



NCRI
INFORMATICS
INITIATIVE



NCRI
National
Cancer
Research
Institute

Newsletter

SPRING 2009 ISSUE 13

Welcome to Issue 13 of the NCRI Informatics Initiative Newsletter

We are pleased to announce that ONIX v1.0 has been launched. This release of ONIX is restricted to a small base of users (as selected by the Informatics Management Board) to allow us to focus on a phase of 'extended user testing' before making ONIX publicly available in the summer. By the time of the summer general release, the Informatics Co-ordination Unit (ICU) will have incorporated more functionality and more resources into ONIX. So far, the responses we have received from users have been both enthusiastic and encouraging.

The ICU (in partnership with the National Cancer Intelligence Network) recently hosted a day-long meeting for the NCRI Consumer Liaison Group (CLG). This meeting was held in response to a request from the CLG for more information

about the Informatics Initiative and ONIX. The meeting was well-attended and the members of the CLG were obviously interested in, and appreciative of, the aims and goals of the ICU.

The ICU has also recently appointed a second Consumer Representative, Mr John Rouse, to work alongside our existing Consumer Representative, Mrs Julie Clifton. We are delighted to welcome John to the Initiative, and you can find out more about him inside this issue.

Another recent meeting was February's Informatics Management Board. This latest IMB was a success and the Initiative was praised on its continued progress and in the development of ONIX and was given the green light to continue working on its Implementation Plan.

We hope you enjoy this issue!

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SPECIAL FEATURE

Ethics, Consent & Confidentiality:

Do they really prevent data sharing in biomedical research?

Sharing biomedical data is widely accepted as good practice. Indeed, many funding agencies require investigators to share their data as a condition of receiving funding. Yet developing a data sharing plan requires familiarity with the regulations that govern the sharing of different types of data, specifically patient data. In this article, we look at the regulations of ethics, consent and confidentiality and the challenges that may arise with respect to the sharing and access of data.

Ethical Regulations

In the UK, before any study involving human participants commences scientists must obtain **ethical approval** from the relevant Research Ethics Committee. Once approval has been obtained, one of the requirements is that **informed consent** must be obtained for identifiable patient data to be shared and stored. Scientists are thus obliged to provide participants with a clear picture of what data will be collected, shared and stored, who will have access and how confidentiality will be maintained. Authorities do recognise there are times when it is not feasible to obtain informed consent to use data. Therefore the law steps in and under the **National Health Service Act 2006** and the **Health &**

Social Acts 2001/8 researchers may use identifiable patient data without consent. To do this scientists have to demonstrate that the benefit to the public outweighs the rights of participants' to privacy. In addition to this, informed consent is not required for the sharing of anonymised data but consent must be obtained for the initial data collection and to carry out the anonymisation.

Government Legislation

The law plays an important role in governing how patient data is to be managed. One of the most important pieces of legislation is the **Data Protection Act (DPA) 1998**. Other pieces of legislation that have an impact on data sharing are the **Human Rights Act 1998** and the **Common Law of Confidentiality**. Together these protect the rights of individuals to privacy and enforce the non-disclosure of confidential information unless prior agreement is obtained for release.

Data sharing Challenges

The recent media coverage of data governance failures has highlighted that those handling sensitive data are sometimes ill-equipped to do so due to lack of awareness of the regulations governing data protection. This not only puts patients at risk but also results in missed opportunities to disseminate information and conduct follow-up studies because important data sharing requirements have not been met.

