Electronic medical summaries in general practice — considering the patient's contribution

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SUMMARY

Background: *Data entry into electronic records is intrinsically complex. Errors may occur in the primary (paper) record and further errors when data is transferred to the electronic record.*

Aims: *To elicit patients' ideas about their personal medical summaries, specifically considering accuracy, level of agreement between doctors and patients, and patients' concerns about computerisation and access to their records.*

Design of study: *Qualitative study using semi-structured interviews.*

Setting: *Nineteen patients aged 20 to 65 years from a large training general practice (eight partners) in a deprived area in the West Midlands.*

Method: *Patients agreeing to be interviewed were mailed a copy of their electronic summary, which contained 'active problems', 'significant (not active) problems', 'allergies', and 'present medication'. Semi-structured interviews were conducted, which were tape recorded and transcribed. The constant comparative method of grounded theory was used to analyse the data.*

Results: *Patients saw the summaries as a tool for the doctor's own use. They expected their general practitioners (GPs) to select the information relevant for their medical care, keep it updated, make it quickly available across the health service where needed, and limit access appropriately. They saw potential benefits of computerisation in supporting continuity of care. No patients had previously asked to see their notes, but most welcomed the opportunity to discuss the content of the summaries, correct any errors, and negotiate a description of problems that more closely reflected their perspective. Over half of the summaries were altered by the GP after discussion.*

Conclusions: *Patients trust their personal doctors, both as caretakers of their notes and as gatekeepers for access. Electronic medical summaries in general practice are inaccurate to a worrying extent. Negotiation with patients can result in a more accurate summary that includes the patient's perspective. Further studies are needed to look at the feasibility of patient participation in such a process and to see what benefits, in terms of improved continuity of care and improved doctor–patient relationship, may result.*

Keywords: *electronic medical record; medical summary; qualitative research; doctor–patient partnership; computers.*

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Introduction

GOOD records, paper or electronic, are a prerequisite for good medical care. The National Health Service (NHS) strategy reflects this and envisages wide sharing of electronic records.[1] General practitioner (GP) experts point out that while extracting data is easy, data entry into electronic records is intrinsically complex, and doctors are as yet untrained in expressing their meaning using coded data.[2]

Errors may occur in the primary (paper) record[3,4] and further errors when data is transferred to the electronic record.[5] Some highly motivated practices have demonstrated improvement in electronic data quality for a limited number of chronic diseases.[6,7] It is likely that some errors can only be discovered and corrected in discussion with the patient. Even when they were aware of inaccuracies, two-thirds of the patients in Baldry's study informed no-one at the practice.[4]

Voices in the profession are urging increased doctor–patient partnership, highlighting that doctors frequently fail to acknowledge patients' explanatory frameworks and their expertise.[8] Patients value patient-held records and report that they help break down barriers between patients and doctors.[9] There is accord about what should be included in a record, although patients and doctors have been less in agreement about the inclusion of sensitive information or 'unflattering' terms.[10]

A previous study in this practice had demonstrated that patients trusted the doctors to maintain the confidentiality of their records, but were not fully aware of who did have access.[11] This qualitative study was designed to explore with patients the content, accuracy, and sensitivity of their own summaries, as well as eliciting their views on computerisation and access to their records more generally.

Method

The study, which was conducted by the lead author, was approved by Shropshire Local Ethics Committee. A sample of patients aged between 20 and 65 years was sent an invitation letter. Patients with psychosis, learning disability, and those known to have poor English were excluded. Patients agreeing to be interviewed were mailed a copy of their electronic summary, which contained 'active problems', 'significant (not active) problems', 'allergies', and 'present medication'.

Semi-structured interviews were conducted by the lead author in a non-clinical room in the surgery. Patients were given a standard explanation of the purpose of the study, and told that any specific comments on the content of their summaries would be taken back to their GP. Any such comments were managed at the end of the interview. Subsequent

changes made to the records were noted for the study.

Patients were asked whether the summaries included what they thought were significant problems, and also whether they had any concerns about access to or the computerisation of their records.

The interviews were tape recorded and transcribed.

Analysis

Using the constant comparative method of grounded theory,[12] initially, a number of transcripts were studied in fine detail, to ground the analysis in the data. This focus was then extended to all the transcripts, which were studied repeatedly to allow ideas to emerge. These were grouped into categories and then higher order themes according to the meaning that they embodied. The properties and dimensions of the categories were confirmed by testing whether they applied within each transcript and across transcripts. Towards the end of the analysis, no new understanding of the data was emerging. Three transcripts were read in fine detail by the co-author as an independent test of the categories and themes. Both authors also discussed the ongoing analysis regularly.

Results

Forty-nine patients were sent invitation letters; of these, 19 of the 20 who accepted came for interview. Those coming for interview represented a spread in terms of age, sex, and number of items on the summary (0 to 14). They reported being motivated variously by curiosity about their records and wanting to help the practice by offering their views.

