

APPENDIX VI: ANNEXES TO CHAPTER EIGHT AND A HALF—OPENEHR DOCUMENTS OF RECORD

Annex III: Transcript of Lecture about openEHR for Medinfo 2007, Brisbane

The story of the origins of openEHR is told in this keynote talk, recorded by David Ingram for the Medinfo 2007 meeting in Australia.¹

Hello, I'm David Ingram and I chair the board of the openEHR Foundation, otherwise known as open air.

My good friend and colleague, Sam Heard, has asked me to record this introductory talk for the Medinfo 2007 conference session in Brisbane, devoted to openEHR. I'm speaking at my homebase of UCL in London and am sorry not to be with you. One thing I know for sure: health informatics conferences in Australia are always among the best and most memorable in the world.

Sam it was who introduced me back in 1990, to join him in bidding for a research grant to explore health record architecture. We competed for funds in the European Union's Advanced Informatics in Medicine programme, against large consortia which had spent several years preparing their heavyweight bidding strategies. Adopting a very practical bottom-up approach, put together very quickly with Alan Maskens and other colleagues across Europe, we proposed to explore and systematize the foundations of generic architecture for electronic health records, by implementing and studying them iteratively in their real life personal and clinical contexts. This was the basis of the Good European Health Record project that one through. It was a good project at a human level, conducted in a very practical and generous spirit across health care academia and industry, and it has led to many good things. It was where Dipak Kalra joined us to lead the clinical subproject and David Lloyd came from his post as a London NHS IT manager. It was where Jo Milan, my colleague of many years standing, introduced us to Tom Beale, who in turn introduced us to the Bertram Maier world of object modelling. It was at this time, too, that Martin Severs and John Williams were first working to establish realistic health informatics

¹ <https://youtu.be/Nlw1LrDmv7c>

agendas for the UK Medical Royal Colleges. Many good and enduring relationships have their origins in and around the GEHR project, as it was known.

In that project we learned a lot about the nature and complexity of health record architecture. We took some early steps towards formulating core requirements, devising candidate architecture, and implementing pilot systems. Much of our foundational work on clinical requirements was incorporated within the first send CEN 12265 European health records standards publications.

As the GEHR project drew to an end, we began to formulate ideas for a wider community within which to maintain and develop this bottom-up evolutionary approach to electronic health records, efficient and fit for purpose. A lot of water has flowed under the bridges of many research projects and other endeavours since then. We've learned a lot and done a lot together, and separately, feeding into subsequent CEN 13606 and other iterations of standards, and improving the scope detail and testing in real life of the various formalisms. The idea of a wider community began to take shape some five years ago, when we established the openEHR Foundation. Archetype methodology is now on the world stage very widely thanks to this journey from GEHR to openEHR. We're still refining it and how to use it clinically and to implement it in real systems, alongside evolving terminology standards. It is providing a valuable key to the design and implementation of comprehensive, safe, and sustainable containers for electronic health care records and for the management of communications with them, widely, across health care services. The openEHR Foundation itself, and the way it is now seeking to foster wider community, sharing insights and results, is one very tangible outcome of this journey. The impact of our research of fifteen years in helping frame the international standards process for electronic health records communication in many places, is another.

At the heart of openEHR, Sam is as ever the inspiration and the go-getter. Dipak and David bridge to meticulous and laborious clinical systems implementation and standards work. Thomas is the hugely devoted community participant and information architect, and Jo is the sceptical engineer. Sam, Tom, Peter Schloeffel and other colleagues at Ocean Informatics, have helped us hugely in pushing forward the government and industry focus. I am the empiricist and sometimes, when needed, the peace maker. Quite a group, we have our moments! The same as any useful group dedicated to change and change is needed.

For many people, the slow and erratic progress of health care information infrastructure is still baffling and exasperating. Health care delivery is such an obvious candidate for IT support, 'surely health records aren't that different from bank account

records,' they say. 'We know how to create electronic records and repositories, why can't we have them now in health care?'