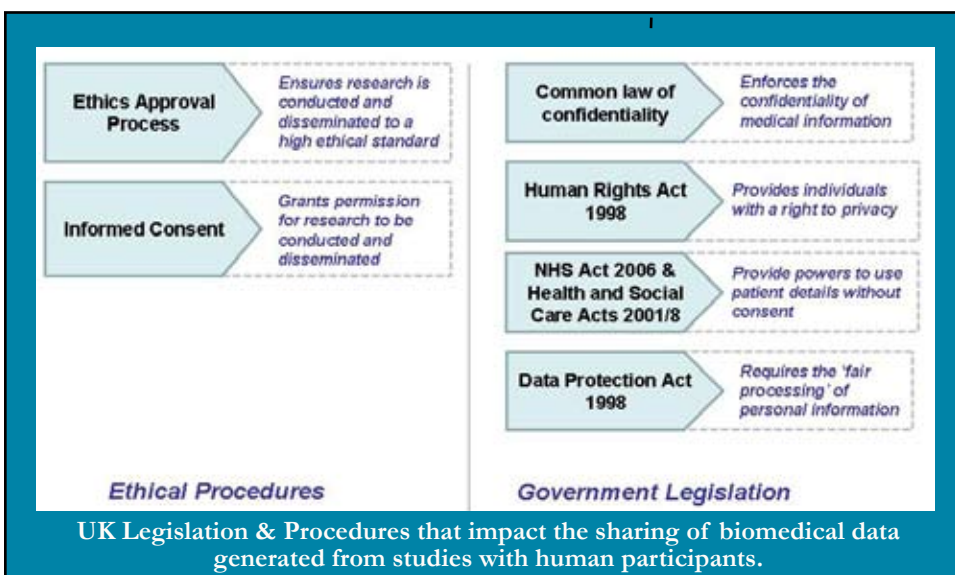
The interpretation of regulations can

itself be challenging with some grey areas particularly with respect to when informed consent for data sharing is not required. What is considered of significant benefit to the public is open to interpretation and makes it hard for scientists to determine what cases are valid and should be brought before the authorities.

Another area where challenges may arise is with informed consent after the study has been conducted and further manipulation, sharing or use of data is desired that was not originally consented to. This would involve re-consenting which may be difficult and time consuming and thus lead to the loss of opportunities for data sharing.

The situation becomes more complex if scientists are part of international collaborations involving studies with non-UK human participants. The regulations of that country need to be understood. For instance in the US, the collection and use of health research data may be governed by federal human research, privacy and security regulations such as the Common Rule and FDA regulations, and the HIPAA Privacy Rule, as well as numerous state research and privacy laws. The responsibility is on the researcher to ensure that their research meets all international ethical and legal requirements and scientists may be ill-equipped to do this.

At first glance, the rules of ethics, consent and confidentiality appear to act as a barrier to data sharing. On further inspection, one can see that provided there is a clear understanding of the regulations and these are correctly implemented there should be minimal hindrance to the sharing and access of data. The key is to firstly ensure adequate security measures are in place to assure review boards and patients that identifiable data will be protected. Secondly, the informed consent process must be forward-thinking, ensuring that current and possible future uses of data are consented to at the outset of a study and finally scientists need to be provided with the relevant support and training to understand national and international regulations as well as good data management procedures. ■



UNIT ACTIVITIES

NCRI ONIX update

Restricted launch

The first version of NCRI's **ONcology Information eXchange (ONIX)** - a portal for the cancer research community was successfully launched this January to a select pool of end-users from across institutes of the NCRI partner organisations, including: Cancer Research UK, the Wellcome Trust and the Medical Research Council. End-users from these institutes are currently 'road-testing' the portal, providing feedback and suggestions on how they will use it in their day-to-day work before the system's public launch in summer 2009.

The Resource Catalogue

At present the portal holds just a small fraction (10-15%) of the sophisticated functionality that will be eventually available to researchers in March 2010. Its main feature is the **Resource Catalogue**, which is a searchable, filterable list of databases, data resources, research projects, data tools and standards that we intend to grow into a global, comprehensive listing of all pertinent cancer research information. Currently, the Resource Catalogue contains information on 112 resources entered by the scientists or organisations responsible for the specific resource. We are keen on continuing to populate it with as many relevant resources as possible. To do this, we would like to enlist your help, and encourage you to send us details of any resources that you know of, are involved in, or make use of, so that we can ensure they are included. The more richly developed the Resource Catalogue is, the more use it will be to the cancer research community. We welcome your suggestions!

For entries in the Resource Catalogue contact:
Stuart.Bell@ncri.org.uk

ONIX @ UCL Medical School

ONIX is being developed in a step-wise fashion with incremental releases to accommodate community feedback and requirements. April sees the release of version 1.1. This

version has increased functionality to accommodate the training needs of 300 medical students during a practical session at University College London (UCL). During the practical session, 'Cancer Biology in the Clinic', ONIX will be used by the students as a one-stop tool to access different informatics resources that will help them answer questions such as 'Which genes are mutated in lung cancer?' and 'How is a patient likely to respond to tamoxifen?'. This 'exercise' will not only demonstrate the usefulness of ONIX as a teaching tool for the next generation of clinicians and scientists but will also be a testing bed to allow experience from initial work to benefit later versions and activities.

ONIX & Terminologies

Terminology plays an important role in the accurate exchange of knowledge in basic and clinical research but is essential for achieving computable semantic interoperability in information systems (i.e. understanding the meaning of the content once it is received electronically).

The NCRI Informatics Initiative aims to promote awareness and use of controlled terminology that can help develop and communicate information useful to scientists, clinicians, patients, and the public. That is why it has always been part of the overall design of ONIX to provide some form of vocabulary service, if at the very least just to support users in refining their queries by being able to quickly access lists of synonyms/preferred terms. In the longer term, it is essential to

do this to support our drive toward searching and browsing efficiently for information, by making querying more 'biologically savvy'.

