BCS Thought Leadership Debate, 16 May 2005

What’s So Different About Electronic Patient Records?

This report summarises the views expressed at a BCS Thought Leadership Debate about issues surrounding electronic medical records. The event was on 16 May 2005 at the Institute of Directors in London. Two speakers stimulated debate with short talks and then the 45 participants discussed the topic in small groups over dinner. Most participants were from health or health IT. At the end of the evening each table reported back to the entire gathering.

The Story So Far

The word ‘so’ in the title of this debate - what’s so different about electronic patient records? - adds an accusatory tone and invites the response one sometimes hears: ‘There’s nothing different; there’s just a universal failure to get on with it. We have the technology.’ And if indeed there is nothing ‘so’ different about electronic health care records, there is nonetheless a lot to account for in explaining away the reality that work has been going on in this area for 40 years and that progress has been slow.

Decades of strategies and of effort by some remarkable people have gone into coding schemes and terminologies and into representational techniques from other fields which have not fared well in health. A bank statement represents a limited number of types of transactions which have standard form; an airline seating plan is just that. But representing health-related information in computer systems is a real challenge. The techniques we need are still close to the edge of our information sciences, and over the edge for current production systems. In general no other field even attempts what health care expects.

Patient Record Complexity

The issue here is that patient records are a mixture of data, facts, opinion and observations from and for a wide range of clinical professionals and purposes.

The temporal and contextual properties of this varied information make health records unlike any other. Information that is hugely important in one context - such as automated blood pressure readings taken in hospital after heart surgery - may be of little significance to a GP during an appointment some weeks later, whereas a single routine reading can be highly significant years later in the event of unexplained heart failure.

In addition, although basic data such as blood pressure or haemoglobin readings are precise and easily categorized they might be linked to observations and non-unique interpretations or opinions such as ‘it is low’ or ‘possibly due to inflammatory
bowel disease’. Indeed, patient records can contain seemingly contradictory statements, but there might be no contradiction if the statements are by different observers at different times.

Such observations, interpretations and opinions are difficult to record in a structured form. Possible relationships between pieces of information make patient records very complex – but these records must meet the needs of different specialists: some might be interested in a patient’s psychiatric history, others in the progress of diabetes. Different specialists will want specialist information and will interpret it in their own specialist ways.

Communication

The combination of opinion and factual data which might or might not be relevant, and the problem of structuring all this information in a patient’s record, mean there is an issue of communication between health care professionals – especially as some information might be stored only in a GP’s head. Can a patient’s current GP or specialist interpret what another GP wrote 30 years ago? Health care is unlike other fields, such as banking, where different banks’ records can be brought together to show all a person’s transactions over many years. With health records the important issue of context can be lost as records move around or are transcribed or recreated, following patients who are increasingly mobile.

The IT Response

All this adds up to huge complexity – which is almost always not appreciated. Systems specialists new to the field fail to spot the complexity, because health care is unlike any other record system they have encountered. If they do glimpse it they attribute it to doctors being unable to agree on anything. At the same time health professionals no longer see the complexity, because they have spent years practising how to handle such information without thinking about it.

There have been two typical responses.

The first shies away from the complexity and asserts that everything will come together through ‘enterprise interoperability’. This means the complexity is pushed on to the design of the interoperability – which never appears.

The second response denies the complexity – which gets pushed on to the requirements, specification, and design of the ‘solution’, and the whole thing crashes under its own weight.

There sometimes seems to be a blind faith in health care, although predominantly far from the sharp end of care delivery, that top-down IT solutions, addressing untested requirements and loosely-assembled specifications, can cure problems without the immense growing pains associated with such disruptive technology
and without commensurate and complementary focus on bottom-up investment in know-how, disciplined experimentation, user capacity development and organizational change.

System Development Issues

So the system problems seem to have revolved around a number of unresolved issues about:
* Requirements: who owns them, if anyone; whether they can be defined and articulated in a way that can underpin sound specifications and implementations; how they are expressed and standardised, in terms of functions, data and accountability; and whether they are realistic and flexible enough
* Specifications: how do we frame the practical development, procurement and standardization of health record systems that are fit for their purposes, as expressed through the requirements
* Implementation: how do we approach implementation and user capacity building so that health records are practical, scaleable, and interoperable, and can thereby contribute effectively, in both health and social care, from the most general to the most specific services.

Too Ambitious?

We will wait a long time if we seek perfection, but what we do must be good enough. But do we have a concept yet, and are we prepared to accept good enough for now? Do we need health targets for the UK Connecting for Health programme: for example aiming to cure 75% of ill people by implementing IT – and if not, why are we pursuing the programme if not to improve people’s health? Is IT to be just a substitute for paper or do we expect it to bring something more? Are we entirely clear about what the programme is intended to support?

Perhaps we need to focus at least initially on simpler tasks, and get them done, without shying away from those of greater complexity. The UK is arguably leading the world, at least in the concept of what we are trying to do in health care systems, and some remarkable people are leading the fraught agenda of the Connecting for Health programme – but can it succeed on anywhere near the scale of aspiration or in the defined timescales? A job will be done as well as it can be – and this time we must learn from it: little has been remembered from the lessons of earlier efforts.