

Commentary from Chair - Feb 2007

There has been some energetic discussion about *openEHR*, standards, publication versus implementation on the openEHR Clinical list over recent weeks. Professor David Ingram (CHIME department, UCL), Chair of the *openEHR* Foundation discusses some the issues raised.

Some thoughts on *openEHR* and Standards

Recent postings on the *openEHR* lists seem to confirm that we are at a seminal stage of evolution of the mission that the Foundation has set for itself. There's a lot happening and much deliberation and discussion at high levels, behind the scenes, as well, which has to be confidential.

For me, the list discussion seems to reflect a mixture of several interacting wicked problems in health IT: requirements formulation and review, discipline of systems specification and design, implementation strategy grounded in evidence-based practice, clinical and technical harmonisation and standardisation. We're not good at requirements engineering unless we have real artefacts against which to critique them; we evolve the discipline by doing things and learning from what happens and from our mistakes; certain kinds of relevant evidence cannot exist until we do things at a relevant scale, but we shy away from experimenting at that scale because there isn't supporting evidence; we create a standard and that helps for a while until technology or events overtake it, whereupon, if there is not explicit and shared discipline underpinning the standards process, we tend to create a repeating free-for-all, perhaps coercing events in perverse and unsuccessful ways. All of this takes energy, time and money, which is then, all too easily, spent unproductively.

I would like to suggest some linkage between the different areas of debate. It's off the cuff as, although I read the lists, I don't have time to engage very much other than by working with Sam and Dipak to try to keep the Foundation on course and resourced, however much that resource is still below the level we would like to see. The problem we face as a board and as a community is in keeping the right (open and sharing) values and developing the right business case and understanding, for the mission we have all signed up to.

One theme that comes through strongly from recent posts (to someone as long in the tooth as me, but still possessed of some innovatory energy) is the inevitable and, indeed, highly desirable evolutionary nature of the health informatics domain. We have to see learning, formalising, standardising, relearning, reformalising and restandardising as natural and necessary parts of the quest for value in our changing world. Every generation has to reinterpret and relearn basic truths and it is the lot of the older generation to berate the lack of knowledge and understanding of history, and of the younger generation to want to kick free and do its own thing. That's the way we are and for good reason. It is the nature of those that have, to defend their inheritance and of those who have not, to seek to knock it down. One who seeks to impose control, or in other ways to defy these evolutionary forces, will in the end get caught up in a vortex of conflict, confusion and illusion, from which they are unlikely to emerge intact. That said, pioneers and innovators have always put their heads on blocks, and many of course have lost them.

The important thing is to be on a productive journey that we can sustain and enjoy, because that way comes staying power and the ability to influence for the good. But we have to be quite humble about this.

openEHR is, if you read the founding principles and values on which it is based, committed to openness and sharing within a community of people joined by their wish to help achieve value from electronic health records. It's that broad. Openness can be hard to achieve. Surely, peer review and publication is a tried and tested mechanism of openness in the world of ideas, concepts, theories and experiments. It can be, and often is, a block on innovation as it cannot be immune to the undue defensiveness of orthodoxy. I see the efforts of Research Funders to ensure that the outputs of research they sponsor can be shared

across research communities. I see the practical difficulties they face in realising that aspiration. Inevitably, peer review has flaws and these have been studied and rehearsed in the literature, over decades. Peer review is evolving in ways people have mentioned – open peer review, Google Scholar etc. One notable finding that I remember from researching a paper on ‘Information Explosion’ that I gave to the Royal Society of Medicine, 20 years ago, concerned a particular domain of clinical literature where only 1.5%, I believe, of papers in the field concerned contained any new experimental data! That’s the price we risk paying for overly restrictive and derivative science governance and EHR governance must not get into that degree of ideological fix, else we’ll never do anything.

