

e-DiaMoND: Challenges for the e-Scientist in the e-Health domain

S. Lloyd¹, A. C. Simpson¹, D. J. Gavaghan¹, J. M. Brady¹, D. Watson²

¹University of Oxford; ²IBM (UK)

Abstract

The primary aim of the e-DiaMoND project is to explore the potential for using grid-based architectures to support the UK's NHS Breast Screening Programme. The key deliverable of the project is an infrastructure to enable the capture, storage and transport of digital mammography information, together with the deployment of selected applications to show the potential uses of such a resource. In this paper we outline the key challenges – as experienced by the e-DiaMoND team – faced by e-Scientists working in the e-Health domain. We also detail some of the lessons learnt thus far.

1. The e-DiaMoND project

e-DiaMoND is a multi-disciplinary, collaborative research project funded by the UK e-Science Programme and IBM, the primary aim of which is to explore the potential for using grid-based architectures to support the UK's NHS Breast Screening Programme. The key deliverable of the project is an infrastructure to enable the capture, storage and transport of digital mammography information, together with the deployment of selected applications to show the potential uses of such a resource.

A national digital mammography archive would have the potential to provide major benefits for the UK. For example, such an archive could: ensure that previous mammograms are always available, and could link up seamlessly the screening, assessment and symptomatic clinics; it could provide a huge teaching and training resource; it could enable algorithms to standardise the storage and display of images, regardless of the capture parameters or what kind of digital system was used; it could be a huge resource for epidemiological studies, such as, for example, those relating diet to breast cancer risk and patterns in mammograms; and it could aid in progress towards the next generation computer-aided detection technologies.

The partner organisations involved in the e-DiaMoND project are the University of Oxford, IBM (UK), and Mirada Solutions Ltd. The project also involves a number of clinical partners: King's College London and Guy's and St. Thomas' NHS Trust Hospitals, London; the

John Radcliffe Hospital, Oxford; University College and St George's Hospital, London; and Edinburgh University and South East Scotland Breast Care Units.

In this paper, we focus not on the technological aspects of e-DiaMoND, as these experiences have been reported elsewhere. Rather, we outline the key challenges – as experienced by the e-DiaMoND team – faced by e-Scientists working in the e-Health domain. We also detail some of the lessons learnt thus far.

2. The challenges

Projects such as e-DiaMoND face numerous challenges, whether they be enabling genuine collaboration between organisations with their own (often conflicting) agendas or handling significant budgets distributed across several sites. Of course, projects of this scale are not new, and the project management literature is full of methodologies describing how to manage projects of this scale and complexity. The difference, of course, is such literature is focussed on development and deployment within a commercial world and not in an academic context. Working in a complex domain (the primary focus here), balancing competing research and development drivers, and using immature (and fast-moving) technology are not usual constraints. When combined, these constraints add significant levels of complexity.

The e-DiaMoND project has worked extensively with the four collaborating clinical partners to determine the user requirements for a deployed system such as e-DiaMoND. This requirements analysis required not only an

understanding of the way in which clinicians currently work, but also planned changes in these work practises both at local and national levels.

An irony of attempting to develop technology to satisfy the needs of a national programme within a national healthcare system is the levels of local autonomy and differences in practice that have to be accommodated. As an example, we consider the issue of case annotation.

Each clinic performs the process of taking X-Rays for women, and completing a form or forms for each case in each screening round. These forms are annotated and used by administrators, radiographers, and one or more radiologists. Different individuals – filling different roles – may complete different parts of the forms: the exact manifestation of who does what differs between clinics. To complicate matters, clinicians do not use standardised forms or systems, with even some aspects of the terminology differing.

e-DiaMoND has deployed a data acquisition system which effectively considers a superset of the data collected at each of the four clinics. This has required a standardisation of data entry and tailoring of mandatory and optional fields for each site through local configuration files. Each clinic, then, requires a local ‘mapping’ of terminology where non-standard classifications are used.

The issues identified during the development of the e-DiaMoND data acquisition system have highlighted the challenges in deploying systems across clinical sites where clinicians have different work practices. Clinical acceptance and willingness to change may be difficult for this reason and such accommodation often requires the project teams to not only understand the reasoning behind the way in which people work but also the impact of them having to change.

Such considerations inevitably impact upon project development. Within the UK, staff currently work almost exclusively within a non-digital environment. The X-Rays exist in film format and patient information typically exists primarily in hardcopy form. Thus, the "patient folder" is core to the effectiveness of patient care. Any contemplation of a move towards performing the task of ‘reading’ i.e. viewing up to 120 cases at a time and making a decision to recall or not recall, on digital equipment instead

of film and light boxes, is a big step for the radiologists. Inevitably this impacts upon both requirements and expectations: not only would the systems deployed have to be at least as fast as reading from film, but the display quality and usability would have to be acceptable. Projects such as e-DiaMoND, therefore, have the difficult task of delivering a prototype system within a short timescale whilst recognising that full acceptance would take substantial technical and clinical effort. This requires an element of courage and faith from all parties: managing expectations is essential in this respect.

A key challenge within e-DiaMoND has been the expectations of those observing and measuring the project. The project team comprises a mix of clinical and technical resources. In addition, those employed as researchers have the difficulty of balancing the immediate needs of the project – where development work is essential – with the long-term needs of their career – where performance is measured in terms of research results.

The involvement of commercial collaborators has allowed the project team to focus on delivering core architecture and delivery of a Grid architecture based on a combination of commercial products, open source software and bespoke code. The delivery of this architecture alone has taken significant time to design, prove the concept, deploy, and test. With only two years in which to gather requirements, design and deliver an infrastructure, collect and manage a huge data set, and develop grid-enabled clinical applications, there is little activity that has not been on the critical path. As a result, genuine research into the use of the architecture can only commence once this architecture has been implemented and data acquisition has been ethically approved and applications built and tested. Additional complications in this respect include the use of emerging technology, which has resulted in aspects of the design requiring significant change at crucial stages of the project.

If the e-DiaMoND system were to move past the prototype stage and towards deployment, it would – obviously – have to comply with NHS-dictated standards and procedures and guarantee a high degree of interoperability. With respect to the development of a prototype that is – by design – limited in scope, such considerations are not to the forefront, but always lurking: by designing for forwards-compatibility and

scalability, it would be difficult for this not to be so. This issue is complicated by the fact that some of the basic tenets of interoperability – such as, for example, the use of the NHS ID number (or similar) as a unique identifier for patients – are not yet in place.

The management e-DiaMoND has required the team to consider a ‘product management’ approach where understanding the ‘market’ has been crucial to securing confidence of potential users. Whether a product-focused approach is consistent with the undertaking of a research is open to debate.

3. Lessons for the future

We would contend that the e-DiaMoND project experiences could not only inform similar projects, but could also steer any future activity in this area for the project team. Important lessons include a need for a thorough understanding of the legal and ethical requirements of working with NHS data, approaches for the capture of requirements in an environment in which clinicians are not technically literate and their time is valuable, and the importance of communication and standard terminology.

The project team have identified potential paths along which future developments for e-DiaMoND may be steered. This process has involved identifying key healthcare initiatives including the deployment of PACS systems and the development of relevant standards. In addition, identifying exactly what grid-based technology can offer the NHS has been essential. Future developments along the team's chosen paths will inevitably require us to work closely with the vendors of healthcare systems to ensure interoperability and standards adherence, as well as a consolidated approach to driving through the adoption of standards within the NHS.