



ORIGINAL PAPER

Sharing a written medical summary with patients on the post-admission ward round: A qualitative study of clinician and patient experience

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Abstract

Rationale, Aims and Objectives: Sharing aspects of the traditional medical record with patients has been successful in primary and antenatal care, but has not been investigated in the UK inpatient setting. Our aim was to evaluate the impact on patient and clinician experience of providing patients with a written lay summary of their care-plan in the acute care setting.

Method: We carried out a qualitative interview study on two acute medicine wards in an NHS University Teaching Hospital for a 4-week period in 2019. A summary record, designed in response to suggestions from doctors and patients from a previous study, was distributed to patients on the first ward round after admission. Eligible participants included all doctors and nurses working on and all patients and their families attending the acute medical units; patients were excluded if they lacked capacity to consent or were under 18. We interviewed 20 patients, 10 relatives, 10 doctors and 7 nurses.

Results: Patients felt that the summary improved their ability to remember details about their care so they could more accurately and easily update their relatives. They did not feel that the summary induced anxiety. Patient-doctor communication was improved: patients felt empowered to ask more questions and doctors felt that it solidified their plan and encouraged them to avoid medical jargon. Most patients felt the summary included the 'right' amount of information. Healthcare professionals were more concerned about the risk of breaching confidentiality than patients. Doctors felt that providing summaries was time-consuming; there were differing opinions about whether this was a worthwhile investment of time. Clinicians recognized that the traditional medical record has many roles.

Anna L. Crucefix and Aaron P. L. Fleming contributed equally, and should be considered joint first authors.

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Conclusions: A summary record could empower patients and improve patient-doctor communication but would require additional clinician and administrative time.

KEYWORDS

diagnosis, explanation, healthcare, medical ethics, patient-centred care

1 | INTRODUCTION

There is minimal transparency in the writing of hospital medical records: patients rarely request to see them and what can be seen is hard to interpret. Verbal communication, the mainstay of the patient-doctor interaction, can be misinterpreted or forgotten¹; in a recent study in a UK hospital, 27% of patients did not remember being told their diagnosis.² Patients often feel disempowered and struggle to become involved in their care.³ To enhance patient autonomy, patients need to be supported in making their own informed decisions. One proposed way of doing this is to increase patient access to their medical records.

The sharing of patient records has been shown to empower patients, improve medication adherence⁴ and enhance patient satisfaction in primary care,⁵⁻⁷ antenatal care,⁸ and for specific diseases.^{9,10} To our knowledge, however, written patient information has never been shared in the acute setting in the UK. Access to inpatient medical records in a U.S. hospital was found to improve patient understanding and provide a sense of control, whilst most clinicians felt that it did not affect their practice.¹¹ However, several concerns were raised, in particular that that patients could be overwhelmed with information and become more confused.¹¹ Previously stated anxieties include clinicians censoring records to remove unlikely but worrying differential diagnoses, difficult discussions such as end of life care, or medical uncertainty highlighted in medical notes to be explored by other colleagues.¹² There are questions about the security of these written notes and the risk of them being lost.¹² There is also the possibility of third parties, such as relatives, accessing patient information without consent.¹²

An evaluation of patient and clinician views on sharing the medical record, and alternative approaches to improving communication, was conducted via in-depth interviews and a questionnaire which we have previously reported.^{2,13} Participants were very positive about sharing a summary note: it would allow patients to review information about their care in their own time and support them in asking questions, without changing the clinical notes used by the treating team. Such a note might alter the nature and quantity of communication between patients, doctors and nurses.^{14,15} Clinician and patient participants made suggestions of the ideal content of such a note. The aims of this study were to explore (a) the impact on health care professionals, patients and their relatives and (b) the practical issues of sharing such a summary record with patients admitted to the acute medicine ward.

2 | METHODS

This was a qualitative interview study conducted in January 2019 in a University Teaching Hospital which uses electronic patient records.

Relevant approvals were obtained from North West Preston Research Ethics Committee (18/NW/0289), the Health Research Authority, the local Research & Development department and Hospital Caldicott Guardian.

2.1 | Involvement of patients and the public

A patient and public involvement (PPI) panel was convened and consulted with at the initiation of a related study interviewing patients and doctors about ways of sharing the medical record.² Patient and clinician participant feedback from this study led to the development of the written summary plan and the interview guide.

2.2 | Development of written summary plan

A summary care pro forma (Appendix S1) was informed by the findings of a previous mixed methods study which asked patients and doctors what they would want included in a summary care record.² This included information about the patient's likely diagnosis, differential diagnoses, treatments, tests and space to write questions.

