



NCRI INFORMATICS INITIATIVE

Meeting of the NCRI Implementation Task Force

Minutes of the meeting held on Friday 8th April 2005 at the MRC Head Office, London, W1B 1AL



Present

Richard Begent	Chair of Task Force
Alvis Brazma	EBI
Ken Buetow	NCICB
Sally Burtles	CR-UK Drug Development Office
Jane Cope	Administrative Director, NCRI
David Gavaghan	Oxford Computing Laboratory
David Ingram	CHIME
Monica Jones	NCRN
Rob Maddocks	LogicaCMG
Eva Morris (on behalf of Phil Quirke)	Department of Pathology, Leeds
Steve Oliver	University of Manchester
Alan Rector	University of Manchester
Richard Wooster	Sanger Institute
Peter Kerr	NCRI Informatics Unit
Fiona Reddington	NCRI Informatics Unit
Helen Parkinson	NCRI Informatics Unit/EBI
Stephen Turner	NCRI Informatics Unit
Max Wilkinson	NCRI Informatics Unit

1. Introduction and Welcome

Richard Begent welcomed everyone to the meeting, especially Jane Cope, Rob Maddocks and Eva Morris who were attending their first meeting. Richard Begent explained that since the last meeting of the Task Force, the NCRI Board had requested that the Informatics Initiative produce a business case for consideration by the Board in June 2005. A letter from Jane Cope, on behalf of the Board, was tabled and outlined a number of key issues the NCRI Board would like the business case to address. Rob Maddocks from LogicaCMG will be supporting the Initiative in the preparation of the business case and that this will be paid for by the NCRI Board. Richard Begent explained that Eva Morris would be representing Phil Quirke at the meeting and would be presenting a potential demonstrator project for approval by the Task Force. The minutes from the last meeting were approved and the group agreed that all matters arising were addressed by today's agenda.

Richard Begent explained that since the last meeting both of the NCRI demonstrator projects had been funded. Cancer Research UK will fund the platform reference model project and the Medical Research Council (MRC), The Wellcome Trust and The Department of Health (DoH) will fund the imaging and pathology project. Also, the DoH have funded the second stage of the electronic remote data (eRDC) project. Monica Jones was invited to update the group on this and explained that this is a very positive step and will provide a focus for a national system for the collection of clinical trial information. Sally Burtles enquired as to whether the project would be including any early phase trials and expressed an interest in meeting with Monica Jones to discuss areas of complementarity. Monica Jones replied that there were no plans to include any phase I trials at this point but that she would be happy to meet with Sally Burtles to discuss possible inclusion. Richard Begent



NCRI INFORMATICS INITIATIVE

suggested that the Informatics Unit could facilitate this meeting and both Sally Burthles and Monica Jones were happy for this to be the case. Monica Jones also explained that a Programme Manager post will be required to act as a liaison between the eRDC project and the NCRI Informatics Unit and Jane Cope explained that the funding for this post will need to be requested in the informatics business case.

2. Update on Data Sharing

Fiona Reddington updated the Task Force on the progress of the data sharing initiative since the last meeting (Presentation 1). Fiona Reddington explained that Cancer Research UK (CR-UK) had now formally adopted the draft NCRI Data Sharing policy and that the Informatics Unit would be working closely with CR-UK to implement data sharing across its committees. It is anticipated that data sharing will be implemented across the projects and programmes committees initially. Furthermore, the Department of Health (DoH) has funded a demonstrator project to investigate implementing data sharing via the Health Technology Assessment (HTA) programme and the Informatics Unit will be working with the HTA to draft a project call, in assessing the projects who apply and in monitoring progress. Fiona Reddington also explained that Yorkshire Cancer Research would be including a data sharing section on their new application forms which are due in August 2005.

Steve Oliver highlighted that the Informatics Initiative needs to be careful about what can and cannot be achieved with regard to data sharing. There will need to be a balance between ensuring standards are compatible with the needs of the community and taking a lead in areas where no well-defined standard exists. Helen Parkinson agreed and explained that the MRC/BBSRC/Wellcome/NERC/JISC/DTI consortium and BBSRC are currently undertaking surveys of the standards and ontologies in use across the life sciences and that the Informatics Unit was working closely with these organisations to ensure complementarity and consistency.

