



NCRI
INFORMATICS
INITIATIVE



NCRI
National
Cancer
Research
Institute

Newsletter

SUMMER 2009 ISSUE 14

Welcome to Issue 14 of the NCRI Informatics Initiative Newsletter

There are a lot of things to report on in this issue of our newsletter, as we are at both a very busy and very exciting period in the life of the Initiative.

In the middle of July we will be publicly launching the ONIX portal and we will also be presenting a new business case to the Informatics Management Board. This business case has been compiled by an independent consulting company, and sets out the vision and the case for developing and funding the Initiative until 2013. We hope that the launch of ONIX will be a great success and that the positive benefits shown by the business case will succeed in securing the long-term stability of the Initiative to allow ONIX to be developed to its full potential.

We would like to take this opportunity to remind you that

registration for both the joint Informatics Initiative/caBIG[®] conference (10-11 September, London) and the caBIG[®] annual meeting (20-22 July, Washington D.C.) are now open and links to both meetings can be found on the Unit's website. We hope to see you at one or both of these meetings.

Finally, we would like to say a regretful farewell to Robin Clark, the Initiative's Director. As you will read in this issue, Robin will be retiring in August of this year. We would like to express our sadness that Robin is leaving as he has been both a fantastic driving force for the unit, and a very enjoyable person to work for. We wish him a long and happy retirement.

We hope you enjoy this issue!

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If you have any queries or comments on any article in our newsletter, or would like to contribute to the next issue, please contact us at:

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Cancer Research UK

Data sharing policy progress

There is a vast amount of cancer research being performed across the globe today and technological advances have meant that an ever increasing amount of data is generated each year. More than ever, it is crucial that findings are shared by scientists and clinicians to accelerate progress in the field.

The importance of data sharing has been recognised by the NCRI. Working with partner organisations, a NCRI data sharing policy was developed and formally adopted by the NCRI Board in 2005. This high level policy supports the principle that publically funded research should be made available to the maximum extent possible and encourages a consistent approach across partner organisations. In line with the NCRI policy, a number of partners have also developed policies of their own to meet the particular needs of their organisation, while others are currently working towards this. Along with research funders, many peer-review journals have also recognised the importance of making data available and now make this a condition for publication.

Consistent with the position of the NCRI and other research funding organisations, Cancer Research UK wishes to see the research it supports have the maximum impact

CANCER RESEARCH UK



and whenever possible translated to deliver patient benefit. This can in part be achieved by ensuring research data we fund is made as widely and freely accessible as possible to the research community, whilst safeguarding intellectual property, the privacy of patients and confidential data. We believe that helping to make research data more readily available will reinforce open scientific enquiry, stimulate new investigations and analyses, and reduce duplication.

This year, Cancer Research UK launched a policy on data sharing and preservation (http://science.cancerresearchuk.org/gapp/terms/policy_ds/) that is part of the new **Terms and Conditions for Research Grants and Awards**. The policy is in line with those adopted by other researcher funding organisations and states our expectation that the researchers we fund should make their data as widely and freely as possible to maximise public benefit. It is applicable across all areas of research we fund and was developed in consultation with key members of the research community and with the assistance of the NCRI Informatics Initiative. To assist researchers we will also provide supporting data sharing guidelines and a 'Frequently Asked Questions (FAQs)' document on

our website.

As with the NCRI policy, one key aspect is the requirement that investigators make provision for data sharing at the outset. Candidates will be asked to provide **Data Sharing and Management Plans** as part of the application for research funding. Applicants are asked to outline the type(s) of data they expect to generate and plan when and where the data will be available to the research community. This will vary according to the nature of the proposed project, so candidates are given the flexibility of a free text box to detail their plans. Applicants may be restricted in their ability to make findings available for a number of reasons. For example there may be restrictions when co-funding is provided by the private sector (e.g. by a pharmaceutical company) or host institution resulting in some restrictions on the disclosure of data. Similarly legal, ethical and regulatory restrictions may affect sharing – particularly with studies involving patient data. Applicants are asked to give details of where restrictions apply and where possible, explore ways these issues can be addressed.

Progress made in implementing Data Sharing and Management Plans by Cancer Research UK funded researchers will be monitored and the policy and guidelines will be kept under review. We believe that implementing this policy will not only encourage sharing, but ultimately facilitate improvements in cancer prevention and treatment. ■



UNIT ACTIVITIES

NCRI ONIX update

ONIX User testing

The first version of the **ONcology Information eXchange (ONIX)** - a portal for the cancer research community - was successfully released in January 2009 to a select pool of end-users from across institutes of the NCRI partner organisations. Since then, the NCRI Informatics Initiative conducted a community review of ONIX with an expanded User Group. Participants were drawn from organisations such as Cancer Research UK, The Gray's Institute of Radiation Oncology and the Wellcome Trust Centre for Human Genetics. The User Group to provide a final review of ONIX in preparation for its formal release in July 2009. More specifically it explored ONIX's current features - the Resource Catalogue and Keyword Search, and participants' general thoughts on ONIX.

Some useful insights were gleaned from the testing sessions with participants confirming the need for a resource, such as ONIX, which brings together cancer-related data and information. It was felt that this had the potential to create a greater awareness of what research was being conducted in the UK and by who, as well as bringing currently hard-to-find data, information and resources to the forefront. Importantly, testers gave specifics on the type of data and information that they would

like access to and the key motivators for using a resource like ONIX. In addition, they also provided some very useful comments on ONIX's content, design and usability.

