

# Report for 2005 from the openEHR Foundation Board

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Professor David Ingram (Chairman), Dr Sam Heard, Dr Dipak Kalra

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## Progress

It has been a year of feedback, revision and enhancement of the *openEHR* Architecture. This process has been driven by progressive software implementation experience, by practical clinical experience of the use of the *openEHR* archetype methodology and tools, and by improved understanding and refinement of the underpinning user requirements that inform the *openEHR* Architecture. It has also been a year of implementing and trying out new governance arrangements for the Foundation, through the Architecture and Clinical Review Boards, and considering future plans for the Foundation, itself.

Successive 0.9X versions of the architecture have been issued during the year and there has been much updating and enhancement of the core documentation of the Foundation. On completion of the current change management round, the release of a seminal Release 1.0 of the *openEHR* Architecture is now planned for February 1<sup>st</sup> 2006. The delay in publishing and making this available has reflected the need to make it a substantial and stable release, which deals carefully with all previously outstanding issues.

In summary of the progress over the year:

- The term '*openEHR*', which is a registered trademark of the Foundation, now clocks up some 38000 hits on Google.
- *openEHR* documents, software and educational materials are accessible within the new *openEHR* Subversion Repositories.
- The *openEHR* discussion lists are busy (and often passionate!).
- The *openEHR* Architecture Change Management Plan has come to life and is an effective, open and transparent activity, supported and sustained by Tom Beale and a core team of supporters within the Architecture Review Board (ARB).
- The *openEHR* Clinical Review Board (CRB) has just been established, with Dr Dipak Kalra (Clinical Senior Lecturer, CHIME, UCL) as the founding chairman. It will oversee the development of methodology and tools for implementation of *openEHR* archetypes, and their practical evaluation, governance and dissemination. In these ways, the CRB will provide overview of the relevance and usefulness of these resources, for clinical professionals and patients, working towards better quality health care records in their individual and shared practice.
- The *openEHR* web site and repository of open-source material is becoming ever-busier, with of the order of 500 visitors each day to the domain servers at UCL in London, from all around the world.
- A formal basis of integrating *openEHR* records with existing data sources, including HL7 version 2 and EDIFACT messages, using "legacy archetypes", has been described.
- *OpenEHR* archetypes have emerged *de facto* as a preferred way of modelling clinical and related information in Australia. They are also being used in the UK (Medical Research Council CLEF project), Spain, Sweden, and Turkey, and are likely to find growing use in Europe, due to their being standardised as Part 2 of prEN13606 of CEN, for electronic health care record communications.
- A major area of work and investment of resources over the year has been in the consensus-building and leadership activities of the core Ocean Informatics and UCL team of *openEHR*, working closely with the health informatics standards activities of:
  - CEN, closely involved in international advancement of the prEN13606 standard

- ISO, taking this work through for balloting within ISO
- HL7, attending international meetings to advance the harmonisation of both prEN13606 and *openEHR* archetypes with the HL7 message paradigm.
- *openEHR* members in Australia and the HL7 Australia organisation are collaborating on integration of *openEHR* archetypes with HL7 version 2.
- There are now some 5 active *openEHR* software and system development teams in different countries, building and sharing open-source software components, as reported on the web site.
- A number of University, commercial and other development teams are exploring related areas of implementation – including the binding of *openEHR* archetypes to terminologies, decision support, security services and knowledge management.
- A number of technology transfer activities are beginning to emerge, including research on EHRs and establishment of commercial EHR services, based on or closely connected with the *openEHR* Architecture. The deployment pages of the *openEHR* web site give brief descriptions and pointers to some of these activities.

*openEHR* is perhaps unusual in placing so very few limitations on how its copyright materials can be used by licensees. The trademark is important, but the use made of the materials is left very much to the individual inspiration and inclination of licensees. This is a pragmatic choice. We believe, from practical experience, that, in such a wide-ranging domain, with such diverse stakeholder interests and perspectives, no other approach can generate the range and quality of sharable tools and methodologies that is required to sustain and evolve the work to a good enough standard. This is especially true given the diverse international context of the requirements and priorities in the domain, for both the developed and the developing worlds.

