy documents. A workshop was held to validate draft findings. Full details of this review can be found in Appendix 2.

2.4.1 Interviews

A target list of key people involved with e-health policy was drawn up from personal knowledge of the research team and by reference to policy documents. Individuals were contacted for either face-to-face or telephone interview, or (where preferred by potential participants) e-mail correspondence. An interview schedule was developed to guide the interviews or e-mail correspondence. The notes from interviews were drafted and sent back to the interviewees for review, amendment and confirmation.

2.4.2 Document review

Key documents, identified by interview, research or market knowledge, were processed, synthesised and their e-health impact documented. Draft recommendations were derived from the material evaluated and the resulting items on the list of e-health issues were prioritised by the research team.

2.4.3 Workshop

The top issues from the document review, ranked by their potential effects on service delivery, were used to frame a workshop at the national Healthcare Computing 2004 conference (Harrogate, March 2004). The workshop participants ($n=60$) used a blind voting system to identify the areas that were felt to be most crucial to the support and enhancement of health or care delivery. The workshop resulted in refinement of, and additions to, the recommendations arising from the interviews and document review.

2.4.4 Review and adaptation of recommendations

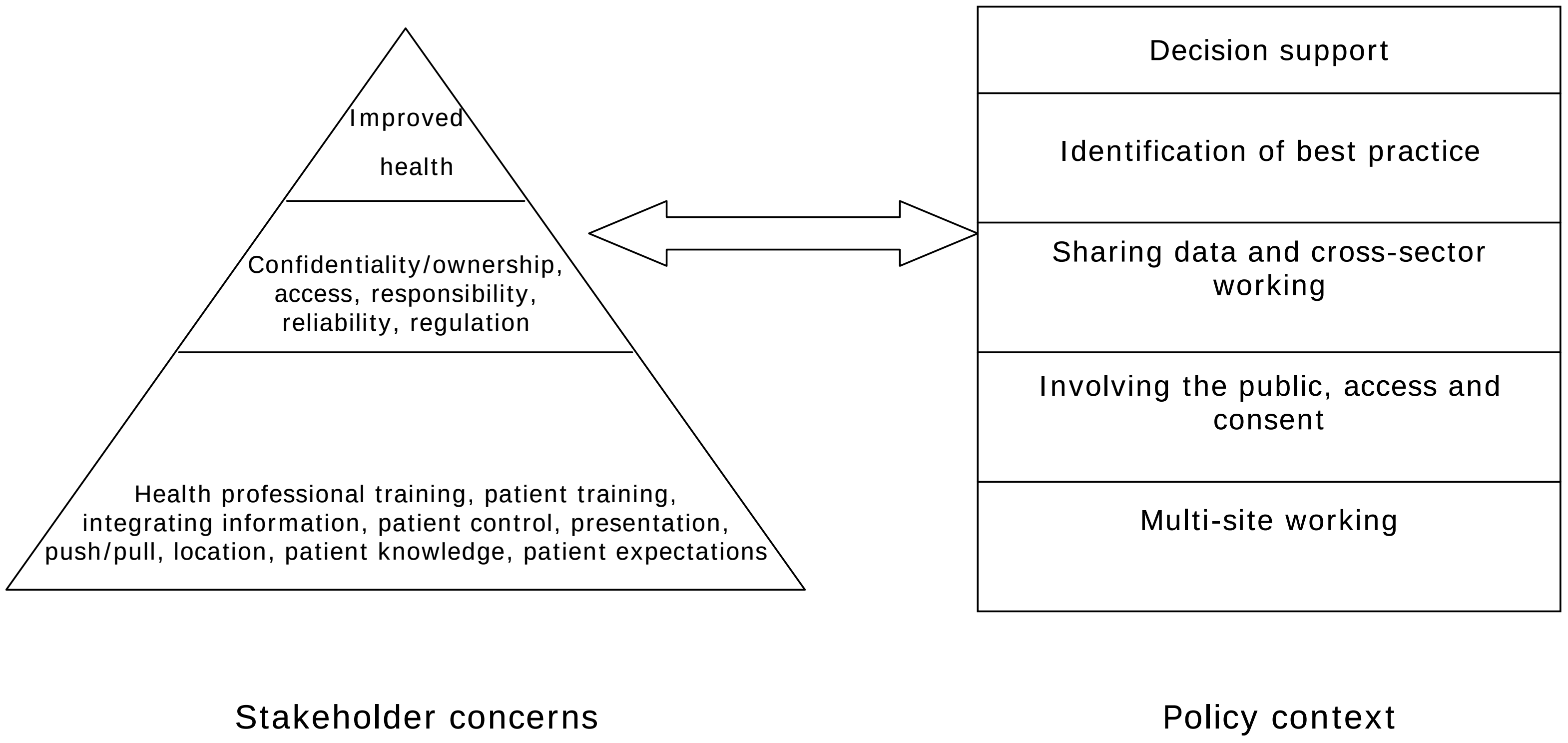
Recommendations from the policy context review were compared with the concerns raised by stakeholders. Two members of the research team (RJ and LC) independently ranked the correspondence between the stakeholder concerns and the policy context recommendations on a scale of 1 (no correspondence) to 3 (strong correspondence). Analysis showed there to be strong agreement between the researchers. Stakeholder concerns and particularly that of 'technology meeting needs and improving health and quality of life' were not addressed consistently by the policy context recommendations. The recommendations were adapted to take these stakeholder concerns into account.

Policy context recommendations were also re-grouped from 'source-oriented' to five 'research-oriented' groupings (see Figure 2) following e-mail and telephone conference discussion between members of the research team.

2.5 Synthesis and conceptual mapping

The two lists, one from stakeholder consultation and the other from the policy context review, were then again reviewed and similar areas of research grouped. Reference was also made to the work of the Scottish Consumer Health Informatics Network (see http://www.gla.ac.uk:443/departments/dph/chins-index.html and Marsden and Jones, 2004). We concluded that the scope of e-health research could be described by a simple block diagram with six elements. The recommendations were regrouped according to this 'conceptual map'.

Figure 2 Research areas identified from stakeholder concerns and policy context review



Section 3 Results

3.1 Stakeholder consultation

Full details of the stakeholder consultation are given in Appendix 1.

3.1.1 Professional stakeholder participants

Recruitment of participants for the professional stakeholder groups was problematic, with only 37 participants recruited. A number of potential participants stated that they would agree to participate only if reimbursed for their time, and several individuals who consented to take part in the study either did not return further e-mails regarding the arrangement of interviews or did not ‘attend’ the telephone focus groups or interviews as arranged. However, all stakeholder groups were represented by between one and five members.

3.1.2 Professional stakeholder themes

Fifteen themes emerged from the analysis (one at the top level, five at the middle level and nine at the bottom level; see the left-hand side of Figure 2). Despite the disappointing recruitment rate, saturation of data was achieved after completion of seven focus groups. However, although further interviews and focus groups revealed no new themes, it was decided to continue data collection to allow representation of all of the professional groups in the consultation.

3.1.3 Lay stakeholder consultation results

Lay participants believed that ‘improving health and quality of life’ was the most important theme raised by the professional groups. The themes ‘accessibility’, ‘regulation’, ‘responsibility’ and ‘reliability of information’, ‘confidentiality’ and ‘ownership’ were perceived as integral to enabling technology to improve health, thus introducing the idea of a hierarchy of themes. Improving health is at the top of the hierarchy, supported by accessibility, regulation, responsibility, reliability of information, confidentiality and ownership. These in turn are supported by the remaining themes.

3.1.4 Stakeholder recommendations

Stakeholder recommendations were developed from the 15 themes to emerge from the analysis of the professional stakeholder consultation (see Table 1). These recommendations are presented within the hierarchy indicated by the discussions with lay stakeholders.

Table 1 Stakeholder recommendations

Themes by hierarchy level	**Stakeholder recommendations**
Level 1 Technology meeting needs and improving health and quality of life	To review the costs and benefits of a range of recent e-health applications, including the modelling of new forms of care made possible by information and communication technology (ICT) support. Further, to present those examples of e-health applications shown to have a demonstrable effect on improved health and quality of life to professional and public stakeholders to obtain their views as to the nature of the most appropriate investment in e-health.
Level 2 Reliability Regulation Accessibility Confidentiality, security, ownership Responsibility	To investigate how health professionals and patients discriminate between reliable and unreliable health-related information. To examine the circumstances in which regulation of information provision and use is necessary and further when education and empowerment of professionals or patients is a more effective option. Additionally, what are health professional and patient attitudes towards the regulation of health information? To investigate the extent to which health professionals advise patients as to reliable sources of information on the Internet, television and other media. Further, to examine the level of preparation and support health professionals require to provide such advice and, additionally, patients' expectations of this advice. To determine the subject of responsibility if health-care errors are made as a result of information transfer. To explore how social organisation and different technologies can be used to help prevent inequity of access to information for both patients and professionals. Further, to identify initiatives where groups traditionally considered to have restricted access have successfully achieved training and access to new technologies. To explore health professional and patient attitudes towards ownership and sharing of data.
Level 3 Processes that support effective uses of e-health	To identify and explore examples of effective informatics training for health professionals, and how these can be disseminated to achieve improved health care. Further, to explore the attitudes of health professionals towards such training and use of the skills acquired in practice. To examine how the NHS can work with other information and education providers to facilitate patient involvement in e-health. Further, to explore patient attitudes towards initiatives to support patient involvement in e-health. To investigate how information can be better integrated so that patients can, for example, access their own medical record on the Internet, obtain relevant and validated information about it and order a prescription. To what extent does implanted or wearable technology remove the patient's own control of the condition? Further, how can ICT best be used to encourage and facilitate patients to take responsibility for their health?

	To what extent should health information be tailored to the needs of certain groups of patients and professionals or, further, individualised?
	To identify instances/circumstances when patients want to enquire via known professionals and when from an anonymous source.
	To examine the costs and benefits of providing information in different locations (e.g. mobile versus static for professionals; NHS versus home for patients).
	To explore how the use of patient (e-)power for both patients and professionals should best be assessed.
	To investigate the extent to which recently introduced information technology (IT)-based services (such as e-booking) escalate patient expectations and consequently decrease satisfaction.

3.2 Policy context review

Policies did not always appear comprehensive or consistent. There was no consistent definition of e-health between documents. Although there appeared to be willingness and commitment in principle to capitalise on information and communication technology (ICT) to support health and the emerging social-care domain, more synergistic planning was needed. Many health policy documents referred to the potential of ICT to enable policy realisation and proposed initiatives, but cross co-ordination between such ICT initiatives was not usually evident. Table 2 shows the recommendations derived in the five areas of the policy context review (full details of which are given in Appendix 2).

Table 2 Policy context recommendations after regrouping

Grouping	Recommendations
Decision support	To explore attitudes of clinicians and their patients among those clinicians who do and those who do not use decision-support tools. In particular, to examine their perceptions of benefits and barriers to use.
	To assess the quality of information available from repositories of health data, how data can be legally, ethically and cost-effectively aggregated for public health policy and decision support.
	Via pilot studies, to explore the potential benefits of birth-to-death records to decision-making and other aspects of health care, what policy changes would be required to achieve them and the costs of such records.
	To review decision support/expert systems used in the NHS to ascertain their impact on patient services.
Identification of best practice and barriers to implementation	To investigate working practices in other sectors (such as e-business) to identify best practice and barriers to similar uses of ICT in the health sector.
	To review Internet-based services for citizens in other sectors to see what lessons can be learnt on when to implement e-health solutions for patients.

	To review research findings on telemedicine (e.g. using coronary heart disease or cancer services) and barriers to their implementation. To review research findings on e-health to identify initiatives that have had a demonstrable effect on improved health. To assess the costs and benefits (including improved patient safety) of hospital systems that combine e-prescribing, order entry, decision support, bar coding for medication management and robotic dispensing. To audit NHS procedures that aim to safeguard confidentiality of patient data.
Sharing data and cross-sector working	To investigate the efficacy of developing a *code of collaboration* under which organisations can explicitly share data and input to health records consistently, unambiguously and sensitively. To develop and test guidance on regulation and responsibility. To determine how we can best deal with combining multiple sources of data, dealing with apparently conflicting information from different sources, with minimum patient risk, minimum cost, patient consent and confidence. To examine the costs and benefits of cross-sectoral records and patient safety issues associated with cross-sectoral working. To investigate how ICT can best contribute to pharmacy clinic services sharing data with the NHS and patient. To investigate the potential of e-health to enable effective interfaces, for example between health and social care, local specialists and specialist services, carers and professionals.
Involving the public, access and consent	To examine the costs and benefits of different ways of addressing equity in informing citizens. To investigate ways (quality marks, portals, patient and health professional training) to assist the assist the public in obtaining quality information from the Internet. To investigate what services patients desire for electronic ordering and home delivery of medicine and how they can be delivered safely, equitably and cost-effectively. To investigate patients' knowledge and views on confidentiality and their attitudes as to how their data should be used in terms of potential benefits to health and quality of life (e.g. in research). To identify how e-health technologies can enable and improve family support for seriously ill children and provide just-in-time information tailored to individuals. To examine the costs, benefits and attitudes towards and use of ICT support for patients with severe and chronic disease in their homes, such as video links to NHS and voluntary services, and smart cards with patient records. To review the experience of UK citizens accessing health care in other countries (and vice versa), and to identify where health and other outcomes could be improved through the use of ICT.

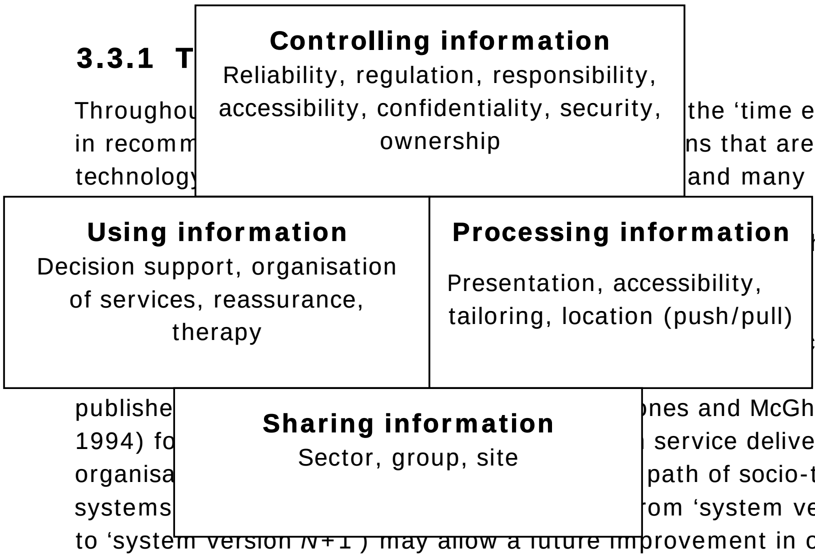
Multi-site working	To investigate the costs and benefits of using different technologies to support community-based staff (e.g. notepad computers, electronic links to supporting organisations, teleconferencing in cancer services). To explore the changes in work patterns, potential for patient involvement and legal issues in home care (e.g. for older people). To investigate the use of ICT use in multi-site working in relation to such issues as culture change, governance, health professional training, patient expectations and changes to health outcomes. To determine the costs and benefits of the use of health data cards.

3.3 Conceptual map of e-health research

Review, by the research team, of the recommendations from the stakeholder consultation and policy context review suggested that we could use the long-established method of describing the collection and use of health information to put e-health activities into four categories (see Figure 3).

- *Using information* Information is used in decision support and the organisation of services as well as for reassurance of professionals and patients, and in therapy (such as cognitive behavioural therapy). A number of research recommendations arising from the policy context review concerned use of information in decision support.
- *Sharing information* Both policy context review and stakeholders identified sharing information as having a large number of research questions including both how information should be shared across sites (including hospital to home), across sectors (for example, between social services and NHS) or between different professional (and patient) groups (for example, between doctors, nurses, dentists, patients).
- *Controlling information* This is the group of concerns ranked second by stakeholders. It is slightly ‘wider’ than control, incorporating issues of accessibility as well as reliability, confidentiality, security, ownership and regulation, but we have yet to find a better term.
- *Processing information* This covers a wide range of topics from how best to present information (should it be tailored?), to where to present it (should it be ‘pushed’ to the user, or should it wait until the user ‘pulls’ it?), to how best to integrate information from a variety of sources and what services are required (for example, in electronic ordering and home delivery of medicines).

Figure 3 Scope of e-health



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Througho the ‘time element’ in recomm ns that are heavily technolog and many of these hat have funding of eptual viously publishe nes and McGhee, 1994) fo service delivery and organisa path of socio-technical systems om ‘system version *N*’ to ‘system version *N*+1’) may allow a future improvement in outcome that cannot be currently measured but which can be modelled or predicted. Nevertheless, it maintains the emphasis given by stakeholders on the need for e-health to improve health and quality of life.

All research into this area should be underpinned by some obvious principles of research and development; that as well as innovating in new forms of service delivery and organisation we should first identify best practice and the barriers to implementation, and that stakeholders (both professional and public) should be involved in research and development.

Figure 4 E-health research

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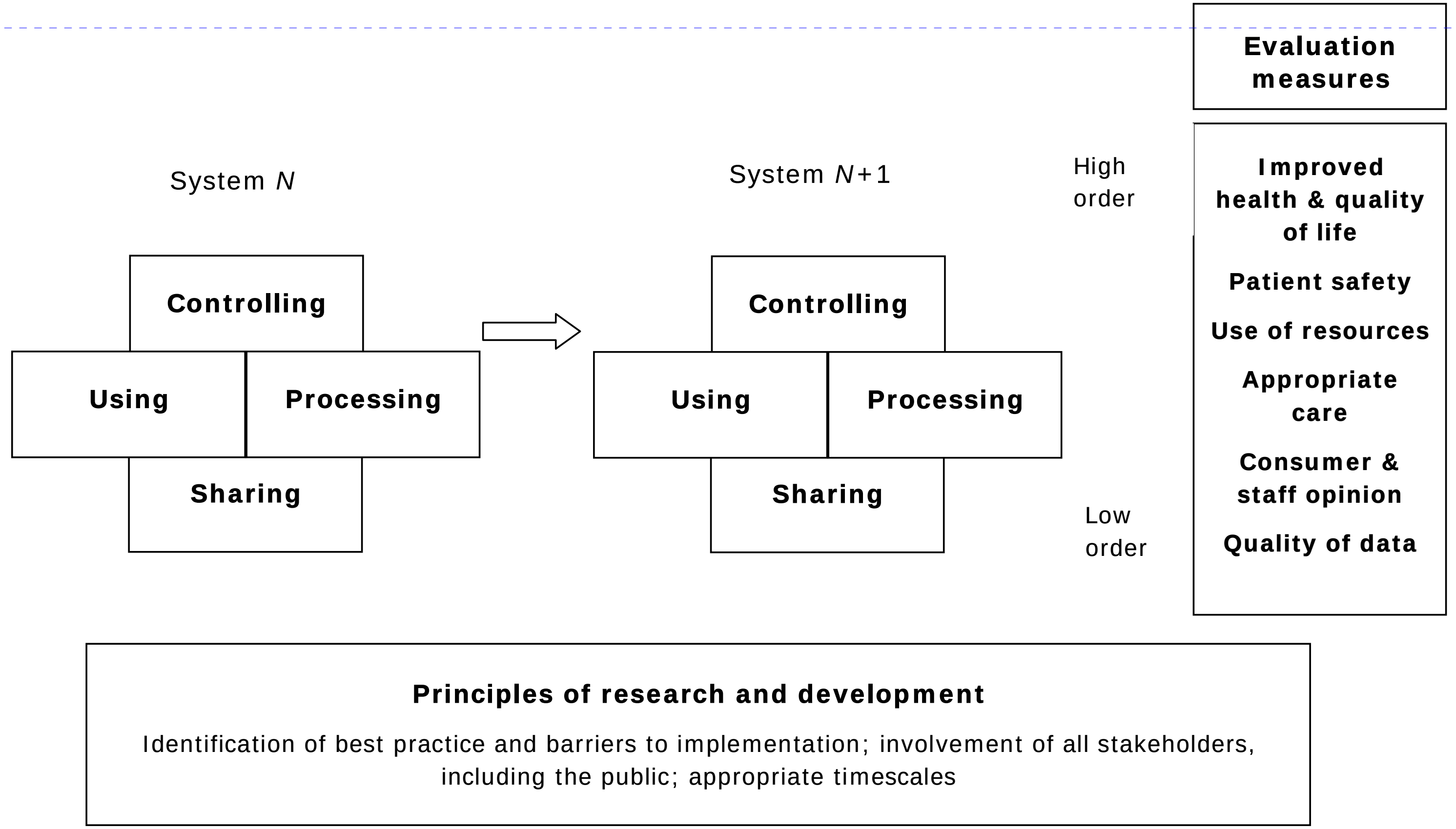

Identification of best practice and barriers to implementation; involvement of all stakeholders, including the public; appropriate timescales

3.4 The e-health research agenda

In this section quotes from the stakeholder consultation (shown in italics) and some sources from the policy context review (shown in boxes) are shown to illustrate (but not give exhaustive referencing to) the recommendations.

3.4.1 Improved health and quality of life

The overriding concern of stakeholders was that spending money on e-health should be worthwhile and should lead to improved health and quality of life. While this may be an unstated assumption of policy documents, it is an aspect of e-health research which must be made explicit and can be 'woven in' to many specific research questions.

For example, an assumption of informatics policy over the last few decades has been the goal of electronic birth-to-death records. Policy context review suggested that research is needed into how such records could benefit decision-making and suggested that research was needed into the policy changes required to achieve them. However, these records come at a cost and any such study should also explore the costs of this e-health development and benefits in terms of (measured or modelled) improved health.

Another goal high on the policy agenda is cross-sectoral working. Research is needed into appropriate ways of sharing information across sectors but such sharing comes at a cost so that any study should examine costs and benefits (in terms of quality of life) as well as patient safety issues.

1.1 To review the costs and benefits of a range of recent e-health applications, including the modelling of new forms of care made possible by ICT support.

1.2 To present those examples of e-health applications shown to have a demonstrable effect on improved health and quality of life, to professional and public stakeholders to obtain their views as to the nature of the most appropriate investment in e-health.

> The challenge for the NHS is to harness the information revolution and use it to benefit patients.

(Tony Blair, All Our Tomorrows Conference, London, July 1998)

3.4.2 Using information

Information is used either to make a decision, for operational purposes in organising services, or for re-assurance (for either a professional or for patients or their families).

2.1 To explore attitudes of clinicians and their patients among those clinicians who do and those who do not use decision-support tools. In particular, to examine their perceptions of benefits and barriers to use.

2.2 To assess the quality of information available from repositories of health data, and how it can be legally, ethically and cost-effectively aggregated for public health policy and decision support.

> *…you don't want to be the one sent to the court because you retained information on a database that was traceable, do you?*
>
> (NHS primary care trust manager)

2.3 Via pilot studies of birth-to-death records, explore their potential benefits to decision-making and other aspects of health care, what policy changes would be required to achieve them, and the costs of such records.

> *…we did have a discussion around the birth-to-death electronic health records as being perused by the [NHS] and the one thing that immediately emerged from the discussion was security and access control and how to divide up the information to stop people seeing all of it, or the most sensitive parts of it…*
>
> (Older people)

2.4 To review decision support/expert systems used in the NHS to ascertain their impact on patient services.

> ICT could play a key role in modernisation of the NHS including greater emphasis of its use for electronic patient records to improve the delivery of patient care and improvement of safety.

(National Patient Safety Business Plan, 2003/04)

3.4.3 Sharing information

A major concern for research, particularly in the policy context review, was how information should be shared across site, sector and professional groups.

3.1 To examine how the NHS can work with other information and education providers to facilitate patient involvement in e-health.

3.2 To explore patient attitudes towards initiatives to exploring patient involvement in e-health.

3.3 To what extent does implanted or wearable technology remove the patient's own control of their condition? Further, how can ICT best be used to encourage and facilitate patients to take responsibility for their health?

> *…it's [use of implanted device] very quickly taking away the control from the patient…and ownership of their own health care. Basically I'm thinking that these people typically…will be used to managing their own health care, their own blood glucose….and would have been in good habits…*
>
> (Suppliers)

3.4 To investigate the extent to which recently introduced information technology (IT)-based systems (such as e-booking) escalate patient expectations and consequently decrease satisfaction.

> *…as soon as you bring technology into this arena…I think there is an important issue when this technology is rolled: managing people's expectations…*
>
> (Suppliers)

3.5 To investigate the efficacy of developing a code of collaboration under which organisations can explicitly share data and input to health records consistently, unambiguously and sensitively.

Indicated by *More Radical Steps* (British Computer Society Health Informatics Committee (BCSHIC)/ASSIST think-tank position paper; BCSHIC, 2003).

3.6 To determine how we can best deal with combining multiple sources of data, dealing with apparently conflicting information from different sources, with minimum patient risk, minimum cost, and patient consent and confidence.

The report *Delivering 21st Century IT Support to the NHS* (Department of Health, 2002) stated that a patient's NHS number could be recorded on social-care records only when there was a care plan for that patient that included the provision of health services.

3.7 To examine the costs and benefits of cross-sectoral records and patient safety issues associated with cross-sectoral working.

> *…it's not just GPs who refer patients. If we have more specialist staff then…particularly out in the community…e-booking is appropriate for… other professionals. …It would make good sense for specialist diabetes nurses for example, in hospital, to be able to refer patients to their GP and book appointments for them…*
>
> (NHS staff in secondary care)

3.8 To investigate how ICT can best contribute to pharmacy clinic services sharing data with the NHS and patient.

3.9 To investigate the potential of e-health to enable effective interfaces, for example between health and social care, local specialists and specialist services, carers and professionals.

3.10 To investigate the costs and benefits of using different technologies to support community based staff (for example, notepad computers, electronic links to supporting organisations and teleconferencing in cancer services).

3.11 To explore the changes in work patterns, potential for patient involvement, and legal issues in home care (for example, for older people)

3.12 To investigate the use of ICT use in multi-site working in relation to such issues as culture change, governance, health professional training, patient expectations and changes to health outcomes.

3.13 To determine the costs and benefits of the use of health data cards.

3.4.4 Controlling information

Research into the reliability of information, if or how it should be regulated, how it can be accessible while maintaining security and confidentiality, and who is the owner of information, particularly if there is considerable sharing.

4.1 To investigate how health professionals and patients discriminate between reliable and unreliable information.

To get an agreement on how citizens and their carers can get access to good-quality health information.

(Policy Lead, Department of Health)

4.2 To examine the circumstances in which regulation of information provision and use is necessary and further when education and empowerment of professionals is a more effective option. Additionally, what are health professional and patient attitudes towards the regulation of health information?

> *…I think all we're doing now is putting technology in for information that people always got from granny through the garden fence or down the pub, and now you can do it on a global basis rather than being able to do it in your street. But if we try to…restrict… or regulate against that then I think you're going to just drive the information that they're using underground, and in some ways make it more harmful than if you try to kite-mark badge or cross-certify the good-quality information, as far as we can identify what that is…*
>
> (Academic researchers in e-health)

4.3 To investigate the extent to which health professionals advise patients as to reliable sources of information on the Internet, television and other media. Further, to examine the level of preparation and support health professionals require to provide such advice, and additionally, patients' expectations of this advice.

4.4 To determine the subject of responsibility if health-care errors are made as a result of information transfer.

> *…everybody needs to be clear about what their responsibilities are and the process and almost have in place a contingency for when things don't go according to plan…*
>
> (Suppliers)

4.5 To explore how social organisation and different technologies can be used to help prevent inequity of access to information for both patients and professionals. Further, to identify initiatives where groups traditionally considered to have restricted access have successfully achieved training and access to new technologies.

Indicated in numerous policy documents including *The National Strategy for Local E-Government* (Office of the Deputy Prime Minister, 2002), and in interview with Bob Gann, Director of NHS Direct Online.

4.6 To explore health professional and patient attitudes towards ownership and sharing of data.

4.7 To develop and test guidance on regulation and responsibility.

> *…it's making sure that everybody's clear from the outset, …you know, whose responsibility it is, almost like a work flow, …a process…that should be followed, …a protocol that should be in place…*
>
> (Suppliers: responsibility)

> *…for example, …trying to…register the providers of the pharmaceuticals that are doing trading over international boundaries, because each country has its own regulation system but there's nothing that's actually international, and so there are plenty of companies around shipping the drugs in by the post to patients in the UK…*
>
> (Academic researchers in e-health: regulation)

4.8 To examine the costs and benefits of different ways of addressing equity to inform citizens.

> *…the libraries are very good…for people who don't have access to the Internet. [District of a city] has a bank of computers for the local residents to use free of charge and actually there are a lot of other ones around the city…*
>
> (NHS primary care trust manager)

4.9 To investigate ways (quality marks, portals, patient and health professional training) to assist the public in obtaining quality information from the Internet.

> *…perhaps now is the time to suggest that …the Department of Health looks seriously at some form of independent accreditation body that can look at different sources of information, say whether they fit within a peer review or fit within a certain criterion …an accreditation mechanism…*
>
> (NHS e-health innovators and implementers)

4.10 To investigate patients' knowledge and views on confidentiality and their attitudes as to how their data should be used in terms of potential benefits to health and quality of life (for example in research).

3.4.5 Processing information

The way information is presented, tailored and filtered, or where it is presented (that is, should it be pushed or pulled?, should it be in hospital or the home?) could be described as data processing.

5.1 To what extent should health information be tailored to the needs of certain groups of patients and professionals or, further, individualised?

> *…if we can actually start to get them thinking about how to present information in a way that's going to be right for the patient or client, whether that's video or interactive TV…whether it's animation, whether it's sounds, whether it's in six languages or whatever…*
>
> (Academic researchers in e-health)

5.2 To examine the costs and benefits of providing information in different locations (for example, mobile versus static for professionals; NHS versus home for patients).

> *…Where digital NHS TV or other digital channels are available, where patients now have these screens above their bed, where they buy their card to plug in to watch television…if you could actually make something available there by a contract with the TV provider for inpatients you could actually help them to identify the resources that are available to their immediate condition and the learning is likely to be much greater if it's immediate and relevant to them at the time...*
>
> (Academic researchers in e-health)

5.3 To investigate how information can be better integrated so that patients can, for example, access their own medical record on the Internet, obtain relevant and validated information about it and order a prescription.

5.4 To identify instances/circumstances when patients want to enquire via known professionals and when from an anonymous source.

5.5 To investigate what services patients desire for electronic ordering and home delivery of medicine and how they can be delivered safely, equitably and cost-effectively.

'Pharmacy in the future' recognises that pharmacy will have to respond to a world where people will demand a greater variety of ways of accessing services at times convenient to them.

(Pharmacy in the Future – Implementing the NHS Plan; Department of Health, 2000).

5.6 To identify how e-health technologies can enable/improve family support for seriously ill children and provide just-in-time information tailored to individuals.

> *…to be able to record how the…syringe pump's doing…what sort of temperature it is, what their wound might look like…you can do that remotely. It doesn't mean to say that staff aren't going in, but it doesn't have to be qualified staff: it could be unqualified staff, maybe to support the patient in their home. …We'd only use it with our…haematology patients when they've reached the end of their treatment and it's not working anymore…miss out on the palliative care team because after the time from end of treatment to time of death is short…so our haematology nurses who know these patients extremely well would be able to do that from a distance and support the district nurse going in….*
>
> (NHS staff in secondary care)

5.7 To examine the costs, benefits and attitudes towards and use of ICT support for patients with severe chronic disease in their homes, such as video links to NHS and voluntary services, smart cards with patient records, etc.

> *…we're implementing a home palliative care project…using video telephone conferencing so the patients will have a webcam at home [that] works through their television and which they can link to a nurse*

> *through a hospital. … The hope is to enable people to stay at home to die as opposed to being forced into hospital…because [there is a] of lack of sufficient support in the community to enable them to do that…*
>
> (NHS staff in secondary care)

Telecare technology will be used to provide reliable but unobtrusive supervision of vulnerable people who want to sustain an independent life in their own home. Video links with electronic monitoring will allow community health and social workers to 'visit' patients at home more easily.

(NHS Executive, 1998).

3.4.6 Principles of research and development

A number of recommendations illustrated the general principles which should underpin any research and development in e-health, namely that as well as innovating in new forms of service delivery and organisation we should first identify best practice and the barriers to implementation, and that stakeholders (both professional and public) should be involved in research and development. Some of the areas to be reviewed are shown below.

6.1 To identify and explore examples of effective informatics training for health professionals, and how these can be disseminated to achieve improved health care. Further, to explore the attitudes of health professionals towards such training and use of the skills acquired in practice.

Wanless (2002) recognises that use of ICT should be coupled with 'increased training in the value of quality information, the risks from bad information and the techniques of sensitive information handling supported by technology'.

> *I was talking to a ward sister…[who] wanted someone to do Word tables for her. She felt she was a nurse and didn't want to get into understanding how to make use of the technology. There is a huge amount of training that's required, …not so much that she doesn't know how to do a table really it's that she doesn't think that she ought to know how…*
>
> (NHS e-health innovators and implementers)

6.2 To investigate working practices in other sectors (such as e-business) to identify best practice and barriers to similar uses of ICT in the health sector.

The report *Delivering 21st Century IT Support for the NHS* (Department of Health, 2002) emphasised the needs for national standard specifications and working with industry partners to deliver national solutions.

6.3 To review Internet-based services for citizens in other sectors to see what lessons can be learnt on when to implement e-health solutions for patients.

6.4 To review research findings on telemedicine (for example using coronary heart disease or cancer services) and barriers to their implementation.

Information for Health (NHS Executive, 1998; for example) claims 'opportunities in the field of telemedicine will be seized to remove distance from healthcare, to improve the quality of that care', but routine applications remain few.

6.5 To assess the costs and benefits (including improved patient safety) of hospital systems that combine e-prescribing, order entry, decision support, bar-coding for medication management and robotic dispensing.

6.6 To audit NHS procedures that aim to safeguard confidentiality of patient data.

...I think even if they understand what [an] electronic database is they might be very worried about who else can access the information...

(NHS primary care trust manager)

6.7 To review the experience of UK citizens accessing health care in other countries (and vice versa), and to identify where health and other outcomes could be improved through the use of ICT.

... the fact that the technique is said to be pioneering, and available in the USA but presumably not in Britain, ...we are using a technology to import possibly leading-edge stuff, but it could also be importing some fairly wacky stuff...

(Informatics trainers discussing a scenario of remote diagnosis from the USA)

Section 4 Conclusions

The overriding concern of stakeholders was that spending money on e-health should be worthwhile and should lead to improved health and quality of life. Although such an aim is part of the political rhetoric and may be an unstated assumption of policy documents, it is not often explicitly addressed in the service development and use of information and communication technology. It is significant, for example, that the NHS has a National Programme for Information Technology and not a programme for e-health. The SDO was quite right to name this programme of Research on E-health and we must continue to emphasise health and quality of life.

The problem for research in e-health is that the cost of research often means that the timescale of follow up is short and it may be difficult to measure and change in health or quality of life. Furthermore, it is often difficult to implement changes in the use of technology 'partially' to allow comparison. Nevertheless, this should be the goal of e-health research. In some cases, 'modelling' the longer-term costs and benefits (in terms of health) may be desirable.

We have tried to make recommendations for research which may have a reasonable 'shelf life'. However, this needs more thought out. In commissioning research we think the SDO should make potential applicants show a clear focus on what the research would contribute to e-health over, for example, 3- and 10-year periods. Research that concentrates on human behaviour is likely to have a longer shelf life than, say, research into particular technologies, or even current attitudes towards a technology. Patients as well as professionals can often be too conservative or too radical and it often requires experimentation to clarify the benefits of a new approach.

Section 5 Dissemination

Dissemination is not complete. We have developed a website that will (a) continue to gather stakeholder views and (b) display preliminary findings from this study and invite discussion. A copy of the draft report will be sent by e-mail to all participants in the stakeholder consultation and experts consulted in the policy context review. They will be invited to comment on the website. In addition, various e-mail discussion lists will be circulated, inviting them to the website. We aim to prepare papers and submit conference presentations with the findings of the study.

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