Involving patients in checking the validity of the NHS shared record: a single practice pilot

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ABSTRACT

Objective To assess how involved patients wish to be in the compilation of their NHS core clinical record, and to assess the accuracy of general practitioner (GP) produced summaries.

Design, setting, method and participants In a Scottish urban practice of 6800 patients we compiled a core clinical summary based on historical paper and electronic records. We invited a 1 in 10 sample of our patients of all ages to request, view and check a copy of their core clinical record. We offered patients the chance to discuss and correct any inaccuracies in their core clinical summary by use of a response form, telephone or meeting.

Results Out of 646 patients, 258 (40% of our sample) responded to the invitation to check their core clinical summary. Of those, 187 (72.5%) of these summaries were accurate according to patients. There were 89 inaccuracies reported by patients. Of these, 42 (47%) were of obvious clinical importance including wrongly entered diagnoses, or missing major morbidity such as an operation, or errors in repeat medication. There were 47 (53%) inaccuracies in lifestyle data (smoking, alcohol history or weight), or dates of illnesses.

Conclusion Only a minority of patients chose to view and offer comment on their core clinical summaries. The majority of summaries were deemed to be accurate but there was a worrying level of omission and inaccuracy, including medication. It might be a better use of time to support doctors and patients working together to construct and check summaries rather than on information technology (IT) and the complex ethical debate surrounding the core clinical Spine.

Keywords: core clinical summary, data quality general practitioner, patient

Introduction

The National Programme for IT will connect around 30 000 GPs in England to almost 300 hospitals, and give patients access to their personal health and care information, transforming the way the NHS works. This has many potential advantages including the availability of important information 24 hours a day, awareness of current treatment and allergies, building patient trust, and possible improvements in continuity.
and consistency of care.\textsuperscript{2,3} The potential disadvantages, including breaches of security, cost, and computing problems, have been highlighted in the lay and medical press.

Throughout the UK and beyond, clinicians, technologists and patients are having to confront the technical and ethical challenges of making the general practice core clinical summary ready for more widespread utility within the health service.\textsuperscript{4} Technology overspends and the ‘opt in or opt out’ debate has obscured the simple fact that we do not know the answer to two fundamental questions.\textsuperscript{5} Firstly, how involved do patients wish to be? Secondly, how accurate are core clinical summaries? We sought to answer these questions within our own practice in the hope that we could improve our own standard of information keeping, and possibly shed some light on the national debate.

**Methods**

We are a long-established urban teaching and training practice in Dundee, Scotland, with 6800 patients. Our level of deprivation is similar to that in the rest of Scotland, and we have a diverse mix of patients drawn from many ethnic and sociodemographic backgrounds. Our patients are spread across a city characterised by thriving biotechnology and education sectors, but declining manufacturing industry.

In the process of transferring all our records into electronic format, we listed all recorded clinical events from old paper records. We classified this list into three categories. Category 1 included major medical morbidities, including all surgical procedures; fractures; allergies; current medication; and long-term health conditions requiring medication, including psychological problems impacting on health. Category 2 included reproductive health issues (childbirths, miscarriage, abortion, and sterilisation); genetic risk factors; family history; and bereavement. Category 3 included immunisations and episodes of short-term illness without long-term complications. We put in place a system for regularly updating clinical events from screening of incoming hospital correspondence, investigations and laboratory reports. Each general practitioner (GP) personally checked the accuracy of all their patients’ records, and produced a core clinical summary based on Category 1 information.

We sent a 10% sample (generated from a random numbers sequence applied to the practice age/sex register) of patients a letter, inviting them to view a copy of their core clinical summary and to comment on it. We included all patients, regardless of age, infirmity, anxiety, institutional status or mental capacity.

Those patients who returned our invitation letter with a completed consent form (signed by themselves or a parent or their carer) were then sent a copy of their core clinical summary and invited to comment on it by completing a response form or via a telephone or face-to-face consultation.

This project was approved by the Tayside Ethics Committee.

**Results**

**Responses**

We issued 684 invitations. Twenty-one patients had moved address or had died between the compilation of the sample list and the issue of the invitations. Fourteen letters were returned ‘addressee unknown’. In three instances, invitations were not sent to patients deemed by their own GP to be critically ill, and thus a total of 646 invitations reached the intended recipient. We received 294 (46%) responses to the invitation, of which 36 (12%) were ‘no thanks’ and 258 (88%) ‘yes’. Telephone follow-up of a purposeful sample of non-respondents cited lack of motivation as the dominant reason, but several participants subsequently agreed to take part in learning more about the project.

**Accuracy**

One hundred and eighty-seven (72.5%) patients who had agreed to participate reported that their core clinical record was accurate. Sixty-two (24%) reported one or more inaccuracies, and nine (3.5%) gave no feedback.

There were 89 inaccuracies reported by patients. Of these, 42 (47%) were of obvious clinical importance, including wrongly-entered diagnoses, and missing major morbidity, such as an operation, or errors in repeat medication (such as dosage or drugs). There were 47 (53%) inaccuracies in lifestyle data (smoking, alcohol history or weight), or dates of illnesses. Nine (3.5%) patients reported both clinical and lifestyle inaccuracies. Within the constraint of small numbers, there were no apparent trends in response or accuracy rates by age or sex, although as expected there were no ‘major errors’ noted in children, the majority of whom have no history of major morbidity.

**Patient comment**

We received a considerable amount of praise from patients and from our Patient Liaison Group for
Involving patients in checking the validity of the NHS shared record

Discussion

We found that the majority of patients (60%) did not take the opportunity to look at their core clinical summary, citing lack of motivation as the main reason. This could indicate a level of trust that modern GP record systems are well maintained and accurate. However, it could simply indicate that people lead busy lives and have other things to do apart from checking through records. We were surprised at this low level of engagement. The question ‘how involved do patients wish to be?’ is perhaps best answered by saying ‘a little’. Some of our patients wished to see their summaries and some of them chose to comment and correct information. The majority remained passive throughout the process. Perhaps ‘patient power’ has not yet encroached as far as is popularly believed.

How accurate were our core clinical summaries? ‘Not too good’ is the best-fit answer. Despite adopting a rigorous systematic review of all our patient records, we found a worrying degree of clinical and lifestyle data inaccuracy. This raises the issue of whether patients should trust their GPs to keep accurate medical records. Our experience would suggest that even in a technically literate modern GP practice, there is an unacceptably high error and omission rate in core clinical summaries. To rectify this, patients have to become involved.6 This study confirms the findings by Ward and Innes that negotiation with patients can result in a more accurate summary that includes the patient’s perspective, thus providing an effective means of improving the accuracy of patients’ records.7 It also shows that it is realistic to invite almost all patients to participate.

Conclusions

This simple and brief single practice pilot raises some interesting issues in the national core clinical Spine debate. Health care is about people, not computers. The people we invited to check their core clinical summaries had a misplaced trust in our ability to maintain accurate records. There is a need to think through how to place ‘draft’ core clinical summaries on the NHS Spine and engage patients in a dialogue about how they themselves can check this information for accuracy, and offer comment on its relevance, to produce an agreed definitive ‘shared’ record. The core clinical Spine debate would be better served by an emphasis on finding ways of doctors and patients working together to improve and maintain accurate records rather than obsessing over IT systems and ethicophilosophical musing.

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REFERENCES

1 www.dh.gov.uk/PolicyAndGuidance/InformationPolicy/NationalITProgramme/fs/en


CONFLICTS OF INTEREST

RN is a member of the Scottish Executive Health Department Patient Access Group and is involved in a project to transmit and store patient data using wireless technology.

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