

Newsletter

WINTER 2009 ISSUE 16

Welcome to Issue 16 of the NCRI Informatics Initiative Newsletter

This issue covers an update on ONIX deployment and development as well as some of the peripheral activities the Initiative is involved in. Despite only being publicly released in July, the Oncology Information eXchange (ONIX) web portal has long passed the milestone of its 1000th registered user, and has registered users from 48 countries. We hope that ONIX's user base will continue to grow as we further enhance the portal. November of this year saw ONIX v1.3 released. This release contains a number of user-driven improvements such as: no requirement to register or log in to use ONIX's basic functionality, an improved user interface, the application of operators is now allowed within Quick Search and a beta release of a redesigned Resource Catalogue

Also in November, the Initiative held its 9th Informatics Management Board. In keeping with all previous Management Board meetings, the Initiative was deemed to have achieved all of its objectives for that period. The Board were also happy to approve the new Informatics Initiative Business Case, which runs from 2010-2013. Currently, the Initiative is in discussions with the NCRI Partners on obtaining funding for this next phase of the project.

Finally, the Initiative is co-ordinating a joint event with the British Library called 'Cancer Research - Lost in Translation?'. This event will be held in the British Library on 19th January and will feature a number of distinguished speakers.

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 email us at: info@cancerinformatics.org.uk

ONIX, RIC and UKPMC Collaboration

Closing the Loop on All Aspects of the Research Lifecycle

The NCRI's ONIX team are collaborating with the British Library on a project to simplify the process of research information management for the cancer research community.

British Library

The British Library (BL) has traditionally been seen as a resource for the arts and humanities, rather than the scientific communities. But BL holds a wealth of scientific information and is currently involved in two exciting developments of benefit to the cancer research community: RIC (Research Information Centre) and UKPMC (UK PubMed Central)

RIC

The RIC is a virtual research environment that will provide an integrated suite of tools for finding, creating, managing, sharing and disseminating all the types of information associated with a research project. It aims to address the 'pain points' of research information management.

The RIC will cover all aspects of the research lifecycle: idea discovery, reviewing the literature, finding and collaborating with colleagues, sharing knowledge, seeking funding, organising information, writing papers, preparing presentations and preserving research findings.

It is being developed in response to the scientific community's need for intuitive, customisable tools that enable researchers to:

- Access and organise key resources
- Perform efficient, federated searches
- Annotate, share and discuss information
- Keep up-to-date on funding opportunities
- Support collaborations through project-based workflows

- Organise research projects in a secure, on-line environment
- Manage outputs, such as funding proposals, papers, presentations and datasets

For further information go to <http://www.bl.uk/reshelp/expert/help/science/ric/ric.html>



UK PubMed Central

The ambition of UKPMC is to become the information resource of choice for the UK biomedical and health research communities. It is funded by the 8 largest funders of medical research in the UK (Wellcome Trust, Cancer Research UK, Medical Research Council, Biotechnology and Biological Sciences Research Council, Arthritis Research Council, British Heart Foundation, National Institute for Health Research (NHS) and Chief Scientist's Office (Scotland)).

In 2006, the eight funders of biomedical and health research came together to develop the concept of UKPMC. One of their first steps was collectively encouraging the research community to submit their published research outcomes to the repository through mandates. The funding organisations also recognised the potential of developing innovative tools and services to augment the researcher's

experience of using UKPMC, ultimately leading to more efficient and effective research.

UKPMC is based on PubMed Central, the U.S. National Institutes of Health free digital archive of biomedical and life sciences journal literature. It offers researchers a free, direct, single point of access to:

- 1.6 million+ full text, peer reviewed published journal articles covering all fields of biomedical and health research
- 19 million+ PubMed abstracts
- 2,400+ National Health Service (NHS) clinical guidelines
- 5,000+ PhD theses from biomedical and health research students across the UK held at the British Library
- 1.8 million patents of relevance to the health and biomedical sciences

It is due to release a new interface and additional content in January 2010.

For further information go to <http://www.ukpmc.ac.uk/>

The Collaboration

Collaboration with ONIX was a natural extension for this work, given its position as a major source of information for cancer research data. UKPMC is registered as a resource in ONIX and UKPMC is the default resource for RIC, so this "closes the loop" of information management.

Typically, a user researching for a research proposal will review the literature through ONIX and UKPMC, and obtain links to information on sources of funding through RIC. Once the research project has commenced, the user can use RIC as a resource for experimentation using myExperiment, caBIG® and ONIX data sets. It can also be used as a means to disseminate outputs (data which can be published in RIC, and published articles which are published in UKPMC – and made available via ONIX and RIC. ■

UNIT ACTIVITIES

ONIX Update

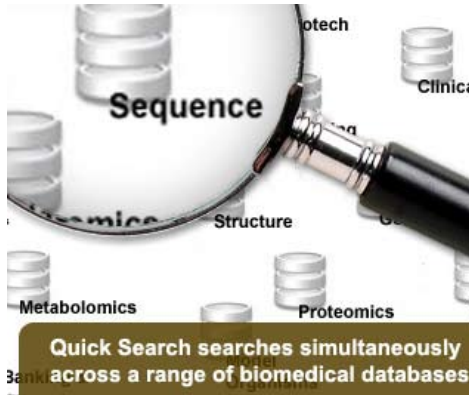
New point release: v1.3

The NCRI Informatics Initiative releases a new version of the ONcology Information eXchange (ONIX) approximately every 6 months as a direct response to user feedback. This phased release approach aims to best meet the research community expectations in terms of functionality.

