

## Decision Support and the Personal Health Record

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### Foundations of Decision Support

The idea that computers might help clinicians make decisions – render diagnoses, craft treatment plans, give advice – was among the first exciting uses, or potential uses, for computers in health care. It seemed a small step from the imperative to use information technology for storing patient information to seizing the opportunity presented when intelligent machines could be used to *analyze* that information.

It turned out that a larger step, or many of them, would be needed if users – now including patients, in principle – were to realize the opportunity of computer-assisted diagnosis or any other kind of decision support. Clinical decision support systems or expert systems (for their attempts to emulate human experts) were and for the most part remain inferior to their human counterparts. But competing forces are at work.

One force is that human inferential capacity, including the ability to incorporate background knowledge, is difficult to trump. The countervailing force consists in the quotidian limit on human objectivity, memory and recall; there is just too much to remember without bias, preference or the vagaries of cognitive function. Computers are objective and can summon vast amounts of information. Humans try to be objective but can rely on inferential strategies fueled by observations, knowledge about how people behave and understanding of links between and among seemingly unconnected facts.

Personal health records (can) incorporate varying degrees or levels of decision support. Most such applications have long been in use in other contexts and are quite basic and hence uncontroversial:

**Reminder systems:** A personal health record can include a feature that reminds a user to take her medicine at noon, or schedule an appointment for next week, or take insulin when monitored blood glucose reaches a certain level.

**Alarm systems:** Closely related to reminder systems, a personal health record can send a signal, make a phone call, send an email or, well, sound an alarm

if any tracked datum falls outside an accepted range. Critical care units in hospitals have alarms sounding all the time.

**“Consider this” systems:** More complex, but still pretty simple, are computer applications that can offer a number of suggestions in response to information received or to queries. A system might communicate that a patient should consider altering his diet, check whether a medication dose has been missed or see a doctor or nurse.

## Human Decisions, Computer Output

True decision support systems, or clinical expert systems, can do much more than any of these rudimentary applications. They rely on large databases and employ complex inference engines in attempts to render diagnoses or commend various therapies. The literature on ethical issues related to use of clinical decision support systems is well developed and makes clear that an intelligent machine should be regarded as a tool and not a replacement for competent human judgment.

Such a stance is cautious and sound. It also elicits a number of questions about appropriate use: What if a clinical expert system is shown to be better than a human – are we then *obligated* to use it? Answer – maybe, perhaps probably. What if a system is generally pretty good – may a doctor or nurse use one as a decision aid? Answer – probably. May a clinician accept without question the output of a really good system? Answer – probably not; maybe never. And, for our purposes, perhaps the most interesting and difficult question of all:

*Ought patients use clinical decision support systems – embedded in applications as part of a personal health record – and rely on their advice or recommendations? With what constraints? Relatedly, Who is responsible if something goes wrong?*

Behind all these questions is a lattice of tradition and presumption about what constitutes medical practice and advice. Humans and only humans practice medicine and nursing, meaning that only trained and licensed health professionals may diagnose and treat human maladies. Morality requires adequate training, continuing education and the judicious exercise of clinical decision making in the practice of nursing or medicine. Morality also requires that clinicians use the tools necessary to do a good job. It follows from this that there is a duty to reserve for humans those tasks for which they are trained and licensed, and to use tools appropriate to those tasks.

Unlike a hammer or a scalpel, though, computers extend not our hands, but our brains. Making a diagnosis and giving medical or nursing advice is as simple as a mother’s warning and as complex as an internist’s suite of differential diagnoses. So, when does computer output constitute the practice of medicine?

## Personal Health Tools

As patients acquire a greater role in their own care, including the assumption of increased responsibility for controlling health information, personal health records and other patient-driven resources need to be assessed in terms that help make clear when a use is appropriate and when it is not. There is no bright line between (ethically) acceptable use and unacceptable use.

There are, however, a number of rough-and-ready rules, or at least guidelines, that can help in this process. We can plot these on three axes: education, scope and consequences.

**Education:** Adequate education or training in the proper use of a personal health record with decision support functions is essential. Patients and providers must be familiar with a device's intended uses and known limitations. They must *understand* and *appreciate* these functions and limitations. They need to be encouraged to question each other and appropriate authorities if there is something they do not understand. Any sense that a device is not functioning properly or that its output is counterintuitive or faulty should trigger a query.

**Scope:** We earlier itemized a number of simple "decision support" systems, rendered here in quote marks because the decisions are, well, pretty simple. The question whether more complex decision support ought to be included as part of a PHR should be answered as a function on the breadth of the kinds of decisions that might be made. "Take your medicine at noon" is simple; "change the dose" is not. As the scope of decision support embedded in PHRs grows broader, additional education is required. It might even be there are kinds of decisions or recommendations no automatic system should give.

**Consequences:** One of the measures of any technology's suitability is the risk of various bad outcomes. The riskier the technology, the more we should either reduce that risk (by increasing education or limiting scope) or eliminate it – by forbidding its use. One of the ways to reduce the risk of any decision support system is not to take it seriously. In the hands of a human expert – a physician or nurse – we can counsel (or require) the clinician to default to professional judgment. In a PHR, the risks of certain decisions might be so great as to require they not be given. This is, of course, going to depend on the consequences of not having the advice or decision in the first place

What this amounts to is a demand for more research and experience in the development and use of decision support features for personal health records. Indeed, while the literature on ethics and decision support systems is extensive, it is so far silent on the role of PHRs. Whether any consequence can be mitigated by increased education or throttled scope is an empirical question, and we have ample reason to believe the best way to reduce uncertainty in the use of health

tools is by learning more about how they work, how they are used and how to ensure they do more good than harm.

### **Readings on Clinical Decision Support Systems**

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