Monica Jones outlined that there is a lot of discussion going on within various organisations with respect to data sharing. Helen Parkinson agreed and told the group that the Informatics Initiative will be holding a workshop based on data sharing in clinical trials towards the end of 2005.

Ken Buetow explained that the NCICB are investing in the infrastructure to enable data sharing and that it was a contractual requirement of those involved in the caBIG initiative that data was shared. NCICB also have a convening role, similar to that of NCRI, with regard to facilitating data sharing discussions. Richard Begent suggested that NCRI should collaborate with NCICB in this process. Jane Cope welcomed the progress to date but outlined that communication with the Chief Executives of the NCRI Partner Organisations will be necessary if data sharing is to be formally adopted by all the Partner Organisations. A paper outlining the progress of the data sharing initiative will be presented to the NCRI Board in June 2005 for endorsement. Once approved by the Board the Chief Executives of the NCRI partners will be approached. Ken Buetow agreed that a proper communications strategy will be key and that the Informatics Unit and Task Force should look at ways of actively disseminating the work of the data sharing initiative. Helen Parkinson explained that the Unit are organising a workshop at the NCRI Cancer Conference in October 2005 and that this will act as a showcase for the work of the initiative. Rob Maddocks agreed that a proper communications strategy will be key to the success of the Initiative and that this will be included in the business case.

David Gavaghan enquired as to how the infrastructure needed to enable data sharing will be matched with the requirement to share data. Fiona Reddington explained that during the data sharing pilots people are being asked how they share their data and what repositories they use. This will help identify areas where no community adopted resource exists and this





NCRI INFORMATICS INITIATIVE

can then be highlighted as an area for strategic investment and reported back to the NCRI Board for consideration. Helen Parkinson added that the Unit will be working with the BBSRC to separate domain specific issues from technology specific issues. Richard Begent also explained that an effort will be made to advocate the use of existing suitable resources where possible, e.g. the infrastructure provided by the NCICB.

3. Update on Focus Areas

Peter Kerr presented an update of the “Integrating Functional Genomics and Clinical Trials” workshop that was held at the end of January 2005 at the Royal Society of Medicine in London (Presentation 2). Alan Rector explained that following the workshop that he had been involved in a number of teleconferences with the NCI and that the workshop had facilitated a greater level of interaction between the organisations than had previously been achieved.

Helen Parkinson presented an update on the proposed “Genetic Variation” workshop to be held in Summer 2005 (Presentation 3).

Max Wilkinson presented an update on the Training review that is being conducted and will be included in the business case which is presented to the NCRI Board (Presentation 4). Max Wilkinson explained that he would be meeting with the NCICB training team at the annual caBIG meeting in Washington and that a draft of the training review will be sent out to the Task Force for consultation prior to inclusion in the business case.

Stephen Turner presented an update on the Infrastructure review that is being conducted and will be included in the business case that is presented to the NCRI Board (Presentation 5). Richard Begent explained that the eRDC project will address a lot of the current infrastructure requirements for the clinical trials section of the matrix and may prove to be extensible to the area of epidemiology. David Gavaghan enquired as to whether Ken Buetow had a view on how useful legacy data will be with regard to data sharing and integration. Ken Buetow replied that the usefulness of legacy data was likely to be context specific. Whilst population data and DNA sequence data are undoubtedly useful when shared, clinical trial data tends to be more aim specific and thus more difficult to share and integrate.

David Ingram informed the group that the issues of confidentiality and consent would need to be carefully addressed with respect to data sharing and queried how the Informatics Initiative would be integrating with the work of the MRC in this area. Fiona Reddington explained that several members of the Informatics Unit have been involved in the MRC Data Sharing and Preservation Initiative and also with the work on consent and confidentiality. Fiona Reddington also explained that other NCRI Partners were also working in this area and that the Informatics Initiative would be looking to the UK Clinical Research Collaboration (UKCRC) to provide a lead on the national policies regarding consent and confidentiality. Jane Cope agreed that this was the correct way to proceed. Steve Oliver reinforced the point that many of the projects that are encompassed by the Informatics Initiative are international and a flexible approach will need to be taken to any standards or policies advocated by the Initiative to ensure complementarity. Ken Buetow agreed and outlined the need to recognise that what is built now in terms of hardware and software will not be future-proof. The Initiative will need to identify what is concrete at this stage and allow for standards and policies to be interchanged in any design for an informatics platform.