*openEHR* will always remain open to alternative information modelling approaches to the electronic health record. There are no unique or right ways to model such complexity. Choices must be made in order to achieve effective management and communication of different levels of granularity and organisation of clinical record information. Systems implemented in practice must be usable, appropriate and effective. The motto adopted by *openEHR* is ‘implementation, implementation, implementation’, reflecting that what can be done, well enough, has to be the yardstick, rather than what might be achievable, perfectly, at some future date. This is an incremental strategy that, experience shows, is best suited to the evolution of good practice within complex domains. It also recognises the reality that in different clinical, technological and enterprise contexts, in different product and commercial contexts, and at different times and in different places, one size will seldom, if ever, fit or, more importantly, be good enough, for all.

*openEHR* is an important, but still small, part of a wide and growing international community dedicated to good practice in shared electronic health records. In the spirit of its founding mission, members of *openEHR* are also actively sharing their experience and insight within many national and international communities. Its Board members, for example, are or have been active in the leadership of several key CEN, ISO and HL7 standards-making activities as well as in key national and international health care, clinical research and health eScience initiatives.

We believe that the *openEHR* Foundation is now approaching another key stage of its evolution. This will mark its transition from an organisation and community based solely on the freely given efforts and resources of its members and supporters, to one that must be focused and sustained by investments made at the centre of patient organisations and clinical care services and professions.

## Reflections on the current state of play

There is an ongoing, usually constructive and always difficult, debate about how to move forward and build necessary new discipline for the electronic health record field, while conserving and exploiting

hard-won gains from previous standardisation and harmonisation efforts. Any reading of the mission documents of the Foundation shows that we do not believe the *openEHR* Architecture to be the be-all and end-all of models of health care records; that would be clearly vain and inevitably in vain! *openEHR* stands much more for the importance of an inclusive community of interest and of practice, where dialogue is built around shared practical efforts to create systems and records which work and are responsive to real health care drivers, from patient, clinical, technical and enterprise management perspectives.

The EU GEHR project, some 15 years ago, set out to study the requirements for an electronic health care record architecture, under the headings of comprehensiveness, clinical excellence, ethico-legal acceptability and system portability. The requirements base and architecture of *openEHR* dates from that time, and has been successively updated since then, notably in Synapses and other EU, Australian and UK projects and within international standards groups. In this way, it has remained at the clinical heart of the ongoing dialogue. Anyone who has observed and participated over that time will recognise that the formal modelling is a secondary exercise, but necessary for grounding and coordinating the debate; the goal is support of real systems that work in real life. The key issues that arise are conceptual and policy ones and the complexity of the problems means that any information models must be seen and approached not as right or wrong answers but as potentially useful abstractions and simplifications, closely aligned with real-life purposes. These solutions will never be complete or finished, in any absolute sense. They are at the core of an incremental process to create, sustain and evolve systems that can capture, process and communicate health care records, safely and acceptably.

Now, though, the debate is less about requirement and proof of concept and more about implementation, relevance and governance. There is debate, too, about interrelationships with developments in clinical terminologies (notably SNOMED-CT), workflows and knowledge management, such as in the semantic web. This debate is taking place in the context of new national HCII programmes, spending large sums of public money and seeking to create a core health records infrastructure for all citizens within countries or communities. A national electronic health record that can provide access to the related clinical and scientific knowledge that underpins clinical interventions is a central concern and a new territory being explored in many countries. The aspirations for what such a record might contribute are huge, but the practical reality – the art of the possible - sometimes takes a back-seat to the dizzying processes of framing, financing and contracting the delivery of such a major endeavour.

*openEHR*, though passionate about what it believes in, must be realistic about what it can offer in this environment. It believes that the manner in which it seeks to share insights and helps to shape real progress is among the most important contributions it can make. The good-enough solution is an important, though elusive, goal.

