Do we need a national electronic summary care record?

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Clinical summaries are central to good communication when patients cross the boundaries of care. A discharge summary encapsulates the key information that a general practitioner might need when a patient returns after hospitalisation. A referral letter synthesises a GP's knowledge of a patient and the clinical questions that need to be answered. A specialist's letter summarises what is needed for a patient to return into the GP's care. These documents are created by a single clinician for a specific purpose, and are prime targets for computerisation. Electronic referrals and discharge summaries are natural extensions of existing clinical tasks and have been shown to improve the quality and timeliness of clinical communication.[1-4]

It seems but a small step to extend this thinking and imagine every patient having a perpetually updated online summary of care, or electronic summary care record (SCR). Indeed, such an SCR is widely seen in many countries as a useful staging post to a full-blown national shared electronic health record (SEHR). Australia is also embarking on the creation of a national personally controlled electronic health record, a form of shared record structured around patient-controlled access.[5]

A shared record allows for existing clinical records, stored locally in primary care locations or in hospitals, to be seen remotely by other providers, with patient consent. In contrast, the SCR is typically created not by clinicians, but automatically, by uploading extracts from existing records. This structured summary is typically stored centrally in purpose-built systems, not locally in existing systems, and usually contains elements such a patient's name, address, age, allergies, current medications and perhaps diagnoses. Although such an SCR is nothing like a distributed shared record, it is still a likely candidate for early implementation as part of the national program in Australia. While we await the larger SEHR, clinicians might (at least at every unscheduled encounter or emergency presentation) access the SCR for crucial information. What is wrong with that?

Plenty, it seems. There is now robust evidence for the positive impact of many e-health interventions on clinical safety and outcomes. But, surprisingly, there is almost no literature about the benefits of the SCR. When the Royal College of General Practitioners in England recently examined the literature, they found little evidence to guide SCR creation or use.[6] The SCR is thus an essentially unevaluated idea. In the only major review of the SCR internationally, a recent analysis of 416 325 encounters in primary care, out-of-hours and walk-in centres in England found that the SCR was used in only 4% of GP consultations (21% if only those patients for whom the GP had actually created an SCR were counted).[7] When accessed, the researchers found that the information in the SCR *seemed* to support better quality care, but that any benefits were more subtle and contingent than anticipated.

Australia has been slow to advance its national e-health system in comparison with other nations,[8] and the one great advantage of being a slow follower is that we can learn from the experiences of others. Given this evidence, should we lead with the SCR as a stepping stone to the national shared record? The answer is probably no, given that the SCR has several unresolved problems.

ABSTRACT

- Electronic referrals and discharge summaries can improve the quality and timeliness of clinical communication.

- The electronic summary care record (SCR) extends the concept of digital health summaries to create a perpetually updated and centrally stored summary of care, extracting key data from local systems after each encounter.

- The only major SCR evaluation to date, in England, found that rates of usage were low, and any impact on care was difficult to quantify.

- The SCR is seen by some as a first step to building a national distributed shared electronic health record (SEHR). However, the SCR may be a problematic diversion, creating a need for centralised databases, while the SEHR can function by sharing locally stored records, letters and discharge summaries.

- Uncertainty about the quality and provenance of SCR data raises concerns about patient safety, as key data may be absent and old data may persist, partly because of a lack of ownership of the summary.

- A national e-health strategy should emphasise the true stepping stones to a distributed and shared electronic record, including encouraging the uptake and meaningful use of electronic clinical records, clinical messaging, electronic discharge summaries and letters, and services such as decision support and e-prescribing, all of which have good evidence to support them.

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1. What is the problem being solved?