The University Teaching Hospital where this study took place uses an electronic patient records system which allows creation of 'dotphrases'. A 'dotphrase' is a section of predefined text that can be added to the medical notes with spaces for the clinician to fill in information for each patient. During the first ward round after admission (known as the post-take ward round, PTWR), the medical team added a summary plan 'dotphrase' at the end of the patient notes (Appendix S1). This was printed off by a ward clerk and handed directly to the patient, along with a notice that the summary was the patient's own responsibility (Appendix S2). If the medical team felt that providing a written summary plan would distress the patient, they could choose not to do so, and we enquired about such cases in subsequent interviews to determine frequency and reasons for this. The summaries were only written for the PTWR, not for further ward rounds. The process of creating and the content of the summaries were observed by members of the research team.

2.3 | Inclusion criteria

Patients were eligible for inclusion if they were admitted to one of the wards where the study was taking place and were given a written PTWR summary.

Doctors and nurses were eligible for inclusion if they worked on one of the wards where the study was taking place.

2.4 | Exclusion criteria

Patients who were aged less than 18, had cognitive impairment sufficient that they lacked capacity to consent or insufficient spoken English to undertake the consent process were excluded.

2.5 | Recruitment

Permission was sought from the clinical director of acute medicine to approach the healthcare professionals on acute admissions wards in a University Teaching Hospital. Doctors and nurses were sent an email invitation including a participant information sheet (PIS) and invited to meet the principal investigator (Z.F.) to answer any questions. The consultant doctors interested in taking part then incorporated this written summary plan into their PTWR for appropriate patients.

Patients who had been given a written PTWR summary were identified by a member of the clinical team or a GCP-trained medical student and given a PIS on the ward. After they were given time to read it, a member of the research team answered any questions and took their consent. The consent form was signed immediately before the interview took place.

2.6 | Data collection and analysis

A semi-structured interview guide (Appendix S3) was developed based on data from patient and clinician interviews from a previous study, purposively sampled to represent a range of ages, clinician experience and gender.² Interviews were conducted by AF and AC, two GCP-trained medical students who were male and female respectively. Interviews with patients took place at the bedside or in a private room where available. Interviews with clinicians took place in their offices or a private room. Interviews lasted around 15 min and took place with two researchers: one writing down the interviewee statements verbatim in real time, while the other conducted the interview. Where participants wished to discuss things beyond the initial guide, this was annotated in free text; subsequent interviews were then adapted to include themes which emerged from initial interviews with patients, relatives and clinicians. Following each interview, the interviewers reviewed the notes to minimize risk of misinterpretation. No repeat interviews were carried out. Interviews were conducted until data saturation was reached.

Interviews were double-coded using NVivo 12.5.0. Thematic analysis of the data was carried out with themes generated both deductively using the interview questions (see Appendix S3) and inductively from the data itself (A.F., C.L.). Coding differences were rare: where present, they were noted, discussed and a consensus was reached. Participants were not asked to provide feedback on the findings.

3 | RESULTS

Thirty-eight interviews were conducted in total: 10 doctors, 7 nurses, 13 patients and 1 relative were interviewed individually; 7 interviews were conducted with patients and their relative(s) together; in these cases, patient and relative views were analysed separately, leading to a total of 45 interview files. 13/33 patients approached chose not to be interviewed or were unable to be interviewed for reasons such as early discharge or not being at the bedside. All doctors and nurses approached agreed to be interviewed. Doctors interviewed reported that the only reasons for not giving summary notes to patients was because the patient lacked capacity, were confused, or, in one case, had visual problems.

The demographics of the patients and relatives interviewed were not recorded. Hospital-wide data on adult admissions for this time period showed 53.1% of patients were female (average age of 54.8) and 46.9% were male (average age of 59.9). The district council in which the hospital was based had an index of multiple deprivation (IMD) 2015 score of 13.8 and in 2019 the local authority district was ranked 205th out of 317 local authorities from most deprived to least deprived.¹⁶ The IMD is the official measure of relative deprivation for small areas in England. In addition, 82.8% of residents listed English as their first language.¹⁷

Illustrative quotes have the interviewer type identified by N = nurse; D = doctor; P = patient; R = relative.

3.1 | The summary empowered patients

The summary notes helped patients to better understand their care, through both improved recall and enhanced communication.

