



NCRI
INFORMATICS
INITIATIVE



NCRI
National
Cancer
Research
Institute

Newsletter

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Welcome to Issue 15 of the NCRI Informatics Initiative Newsletter

Since the last issue of the Informatics newsletter we have publicly launched our ONcology Information eXchange (ONIX) portal, and it is now freely available for all to use. The initial launch was a great success. It was widely reported amongst the biomedical research community, and was even picked up by The Times. In the few weeks which have elapsed since the launch ONIX has already developed a substantial user base. We intend to improve and refine ONIX to meet users' expectations and we will be releasing a further, improved version of ONIX in the next few months. We hope that the initial uptake of ONIX will be followed by a growth in user numbers and see ONIX embedded as a core research tool.

This issue focuses on our recent joint conference with the NCI's caBIG[®] group which the Unit hosted at the Wellcome trust in September. This, the third such conference, was very well received by the delegates. The event attracted presenters and delegates from around the world and was an excellent showcase for how informatics is having a demonstrable impact on healthcare around the world.

There is still time to register for the NCRI annual conference, if you haven't already. This will be held in Birmingham from 4-7 October. During the conference the Informatics Initiative is co-hosting a parallel session with the National Cancer Research Network. We hope to see you all there.

And finally, a small item of personnel news from the Unit. As Robin Clark retired in August, Dr Alan Hogg has stepped in as Interim Director of the Informatics Initiative. Alan will continue in this role until a permanent replacement for Robin is recruited.

We hope you enjoy this issue!

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Biomedical Informatics without Borders: From Collaboration to Implementation

10 - 11 September, 2009
London, UK

This was the 3rd successive annual joint conference of the National Cancer Research Institute's Informatics Initiative and US National Cancer Institute's cancer Biomedical Grid (caBIG[®]) initiative. Apart from highlighting the close collaboration of the two initiatives and the sharing of experiences with other similar international efforts, this year's meeting focused on the challenges of delivering the promise of personalised medicine and bringing consumers the support and the tools they need to directly control their care and manage their health.

Implementing Personalised Medicine through IT

The Friday morning Plenary Session of the conference brought together two "distinguished disruptive innovators", so described by session moderator, Dr. Ken Buetow of the NCI. This session analysed the current shortfalls in the application of IT for the delivery of personalised medicine and looked at two real world examples where the introduction and adoption of IT was having measurable benefits in the clinical setting, paving the way to a '21st century learning economy'.

Dr. Laura Esserman, Director of the

Carol Franc Buck Breast Care Center at the University of California, San Francisco opened the session with an overview of the ATHENA Breast Health Network in the context of the provision of personalised medicine. She began by explaining that our approach to clinical care, data collection, sharing and analysis and notions of how we integrate information across systems have to change if we are to truly implement personalised medicine.

The ATHENA project aims to link all aspects of care and, to achieve this a comprehensive informatics infrastructure is required to seamlessly integrate clinical care and research. Dr. Esserman stressed that it is essential not to look upon clinical care and research as two different systems. In the ATHENA project all information collected is shared widely and made available for multiple purposes in order to link all aspects of care.

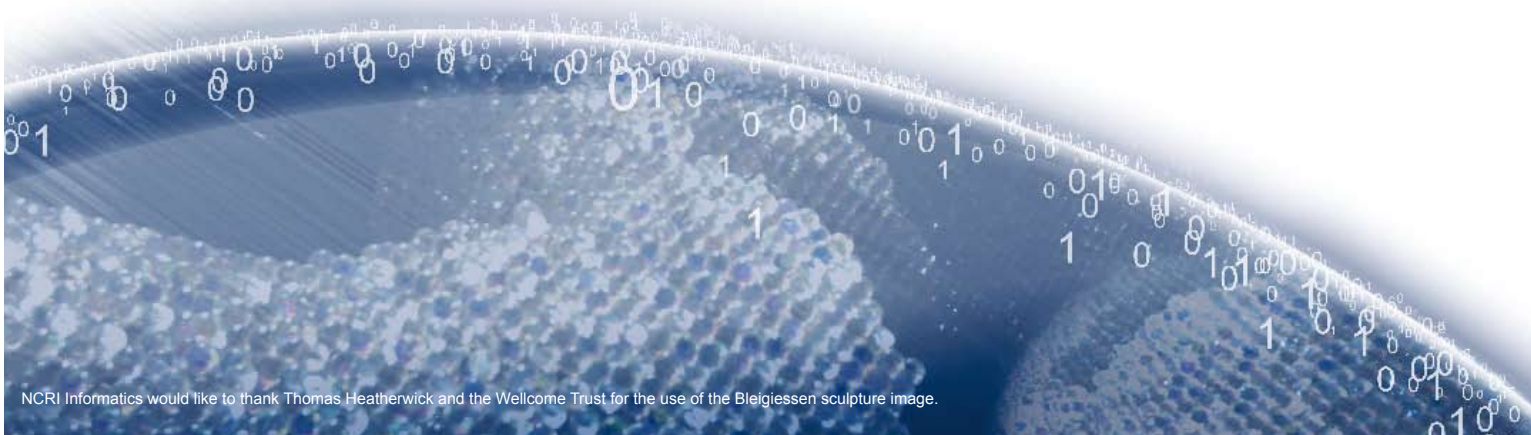
Dr. Esserman concluded by saying that collectively we need to take a step back and think about our common purpose and use that vision to foster



change and continuous improvement to help deliver personalised healthcare.