The aspect of current debate that gives me most pause for thought is the rehearsal of some of the old saws about Stalinism and Religiosity, which seem faintly 20th century, I have to say. I can’t remember who it was who said, or how long ago, that orthodoxy is my doxy, heterodoxy is another man’s doxy! But we still keep tying one another to virtual stakes. Well the stakes are high and the air is hot, but let’s not get too boring about all that stuff. The closeness of the underlying mindsets of the far right and the far left in any continuum is usually the closeness of neighbours on a rod bent into a circle! We’re in danger of getting overly attached to models and metaphors as I have said before. They only matter in so far as they help us achieve the wider mission which is about delivering value.

openEHR it seems to me is proving a very useful melting pot and stage in community building, internationally. Its founding spirit was collegial and obviously close colleagues do fall out; they wouldn’t be achieving much of lasting importance if there were not real tensions of mission and perception and *openEHR* certainly has these. But let’s not forget that *openEHR* has got a long way, in a good spirit, and it has captured, communicated and mediated a lot of useful business and debate.

Our challenge as a Board is to discern how we should evolve, refocus and revamp our efforts in order to support the Foundation into its next phase, which we see as perhaps best vested as a Community Interest Company. This vehicle would engage substantial partners committed to the strengthening of the clinical discipline, capacity and wherewithal to use electronic records effectively. It would, most importantly, look after the important IPR vested in the Foundation and ensure its open development and sharing. In my personal view, the breadth of the mission needs reemphasising. If we are to build the discipline necessary to achieve it, we have to support diversity in implementation, within a framework of learning and communication about the underlying issues.

I and several of my long-standing colleagues have been working on the performance of archetype object-relational databases for a long time. Jo Milan, now in CHIME, developed the clinical object dictionary for the Marsden NHS Trust systems, its realisation within a state of the art object relational structure and its indexing to achieve enterprise-wide sub-second response times for access to enterprise data bases. This major work evolved over thirty years, capturing and communicating clinical information for this pre-eminent cancer acute services and research trust environment. The infrastructure he built was shown, a year or so back, to be an outlier at the high end, across all of the NHS Acute Trusts (as independently studied by the National Audit Commission) in terms of clinician appreciation of clinical value, technical and organisational value for money and success in doing away with paper, all assessed over something like 35 different areas of evaluation. Not published of course!

This knowledge did not, and arguably, given its frame of reference, could not influence the choices made by our national programme at all. It was and remains an open, extremely well disciplined and engineered system, evaluated as performing to a very high level, owned within the NHS, with 30 years of evolution, through multiple network, server and database technologies, and tuned to amazing levels of performance. It is a beacon of health informatics excellence, largely unrecognised because largely unseen, for what it is and what it represents. Obviously, there are other sides to any such story, but in studying it we may find insight into the *openEHR* dilemma. Is it practical exemplars and evaluations that we lack or, more significantly, lack of joined up knowledge and insight about clinical systems, more generally? The Marsden exemplar was left aside, unseen, despite arrangements made with the DoH to launch the 1997 Information for Health Strategy there! A lot of money further down the line, the choice made when procuring a replacement, London-wide system, was rejected, after several years of costly work, much of this within the hard-pressed service, not within the central national programme. The

suppliers themselves appeared to have lost contact with key areas of their system's inner design and implementation. Users and those procuring it had possibly not looked that deeply into these aspects when decisions were made, and were taken unawares by the inflexibility of the system to meet the requirements of the health service that gradually emerged. *openEHR*'s quest to foster clarity about the interaction of technical, clinical and organisational aspects of data standards and systems design is ever more crucial.

We have worked on the evolution, through numerous projects, of the approach to clinically led standardisation of data that is now vested in the *openEHR* archetype concept. There is much evaluative research in systems that have been in operational use for years, here and elsewhere, that are from earlier stages of this evolution and Ocean are pushing quickly with their native implementations of new fully *openEHR*-based systems.

We at UCL, Ocean's close partners on the *openEHR* journey, know about Marsden clinical object definitions and how they perform and are managed in their 24/7 30 year environments. We know about Synapses clinical object dictionaries, which took forward the Marsden and GEHR project work, and how they have performed in an exhaustive set of experimental contexts of records of varying clinical depth, extent and complexity, implemented in a variety of database persistence environments. The underlying server technologies developed in this research have been thrashed to extinction by partner industry teams, seeking to probe their resilience and serviceability and they have stood it. UCL's team is now looking to work across the breadth of operational HL7, CEN 13606, *openEHR* and Marsden-based clinical data environments, looking to see how well the *openEHR* archetype now stands the many and varied tests of real implementation and sustainability in the real 24/7 clinical services that we have provided and supported for years. Cancer, chronic disease management and community-based services, linking primary care, community pharmacy and acute hospitals, as well as sports medicine and child health epidemiology are the domains we are close to.