As part of moving this forward, we plan to pilot the service by implementing the **LexEVS** component developed by the Mayo Clinic in the US as part of the NCI's caBIG® programme. LexEVS is an Open Source component based on the LexGrid model, which defines how vocabularies should be formatted and represented programmatically, and is intended to be flexible enough to accurately represent a wide variety of vocabularies and other lexically-based resources, including: Open Biomedical Ontologies (OBO), Web Ontology Language (OWL) and the Unified Medical Language System (UMLS) Rich Release Format (RRF).

During the pilot phase, we plan to initially install an instance of the **NCI Thesaurus**, although as our experience increases, we will undoubtedly host other vocabularies.

The US National Center for Biomedical Ontology (NCBO) has also adopted the LexGrid model for vocabulary storage. Additionally, NCBO has developed the **BioPortal** application to support a variety of user interactions with the NCBO's repository. Part of our work at this pilot stage will be to evaluate the usage of interfaces, such as the BioPortal, against our own needs and access to the vocabulary service from within ONIX.

Our aim is to implement this service into ONIX by June 2009. ■



ONIX being demonstrated to a select pool of end-users from the NCRI partner organisations.

MEETING UPDATE

Consumer Liaison Group - Informatics Workshop

12 February, 2009

London

One of the aims of the NCRI is to ensure that patients benefit from research conducted in the UK. To fulfil this aim the NCRI, through its Consumer Liaison Group (CLG), has given patients the opportunity to engage in the discussion on how these benefits can be realised. The NCRI Informatics Initiative and the National Cancer Intelligence Network (NCIN) hosted a joint workshop for the CLG to allow such dialogue to take place.

The morning session was dedicated to NCIN, featuring talks from Chris Carrigan, Head of the NCIN Coordinating Unit, Professor David Forman, Analysis and Information Lead and Dr. Michael Chapman, Research Programme Manager. They explained how NCIN will implement the Cancer Reform Strategy by building a national cancer data resource, which will supply extensive information on cancer services and outcomes with the aim of improving quality and enabling patients to make informed choices about their healthcare.

In the afternoon session, the NCRI Informatics Initiative summarised their work in developing the IT infrastructure – The NCRI Oncology Information Exchange (ONIX). Explaining how ONIX will provide scientists with easy access to the latest data and information by bringing together a range of biomedical resources to create an information network that spans the whole spectrum of research from genomics to epidemiology. This session featured talks from Dr. Stuart Bell, Section Head of Community Alliances and Dr. Alan Hogg, Section Head of Platform Development with a live demonstration of ONIX from Miss Abi Ajose-Adeogun, Scientific Programme Manager.

The day concluded with a guest speaker, Dr. John Overington, Team Leader at the European Bioinformatics Institute, who provided an excellent example, through the ChEMBL project, of how informatics is being

used to unlock the potential of existing biomedical data.

This workshop was successful in not only creating awareness amongst the CLG members of the work of both initiatives but in providing a forum to discuss the topical issue of information governance, explaining the concepts and challenges of informatics and identifying ways patients can get involved to influence the direction of both initiatives. ■

UNIT NEWS

New Consumer Member

JOHN ROUSE

John has worked in information technology for thirty years, from the early days of TTL logic and Teletypes, ALGOL and FORTRAN, and has supported the Royal Mail computer network for the last 15 years. In addition to his extensive computer skills, he has obtained a psychology degree from Open University, during which he took a one-year course in research methods in education and the social sciences.

John has a long history of consumer involvement, from helping with a food co-op in Liverpool to touring the country promoting the Co-operative Housing movement. In 2008, he joined the board of British Mensa Limited, and studied the governance of voluntary organisations.

When his wife was diagnosed with melanoma, he became a passionate

cancer advocate with a strong interest in cancer research:

“When a mole on my wife’s abdomen turned out to be a melanoma, we started spending lots of time in the dermatology department of our local hospital. One day a new poster appeared, inviting people to join a group aiming to improve cancer services. As we had plenty of suggestions already, we went along, and after my wife’s death, I continued to attend the meetings. This group really does manage to make a difference to cancer services – from championing the use of patient-held log books to campaigning for drinks machines in all out-patient waiting areas, as well as sending representatives to various sub-groups of the Network. We had training days, arranged by Macmillan’s ‘Cancer Voices’ network to familiarise us with the organisation of the NHS and the terminology and acronyms used.

The Users’ Group facilitator encouraged us to attend Macmillan’s regional conferences, at which I signed up for the ‘Opportunities Exchange’ programme.

One ‘opportunity’ in particular caught my eye – a board member was wanted for the National Cancer Research Institute Informatics Initiative. This is a scheme that aims to provide a single point of access to all resources useful to those doing cancer research.

Apart from the obvious reasons and my interest in cancer research, this opportunity seemed to draw together many strands in my life. I attended for interview and was invited to join the Informatics Management Board”. ■



Dr Jane Cope, NCRI Administrative Director, opens the CLG Workshop.