The second of the two plenary presentations was given by Prof. Sir Alex Markham. With his roles as Chair of the NCRI Informatics Initiative, the National Cancer Intelligence Network and the NHS Research Capability Programme Board, Alex is unmatched in his knowledge of how IT can be used to improve patient care, and ultimately pave the way to a true personalised medicine scenario. Alex addressed the issue of personalised medicine specifically from the point of view of the National Programme for IT being introduced in the UK.

Outlining the vision behind this project (which tied in closely with the vision of Dr. Esserman) Prof. Markham explained how this complex issue, which is viewed warily by the public, needs effective communication to inform and reassure stakeholders of its value. The public and patients want choices, but choices are not possible without information. Notwithstanding the difficulties behind implementing this, the largest IT project in the world, Prof. Markham gave examples of the successes so far. From the Secondary Uses Service to the Choose and Book system, to the Care Record Service and the NHSmail system, he showed how already the National Programme for IT is delivering measurable and necessary improvements to the health service in the UK. As with any programme of this scale and this ambition,



there will be the doubters and those who drag their feet through not being willing to risk their reputations on a new concept, but the potential goals and potential benefits to society mean that those risks need to be taken. Prof. Markham said that he was optimistic that the right decisions were being made and that success would be achieved in the end.

Prof. Markham concluded by saying that the most important thing we have to do in order to deliver personalised medicine (and the IT that surrounds it) is to gain public trust and support.

Empowering the cancer community: The Consumer perspective

The audience had the chance to hear the consumer perspective on the use of informatics for improving the value and the quality of cancer research and healthcare during the 'Empowering the cancer community' session.



Mr David Ardron, chair of the NCRI Consumer Liaison Group (CLG), gave a very powerful and passionate presentation on "Coordinating the patient voice in the UK Cancer Research". He explained that in the UK patients are now represented at various levels of research governance and management by sitting on a

range of boards and committees where they are directly involved in the discussions on service development and the UK's research agenda.

He also identified existing gaps in information, services and research and highlighted the successes stemming from consumer involvement, the most significant of which is a shift in the research agenda reflected in the Cancer Reform Strategy's priorities towards delivering a patient-centred NHS. This approach has enriched the cancer community with studies demonstrating that greater patient involvement had made for "richer data and enhanced credibility of findings."

However, teasing out the impact of user involvement is not straightforward. CLG members have been instrumental in advising on the development of metrics to capture consumer involvement activity and examples of the impact that consumers have on various aspects of the cancer research process. He also mentioned that a mapping and evaluation project is underway and a research proposal is currently being developed for submission as part of the Medical Research Council's call:

Methods to assess the impacts of user involvement in health and social care.



Ms Diane Paul, an NCIPatient Advocate, put forward her view on creating more effective treatments through personalised medicine in her talk "A Survivor's Perspective on Personalised Medicine". Ms Paul explained that from a patient's point of view personalised medicine

was the best option in delivering more meaningful and thus effective treatments. She felt that this was the case because it focused on the overall health of individuals, was based on statistical information about diagnosis and treatment, took into account patient's desires and looked at specific treatment outcomes and side effects. This she felt would lead to the use only of treatments that provided benefits, more meaningful time spent in treatment and the ability for reasonable plans to be made for the future. She stressed the importance of international collaboration in the success of personalised medicine, which she stated would cut drug development costs, allow a larger pool of patients for clinical trials and would deliver treatments more rapidly to patients.

To see presentations from the conference and listen to podcasts, please visit: <http://cancerinformatics.org.uk/nci-ncri2009conference/> ■

The Army of Women / caBIG® collaboration



The US National Cancer Institute's caBIG® initiative has formed a partnership with the Love/Avon Army of Women (AOW) that aims to unite women and researchers through biomedical informatics to eradicate breast cancer.

The Love/Avon AOW, launched in October 2008, aims to recruit women with and without breast cancer who are willing to participate in research and help scientists move the field forward.