Changes made to the summaries

After discussion with their own GP following the interviews, 12 summaries were altered, either because there were errors — in eight records there were two coding errors, two significant allergies had been omitted, as had seven noteworthy illnesses — or because the coded terms used were qualified to give a more meaningful description of the problem (eight records).

Themes and categories from analysis

The major themes that emerged were the utility of the summaries, their organisation, and the opportunity for patient involvement (Box 1).

Utility of the summaries

Patients saw the summaries as having utility mainly for doctors delivering medical care. As such, they thought items would be selected to allow anticipation and management of future problems. Importantly, they saw this as a valid criterion when sensitive problems were considered for inclusion.

Patients thought that summaries should support continuity of care across time and the health service. They were particularly concerned to ensure that information needed in an emergency would be readily available. They also considered that their own representation of their history might be inaccurate to the detriment of their care and that a summary should prevent this.

Patients had diverse views on the utility of recording personal information. Some thought it would facilitate them being seen as an individual. Others thought that they might be treated more sensitively if doctors or staff were aware of personality traits, such as anxiety.

' … gaining an understanding of me. Maybe if it had come up on the screen, about my anxiety it might of helped speed up the process to try and get those results. It's only just something very, it's nothing serious, but it's a lot to me.' [Patient 19.]

Most thought that personal information was useful in a relationship with their own doctor, but doubted the benefit of including it on a summary for wider dissemination. They were anxious about the potential for labelling of patients.

'Now if you see this [anxiety] *you might get worried and say "Oh my God the woman is a bit unstable, she might go over the edge, she gets worried you know", and of course the other thing about it is that if I was a doctor and I saw this as a doctor and if that person came to me with minor problems she might say that she's just too worried about it and if we put her mind at rest she'll just go away and she'll be quiet. Now that could also mean that if I have something more serious that it gets perhaps pushed aside in the same way.'* [Patient 12.]

Some thought the summaries could usefully give feedback to patients. They suggested, for instance, that it should show current and the 'normal' values for test results.

Management of summaries

Patients perceived that the NHS has problems with the management of information. Many had experiences of seeing doctors 'flick through pages of notes' (Patient 13), and doctors other than their own having difficulty finding relevant information. They hoped that electronic summaries would correct this.

There was an expectation that information held electronically would be linked; for example, as it is on the Internet. For

Themes	Categories
Utility of summaries	Anticipation of future problems
	Continuity of care
	Focus on individual
	Feedback to patients
Organisation of summaries	Linking of information
	Differential access
	Quality
	Computerisation
Opportunity for patient involvement	Respect for patient's story
	Negotiation
	Updating and correcting
	Control over access
	Ownership

Box 1. Categories and themes emerging from the interview data.

example, a one-line description of a problem on a summary should lead to the full notes.

They suggested the records should be organised to support differential access. General practitioners might need the full medical record as well as a certain amount of personal information; hospital doctors needed the relevant past and current medical information, and so on. They thought that computerisation could support this process.

'I think it would be a bit unnecessary for it to appear there, I don't know whether there's a sort of sub-screen where you can select relevant information and if it's to do with that particular thing then you send it but if it isn't then … perhaps there is a flag on the system that it remains in the background unless it's something that is related.' [Patient 15.]

Unsurprisingly, patients had high expectations of the quality of the summaries. They expected them to be complete — including information that may have come from hospitals or from outside the UK — to be actively managed, and to be updated frequently.

Most articulated the possible benefits of computerisation for electronic communication between GPs and hospitals and the potential for reducing errors, such as those owing to doctors' handwriting, but many saw the computer as having an almost magical ability to save time and give the doctors instant information that would help them make diagnoses.

'I think it would be much easier. Especially here because we only had a small group of doctors before, well here there are a lot more. So I mean if I can't get to see you I might have to see somebody else who doesn't know anything about me. So it would be easier, they can just bring it up on the screen and they would just know straight away.' [Patient 11.]

Patients did express anxiety about computerisation, mainly about access as discussed below. Some mentioned the problem of information being entered incorrectly, and one the possibility of the computer corrupting data.

Opportunity for patient involvement

Patients initially saw a very limited role for themselves in relation to the summaries. They thought that doctors' medical knowledge and the role of the summary left the responsibility and the control mainly with the doctor — the patients only needed to make sure they told the doctor everything that might possibly be relevant.

'I think as a patient it is up to me to inform you of anything that is wrong or changes and you go from there. If you think it is important to be put down it should be put down.' [Patient 9.]