The first and most basic rule of informatics is that information technology should be problem-driven, not technology-driven.[9] Because a national shared record will take a long time to build, the thinking seems to be that we need the smaller "minimal" data in the SCR now to see us through the bridging period. As Greenhalgh, lead author of the English SCR evaluation, has pointed out, the example most often cited in support of building the SCR is the presentation of an unconscious patient to an emergency department. Yet it is entirely unclear whether the SCR is truly fit for this purpose, or how often it might actually change care in the first few minutes after presentation.[10] It is not known whether the cost of a national SCR justifies its deployment for just this one specific purpose (and indeed, the English SCR began without a Treasury-approved business case being presented). The SCR thus risks being a technical and political, rather than clinical, staging post. Defenders of the SCR often conflate it with the SEHR, not realising how much they differ from each other.[11]

There are indeed natural points in health care at which we do create and use summaries to great effect. Instead of supporting such real clinical summarisation tasks at hospital discharge or referral, the SCR elects to do something else that is "based on an unresearched and unverified need".[12]

2. The summary care record changes the approach to designing national e-health infrastructure

An SCR typically requires development of special centralised summary databases — a classic "top-down" approach to e-health. This is at odds with recent thinking that a "middle-out" approach is more likely to succeed,[13] an approach strongly endorsed in the final report of the National Health and Hospitals Reform Commission.[14] A middle-out approach would see sharing of existing clinical records and summaries, including discharge summaries and letters, rather than imposing a new system from above. The risk is that we think we are building a distributed record system, but that the SCR becomes a Trojan horse for top-down, centralised e-health — a risky proposition given the international evidence.[13] The concept of making a strategic exception for the SCR should be ringing warning bells. It may be that the SCR, rather than being a quick stepping stone on the way to achieving a full national shared record, will turn out to be a problematic diversion that fundamentally changes our national e-health strategy.

3. An extract is not a summary

To be of value, the SCR should provide an authoritative high-level view of a patient. To create a patient summary is an act of knowledgeable synthesis, not just of mechanical data extraction. GPs are familiar with the notion of a clinical summary and understand that, in creating a summary from multiple sources, data must be interpreted, intelligently added, and merged or deleted to keep it consistent and up-to-date. Who is to decide whether a drug should remain on a patient's current medications list when they are treated by multiple clinicians? How do old drugs get dropped off the list? This synthetic act requires time, access to a wide variety of detailed data sources, clinical knowledge and familiarity with the patient. It might also require team consensus. The quality of an SCR is compromised if crucial data are missing, if old data persist, and if no one is there to "join the dots" across the data.

4. Absence of evidence is not evidence of absence

In the English system, there is no guarantee that every encounter will appear in the SCR, as a clinician may fail to enable the upload for a variety of reasons. A reader does not know whether key information is missing. This raises significant concerns about patient safety.[15] In rolling out an unevaluated e-health system, no matter how apparently simple, there is always the risk of unintended consequences for patient safety.[16]

5. A multiplicity of authors

Data quality and clarity of provenance are essential prerequisites if clinical data are to be trusted and not lead to patient harm. In England, SCR data are currently uploaded by a patient's GP, but the intention is for it to be extracted from the records of multiple contributors, with no individual clinician responsible. As one critic has pointed out, "in no other safety critical system would people just heap up data and hope that someone will deal with it".[17] With multiple authors contributing to the SCR, it may be very difficult to attribute errors to individual clinicians. Improving the level of clinician accountability may require even greater centralisation of processes, governance, systems and resources.

6. The summary care record is not infrastructure

The SCR is either a specific solution to a real clinical problem or it is generic infrastructure that supports multiple uses. If English usage rates reflect the long-term utility of the SCR as a point solution, then it is unclear how much benefit will come from this large investment. The key to national infrastructure is that it underpins multiple uses, some unanticipated. If the SCR is infrastructure, then it should feed into other systems, some of which we already know well, and not be an end in itself. The SCR is a specific solution to an ill defined problem, masquerading as infrastructure, which prevents us asking what it is for.

Other models

A response to this critique is that the problem lies not with the idea of an SCR, but the current English version of it. Other models might be better. Rather than simply having an uncurated upload of data, could we not move to a model with a human-curated summary? Human-created summaries stored electronically may be of use in the same way that paper summaries are.[18] Someone, possibly a GP, could be the custodian, perhaps after each visit. The curator would not just upload data, but would actively manage it to maintain a consistent and accurate picture of the patient's health. To avoid it becoming out-of-date between visits (when patients might see other GPs or specialists or go to hospital), the curator could be prompted to update the SCR when these other encounters happen.