So far, it has recruited over 300,000 women and the goal is to recruit one million within the next couple of years.

caBIG® will provide the tools and secure informatics infrastructure underneath their effort - web technology, connectivity and collaboration - to create the largest ever online (electronic) cohort. These large numbers of participants are necessary to provide the power to design

successful longitudinal epidemiological studies that look at the risk of breast cancer and how to prevent it.

What this collaboration hopes to accomplish is the demonstration of a new '21st century model of biomedical research' that is empowering consumers and uses the next generation of technology to access and aggregate information.

For more information on the AOW, please visit: <http://www.armyofwomen.org/> ■

UNIT ACTIVITIES

ONIX launch hits the spot

Coverage update following the July launch and press release

A large number of academics will have read a feature in the Times Higher Education on the launch of ONIX, The ONcology Information eXchange. The feature announced that those in the field are set to benefit from a portal that will collate all the latest cancer research in one easily accessible place – and contained a highly positive analysis of the new web portal. In the piece, Dr Stuart Bell, head of Community Alliances at the National Cancer Research Institute (NCRI) Informatics Initiative compared ONIX to “a big encyclopaedia of cancer research information,” and said that “it promised to save substantial amounts of researchers time by improving the efficiency of the day-to-day work necessary to keep abreast of the fast-moving field.” This was just one of a number of pieces appearing across national and trade press marking a successful publicity campaign.

An announcement appeared on the day of the launch, the 17th July 2009, in the Times diary section – heralding the arrival of a free portal for scientists and clinicians to access international data on cancer.

Key title Pharma Times ran a great piece announcing the NCRI's launch of an online portal for cancer researchers.

Ecancermedalscience – the open access cancer journal founded by the European Institute of Oncology ran a long piece which included quotes from Professor Sir Alex Markham and talked about ONIX's powerful search technology.

Science Business ran the story under the headline: “New cancer research database for industry and

academics.”

A lengthy piece: “ONIX – New online portal for cancer researchers” appeared in PharmaNews and also in the global addition, WorldPharmaNews.com.

Ehealthserver – a key web site targeting the health sector - published the launch press release both on its European and global sites.

OncologyTimes, MedicalNewsToday, and ehealthnews.eu ran coverage.

Dr Stuart Bell also conducted an interview for European medical innovation web site MedNous which

Importantly it promoted the message that ONIX would be further refined for usability through user feedback and will be continuously developed to include many more functions and information.

Not only was coverage secured in target media, the Cancer Research UK press team went further to generate interest within the scientific community by targeting the internal communications teams at all universities and organisations linked to the NCRI and to ONIX. This included mentions in emails, web site publications and printed news letters received by clinicians, scientists and those in industry.

While it is impossible to measure the actual coverage achieved by internal communications, there was a glowing response from the scores of organisations contacted.

Cancer Research UK's 4,500 researchers were targeted directly. Communications were sent to the internal communications networks, at Cancer Research UK's Cambridge Research Institute, London Research Institute, Beatson Institute, the Paterson Institute, the Experimental Cancer Medicine Centre network and the Dundee Cancer Research UK Co-operative.

Organisations contacted outside Cancer Research UK included the Wellcome Trust, Marie Curie Research Institute, Northern Institute for Cancer Research, The Institute for Cancer Research, MRC, and Pfizer, Roche Products,

AstraZeneca and Lilly UK as well as many others.

Steve Palmer, head of press at Cancer Research UK, said: “We were really pleased with the two-pronged launch plan. We targeted key trade titles and also executed a wide-reaching internal communications plan to engage with thousands of people with an interest in cancer researcher through their organisations news letters and emails. We were delighted with the result and achieved exactly what we set out to do.” ■

The graphic features the ONIX logo at the top, which consists of a circular arrangement of green and grey dots. Below the logo, the text reads: "NCRI ONCOLOGY INFORMATION EXCHANGE (ONIX) An Online Data and Information Discovery Tool".

The main body of the graphic is green and contains the following text:

ONIX is a new Internet portal that enables scientists to easily **discover** and **share** the vast amounts of **information** generated in cancer research. Through its features it creates an environment that is effective in **raising** the **awareness** of, and **improving access** to cancer-related data and information generated from across the UK and beyond.

The current features of ONIX include:

- The Quick Search**: An easy-to-use search engine that allows simultaneous searching of data from across multiple external resources.
- The Resource Catalogue**: A register of scientific resources encompassing a range of disciplines.
- The Terminology Browser**: A feature that enables users to browse and search scientific vocabularies.

At the bottom, it says: "Visit ONIX today to gain access to a growing cancer information network. www.ncri-onix.org.uk"

explored the benefits of the new system in great detail.

The entire trade coverage was highly positive. It promoted the key messages to say that ONIX provided researchers with access to a wealth of data and that ONIX pulls together an enormous searchable list of sources of information, analytical tools and research projects from around the world. The publicity also strongly conveyed the fact that ONIX would reduce duplication of research – saving money and speeding up projects.