The feedback obtained from this community review has been very useful and has made a significant contribution to the development of ONIX ensuring that we create a resource that benefits the broader cancer research community.

ONIX will be launched to the public on the 17th of July 2009.

ONIX @ UCL Medical School

Second year medical students and staff had the chance to use NCRI ONIX v1.1 during the Computer Assisted Learning session part of the Cancer Biology course at the University College London (UCL) Medical School. The purpose was to test the effectiveness of ONIX as an educational tool for the next generation of clinicians and scientists and gather feedback.

Following a one hour introductory lecture in cancer biology, students were given two clinical cancer cases and were asked after analysing the patients' clinical information provided to examine the cause and clinical course of the disease and extend their knowledge by finding relevant information regarding the molecular basis of the disease through online sources (e.g. identify mutated genes in lung cancer). Using ONIX's 'Keyword Search' capability -students could simultaneously access and

query a number of different specialised databases instead of accessing and querying each database one at a time or using more generic search engines, such as Google or wikipedia, where one can retrieve a lot of information whose validity and relevance is very difficult to assess.

Using ONIX students with little prior knowledge of cancer were able to:

- Get to relevant information faster
- Access information from resources, which are built and curated to high standards and have the approval of the expert scientific community
- Use it to acquire information about questions that had been set to them
- Apply the information to solve problems
- Gain an understanding of how computer databases can be used in their future studies

The overall response based on feedback questionnaires from 187 students was very positive; the majority (95%) found the idea of being able to search multiple cancer specific resources at the same time as something that is useful and will make a significant difference to their work (76%).

The Unit is planning similar training with other universities and with the General Medical Council and NHS Connecting for Health training groups amongst others with a view of enabling the training of other communities. ■



ONIX at UCL's Cancer Biology Computer Assisted Learning session.

MEETING UPDATES

NCI caBIG® Annual Conference

20 - 22 July, 2009
Washington, D.C.

Once again the Informatics Initiative is delighted to participate in this year's meeting with a presentation by Mr Edward Zukowski titled '**caGRID adoption at NCRI UK**' during the 'Collaboration via the Grid' session in the afternoon of the second day. The talk will cover how caGrid security infrastructure has been used for building NCRI's ONcology Information eXchange (ONIX), our experiences with building caGrid services wrapping UK resources (e.g. UK PubMed Central), work on extending vocabulary infrastructure with semantic discovery plus our plans for future extensions.

For more information you can also visit us at our exhibition stand (**Booth 20**) throughout the conference. ■

NCI caBIG® & NCRI Informatics Initiative Joint annual conference

10-11 September 2009
London, U.K.

We are pleased to announce that registration for the 2009 joint conference has opened.

This year's meeting will focus on implementation experiences of interoperable tools and technologies aiming to provide better access and connect biomedical resources.

On the second day, delegates will have a unique opportunity to attend one of two workshops:

Workshop 1 - caBIG® Tools

Tools will include: the TCGA Data Portal, the Cancer Molecular Analysis portal, the Cancer Genome Workbench and the caIntegrator.

Workshop 2 - Data Sharing

The Research Culture, Funder Requirements, and Regulatory and Ethical Considerations.

For more information and to register, please visit the conference website. ■

UNIT NEWS

Message from Outgoing Director

ROBIN CLARK

Many of you will know that I am retiring as Director at the end of my three year term in August 2009. As I take stock of how the Initiative has progressed since 2006 I am enormously encouraged by the huge strides the community has made in making cancer research information easier to find and more useable when located. The conclusion which seems so obvious, but in practice is so hard to achieve, is that we are beginning to be able to better build on what is already known. Part of the reason for success is that the Initiative has a clear plan, a committed Management Board and has enjoyed great support from our funding organisations. From the Board I would especially like to thank the Consumer representatives who have given of their own time to support our work.

We now have a regular and thriving international conference, have delivered pioneering training to the next generation of clinicians, seen the implementation of data sharing policies by a growing number of funders and, of course, released the first version of NCRI's Oncology Information Exchange (ONIX) and the start of the informatics platform.

But I don't think of my departure as an ending but more the beginning of a new phase. The public launch of



ONIX this summer is only the start – for example, our plans for expansion of the platform in both content and functionality extend into 2013. As part of our continuing community building work our collaborations with a number of NHS linked organisations, the British Library, the European Bioinformatics Institute and the US caBIG® program (to name only some of our valued partners) are also bearing fruit and each now has a set of very tangible activities with associated benefits.

So, as I move on, I want to thank you all for the support, understanding and encouragement that the Initiative has received from you the research community: not only has that been rewarding for me but much more importantly for its impact in lessening the incidence, mortality and suffering from cancer. Thank you. ■








**BIOMEDICAL INFORMATICS WITHOUT BORDERS:
FROM COLLABORATION TO IMPLEMENTATION**

WELLCOME TRUST, LONDON

SAVE THE DATE
10 & 11 SEPTEMBER 2009

WWW.CANCERINFORMATICS.ORG.UK/NCI-NCRI2009CONFERENCE