

# Information sharing in health care: a patient's perspective

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When it comes to getting ideas for improvement, no vantage point in health care is better than the horizontal position.<sup>1</sup>

**THERE ARE FEW INDUSTRY SECTORS** more in need of better solutions to information sharing and knowledge management than health care. The issues surrounding information management in the health care sector are pressing and complex. This paper explores my subjective experience of information sharing as a patient within a medium-sized Australian public hospital and illustrates the potential impact on safety and quality.

I am a health services researcher. My case was not urgent or complex, I am not disadvantaged or seriously ill, and the hospital's waiting list for the procedure was short. The outcome of the surgery was good and my satisfaction high. The case is, however, extremely pertinent to the current debate around information sharing in health care.

## Surgery was successful

An appointment was offered within a week of referral by my general practitioner. The hospital, a tertiary referral facility offering most services to patients, is situated in a growing urban area.

I was examined by a specialist, and a decision was taken to perform exploratory surgery. A further appointment with an anaesthetist was made due to concerns about a recent chest infection which might require a delay in performing the surgery. At this appointment, routine electrocardiography was performed which

produced an unusual reading. I explained that this result always occurred and it had been investigated by a cardiologist several years ago at another hospital and concluded to be an invalid reading. Nevertheless, the anaesthetist asked me to return to my GP to obtain a referral to a cardiology specialist and asked the nurse to track down my medical record from the previous hospital.

The GP decided to refer me to a private radiologist collocated at the hospital. An echocardiogram subsequently revealed that the heart seemed entirely normal. I took the report from the radiologist to the anaesthetist who was satisfied that I was clear of suspected heart damage. A decision was made to postpone surgery for 8 weeks due to the continuing chest infection.

Upon arrival at day surgery at the appointed time, another anaesthetist explored the issue again with me and then surgery went ahead as scheduled. The procedure was successful and I went home the same day, suffering no effects and within the estimated time frame.

## Information sharing issues and analysis

During the course of this unplanned research as a participant-observer in one part of the health system, I had cause to think about the patient's role in information sharing, the limited sharing of patient data within the health authority, and the extent to which physical arrangements in the hospital seemed to dominate information-sharing practices.

My previous knowledge of the unreliability of electrocardiography for me was, I think, correctly subjected to further checking. Serious complications can and do occur during anaesthesia with undiagnosed heart problems. Surgery was delayed due to the chest infection, but

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the absence of a centrally located patient record containing the reports of the cardiologist meant that surgery would have had to be delayed in any case until these were obtained. The absence of a shared medical record is an issue still not resolved satisfactorily. Delays in surgery due to the unavailability of information at the right time are expensive and undesirable.

Perhaps more surprising, however, was that the collocated private radiology clinic was unable to send a report to the anaesthetist literally 5 metres away in the same hospital, or to place such a report on my medical record held by that hospital when I requested them to do so. I had to collect the report at a later date, transport this to the GP, then transport it back to the hospital to be viewed by the anaesthetist several weeks later. Thus there were many opportunities to lose, forget or damage the report.

The flow of information in health care is towards the clinician ordering the tests. In this case, the radiology report went to the GP, not directly to the clinician who needed it, even though the latter was in the office next door. It is likely that this scenario is replicated hundreds of times every day in the health care system. Clinicians with an interest may be unable to access information in a timely fashion because they are not in the direct path of information flow. Not only does this situation represent waste, it also represents unsafe practice. Providing information rather than restricting it must be seen as care itself if we are to shift the current paradigm of knowledge management in health care.

My medical record at the hospital contained all of the reports as affixed by different staff, but each time I saw another staff member, I was asked for the report again. This led to some discomfort on my part, as staff scrambled through the paper in the record attempting to find the information. But even more discomfiting was the method used to record information revealed through the various examinations. Notes were scribbled sideways in the margins, and "PTO" signs inserted by hand referring the next reader to more notes on the same theme joined by arrows and lines overleaf. Each new anaesthetist viewed the last lot of notes with more dismay than the previous anaesthetist, put them

aside, and asked me to explain what was going on. One anaesthetist rewrote the notes in a neat and legible hand after discussing the issue in detail with me and referring to the reports, but this new sheet was not on the record when it was opened by the last anaesthetist who would subsequently be present at surgery. So the story was told yet again, and the reports consulted again, and I was told that I must keep copies of all reports and always bring them again in case reports had been lost.