There are two salutary threads of wisdom to remember as we, quite rightly, aspire to and strive for all the good things that might be in this field. First the wisdom of the redoubtable Fred Brooks, former head of computer science at UNC Chapel Hill, as conveyed in his book, *The Mythical Man-Month*. Two particular messages, born of the wealth of his personal experience in grappling with complex IT implementations. One, systems need architects, and two, if you have a project running late and you just give it more resource, it will run even later. Implementing IT in and around complex human organizations, needs clear and realistic goals, direction and oversight. Poorly formulated and implemented IT projects can make matters worse and can easily absorb large amounts of unproductive effort. The second thread of wisdom is captured in the concept of the wicked problem, as expressed by Rittel and Webber. This is a prevalent kind of problem which may be loosely described, but which lacks clear ownership definition and permission to work on it. Which, nonetheless, if tackled in a real-life project by some brave souls, must be done successfully or there's hell to pay. Which, in reality, is never fully solved because increasing understanding of the nature of the problem leads to adaptation of the wider social organizations within which possible solutions are implemented. There is thus the continuous re-framing of the problem in need of solution. Combine Brooks, Rittel and Webber and you have what might be called the BRW problem, as very well exemplified by the electronic health record.

So, a good first step is to embrace rigorous system architecture at the clinical centre of the EHR enterprise. And a second is to work iteratively and avoid putting resources into the digging of huge holes. At heart, as with many fields of computerization, the problems encountered reflect lack of grounding of systems within the domain they must work in, and over optimism about how practically to realize benefits and avoid disbenefits, since both are possible. I have now seen three very costly eras of attempts to get to grips with health care information infrastructure. I've seen similar eras in other fields as well, e- learning for example. eHealth, as Europe now describes the health informatic field, has too often being characterized by money injected top down, targeting poorly formulated clinical requirements with inadequate product under the say-so of many who are driven and motivated by too great an imperative of doing things, and too little of learning how. Each era has tended towards impasse, whether by technological, organizational financial or political insolvency. Such impasse is inevitable given the mismatch of the challenge faced with the methodology, tools, and capacity deployed in tackling it.

openEHR needs to be, and has tried to be, a little different. It is thus very interested in how health care thinks about, communicates about, and accounts for the services it provides. It wishes to publish and make fully available all its processes and outputs, to help promote learning and good practice in the field. It plans to remain as small as possible, consistent with building a useful role. Just as well, as it hasn't any money and has relied on its core partners and participants to keep it on the air.

I mustn't outstay my welcome, here. I wish you all a very interesting and productive meeting. In closing, I want to say that openEHR must be ready, soon, to fly with its own wings. It has created a presence and a proposition that is aimed at minimizing obstacles to wider uptake and adoption of the intellectual property that is lodged within the Foundation. It is trademarked, fully documented, and explained, and free of financial obligation. It can only grow further on the basis of how well it enables clinical progress with the EHR. It needs wider sponsorship now as it is rapidly outgrowing the support and shelter that our small group can provide, here at UCL and Ocean Informatics, with Sam Tom and colleagues. We're looking for partnership to take it forward to the next level, maintaining the clear goals and principles on which it is based. We need to broaden partnership and governance so that the current and future IP of the Foundation, continuously evolving as changing health care needs pull it and its models and formalisms, forward in new directions, is first and foremost available and used, but at the same time properly maintained, communicated, and protected, as now.

As I've said, a Brooks, Rittel, Webber problem needs architect and architecture. It is never solved for all time. Approached in the right way and in the right spirit, experience and trust in iterative solutions of the problem, and in products and systems based on them, can steadily improve. We must guard against our own protectiveness and dogmatism which would surely kill such endeavour. We must always value and promote inclusiveness.

Thank you for your interest. From the time that we thought of and created openEHR, Google hits for the term went from zero to 10,000 in three years, from 10,000 to nearly 100,000 in the next three. The web lists have members now in around 80 countries. The website and repository of resources, lodged within the Foundation, based here at UCL, is abuzz with visitors. It can grow. It can die. It could be laid down, its job done. Time will tell. But openEHR, or something very like it, needs to run its course and see where it can get to. That is all that we should wish for it, and for ourselves as its founders and supporters. I hope we will succeed in keeping it going in that spirit. I'm sure that the way in which it works is the key to its chances of future utility and success.

Thank you for listening and goodbye.