Who Sees What: Exploring public views on personal electronic health records

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We aim to improve quality of life by promoting innovative solutions that challenge mainstream thinking on economic, environmental and social issues. We work in partnership and put people and the planet first.

nef (the new economics foundation) is a registered charity founded in 1986 by the leaders of The Other Economic Summit (TOES), which forced issues such as international debt onto the agenda of the G8 summit meetings. It has taken a lead in helping establish new coalitions and organisations such as the Jubilee 2000 debt campaign; the Ethical Trading Initiative; the UK Social Investment Forum; and new ways to measure social and economic well-being.

Introduction

Developing a joined up system of electronic patient records (EPRs) presents the NHS with significant new opportunities for improving treatment, healthcare management and medical research. Electronic systems which store health records on local or national databases promise to make patient records available instantly whenever and wherever they are needed; to provide a wealth of new management information; and to facilitate new ways of conducting observational epidemiological research and recruiting participants for clinical trials, making possible some projects which would previously not have been feasible.

However, realising these benefits involves a fundamental shift in the way that patient records are kept and used. It means making sensitive information about patients available more widely and storing them in systems which have been criticised by some security experts. While many developed countries are rolling out these systems, the NHS's unrivalled reach and scope makes its development of EPR both especially challenging and especially potentially rewarding.

The move towards EPRs began in 1998 when the National Health Service (NHS) Executive set a target for all NHS trusts to have EPRs in place by 2005[1]. This was followed in 2002 by the Department of Health's national strategic programme for the NHS which included the creation of the National Programme for Information Technology (NPfIT)[2]. The key task of the NPfIT was to create a NHS Care Records Service which would consist of a national Summary Care Records (SCR) Service which would hold basic medical information, and local Detailed Care Records (DCR) Services, containing more comprehensive clinical information, eventually replacing patients' GP records. The Secondary Uses Service (SUS), which is used for the administration of secondary care, would be developed to provide access to data for other purposes, such as medical research.

The last comprehensive audit of progress on EPRs was the 2007 report of the Health Select Committee. This highlighted a number of problematic areas, including a lack of clarity around the contents of different records, disagreements over the consent provisions on the rollout of SCRs, and the balance between security and the needs of different users of patient data including researchers. Since then, rollout of SCRs has continued but organisations including the British Medical Association and Liberty have called for a halt to the process while consent and public information procedures are reviewed. A review of SCRs published by University

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[1] NHS Executive (1998) *Information for health. An information strategy for the modern NHS 1998-2005* (*Leeds*: NHS Executive).

[2] Department of Health (2002) *Delivering 21st century IT support for the NHS. National strategic programme* (London: DoH).

College London in 2010[3] identified some benefits for the quality of consultations but also highlighted that the debate around the content of records was ongoing and that the benefits they were expected to deliver remained, in parts, undefined.

Public trust in the Health Service's ability and willingness to safeguard their privacy is a cornerstone of the NHS. If the public stop trusting that the information they share with their clinicians will remain private, then it may become impossible to obtain the level of candour required for effective, safe treatment, posing risks to public health.

The controversy around the new electronic patient records systems, therefore, is one with which the NHS must engage. It would be short-sighted to allow the debate over the new systems to be monopolised by those who view them as another arm of the 'database state', or to roll out new systems with accompanying public outreach programmes which, whether by accident or design, do little to contribute to public understanding of the system.

The Wellcome Trust's decision to fund **nef** (the new economics foundation) and the Centre for Science Education at Sheffield Hallam University to undertake a mass public engagement exercise on this topic was timely and important. Over the past two years nef has engaged with 6000 people across England and uncovered a picture of how they understand the Health Service's obligation to safeguard their privacy which differs uncomfortably from current practice. We hope that our findings will encourage the Health Service to work towards a new 'social contract' which permits the use of personal data for projects of public benefit, while ensuring that public trust in medical confidentiality is not jeopardised.

Recommendations

Recommendation 1: The right of patients to opt out of a database system at any time should be recognised. An accessible and simple system should be put in place to enable patients to opt out, including secure archiving of records which have been used for treatment, with a guarantee that archived records will not be accessed without the patient's explicit consent. This right should cover any database on which personal information is kept. Efforts should be made to ensure that all patients understand how their records are kept.

Recommendation 2: Although sharing with a wide range of clinical professionals is seen as having value, there is little consensus as to its acceptability. Therefore, where patients might benefit from sharing of records outside of the primary care environment, this should take place

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[3] Greenhalgh, T. et al (2010) *The devil's in the detail. Final report of the independent evaluation of the Summary Care Record and HealthSpace programmes* (London: University College London).

only be on the basis of explicit consent. This should be in addition to the current consent-to-view system.

Recommendation 3: Non-medical staff and medical staff not directly participating in a patient's treatment should not have access to identifiable patient information in any form. Only aggregate data which contains no identifying details should be available to non-clinical staff. Where access to individual records is required, for example to investigate malpractice, they should be released only with the explicit consent of the patient.

