

Guest Editorial

Fantastic Data and Where to Find It.

When I was a Junior House Officer in the old RVH back in the mid-1990s I thought digital technology was on the cusp of completely revolutionising healthcare. I wrote a program for my Psion organiser called “WardRound” that allowed me and some of my colleagues to track our patients and their results and to electronically manage handovers, tasks and theatre lists. It was effectively an electronic health record system in our white coat pocket alongside our Oxford Handbook - and we did make some preliminary explorations with the publisher into trying to digitise that too...

Over two decades later, IT has led to some considerable improvements in how we deliver care, but we’ve unleashed a magical menagerie of systems that, while they work well within their narrow area, are often difficult to get to play nicely together. The data within these systems largely stays locked away, out of reach of other systems and divorced from the patient. When we’ve created interfaces, integration engines and messaging standards, those workarounds have tended to be partial, costly to set up and maintain and prone to error and miscommunication.

It’s ironic that in a modern healthcare system, where many of our treatments and diagnostic modalities are at the technological cutting edge, we’re still massively reliant on paper charts, Post-It notes, corridor conversations and custom-and-practice to provide the glue that binds it all together. And then there are the IT systems and procurement processes that don’t work well, and arguably get in the way of patient care.

The Expert Panel chaired by Prof Rafael Bengoa¹ recognised that in order for our Health & Social Care System to survive, we need to transform how we deliver services. The “Quadruple Aim” of healthcare calls for: improving patient experience of care, improving the health of the population, achieving better value by reducing the per capita cost of health care, and improving staff experience. This means substantial process redesign, and digitising the patient record is an inescapable component of that. Professionals need better information. Patients need to be better enabled to manage their own health.

For this to work we need to break down the barriers between our multitudinous silos of data, so that the data can follow the patient across the traditional boundaries between care domains in the system.

In some ways, the digitisation of healthcare is already underway. The Northern Ireland Electronic Care Record (NIECR) is the jewel in the crown of our health IT ecosystem. From the outset it was, and remains, a clinically-led, IT-

supported programme to address real patient-facing issues. There is no doubt that it has delivered major benefits in making patient data accessible, but, behind the scenes, the effort of maintaining all the interfaces to multiple systems is impeding new developments.

Globally, the story of digitising healthcare is not one of unalloyed success, and the example of the costly National Programme for IT (NPfIT) fiasco in NHS England is salutary. Our positive experience with NIECR is something of a rarity - the rule seems to be that large-scale IT deployments in healthcare create more problems than they solve. In his frank and enlightening book “The Digital Doctor”², Dr Bob Wachter explains some of the perils and process problems involved in implementing Electronic Health and Care Records (EHCRs), as well as the human factors that wreak havoc. Issues around security and governance are hugely important. And when problems arise in clinical processes, they very frequently turn into clinical risks that may result in harm to our patients. However, as NIECR shows, it can sometimes turn out right.

We need to understand where the risks lie. If we don’t address the problems caused by disjointed data systems, vendor lock-in, paper records and disempowered patients, we will continue to haplessly chase our data around a system that will collapse. Costs will continue to rise, inequalities will build, the economy will suffer and we’ll lose opportunities to make a difference. Most of all, patients will be exposed to avoidable harm.

It might seem attractive to purchase an all-singing all-dancing EHCR that will do everything - assuming that we even *know* what we want. There is a slight problem - such a fantastic beast does not exist. While some current “megasuites” promise a great deal, they can’t cover the full needs of a regional health economy, so there will always be the need to integrate other systems. Furthermore, many of the specialist bits that they can do aren’t as good as the “best of breed” software solutions that have been specifically designed for those use-cases. There are also serious issues about access and sharing of data in vendor-specific data repositories, as well as providing quality analytics to healthcare planners.

Part of the solution is to insist on interoperability from the outset. “Interoperability” is a tricky word that can mean different things in different contexts. My own view is that it must encapsulate the principle that data is collected once, then shared seamlessly across multiple care scenarios in order to absolutely minimise time spent at the computer and maximise time spent with the patient. For example, a patient’s blood pressure and heart rate, recorded at home, should be available



in the diabetic clinic, cardiology clinic or GP surgery, without the care professionals having to hunt for them or transcribe them from one piece of paper to another. Such free and easy data flow absolutely requires adherence to agreed open standards of data recording and interchange. Fortunately, such beasts are emerging, and it is encouraging to see the health IT industry moving in this direction.

In his report to the English Department of Health³, Bob Wachter identified a serious need that applies as much to Northern Ireland as to anywhere else. Our clinicians must be trained in informatics and process design if we are to create health service transformation. We've made a start with the appointments of Chief Clinical Information Officers (CCIOs) in each Trust, and the NI CCIO Network links them with colleagues in the Health & Social Care Board, the Public Health Agency, and Primary Care. Work is underway to establish Clinical Digital Councils in the Trusts, linking a diverse range of professionals - medical, nursing, AHP, IT, administrative and others - to generate innovative thinking around how we apply digital technology to healthcare. But this is only the beginning. We have a long way to go.

The time has come to embark on a clinically-led, IT-supported, patient-centred, outcome-focused journey towards a regional Electronic Record-in-Common for NI (#ERiC4NI), which will unite and liberate our patients' data, in support of the Quadruple Aim. The Minister⁴ and the Expert Panel have given us the mandate to proceed. For tomorrow's patient and tomorrow's clinician, let's get our geek on.

Shane McKee, Guest Editor

REFERENCES

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