Articles

Sharing electronic health records: the patient view

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ABSTRACT

The introduction of a national electronic health record system to the National Health Service (NHS) has raised concerns about issues of data accuracy, security and confidentiality. The primary aim of this project was to identify the extent to which primary care patients will allow their local electronic record data to be shared on a national database. The secondary aim was to identify the extent of inaccuracies in the existing primary care records, which will be used to populate the new national Spine. Fifty consecutive attenders to one general practitioner were given a paper printout of their full primary care electronic health record. Participants were asked to highlight information which they would not want to be shared on the national electronic database of records, and information which they considered to be incorrect. There was a 62% response rate (31/50). Five of the 31 patients (16%) identified information that they would not want to be shared on the national record system. The items they identified related almost entirely to matters of pregnancy, contraception, sexual health and mental health. Ten respondents (32%) identified incorrect information in their records (some of these turned out to be correct on further investigation). The findings in relation to data sharing fit with the commonly held assumption that matters related to sensitive or embarrassing issues, which may affect how the patient will be treated by other individuals or institutions, are most likely to be censored by patients. Previous work on this has tended to ask hypothetical questions concerning data sharing rather than examine a real situation. A larger study of representative samples of patients in both primary and secondary care settings is needed to further investigate issues of data sharing and consent.

Keywords: data sharing, electronic health records, patients

Background

The introduction of electronic health records (EHRs) to the National Health Service (NHS) in England has raised concerns about issues of data accuracy, security and confidentiality. Such issues are not unique to electronic records, but have been highlighted by the intention to create a nationally held Spine of information which will be contributed to by existing primary care records.\(^1\) There are fears that inaccurate information could be uploaded to the central database and previous work has shown that existing primary care records do contain inaccuracies.\(^2\) There are also fears that there could be illegitimate access to personal information, either due to professional misconduct by a health worker or caused by a malicious hacker attack. In England, there is debate over whether consent to the sharing of confidential information on the national
database should be implied but with the choice to 'opt out', or whether explicit consent to 'opt in' should be obtained from every individual. A 2002 report commissioned by the NHS Information Authority showed that more than one-third of patients would like to be consulted on every occasion that their details are shared. There has been discussion over whether the enormous practical difficulties that this would cause should influence the ethical arguments around patient confidentiality in the new era of national electronic records. One initiative designed to safeguard against the unwanted sharing of sensitive information without explicit consent is the proposed provision of electronic 'sealed envelopes'. Individuals can opt for certain information which they do not want to be routinely shared to be placed in these virtual envelopes. There is speculation that the information that people would not want to share would include records of mental health and sexual health issues, but there is a dearth of research evidence to guide policymakers in this area. We have therefore analysed an audit of EHRs held in one general practice to establish how many patients would want to restrict access to some or all of their records, and the nature of the information they would wish to protect.

Methods

Fifty consecutive attenders to one general practitioner [RF] who agreed to take part in the audit were given a paper printout of their full primary care EHR. Patients were excluded if they had a severe acute medical or psychological problem, or were unable to complete the task, as judged by the practitioner. Each patient was given an information sheet about the project and two coloured pens. They were asked to highlight information that they considered to be incorrect with one colour, and information that they would not want to be shared on the national electronic database of records with the other colour. For the latter task, they were told: 'At the moment your record is only stored at this medical centre. In the near future parts of your record will be copied to the National Care Record. This will contain medical details of all National Health Service patients within a central database. Please circle or underline the parts which you would not want to be shared with the National Care Record'.

Results

There was a 62% response rate (31/50). The response was 54% for males (14/26) and 71% for females (17/24). The mean age of respondents was 35. Five of the 31 patients (16%) identified information that they would not want to be shared on the national record system. Ten respondents (32%) identified incorrect information in their records. The items identified in each case are summarised below.

Items patients did not want shared on the national record

Five patients marked 110 data items related to 19 health issues that they did not wish to be shared to the National Care Record. The majority of items identified were related to mental health, sexual health and genito-urinary problems. The items concerned:

- overdose attempt (identified by two respondents)
- anxiety (identified by two respondents)
- depression
- personal problems
- lack of libido
- erectile dysfunction
- impotence
- referral to sex therapy
- emergency contraception
- routine contraception
- termination of pregnancy
- cervical smear appointments and findings
- stress incontinence
- vaginal discharge
- dietician appointment for advice to lose weight
- asthma
- medication history
- life insurance
- being signed off work.

Items that patients marked as incorrect

Ten respondents each identified one piece of incorrect information. Further investigation showed that three of these ‘inaccuracies’ were disagreements by patients over diagnostic labels given to them, but the data had been recorded as intended by the practitioner (specifically, diagnoses of acne rosacea, transient ischaemic attack and asthma). One inaccuracy was of a patient believing they had a drug sensitivity when the notes identified them as having no sensitivities. The errors identified by the other six respondents were audited by cross-checking with paper records and correspondence, and all were found to be due to simple errors in manual data transcription or data entry. Three related to incorrect dates; the other three concerned incorrect clinical information.
Conclusions

The primary aim of this project was to identify the extent to which primary care patients will allow their local EHR to be shared on a national database. Eighty-four percent of the patients in this study were happy to have their whole record shared. Of the five patients who felt that there was at least some information in their primary care record that they would not want to be shared, the items they identified related almost entirely to matters of pregnancy, contraception, sexual health and mental health. This fits with the commonly held assumption that matters related to sensitive or embarrassing issues, which may affect how the patient will be treated by other individuals or institutions, are most likely to be censored by patients. However, previous work on this has tended to ask hypothetical questions concerning data sharing rather than examine a real situation.5

A secondary finding of this work was to support the results of other studies showing that existing records contain errors and these will be duplicated if they are to be used to populate the new national Spine. Giving patients access to their records is a useful way of identifying errors that have occurred through problems with manual data transcription or data entry. Other work has shown that, while patients anticipate that there will be some mistakes in electronic records, they are generally supportive.7

It is important to note that this was a preliminary study on a small number of patients from one general practice. The sample was not random but consecutive, and acutely unwell or distressed patients were excluded. The results should be interpreted accordingly and not treated as representative of the situation across UK primary care. They are intended to highlight some issues which have to date been under-researched and which require further work to guide policymakers making key decisions over the practicalities and ethics in the sharing of personal data in national EHRs, including the decision to have an ‘opt out’ or ‘opt in’ system. A larger study of representative samples of patients in both primary and secondary care settings is needed to further investigate issues of data sharing and consent.

REFERENCES


CONFLICTS OF INTEREST

Dr Fitton is the founder and director of Fordercare Health Systems Limited, established in 1999 to augment patient access to health records.

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