However, several then talked about the patient's perspective being different from the doctor's, particularly in relation to the severity of an episode in terms of impact on daily life. They thought their view should be respected if the summary was to represent them. In all, eight patients suggested additions to the coded entries so that the summary reflected their perspective more closely. For example 'low back pain' was qualified with: 'chronic, radiating up back, severe, followed injury at work' (Patient 9), and 'thyroid cancer' was qualified with: 'no recurrence for 10 years' (Patient 1).

They also saw room for negotiation in the more sensitive areas. While they felt that doctors should 'have the last word' on whether something was included, they did want to know what had been recorded and welcomed the opportunity to discuss the wording and offer explanatory phrases. For example, one patient wanted 'depression' to be changed to 'reactive depression' and 'bankruptcy' added:

' … which isn't my fault, it wasn't my fault I got into this situation, somebody else has done it to me.' [Patient 14.]

They felt it was appropriate to be given the choice of whether some more personal problems should be included at all; for example, termination of pregnancy.

'So perhaps give the patient a bit of an input as to what goes on and what doesn't. You have got to be careful that the patient may try to be disguising a certain illness. So the doctor has the last say in that he thinks that is significant.' [Patient 6.]

Given the opportunity to be involved with their own summary, patients also began to consider what roles they might play in the process of updating. They thought it would require an ongoing opportunity for reflection with their own doctor. Several made suggestions about how a practice could update records on a regular basis, emphasising that it would have to be at times when the patient was not ill. One man suggested two-yearly reviews with his GP 'as he would with a financial advisor'. Although expecting to see medical terminology in the summaries, patients felt this limited the opportunity for shared control.

'If you want help, want an input from the patients, you will have to use layman's terms.' [Patient 19.]

All thought time would be a barrier, as might some

patients' indifference, but they saw potential benefit to the GP–patient relationship in dialogue and partnership.

'Yes I think it's beneficial to be discussed. I'm not too sure, I always think it's better to discuss anything like that because then nothing is being hidden. The two can work as a partnership surely. It could be discussed between yourself, like supposing we are discussing this statement now, I might say I'm not very happy about having the anxiety down. Surely then you would be able to get across to me the benefits in having that down. So surely that would help reassure the patient?' [Patient 19.]

On the whole, they thought the NHS had the responsibility for ensuring access to their records was on a need-to-know basis. They saw a role for themselves in controlling the dissemination of personal information but otherwise saw little need to have control over access.

They tended to trust the professionalism of clinicians and the lack of material in their records of interest to 'hackers' to protect their anonymity. Interestingly, in expressing the difference between the professional and personal, several patients used the receptionists as an illustration:

'Yes, because I think with doctors you tend to know them in their professional capacity but with receptionists you may well cut their hair or anything, you might know them in a different way … I think it's just the difference in your relationship with them, if it was somebody you knew … I think you perhaps have higher expectations of doctors to be more discreet than [other] *human beings.'* [Patient 15.]

Most concern arose when information was being sent to outside agencies, when the problems were seen as sensitive and when computers were involved.

No patients wanted to own paper or electronic versions of their notes (unless, perhaps, they were out of the country). Even though they were aware of problems with the records and had concerns about access, they wanted to continue trusting the NHS to use the notes to their benefit and felt that their legal right to access was sufficient safeguard for them.

Discussion

Summary of the main findings

This paper indicates that patients trust their personal doctors both as caretakers of their notes and as gatekeepers for access. It seems to be unique in demonstrating that, offered the opportunity, patients are willing to negotiate over the content of their summaries; the changes they suggested being readily accepted by their own GPs. Importantly, discussion with patients revealed significant inaccuracies in the electronic records.

Strengths and limitations

This was a small qualitative study carried out in the authors' practice. The lead author, who also has a background in social work, was aware of the potential difficulties involved in interviewing patients in her own practice.[13] She attempted to limit these by formulating a standard set of open questions and by refraining from engaging with any interviewee on the content of the summary during the interview, except to clarify a misunderstanding. The co-author advised on the methods and helped the lead author identify her own biases and develop role distance. As both GPs take a practice lead on the computerisation of the records, it is likely that this will have influenced both the interviewing and the analysis of the transcripts. The patients interviewed may be less ready to raise concerns than others both because they were from the interviewer's own practice, and because they are predominantly 'working class' and traditionally less assertive. These factors might overemphasise the doctor-oriented, relatively accepting nature of a large amount of the data. However, patients did find a way of raising concerns about the way records are currently organised by talking about the improvements computers could bring. While this paper is likely to underestimate patients' concerns about their records, evidence from other work serves to validate our findings by triangulation, as discussed below.