4. Potential NCRI Demonstrator Project

Eva Morris presented a summary of the potential demonstrator project for approval by the Task Force (Presentation 6). If the project is seen to adhere to the principles of the NCRI Informatics Initiative then funding will be sought for it as a demonstrator project. It was





NCRI INFORMATICS INITIATIVE

highlighted that the project would provide an interface with the NHS, one of the Initiatives strategic partner's who have not yet been directly engaged with via a demonstrator project and would validate the use of Hospital Episode Statistics (HES) data in the context of clinical trials.

Alan Rector suggested that the project authors should speak to Ian Buchan (Senior Lecturer in Public Health Informatics, University of Manchester) regarding the secondary uses of HES data and felt that it was necessary to identify what questions the demonstrator would address that are not already being addressed by other projects. David Ingram agreed that the Initiative needed to be clear about what the criteria for a demonstrator project were so that the Initiative was not seen as an easy route to funding and to ensure that other sources of funding were leveraged if possible. Ken Buetow suggested that the criteria should be that:

- the project needs to address an important problem
- that the problem needs to be solved (and is not already being addressed by existing projects)
- the project will approach the problem in a scaleable, useful way from an IT point of view so that the solution can become a template for solving similar problems.

The group agreed that these were useful criteria and Jane Cope agreed that the Initiative needed to communicate the criteria for a demonstration project in a more public way. The Informatics Unit will work with the project authors regarding what criteria the project would have to satisfy to be considered as a demonstrator.

5. Informatics Report and Discussion

Richard Begent explained that the NCRI Board have requested a business case from the Initiative outlining the potential ways of moving the Initiative forward. Four potential options for inclusion in the business case were presented for discussion (Presentation 7, Paper 1). The group asked for clarification of what the options were being asked to address. Richard Begent explained that these were the options for implementing the vision outlined in the Strategic Framework. Rob Maddocks explained that we need to produce a high level plan for implementation as we will be dealing with people from a business background at the NCRI Board meeting. The following key points were agreed upon:

- The option of terminating the Initiative, disbanding the Task Force and dissolving the Unit was not considered viable. This would not capitalise on the work already delivered or the investment already made by the NCRI Partners. By not continuing with the Initiative a valuable opportunity would be lost and the Partners would no longer have a means for taking an NCRI-wide coordinated strategic approach to funding informatics. Ken Buetow outlined that the NCI recognised the need for a coordinated approach to informatics
- The option of adopting the structure of the NCICB and caBIG was considered but it was felt that significant resources would be required, more formal contractual arrangements would need to be put in place to ensure delivery of resources and that provision would need to be made for the co-existence of complementary projects in the UK which did not fit with the current caBIG workspaces.
- The option of continuing the funding at the current level (i.e. without provision of ring-fenced money to support projects) was not considered feasible. The group felt strongly that additional resources were required to the current funding mechanisms
- The option of continuing funding at the current level with the addition of ring-fenced funding, which could be bid for, was considered a sensible approach although it was acknowledged that tangible benefits will need to be delivered to the NCRI Partners in the short term to convince them of the importance of providing such funding





NCRI INFORMATICS INITIATIVE

- Alvis Brazma suggested that we need to measure how much it costs to manage the data generated by the cancer community. The Stanford Microarray Database have estimated that the costs of managing high throughput data are 25% of the costs of data generation
- There are onward costs associated with sustaining and re-using data and the Research Councils are ill-prepared for these costs
- Ken Buetow explained that Carolyn Clancy, Director of the US Agency for Healthcare Research and Quality (AHRQ), has recently estimated that improved healthcare information management can save \$80 billion per annum in the USA. The group agreed that a comparable figure for the UK would be a valuable addition to the business case
- David Gavaghan stressed that e-Science teaches us that we need a central coordination function in a large initiative or it will fail. Also, some authority will be required regarding imposing the use of standards
- Ring fenced funding will be required for any large-scale initiative
- We will need to time-box and budget-box the different stages of the project. It is important to recognise that the roles of the Task Force and Unit may change depending on the phase of the project



It was agreed that the options appraisal document should be amended to reflect the above points and circulated to the Task Force for further revision and refinement.

6. Date of next meeting

It was agreed that the next meeting would be held within the next 3 months, dates to be circulated to the group in the near future.