The summary's role in aiding memory emerged as a theme, mentioned spontaneously by 21/28 patients and relatives. In particular it was mentioned that the summary helped patients to remember what doctors had said:

It's handy to have something like that... instead of trying to rack your brain in the future you have a record of it that you can take home. You can also refer back to it in the day if you can't remember something. It's a record. P15

[The doctor] went right through it and went through what it all entailed. But my memory isn't very good, I

can't remember everything she said. The second time reading it, it brings back things you've forgotten. P21

The summary also allowed them to pass on relevant information to friends and relatives:

My husband would find it helpful, he would want to know what the consultant has written, sometimes I forget things, it's quite nice it's written down. P8

Nursing staff also thought the summary note aided patients' memory and understanding:

It generally summarises everything so patients know what's happening—good for [the] relatives [too]. N1

The information in the summary equipped patients with the confidence and information to ask questions:

[The] summary gives you more confidence that it is okay to ask questions. [It] gives you more power. P8

The space to ask questions is very useful. I know that feeling when you have ten questions you want to ask and then you forget when the time comes. N4

Patient and relative views focused on the ability of a summary like this to allow mistakes to be pointed out to healthcare professionals at an earlier stage:

If something is missed [...] it can be pointed out to a doctor. R5

The idea that the summary empowered patients and promoted involvement in their own care was felt to have effects beyond the immediate hospital admission:

It means I can go back to my own doctors [...] and tell them what needs to be done! I think it makes me feel very confident. P2

3.2 | The summary changed other communication

The majority of doctor (8/10) and nurse (4/7) participants thought the summary did or would improve communication between patients and doctors. Several participants reported that the act of filling out the summary, or even just knowing the patient would be receiving one, resulted in a change not just in the written information, but in the way that they thought about the plan and spoke to patients:

[It] help[s] encourage getting rid of jargon when speaking to patients, it helps clarify what you're doing. D5

I think it gave me an opportunity to talk to the patient, to break things down [...] to give feedback to the patient, which I might not have done otherwise. D8

Others emphasized that the act of completing the summary helped them clarify a more patient-focused plan:

It almost solidifies the plan, more directed to the patient and what's important to the patient. D2

3.3 | The summary prompted questions about transparency and the 'right' amount of information

Questions about access to medical information formed part of the semi-structured interview and so was discussed with all participants. Transparency was brought up spontaneously in 11/28 patient and relative interviews and 8/17 clinician interviews, predominantly doctors.

Whether patients would rather have access to all their medical records raised a range of views:

I think it's better to know, because you worry more if you don't know... it's the fear of the unknown. P11

I think it would be quite confusing to patients... maybe it's not a good idea. R5

One perspective that was expressed several times was that having more information (such as seeing all their records) could cause worry through a lack of understanding or not having the information adequately explained:

If I read my full medical history and there were things I [didn't] understand, it would make me panic. R15

Three patients, who indicated that they would like access to all their records, said this was because they could then ask questions to better understand what was happening to them. Most clinicians and patients expressed the view that the summary provided the 'right' amount of information:

[The summary] captured what patients want, what I think patients want. D2

I think this [summary] is adequate; it tells me... everything that's going on. P13

This is a very easy, straightforward way of summarising: does what it says on the tin. P15

Two patients disagreed, however:

Not detailed enough, but maybe I have too many things to fit in there. P8



Clinicians were asked about the purpose of the traditional (full) medical record. Most felt the purpose was for transfer of information among clinical staff:

In notes we are communicating between healthcare professionals, it's a different purpose. D2

It was recognized by the interviewees that while clinicians should not withhold relevant information, the full medical records held more data than was practicable to explain in real-time to patients and that the information would be filtered by staff:

Yes, we have duty of candour, openness and honest [y]. But we know more stuff before a patient... they can know the necessities. N5

Not all clinicians felt this way, with a minority expressing the view that medical records should belong to patients:

It's their health, they are completely entitled to know what's going on with them. N3

3.4 | Barriers to implementation

Questions about confidentiality were included in the interview template as we thought this could be a concern for patients. However, 20/28 patient and relative interviews specifically mentioned having no concerns about confidentiality:

I see the worth in it so I don't mind... [it's] not information that anyone can do anything with. R14

Two participants commented that although it did not concern them, they recognized that data protection was a common anxiety. In contrast, 8/17 healthcare professionals voiced concerns about patient confidentiality:

I would be wary about anything in printed form, and patients are not always by their bedside. D2

There were no breaches of confidentiality or lost summary notes reported during the month-long trial period.