Placing it in context

A number of other papers support the validity of the findings in this study. The fact that patients, while appreciating their right of access to notes in principle, frequently had no desire to see their records, accords with the findings in a study by Britten *et al*, who found a substantial proportion of patients wanting access only if offered it by their own doctor.[14] This also fits with Carman and Britten's findings that patients placed their trust in explanation face-to-face ahead of access to, and control of, their notes.[15]

In a literature search, Mitchell and Sullivan found, as we did, that patients were generally positive about the use of computers.[16] However, several studies showed that patients had anxieties about privacy and thought that only non-sensitive information should be on computer. The Bolton Research Group agreed with our findings that patients assumed GPs would adopt a gate-keeping role for access by other professional groups.[17] They identified that 82% of their responders felt that reception staff should have very limited access to the notes. A strong theme identified in this study was the boundary between the outside world and the 'professionals'. Carman identified that the principle of anonymity was a determinant of attitudes to access. Mandl *et al* suggested that confidentiality could be assured by patients having control over access and permissions.[18] Our findings and those of the Bolton Group suggest that a dialogue can best achieve this, as well as providing the greatest accuracy.

The conclusion that patients tend to have rather over-optimistic attitudes to the computer is supported by the findings of Als.[19] She found two groups of patients: those who regarded the computer as modern pen and paper, seeing it as an advantage for the doctors and thus for themselves; and those who ascribed more unrealistic functions to the computer; for example, believing that the computer could help GPs solve advanced medical problems.

Finally, the errors we identified in the summaries were caused by the process of abstracting information from the contemporaneous notes and also by the process of coding, both problems that are discussed by GP computing experts.[2]

Points for practice and the future

Although patients in this study were willing to work with their GP on the content of their summary, further studies are needed to explore whether patient involvement is feasible in practice. Patients with significant psychiatric illness or difficulties with communication are likely to need special consideration when sharing of records is considered.

The suggestion that joint reflection on the content of the records might benefit medical care and the doctor–patient relationship could be examined in further studies.

Inaccurate and insensitively worded records must be a risk to patient care and will reduce trust if shared. We need urgent action to improve accuracy and patient acceptability before widespread sharing of electronic records is implemented.

References

1. National Health Service Information Authority. *An information strategy for the modern NHS*. www.nhsia.nhs.uk. 2001.
2. The Joint Computing Group of the General Practitioners' Committee and the Royal College of General Practitioners. *Good practice guidelines for general practice electronic records*. [Version 2.6.] NHS Executive, 2000.
3. Jones R, McConville J, Mason D, *et al*. Attitudes towards and utility of, an integrated medical–dental patient-held record in primary care. *Br J Gen Pract* 1999; **49:** 368-373.
4. Baldry M, Cheal C, Fisher B, *et al*. Giving patients their own records in general practice: experiences of patients and staff. *BMJ* 1986; **292:** 596-598.
5. Sullivan F, Wilson P. The completeness and accuracy of patient record transfer between practices. *Health Bull* 1997; **55:** 16-19.
6. Hassey A, Gerrett D, Wilson A. A survey of the validity and utility of electronic patient records in a general practice. *BMJ* 2001; **322:** 1401-1405.
7. Pringle M, Ward P, Chilvers C. Assessment of the completeness and accuracy of computer medical records in four practices committed to recording data on computer. *Br J Gen Pract* 1995; **45:** 537-541.
8. Middleton JF. What kind of consultation for partnership. *Br J Gen Pract* 2000; **50:** 268.
9. Liaw ST, Radford AR, Maddocks I. The impact of a computer generated patient health record. *Aust Fam Physician* 1998; **27:** 39-43.
10. Liaw ST. Patient and general practitioner perceptions of patient-held records. *Fam Pract* 1993; **10:** 406-415.
11. Dawson M. *Confidentiality in general practice — a study of patients' perspectives*. [Dissertation.] Department of General Practice, Birmingham University, 1994.
12. Silverman D (ed). *Qualitative research: theory, method and practice*. London: SAGE, 1997.
13. Hoddinott P, Pill R. A review of recently published qualitative research in general practice. More methodological questions than answers? *Fam Pract* 1997; **14:** 313-319.
14. Britten N, Bartholomew J, Morris R, Zander L. Consultants' and patients' view about patient access to their general practice records. *J R Soc Med* 1991; **84:** 284-287.
15. Carman D, Britten N. Confidentiality of medical records: the patient's perspective. *Br J Gen Pract* 1995; **45:** 485-488.
16. Mitchell E, Sullivan F. A descriptive feast but an evaluative famine: systematic review of published articles on primary care computing during 1980–1997. *BMJ* 2001; **322:** 279-282.
17. The Bolton Research Group. Patients' knowledge and expectations of confidentiality in primary health care: a quantitative study. *Br J Gen Pract* 2000; **50:** 901-902.
18. Mandl K, Szolovits P, Kohane I. Public standards and patients' control: how to keep electronic medical records accessible but private. *BMJ* 2001; **322:** 283-286.
19. Als A. The desk-top computer as a magic box: patterns of behaviour connected with the desk-top computer; GPs' and patients' perceptions. *Fam Pract* 1996; **14:** 17-23.

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