

# Short and longer term challenges for NCIN in the coming years

**NCIN Annual Conference  
June 2009**

**Alex Markham**

*Chair of the NCIN Steering Group*

# Short and longer term challenges for NCIN in the coming years



“Quite simply, we want to have the  
best cancer information service  
in the world by 2012”

Mike Richards  
Britain against Cancer  
Dec 2007

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- So we've got 3 years!

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# NCIN, the story so far



- Approved by NCRI Board – June 2006
- