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Patients, Professionals and the Internet: Renegotiating the Healthcare Encounter

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EVALUATING MODELS OF HEALTH SERVICE DELIVERY

PROGRAMME OF RESEARCH ON THE ACCEPTABILITY AND APPLICABILITY OF E-HEALTH STRATEGIES TO MEET THE AIMS OF THE NHS AND THE NATIONAL PROGRAMME FOR INFORMATION TECHNOLOGY

Introduction

The introduction of new technologies into NHS practice and service delivery has accelerated in the last six years. The term 'e-Health' was first used by the NHS in 1998 in the NHS Executive report, "*Information for Health: An Information Strategy for the Modern NHS 1998 – 2005*" [1]. However, the term e-Health has since been adopted and interpreted in many different ways. For example, a recent SDO-commissioned scoping exercise identified 51 unique definitions of e-health [2]. Within the NHS, e-government has been contextualised within the NHS Plan which requires the use of new technology to design an NHS designed 'around the patient'. *Building the Information Core* [3] contains specific targets that relate to the implementation of e-Health systems, linked to the NHS core principles of a seamless service, and which are 'respectful of confidentiality of individual patients and open access to services, treatment and performance'. Targets for the implementation of e-Health technologies have been introduced and revisited over the years. Policy guidance from the Department of Health [4] reviewed these targets set out in the 1998 NHS Executive report and whilst the delivery dates of many have been pushed back, others have been brought forward. For example, the total coverage of all GPs to be using e-booking (now known as 'Choose and Book') for some hospital appointments and out-of-hours remote access have been advanced from 2008 to 2005.

Most recently the National Programme for Information Technology (NPfIT) has focused on procuring and implementing IT in the NHS to improve patient care. It is an essential element in delivering the NHS Plan since it aims to create an integrated

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[1] NHS Executive. Information for Health: An Information Strategy for the Modern NHS 1998 – 2005 (September 1998)

[2] Pagliari, C., and Gregor, P. Literature review of traditional research databases, draft report to SDO, 2004 (www.sdo.lshtm.ac.uk/ehealth.htm)

[3] NHS Executive, Building the Information Core – Implementing the NHS Plan, January 2001

[4] Department of Health, 'Delivering 21st Century Support to the NHS: National Strategic Plan',2002

information infrastructure to improve patient care through empowering patients and improving the efficiency and effectiveness in the way clinicians and other NHS staff work. The programme has four particular goals: electronic appointment booking, an electronic care records service, electronic transmission of prescriptions, and fast, reliable underlying IT infrastructure. Its aim is to 'transform the way information flows around the health service, making it possible to deliver faster, safer and more convenient patient care. At the same time it's giving patients the information they need to look after their own health.' (5)

The value of e-Health in the coming years needs to be placed in the context of the aims of NPfIT: to improve the health and well-being of the population. The appropriateness of any new approach must therefore be assessed in the following areas:

- Its acceptability to and usability by patients and carers;
- Its impact and contribution to improved health outcomes and enhanced quality of life;
- Its safety when it is used by those for whom it is intended, as well as by others
- Its cost-effectiveness and cost-efficiency (in financial and human resources terms);
- Its contribution to addressing health inequalities and promoting universal access to, and acceptability of, ICT systems amongst patients; and
- Its cross-sector accessibility/inclusiveness, including independent/private healthcare providers, local authority departments (such as social services, education, and housing), voluntary sector agencies, the police and other stakeholders committed to health improvement.

Although there is 'excitement around perceived benefits and (the) rush forward with collaborative opportunities using advanced technologies in health information', research is needed in order to demonstrate the value of e-Health in meeting the aims and goals of the NHS and to help inform the successful implementation of NPfIT and future IT policies.

Current call for proposals

This SDO research programme aims to investigate the value of e-Health in meeting the aims and goals of the NHS and, in particular, is aimed at examining how e-Health can empower patients, the public and clinicians in making use of the internet or other electronic media in the access and use of health and lifestyle information or services. To this end, the SDO Programme is inviting research proposals in three topic areas under its programme of research on the acceptability and applicability of e-Health in meeting the aims of the NHS. This programme of research cuts across, and relates closely to, the other themes within which the SDO programme works, for example, on continuity of care, access to health services, and change management (see **www.sdo.lshtm.ac.uk**). **ONE** project will be funded in each of the following three topic areas:

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5 http://www.npfit.nhs.uk/introduction/

EH93 - Harnessing the internet as an effective health information tool to empower patients, carers and members of the general public

EH94 - The attitudes of health care professionals to e-Health technologies and services, and the identification of strategies to support increased uptake

EH95 - A study of the use of e-Health solutions in the management and treatment of disease and in facilitating change in the organisation and delivery of services

Applicants should familiarise themselves with relevant research already commissioned by other NHS R&D programmes (such as the Policy Research Programme and the Health Technology Assessment Programme) to ensure that they can demonstrate that their proposals do not duplicate other research. In particular, applicants should read and show familiarity with the results of the two SDO-commissioned scoping exercises which have been used to inform this call for proposals (Pagliari SDO/60/2003; Jones SDO/59/2003) (**www.sdo.lshtm.ac.uk/ehealth.htm)**. Applicants should also refer to the general criteria for prioritising research topics, developed and agreed by the SDO Programme board, available on the SDO website (www.sdo.lshtm.ac.uk).

Those interested in submitting a proposal for any of the topics should note that a two-stage commissioning process is being used and applicants are invited to submit outline research proposals by **Wednesday 20th April 2005**.

EH93: Harnessing the internet as an effective health information tool to empower patients, carers and members of the general public

Research suggests there are around 70,000 internet sites worldwide disseminating health information issues (Pagliari and Gregor, 2004). In April 2004, some 49 per cent of UK households were connected to the internet (National Statistics estimate). Recent research has revealed how such web-based interventions have improved knowledge and/or behavioural outcomes amongst users (Dean et al, 2004). However, systematic literature reviews of the consumer use of online health information make clear that there is little evidence of the effect this may have on health outcomes (Bessell et al, 2002).

Qualitative research has demonstrated that internet-users are most likely to assess the credibility of a website by considering its source, the professionalism of the design, the use of scientific or official language, and ease of use (Pagliari and Gregor, 2004). However, internet users are less likely to check the quality of the information being provided by, for example, examining the 'about us' sections of the website, disclaimers or disclosure statements. Such evidence also suggests that the internet is used by patients and carers most often to retrieve information on a range of public health issues such as smoking cessation guidance, cardiac and nutritional advice. Reasons for using internet resources in this way appear to be that they are more convenient; timely; anonymous; compared with the information not readily available elsewhere (Pagliari and Gregor, 2004).

Although qualitative research has identified scepticism amongst internet users of some web-based information, many see it as an important source of health-related information. Access to internet resources has also been shown to be inequitable, with many potential users hindered by the lack of the necessary computer equipment, technophobia, problematic design features, off-putting technical language, and lack of permanence of some sites (Pagliari and Gregor, 2004).

The purpose of this research is to:

- understand how and why 'consumers' use the internet for health care information and services;
- examine what subsequent actions they take, and how this effects their behaviour and health status;
- review and assess the degree of inequity in access to, and acceptability of, the internet for health advice and information by people of different ages, gender, socio-economic class and ethnicity;
- assess the internet's value in improving patients' self-management and health behaviour;
- examine methods of best practice in supporting the use of internet-based health advice by patients and the public;
- assess the extent to which patient use of the internet can and should be employed as part of the overall NPfIT in terms of its ability to empower patients, carers and members of the general public.

Specific questions that need to be addressed include:

- What is the potential impact of internet-based health information resources on health outcomes?
  - o What is the likely impact on outcomes in the primary care or secondary care sector?
  - o What are the findings from the many pilots or projects exploring the use of the internet by patients/carers that have been conducted in the public health field?
- How do 'consumers' use the internet for health care information and services?
  - o What actions do consumers take after accessing health care information?
  - o Do these actions have an impact upon health status and empowerment?
- What systems and structures exist by which internet information on health advice can be assessed for quality?
  - o To what extent do UK-based health-related websites adhere to a set of quality standards?
  - o To what extent is such information awarded a mark for quality assurance?
  - o Are systems that introduce quality marks more effective and efficient at directing consumers toward worthwhile information ?
- To what extent do inequities exist in access to and use of health-related internet sites?

- Examine this question in relation to age, gender, ethnicity, education, family income, social class and other relevant factors
- What is the role of the Public and Patient Involvement Groups and the Expert Patient Programme in supporting internet use?
- What can be learnt from projects within the NHS that encourage and support patients/carers in the use of the internet?
- What lessons can be learnt from outside the NHS, for example, from voluntary sector agencies working with age-, gender-, or ethnic communities?
  - Can models be applied from non-health related fields?
- What methods can best be employed to support patients and the general public to improve their 'search and appraisal' skills in order to help them discern and select useful, or best-quality, health-related information.
- What is the potential for a partnership approach, including healthcare and public health professionals and e-Health developers, to educate and guide patients and the general public in their 'search and appraisal' skills?
- To what extent can and should patients use of the internet be integrated within wider strategies employed within the NPfIT?

Methods

Applicants for the study should provide a clear conceptual and theoretical grounding for this research, and should be encouraged to explore a variety of research methods to include both review and empirically-based approaches . Applicants should clearly outline their proposed methods for carrying out this research including a process for identifying and assessing internet-based health information resources. The nature of the research study may require the development of a variety of qualitative and quantitative research methods and may include the collection of statistical and other data where appropriate.

Applicants should demonstrate that they have a research team in place with the appropriate research skills. Indication should be provided about how they will work with the SDO Programme and relevant stakeholders to build in an active programme for disseminating their research findings in policy, practice and research contexts. The methodology should clearly show how interim findings will be available to inform policy developments such as NPfIT.

Outputs

The principal output of this research project will be a detailed report containing details of the research and its findings. The report will also need to include:

- A short and coherent executive summary of no more than three pages;
- A full account of the methods used in the research project, including a critical appraisal of these methods;
- Rigorous and detailed conclusions that examine the use and acceptability of the internet for health advice, its value in improving self-management and health behaviour, and models of best practice;
- A commentary that indicates how these findings relate to current policy and practice in the NHS, and the key lessons to be learned; and

- An agenda that establishes the key areas for further research and the appropriate methods that should be used in this research.

Successful applicants may be required to present their completed work to the SDO Programme Board. Interim findings will be required on a yearly basis to inform policy developments.

References

Bessell, T., McDonald, S., Silagy, S., Anderson, J., Hiller, J. and Sansom, L. (2002), Do Internet interventions for consumers cause more harm than good? A systematic review, *Health Expectations,* 5 (1): 28-37.

Wantland, D, Portillo J, Holzemer W, Slaughter R and McGhee E (2004). [The Effectiveness of Web-Based vs. Non-Web-Based Interventions: A Meta-Analysis of Behavioural Change Outcomes](). *J Med Internet Res, 11, 10; 6(4):e40*

Pagliari, C. and Gregor, P (2004). Literature review of traditional research databases, report to SDO, www.sdo.lshtm.ac.uk/ehealth.html

EH94: The attitudes of health care professionals to e-Health technologies and services and the identification of strategies to support increased uptake

Studies have shown that the uptake of e-Health clinical decision support systems and other computer-based systems by healthcare professionals has been variable (Pagliari and Gregor, 2004). This variability has been argued to be the result of a number of factors, including: the lack of involvement of healthcare professionals during the development and implementation phase; the perceived extra time required to use e-Health systems; the varying quality of web-based medical information; incompatible systems across and between disciplines and institutions; and a lack of guaranteed patient privacy and confidentiality of data.

Within primary care, a few systematic comparative studies have been done to assess the effect of web-based information resources on quality, accessibility or cost of the delivery of care (Pagliari and Gregor, 2004). A study of Scottish GPs in 1999, for example, found that few GPs used email to communicate with patients, citing the lack of data privacy and additional workload as barriers to implementation. It suggested that GPs needed more training in the use of the internet and other computer-based systems and that this was not a core activity in GP practices. Nonetheless, the research showed the potential for electronic information to be used for accessing medical and patient data, supporting clinical and other staff, and for informing patients (see Pagliari and Gregor, 2004).

A key challenge in the implementation of new e-Health technologies is to ensure that clinicians are engaged and supportive of the process. This research study will examine the factors that influence professionals to use (and not to use) e-Health systems and other computerised tools. Specific attention within the research should be placed on the attitudes of professionals to the use of new information systems,

particularly those being developed between organizational and professional boundaries (for example, Choose and Book) and systems such as shared clinical record systems.

Specific questions for the research will include:

- To what extent are new e-Health technologies challenging the cultural and structural norms in which professionals work?
- What is the attitude of professionals towards the use of new information systems and technologies?
  - o What are the roots of resistance to the use of new e-Health systems and how can they be overcome?
  - o Are the factors that help and hinder the uptake of computer-based systems similar across the secondary and primary care sectors and in social care?
- To what extent is the impact of e-Health tools and systems before, during and after the patient consultation positive or detrimental?
  - o What impact does it have on the nature of patient-professional communications and relationships?
- What role should clinicians and other healthcare professionals play in the development and implementation of e-Health systems?
- What kind of support and training is appropriate, acceptable and effective to healthcare professionals in the primary and secondary care sectors to increase utilisation?
  - o What are the training and support needs in this area, and to what extent do these differ between the primary and secondary care sectors?
- What can be learnt from the strategies used to develop, implement and enhance the uptake of internet or computer-based tools for professionals in other fields?

Methods

Applicants for the study should provide a clear conceptual and theoretical grounding for this research, and will be encouraged to explore a variety of research methods. Applicants should clearly outline their proposed methods for carrying out this research including a process for identifying and assessing the attitudes of professionals in different sectors towards the use and development of clinical decision support systems. Where necessary, applicants are encouraged to develop innovative research methodologies. The nature of the research study may require a variety of qualitative and quantitative methods and the use of different case examples.

Applicants should demonstrate that they have a research team in place with the appropriate research skills. Indication should be provided about how they will work with the SDO Programme and relevant stakeholders to build in an active programme for disseminating their research findings in policy, practice and research contexts. The methodology should clearly show how interim findings will be available to inform policy developments such as NPfIT.

Outputs

The principal output of this research project will be a detailed report containing details of the research and its findings. The report will also need to include:

- A short and coherent executive summary of no more than three pages;
- A full account of the methods used in the research project, including a critical appraisal of these methods;
- Rigorous and detailed conclusions that examine the extent to which primary and secondary care clinicians use and/or resist e-Health tools; support and training needs to improve utilisation; and the impact of such tools on the clinician-patient relationship.
- A commentary that indicates how these findings relate to current policy and practice in the NHS and the key lessons to be learned; and
- An agenda that establishes the key areas for further research and the appropriate methods that should be used in this research.

Successful applicants may be required to present their completed work to the SDO Programme Board. Interim findings will be required on a yearly basis to inform policy developments.

References

Pagliari, C. and Gregor, P (2004). Literature review of traditional research databases, report to SDO (www.sdo.lshtm.ac.uk/ehealth.htm)

EH95: A review of the use of e-Health solutions in the management and treatment of diseases and in facilitating change in the organisation and delivery of services.

There is optimism that the uptake of computer based systems and tools, including clinical decision support tools, telemedicine and internet-based tools, will facilitate improved use of medical records, improved detection of adverse incidents, better communication with patients and information-sharing with other professionals, and rapid access to medical information for both clinician and patient. E-Health solutions also have been promoted for their potential to support research activity and the management of health systems in general. However, little evidence currently exists of a positive impact on health outcomes in particular disease areas. Moreover, the ability of new information systems to bring about cultural and structural change has yet to be examined.

A review of e-Health systems in one or more disease or client-based areas where usage is relatively advanced has the potential to identify the generic factors that facilitate and hinder uptake and acceptance of information systems by both patients and healthcare professionals. Fruitful areas to study may be those disease areas where telemedicine and information technology have been well established and where applications supporting high quality treatment now exist in clinical management, education, decision support and modelling. Suggested disease areas for consideration, therefore, might include diabetes, stroke, coronary heart disease

and/or cancer. Consultations from distant locations have been made possible in these areas by the development of high-speed networks which enable transmission of good quality photographs and/or information. Since the conditions manifest themselves in acute and chronic scenarios, benefits can be achieved through regular patient monitoring, drug compliance monitoring, patient reassurance and self-management – all of which can be supported by the use of electronic and computer-based systems by patients and carers. However, e-Health systems come at a cost to the local Primary Care Trust and acute Hospital Trust and the implementation of e-health solutions will require strict cost-effectiveness and outcome monitoring and analysis.

This review will study e-Health systems in specific areas of disease management and treatment to develop principles of good practice that can be used to inform practice in other disease areas and to help inform the successful development of NPfIT. This study will involve the identification of several examples in England of innovative practice in the use of e-Health systems in the treatment and management of disease in order to explore the following questions:

- To what extent does the process through which e-Health systems are introduced, developed and implemented have consequences for their effective use and implementation thereafter?
  o What are the generic lessons or best practice for the process of establishing new e-Health systems?
- What are the key success factors and/or barriers in the development of new e-Health systems?
- What can be learnt from the role of patients and carers in the development and implementation of the service?
  o To what extent has the Expert Patient Programme been influential?
- What are the additional training and support needs for patients/carers and different groups of healthcare professionals?
  o Have any programmes been evaluated?
- What different e-Health systems have been used, by whom, with what degree of satisfaction and impact on health behaviours?
  o Where is there a need for improved technological systems, and what disease treatment and management needs are still unmet by e-Health systems?

Methods

Applicants for the study should provide a clear conceptual and theoretical grounding for this research, and should be encouraged to explore a variety of research methods to include both review and empirically-based approaches. Applicants should clearly outline their proposed methods for carrying out this research including a process for identifying relevant disease areas and methods for assessing best practice. The nature of the research study may require the development of a variety of qualitative and quantitative research methods and may include the collection of statistical and other data where appropriate. In addition, applicants may consider the examination of different case examples.

Applicants should demonstrate that they have a research team in place with the appropriate research skills. Indication should be provided about how they will work with the SDO Programme and relevant stakeholders to build in an active programme for disseminating their research findings in policy, practice and research contexts. The methodology should clearly show how interim findings will be available to inform policy developments such as NPfIT.

Outputs

The principal output of this research project will be a detailed report containing details of the research and its findings. The report will also need to include:

- A short and coherent executive summary of no more than three pages;
- A full account of the methods used in the research project, including a critical appraisal of these methods;
- Rigorous and detailed conclusions that examine the use and effectiveness of e-Health solutions in the management and treatment of the disease area(s) and their acceptability to patients and health-care professionals.
- A commentary that indicates how these findings relate to current policy and practice in the NHS and the key lessons to be learned including generic lessons for the use of e-Health in other areas of chronic disease management; and
- An agenda that establishes the key areas for further research and the appropriate methods that should be used in this research.

Successful applicants may be required to present their completed work to the SDO Programme Board. Interim findings will be required on a yearly basis to inform policy developments.

Application process

The process of commissioning each of these three studies will be in **two stages** and applicants should submit **outline proposals**.

Applicants must submit proposals using the **A4 Outline Proposal application form,** which is available as a Word 97 file or Rich text format from:

- the SDO website: http://www.sdo.lshtm.ac.uk/**calls.**html , or
- by E-mail from: **Donna.Cox@LSHTM.ac.uk**

Please do not use any previously obtained version of an SDO Programme application form.

Applicants are asked to submit proposals by **Wednesday 20th April 2005 at 1pm to:**

Donna Cox
Commissioning Manager
NCCSDO
London School of Hygiene and Tropical Medicine
99 Gower Street
London WC1E 6AZ

AN ORIGINAL PLUS TWENTY-FIVE HARD COPIES (double sided) of the completed **A4 Outline Proposal application form** should be submitted together with **a copy on disk or CD**. Please note we will not accept electronic submissions or hand written proposals. **No late applications will be considered.**

To ensure the efficient and equitable answering of additional queries, all questions about this new scheme should be sent by e-mail only to Donna.Cox@LSHTM.ac.uk with the words 'e-Health Question' in the subject header.

Questions received by 11th March 2005 will have generic answers posted on the SDO website (www.sdo.LSHTM.ac.uk) by 18th March 2005.

No other correspondence about this call can be entered into.

Guidance notes for the completion of the **Outline Proposal application form** can be found at the front of the application form.

Funding of up to **£300,000** is available for funding **each of the three** projects in this topic area. **Applicants should note that value for money is an important consideration in respect of this research.** Proposed costs of the project should not exceed the limits stated above.

Following submission of outline proposals successful applicants will be notified no later than **early June 2005.** They will then be invited to submit full proposal by **late July 2005.** The outcome of the review of full proposals will be notified by **late October 2005.** The project should take no longer than **3 years** to complete and start no later than **December 2005.** Please note that these dates are approximate and may be subject to change.

In addition, applicants should indicate how they will work with the SDO Programme and relevant stakeholders to build in an active program for disseminating their research findings in policy, practice and research contexts.

The SDO Programme will look favorably on proposals which include an element of research capacity building.

Please clearly label the outside of the envelope in which you submit your proposal with the following: **'Tender Documents EH (Appropriate Reference Number)'.** This will enable us to identify proposals and keep them aside so that they may all be opened together after the closing date and time.

Teams should ensure that their proposal complies with the Research Governance Framework, which can be found on the Department of Health website, or via a link on the SDO website under the 'Call for Proposals' page.

Before funding, successful teams will be required to provide proof of research ethics committee approval for their project, if this is required (information regarding this can be found on the SDO website under the 'Calls for Proposals' page).

We anticipate that there will be informal discussions with NCCSDO throughout the duration of the project regarding the final report.

Applicants should visit the SDO website: http://www.sdo.lshtm.ac.uk to familiarise themselves with the work of the SDO Programme in general and with previous scoping exercises in other topic areas.

Addendum

This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.