Recommendation 4: All patients should be given the right to review copies of their electronic patient records in in-surgery booths or similar arrangements. More extensive access including home access and the ability to upload additional information should be offered only where a specific clinical benefit for the patient in question is identified and they and their doctor agree that it is appropriate for their needs.

Recommendation 5: There is very significant opposition to the sharing of identifiable data for the purposes of research without consent. The use of exemptions to the common law duty of confidentiality under section 251 of the Health and Social Care act should be reviewed as this practice has the potential to significantly undermine public trust.

Recommendation 6: As part of their in-surgery access, patients should be able to view an audit trail of who has been accessing their records and when. If feasible, this should also include any occasions where data from their record has been accessed to form part of an aggregated set. This will help to build legitimacy and trust around the way that patient data is used.

Recommendation 7: Those local and regional organisations responsible for the roll-out of joined up systems of electronic patient record keeping must engage with the public in their areas to identify what forms of data sharing are accepted as legitimate. In doing so, they can learn from the example of this project and work through their existing public and patient involvement structures, such as LINks, as well as stakeholder networks in their region, civil society organisations and organisations working directly with young people in order to access as wide as possible a range of participants.

Findings

Our research has explored public sentiment about a range of issues around the use of patient records.

On the issue of consent for the creation of records, we found that there is a strongly held public feeling that there ought to be a right to opt out of any database. 80 per cent of adults and 86 per cent of young people supported some form of consent. For 67 per cent of adults and 59 per cent of young people this means a more robust consent mechanism than the one currently offered in SCRs. Public enthusiasm for the strong public education function of the explicit consent model was tempered by an awareness of the high level of resources that it would require, making it, in the view of most, impractical.

On the use of patient data, we found enthusiasm for the potential of EPR systems to offer benefits to treatment and healthcare amongst 57 per cent of adults and 67 per cent of young people. However, this was tempered by a wariness around sharing identifiable personal data with non-clinical staff. Rather than a 'consent to view' system, many respondents indicated that they wanted an open set of audit trails so that patients could review all accesses to their information, whether or not they were present.

92 per cent of adults and 97 per cent of young people backed giving patients access to their records. However, only 35 per cent of adults and 36 per cent of young people backed home access and only 11 per cent and 13 per cent backed allowing patients to add additional information to their records.

57 per cent of young people backed the NHS's role in supporting medical research and 74 per cent of adults supported the use of EPRs for this purpose. However, 79 per cent of adults and 74 per cent of young people felt that consent was required for sharing identifiable data with researchers and 34 per cent and 56 per cent respectively extended this to the sharing of anonymised data. There was also some opposition to extending the range of people who had direct access to patient records in order to facilitate the recruitment of participants for clinical trials, with only 34 per cent of adults and 10 per cent of young people favouring this approach.

In summary, there was a gulf between participants' understanding of the way that their personal data was likely to be used by the NHS and the reality. Many ways in which data is currently used – for example the sharing of personal data with researchers under section 251 of the Health and Social Care act 2008, the obligatory inclusion of patient data in the Secondary Uses Service database and the lack of transparency about what patient data is available for administrative purposes all risk undermining public trust in the NHS's commitment to confidentiality.

Valuable and socially useful forms of data sharing cannot be protected through obscurity. Doing so cedes the discussion to the most vociferous privacy activists. Instead a new settlement on the use of medical records must be constructed, through a genuine dialogue with the public on the benefits and risks of the uses of medical data.

Methodology

In carrying out this research we used three main approaches: Democs, On the Streets and a suite of school discussion exercises.

Democs is an approach developed by the New Economics Foundation which aims to extend the observed benefits of taking part in deliberative exercises to a wide audience. Democs is built around a bespoke set of information materials – a Democs kit – which enable people to hold their own deliberative events for small groups. A Democs kit on the medical, ethical, legal and technical issues around electronic patient records systems was created for this project and then disseminated via a number of stakeholder networks, including patient groups, carers' groups, NHS local involvement networks, and medical schools. People who held events were asked to feed back quantitative and qualitative data on their outcomes. A modified kit was produced that was suitable for adults with a range of learning difficulties.

On the Streets was a series of public consultation stalls that were used to access a broader range of adult participants than was possible using Democs. Stalls were erected in public spaces and passers-by were invited to review some information materials and give a response. Facilitators with specific knowledge of the topic were available to answer any questions. Participants' responses were recorded using a questionnaire tool.

For schools, a number of classroom activities were designed for Key Stage 3 and 4 science lessons. All the activities were based around a short documentary film giving the perspective of two young people on issues of medical confidentiality. Teachers could then select from a number of lesson plans built around role-plays, research tasks or discussion exercises. After completing the activities – most of which spanned multiple lessons – students fed back to the project team via a voting exercise, which was recorded by their teacher, and by completing a questionnaire.

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