Clinicians were asked about the practicality of completing summaries. Reported completion times for the summary record by doctors varied from 'about a minute' to '5-8 minutes', but no objective data was collected. The doctors perceived the provision of the summary as an extra task. Most wrote additional text, rather than, as the researchers had envisaged, writing their usual PTWR impression and plan in lay terms. Participants were aware of the opportunity cost of the time taken to write the summary, although one noted that it might be of unequivocal benefit if used on selected patients rather than uniformly:

I could see it being used for a subset where I need to try to explain something and I need them to understand it. D10

Three patients saw no need for it since they understood their case well enough already:

I thought a lot of things in there were obvious to me. R10

However, many doctors and patients suggested that it could save time in other ways, for example, by reducing the number of or time taken handling complaints, as there would be a clear record of what had been communicated:

We always put up barriers and we are worried about the amount of time it will take. The evidence shows if you open yourself up more to communication there are fewer complaints, as complaints are about communication. It's a more front-loaded cost but in longer term it would be beneficial. D2

No doctor routinely continued to provide the post-admission summary to patients after the study was completed.

4 | DISCUSSION

4.1 | Statement of principal findings

This is the first study in the UK to investigate providing patients with a written summary of their care whilst they are still in hospital. The response from this group of patients was overwhelmingly positive: they reported that it helped them retain more information, provided transparency and improved their confidence in asking questions. Healthcare professionals reported that the summaries improved their explanations to patients by prompting them to reduce medical jargon and helped to solidify their treatment plan. Concerns about confidentiality breaches were voiced by clinicians but, unexpectedly, these were not shared by patients and no reports of breaches of confidentiality occurred. According to healthcare professionals, the most significant barrier to implementing these summaries is the time taken to write them; they are uncertain whether the benefits described are sufficient to outweigh the extra time burden in the long term.

4.2 | Strengths and weaknesses of the study

Most patient and clinician participants who were approached agreed to be interviewed and this included a wide variety of clinicians working on two wards. Nurses were included due to their role as educators and facilitators of patient-clinician communication.¹⁸ Differences between nurses' and doctors' views have been highlighted where

present, but these differences were few. The interviews were carried out during the patients' acute admission, so their recollection of events was still strong. Interviews were double coded, providing robust analysis.

The study was limited to one teaching hospital which uses an electronic medical record, so the findings may not be transferable to, or technologically feasible, elsewhere. Our participant responses may not be generalizable to other groups as data on participant characteristics was not collected, however information regarding the index of multiple deprivation (IMD) of the area was included to give an indication of the characteristics of the population involved. While no anxiety was reported by patient participants, clinicians retained discretion not to give the summary where they thought distress would be likely. No quantitative data was collected, for example, on time taken to write or distribute the summary or the number of questions asked by patients. Future versions of the summary could include adjustments for easy readability, for example, large font. We were unable to explore the experiences of relatives or patients who lacked capacity or did not speak English; future studies should ensure these groups are included. Interviewers were all clinically trained, which may have biased the research. Interviews were not transcribed verbatim, although having two researchers present ensured that one could ask the questions and the other recorded the interview in notes, with some sections recorded verbatim. Coding differences were few and were resolved via discussion; nevertheless, it should be acknowledged that discussions can be limited by power differentials and a bias towards efficient consensus.

4.3 | Discussion of findings in relation to other studies

4.3.1 | Tailored written information: Knowledge and understanding without anxiety

Our study suggests that patients value a written summary as a memory aid and to help those close to the patient stay abreast of problems. In a study of patients randomized to receive verbal only or verbal and written discharge information in an emergency department, 90% of the group who received written information knew their diagnosis, compared to 73% of the control group.¹⁹ Clinicians expressed concern that providing written information might provoke patient anxiety: in a similar study to ours, conducted in the United States, only 16% of patients reported being worried or confused by the daily notes they were given.¹¹ In a portal study only 8% of patients using the portals were confused or anxious about the information they saw.⁵ In our study, where pertinent information was selected and presented in an accessible manner, no-one reported anxiety, although there were reported concerns about *understanding* the content; future work should examine understanding of written summaries. The doctors in our study reported that they observed a change in their verbal communication during the study: they used less jargon and thought more about the structure of how they were

explaining things, to be consistent with the written information they were about to provide.