As I have said often before, only three things matter in pursuing this mission; implementation, implementation and implementation! The fact that the journals to which we have offered the results of our evaluative studies, as described above, didn't feel able to publish them because they didn't fit their concept of a research output, is disappointing. But we are publishing in lots of maybe more explanatory and telling ways and the story is moving forward. We urgently need more support for it, financially, now, despite our historic success in gaining research grants.

The *openEHR* community and mission needs the right kind of support for the openness and learning that it values, anchored in the professional and public domain. Government and industry, to an extent as well, are now very heavily committed to multibillion dollar and pound ventures that are struggling to cope with the questioning of clinical data fundamentals that any real efforts and implementations in health informatics inevitably engender. I have called this the \$80billion dollar problem, from Blackford Middleton's paper which sought to put a value on the cost to the US economy of failure of information systems in health care. Government has been very good, historically, at spending a lot of money, while still not getting to the heart of resolution and accommodation of these wicked problems. I have discovered that there seem to be many such \$80billion dollar problems (type \$80billion into Google and see what comes up!), enmeshed in controversy and spending much resource passing the buck from one party to another. Of course, the problems truly are wicked, in the Rittel and Webber sense, progress is hard, and the numbers are pretty suspect, I would imagine! It's our role as a community to stay the course, in whatever diverse ways we must, in our professions, universities, businesses and citizen organisations, supporting evolutionary progress in electronic health records.

To achieve that, from what we must acknowledge are our relatively powerless (if not without influence) positions, we must be practical and inclusive and work with good order and discipline, openly. We must not let ourselves be typecast by concept, methodology, or the Machievellian, modelling, Mafiosi; that very human tendency towards undue attachment to model and metaphor. Model and metaphor are at one and the same time essential to the building of good order, but conceptually limiting; time and domain limited and evolutionary in nature. *openEHR* has to be on the side of the patient and professional in holding up their corner of the EHR enterprise, so that technology and management in the other two

corners of the triangle do not overrun them.

The essence of where we are in all this is that IT is, as usual, exposing weakness; in this case in clinical insight about the nature and communication of clinical practice, and therefore in its capacity to use IT effectively. That's what *openEHR* exists to help put right, through rebalancing the agenda and unlocking the dispiriting deadly embrace that leads to a field typified by sort of requirement, sort of specification, sort of system and sort of results. The field is in much need of new spirit, to stop spending money and effort so poorly.

I am very optimistic about all this, as the underlying drivers are at long last (partly, it must be acknowledged, through the amazing efforts of amazing people like Richard Granger) becoming exposed and recognised, and therefore change can come quickly. Maybe I'm too old to feel badly about the turmoil we're going through in clarifying and moving the *openEHR* mission forward. It's part of everyday life and seems quite normal and not so daunting. We have to accept that good IT is invisible and so the ultimate achievement for *openEHR* will be to be able to shut up shop (some would say the next step!) when suitable discipline, education, tools and systems are around and part of the natural order of things. A clinical professorial colleague of mine (an Oz exile in London, so he has a tellingly graphic turn of phrase!) says IT is like a well-flushed toilet; taken for granted when working, until it doesn't work, at which point it rapidly becomes the most serious problem we face! Clinical IT is in that parlous state and I really do look forward to *openEHR* not needing to be there in its current configuration. Given the angry furore that exists around it at the moment, it clearly needs to be there, for now.

Our role, on the Board, is to support the mission and membership in whatever ways we can, to enable *openEHR* to be there. It's tough for us but we're united in the goal of keeping it there, while working to strengthen and develop it into the new more clinically focused mission that I have written about here before. Tom Beale tells me that Version 1.0.1 will be ready for release in a few weeks time, another good step forward in the journey.

David Ingram

For the *openEHR* Foundation Board, February 1st, 2007