The challenge for medicine, in seeking to make effective use of IT, lies first in being a good customer. To that end, it needs a good sense of itself as a discipline, in relation to what it is, how it works and how it communicates about itself. From this comes clarity as to how and to what end it should plan to use IT. A good definition of what constitutes an academic discipline is ‘a useful organisation of knowledge’. It would be conceit and unwarranted supposition of a high order to believe that clinical data is yet as well-disciplined, and thereby as well-understood and well-ordered as is needed and can be achieved. The process of attempting computerisation is a powerful driver for increasing clarity about such matters. But lack of basic understanding and agreement (perhaps, more exactly, lack of awareness that there is such a lack or how and why it matters!) about the nature, meaning and quality of health care data has, many times, created considerable incoherence, waste and disarray. Failed efforts towards computerisation, arising there-from, have been easy targets for blame.

The lack of a sufficiently orderly foundation for information encompassing health care and clinical practice needs to be acknowledged, without shame, and managed, with understanding, before there can be real progress in building and deriving value from health care information infrastructures.

The *openEHR* Foundation aims to derive its future rationale and business plan, not from the billions of public and private money being invested in building health care information infrastructures. It cannot do

that and does not wish to try. It is focused on helping to build the human capacity and community needed to ensure that we learn how to do the job properly and well, once sufficient infrastructure exists. To that end, it needs to reflect, in its business rationale, the commitment of patients, health care professional practice and health care enterprise, to the building and governance of a good-enough, international framework for sharing personal health records. *openEHR* will, we believe, ideally, require strategic investment of perhaps £500K per annum, for the next five years, to sustain this growing mission – a triflingly small sum if we can succeed, in the period ahead, to demonstrate its relevance and resilience.

## Current Plans

So, what do we now offer to stakeholders working to make change happen in this field?

Through the *openEHR* Architecture, we offer and will continue to offer a conceptual framework, information models, service interface definitions, and software methodology for harmonising electronic health records. It is a componentised and adaptable architecture, appropriate to the requirement of managing record information over lifetimes.

Using this architecture, we provide and will further develop capacity:

- to record and share all clinical information – including, for example, images, time-series of laboratory data, clinical instructions, interventions and associated care plans - to support personal health records.
- to achieve *openEHR* archetype- and template- enabling of clinical systems. This is with a view to empowering groups of clinical professionals to define the content and user interfaces of systems they need, independently of the software, after deliberating and agreeing among themselves how, from clinical perspectives, the clinical data and workflows for which they are accountable should best be defined and organised. In this way, they will be enabled to focus their efforts on clinical consistency and fitness for purpose of data, within defined clinical contexts. They will, at the same time, be enabled to work synergistically with the standardised underlying technical infrastructure that is required to scale and integrate electronic health record systems, within both local systems and systems further afield, knowing that this infrastructure remains sound and able to accommodate these continuously evolving patient data and records.
- to version, organise, and control access and sharing of personal health data in EHRs in an ethico-legally acceptable and rigorous framework.
- to integrate EHRs with:
  - terminology systems - SNOMED-CT, LOINC, ICD, ICPC
  - clinical messages - HL7, EDIFACT
  - legacy hospital information systems, via legacy archetypes
- to integrate with international standards, such as CEN prENV13606, which tackle the modelling at a lesser level of detail, but are adopting the *openEHR* archetype methodology as a means of separating content and software system constraints.

With the advent of portal technologies, we recognise and will respond to the needs for componentised health record software systems to be slotted within diverse distributed information management systems. These will be built up across diverse locations of data capture, storage, retrieval and analysis. We recognise that systems need to be adaptable in line with local and changing requirements and contexts, while remaining able to communicate safely and maintain the clinical meaning of the information transferred.

We recognise that, while any information model in a changing field of knowledge and practice, delivered in changing practical contexts, is essentially ephemeral, personal health data need to be curated

and protected within an infrastructure that can adapt and survive, so that information remains interpretable, over the patient's lifetime. This is a performance challenge that current systems have scarcely begun to touch but which we will make central to our future work.

In 2006, we hope to demonstrate, ever more clearly, that the *openEHR* Foundation and its community is an idea whose time has come. We will focus on making it as simple, accessible and available as possible to all people and organisations that need it and can and want to use it. We will seek wider financial support for the operations of the Foundation.

We hope, as a Board, to see the huge effort and commitment given to the Foundation, by its many members and supporters around the world, rewarded through its further development, growth and success.