Where do lost reports in the health system go? Too anxious to ask this question during the final phase of the episode, I did not find out. I was sufficiently composed, however, to inform the last anaesthetist, once more, that I had suffered a pulmonary embolism at a previous point in my medical history. The anaesthetist promptly re-reported this on the record and noted a request that I be provided with compression stockings to wear during surgery.

After this interview, the record was placed back in the perpendicular storage trolley at the day-surgery reception area, together with the x-ray films I had brought in. Someone must have looked in the file before I was asked to get changed for surgery, as the stockings appeared. It seemed unlikely that I would have got the stockings had I not repeated my story.

Suitably dressed in operating theatre clothing, I was escorted to the preparation room with the throw away question by the nurse "Now, you don't have any x-rays do you?" as we were entering the lift. Somehow, the x-rays had become separated from the medical record in the perpendicular trolley, so a return was made to reception to find them before continuing to surgery. On reaching the preparation room, a patient trolley was produced which had a slot in it for the record but not the x-rays. These were perched on my lap as I was wheeled in to the pre-operative room, beyond which lay the surgery through a set of double doors.

As the theatre nurse struggled to insert the needle into my hand, the anaesthetist called out through the open double doors and asked me what my correct weight was. I called back the answer, hoping that the clattering in the theatre did not impair the anaesthetist's hearing. The

medical record lay nearby on a table, the x-rays were nowhere to be seen and I received the preoperative sedative with some relief.

## Conclusion

This experience as a patient undergoing treatment in the health system is probably a common one: safe in the end, but arguably full of potential to be otherwise. If my first language was not English I am not sure that I would have been able to adequately communicate my medical history during multiple consultations and to answer important questions, even with an interpreter. If I had been confused, or forgetful, or less informed about the health system, my own history, the location of previous tests or even my own weight, error may well have been the result. If I had been less confident, if I had failed to bring the reports in or follow up on requests, if I had not moved information through the system myself — at best there would have been further delay. It is possible that I would have been relied upon less if I had exhibited less capability, but perhaps not. If not, who would have been relied upon? What would have happened if information which I did not realise was crucial had gone missing?

We must get over the difficulties of implementing an electronic medical record, not just to improve efficiency within the sector but, more critically, to improve safety. Information needs to be in the right place at the right time. In this case, the delay was immaterial — for others, it may be critical. Getting rid of the physical structures (file holders, trolleys with slots for files, the files themselves with their flimsy paper stuck on wire holders) must occur before staff will routinely access any electronic data via hand-held computers, work stations or bedside equipment. The staff seemed to cling to the file but yet not consult it, to put it in the correct slot but not to take it out again. We have to get rid of the old tools before staff will use the new: let's stop ordering trolleys with slots in them.

We know patients don't like to tell their story again and again to different professionals, but it seems that this will continue in the absence of

legible and enduring record systems accessible to the appropriate people. We trust patients to carry reports here and there instead of sending them electronically, but until providers are able to deposit them electronically in some centralised system we will just have to continue to extend this trust, even when some candidates might not be up to the job.

Privacy concerns about electronic data sharing are one of the major factors said to be holding up the implementation of an electronic record system, but this may be something of a furphy if we measure the advantages against the disadvantages of a centralised electronic record system. Perhaps the delay in implementing an electronic medical record system has more to do with information as power, and information flows as control. Professional boundaries are continually negotiated and reproduced through various means, and agreement on the form of the electronic medical record seems to be one of them at present. But lack of appropriate information sharing is one of the major factors involved in adverse events. The process of reinforcing professional boundaries, if this is what is holding up change, needs to be moved out of this arena.

Richardson<sup>2</sup> calls for replacing negotiation with legislation to overcome this blockage. I'd argue that reaching consensus among professional groups by consent is more powerful in the long run. We need to leave the old information tools behind, take up and get used to using the new ones. For this patient, it cannot come soon enough.

## Competing interests

None declared. Stella Stevens is engaged in research, development and teaching work in the area of health services management. The views expressed in this paper are based on her personal experience.

## References

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