November saw a new point release (v1.3). Significant improvements to this new version include:

- No need to log in to use ONIX
- More efficient searching – ONIX now automatically inserts required operator terms and wildcards specific to each resource
- Resource Catalogue completely re-structured and expanded
- Improved presentation of results

The Informatics Initiative is already



working on v1.4 – scheduled for release in March 2010. Any comments or suggestions for improvements for v1.4 would be greatly welcomed by the team. Please email comments to the team via the ONIX site.

To see the new features, please visit: <http://www.ncri-onix.org.uk/>. ■

Action Against Cancer Launch

In response to request for action from the European Council and the European Parliament, on 24th June 2009 the European Commission adopted a Communication on Action Against Cancer. This new partnership seeks to support Member States in their efforts to tackle cancer by providing a framework for identifying and sharing information, capacity and expertise in cancer prevention and control.

The Informatics Initiative was invited to the launch of this new partnership and has subsequently been invited to participate on one of the Working Groups set up around the four core areas of action: health information; primary prevention; identification and promotion of good practice; and cancer research.

The Initiative is seeking to become involved in the 'health information' work package. The scope of this work package



Data Sharing Working Group

Funding bodies unite to address the practicalities of sharing

The Informatics Initiative is taking the lead on facilitating a cross-funders working group on practical implementation of data-sharing. Of late, real progress has been made in the adoption of data-sharing policies by many of the NCRI partners, but the practical implementation of such policies has received less attention. This working group will seek to bring together the main funders of medical research in the UK and address common areas of perceived difficulty in the implementation of data-sharing policies.



Board, and the board was fully supportive of the Unit taking the lead in facilitating this process.

Initially liaising with the Wellcome Trust, MRC and CR-UK, the intention is to invite a wider group of stakeholders to participate in future rounds and to try to reach

consensus on best practice and ways to support data-sharing to make the task as simple as possible for grant-holders. The Unit is keen to receive suggestions and expressions of interest for participation in this project.

For more information visit: <http://www.cancerinformatics.org.uk/datasharing.html> ■

fits very closely with the work of the Initiative, tackling as it does, collection and analysis of comparable data, cancer registration, and evidence to support learning and sharing of knowledge.

The partnership is scheduled to run from 2009-2013, and will be a specific joint action to be supported by the Health Programme from 2010. One of the overall objectives of this partnership is to reduce the burden of cancer in the EU by 15% by 2020.

For more information please visit: http://ec.europa.eu/health/ph_information/dissemination/diseases/cancer_partnership_en.htm ■

This issue was raised by the Unit at its Informatics November Management

MEETING UPDATE

5th International Digital Curation Conference

Data Sharing Workshop, London, UK

02 December 2009



Unit members attended a workshop on managing and sharing research data with a particular focus on consent, confidentiality and disclosure, which took place as part of the preconference activities of the 5th International Digital Curation Conference in London.

This workshop was organised by the UK Data Archive (UKDA) and provided a comprehensive analysis of all of the pertinent issues. The day was divided into three sessions. The first session was an introduction to the topic that covered:

- Data management and sharing as applied to research involving people as participants;
- The legal and ethical aspects of data sharing; and
- Data Management Planning

Following the introduction, attendees were split into two groups for the more interactive part of the day. This included two sessions that analysed attendee-derived case studies as well as pre-prepared examples from the UKDA to explore two areas in detail – **Anonymisation Techniques** and **Obtaining Consent**.

In the sessions exploring **Anonymisation**

Techniques advice was given on anonymising quantitative, relational, geo-referenced and qualitative data. Attendees then discussed examples and the challenges associated with the practicalities of anonymisation with the conclusion that there needed to be a balance between maintaining confidentiality and ensuring enough context is included in a dataset to ensure it can be interpreted accurately. It was also suggested that careful consideration



Image taken from UKDA

be given to what data is collected as in retrospect many find that some of the confidential and/or personal data collected did not make a significant contribution to their research.

The session on **Obtaining Consent** began with a brief introduction that explained:

when to ask for consent; what format should be used to obtain consent; what to include when asking for consent; and the types of research material that require consent. Following the brief introduction delegates then had to evaluate examples of the 'good and the bad' to get a better feel of the style, structure and content of consent forms.

This was an excellent educational workshop in that it not only provided information about the regulations and issues surrounding ethics, consent and confidentiality but gave delegates practical advice and hands-on experience through the case studies and examples provided.

The UKDA will host similar events in the future and it is highly recommended that researchers, funders or anyone wishing to familiarise themselves with ethics, consent and confidentiality with regards to the sharing of research data attend.

The UKDA has also published a '**Managing and Sharing Data: A Best Practice Guide**', which covers a range of data sharing issues.

For more information and to obtain a copy of this guide visit <http://www.data-archive.ac.uk/sharing/sharing.asp>. ■

UPCOMING EVENT

Joint NCRI Informatics / British Library Conference

We are pleased to inform you about the upcoming half-day event that our Initiative will be hosting together with the British Library. This event aims to highlight the challenges different stakeholders are facing in the movement of cancer research information, ranging from information access to misinterpretation of key messages to the public.

Speakers include:

- | | |
|---------------------------|-------------------------------|
| • Sir Ken Calman | • Professor John Gribben |
| • Professor David Cameron | • Ms Monica Jones |
| • Mr Dave Ardron & | • Professor Peter Littlejohns |
| • Dr Ben Goldacre | • Professor Herbie Newell |

We hope to see you all there!



For more information about this event visit: http://www.cancerinformatics.org.uk/event_lostintranslation.html