4.3.2 | Patient empowerment

Patients reported feeling more confident in asking questions, and appreciated the opportunity to spot and correct mistakes; this is consistent with other research conducted on written records^{11,20} and electronic portals.^{12,21,22} Although the summary note provided patients with a degree of additional agency, we recognize that there is still an element of 'curating' what information is given, which is more paternalistic than providing patients with their entire notes. The patients interviewed in our study seemed comfortable with this, trusting the doctor to tell them what they needed to know. Providing a summary of records rather than the entire medical record allows doctors to take on some of the emotional work of worry and uncertainty,²³ while still equipping patients with enough information to ask questions and challenge them. It is not clear, however, whether the patients in our study were aware to what extent the information was being selected on their behalf, which reflects a paradox. Patients have the prerogative to choose not to know things (and/or to prefer paternalistic behaviour from their clinicians), but, if they choose to see a summary record rather than their complete medical record, they will never know what they do not know—and so their choice can never be fully informed.

In primary care the effect of sharing medical notes with patients varies: older, less educated, non-white or non-English speaking patients reported the most benefit in a U.S. study,^{6,24} perhaps because they could seek help in reading and understanding their notes.²⁵ In our study we did not evaluate patient demographics as the sample size was too small for meaningful comparisons; any future research must include this analysis.

4.3.3 | Practicality of using summary records

As with other studies,^{12,26} doctors noted the increased time taken to write and explain the summary note. In previous studies, this was considered a worthwhile investment because of the perceived improved patient understanding. However, in these studies the unedited medical record was distributed, whereas in our study a separate summary note was written, resulting in 'double documenting'.²⁷ Without the additional resource of two medical students, the summary note stopped being distributed at the end of the study, suggesting that, in practical terms, the work needed was too much to undertake for the (at the time, intangible) patient benefit observed. The feasibility of maintaining confidentiality with additional pieces of paper being given to patients was also explored. In our study no patients were concerned about this and there were no reported loss of notes or breach of confidentiality—this is consistent with other studies.^{11,28} Concerns about breach of confidentiality should therefore not be seen as a significant barrier to information sharing in hospital.



4.3.4 | The role of the traditional medical record

Discussion about the purpose and ownership of the traditional medical record is at the core of any consideration about sharing it. Some clinicians perceive it as a 'working clinical document', partly a communication record between staff, and partly a training resource. Senior doctors can give feedback on what juniors have written and juniors can learn from what their seniors have documented. Urowitz noted that doctors feel that they have 'ownership' of the medical records and are unwilling to sacrifice this.²⁹ Doctors know, however, that the medical record can also be used as a legal document which records a history of events. Its traditional construction, style and content were not designed to be patient-facing, and it is not known what would be lost in terms of training or clinical reasoning if records were made routinely available to patients. The summary record, in contrast, was designed explicitly for patients. It creates some accountability as patients are more aware of what should be done whilst they are still in hospital. This could reduce complaints as problems can be resolved in real time. It achieves a balance between respecting and enhancing patient autonomy, while preserving the communication and documentation functions of the medical record.

4.4 | Unanswered questions and future research

This study demonstrated the impact on patient-clinician communication as a result of sharing a PTWR summary; however, barriers to implementation were identified, in particular the need for extra human resource. The intervention could be further iterated and optimized via collaborative design methodologies³⁰ with a range of users. A further mixed-methods multi-centre study would be needed to quantify changes in patient knowledge and understanding of their diagnosis and treatment plan, what they remember of what was said at the consultation, satisfaction and engagement in care (as indicated by confidence in asking questions), including self-care behaviours. The effect on different demographics of patients must be included in any future analysis. While health economic analysis would be secondary to investigating whether the note changed patient knowledge or experience, its enquiry would help ensure that the implementation of such an intervention was properly resourced. Finally, patients could be given the opportunity to see both their full records and a summary, in order to be fully informed about what is contained in the medical record and what doctors are selecting to put in the summary, before being asked which method of information sharing they would prefer.

By putting patients at the centre of future evaluations, and looking for unintended as well as intended effects, we can develop a new model of information sharing which benefits patients and clinicians.

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CONFLICT OF INTEREST

Z.F. had financial support from Wellcome for the submitted work; no authors had any financial relationships with any organizations that might have an interest in the submitted work in the previous 3 years; no other relationships or activities that could appear to have influenced the submitted work.

AUTHOR CONTRIBUTIONS

Anna L. Crucefix and Aaron P. L. Fleming conducted all patient interviews and some HCP interviews. Caroline S. Lebus conducted some HCP interviews. Zoë Fritz conceived of the study. Zoë Fritz and Anne-Marie Slowther designed the protocol, wrote the study materials and got necessary ethics and institutional approvals. All authors were involved in the data coding and analysis, with Caroline S. Lebus and Aaron P. L. Fleming coding all transcripts, and the remaining authors contributing to identification and refinement of themes. All authors were involved in drafting and editing of the manuscript.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of this article.

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