But this would create a new task in information management for the busy GP. There are already real concerns in England that the SCR is generating additional workload for GPs — workload that is not being recognised or rewarded, even without this new curator role.[19] No doubt incentive payments will encourage GPs to upload data, but if the task of curating the SCR is fully costed by GPs, incentives may not be enough. As the quality of summaries is inversely proportional to the time available to create them,[20] GP time would need to be released from other tasks to get the best quality summaries.

Eventually, we may well have a computer-curated summary, with intelligent programs supplanting humans in deciding which elements to add, merge or delete from the summary. It is not clear how safe or effective such technology might be today, or whether this is technically feasible at present. There is a large difference technically between computer-generated extracts (produced by collation of selected verbatim data) and computer-generated summaries, which require true machine interpretation of text.[21] Multi-document clinical text summarisation methods remain a minor area of research,[22] and much more effort is needed before automated clinical record summarisers are widely deployed.

The Scottish emergency care summary is an instructive alternative model. As well as a medication summary, every Scottish general practice sends automatic updates of all prescriptions and adverse reactions to a central database twice daily. Early indications are that this system is providing clinical benefit.[23] The full automation of the Scottish system and its reliance on extracting all prescribing events, rather than a summary alone, may be the critical factors if it proves to be a better model.

Other countries, including Belgium, Denmark and New Zealand, are implementing their own versions of the SCR, but evaluations are hard to come by. A recent evaluation of the summary locum record in the Netherlands identified persisting

technical challenges.[24] Small variations in approach among different countries may ultimately prove to be the difference between success and failure, but right now we don't know which differences are important. It may be that a middle-out version of the Scottish system is what is ultimately needed, in which clinical data such as prescriptions and allergies remain stored in local clinical systems, and summary views are created dynamically and for specific purposes, obviating the need for a centralised data storage system.

Whether or not one chooses to accept that the SCR is a flawed idea, the ongoing problems in England should cause all to pause and think again. In June 2010, the British Medical Association (BMA) adopted formal motions voicing concern about the SCR's opt-out consent model and the implications of the SCR for GP work.[25] In July 2010, the BMA's General Practitioners Committee went further, asking for the SCR rollout to be halted and completely reviewed. The resulting internal review for the Minister of Health was brief,[26] but led to a significant cutback of the information stored in the SCR and an altered patient consent model, pending further evaluation. This is not what success looks like.

In summary, research evidence for the benefits of the SCR is scant. We don't have clarity around its purpose or whether it is fit for that purpose. We don't know what impact the SCR might have on clinical care, or what form of the SCR has most impact. We don't know how often the SCR would be used, or what form of it is most likely to be used. We don't know the safety profile of the SCR, or which form is safest. We don't know the return on investment for the SCR, or the opportunity costs of leading with it ahead of proven e-health systems. And we don't know the long-term program risks of moving to a more centralised e-health strategy than would otherwise be necessary.[27]

Right now, we should keep our eye on the main game, which is to develop a way of sharing our existing health records nationally and connect up the different silos of clinical data. Making clinical data "liquid" enough to move across the system is our primary challenge. We need to ensure that every clinical service has its own electronic records, and that these records are meaningfully used.[28] We need to make sure that these records comply with standards so they can be exchanged when needed, and we need to develop robust, secure and simple ways for patients to consent to different members of the care team to see each other's records.

We must focus on the e-health services that research tells us will make a difference. There is good evidence that electronic record use improves care, that electronic prescribing and test ordering are of real benefit, that electronic discharge summaries are of value, and that decision support and reminders to undertake preventive tasks improve safety and outcomes.[27] By all means let us invest in pilot SCR programs that evaluate dynamic summary views built on top of the shared record (instead of creating a specialised SCR infrastructure, as now contemplated). But implementing a centralised SCR today, with no evidence behind it, and ahead or instead of proven e-health systems, seems simply unjustified.

Competing interests

None identified.

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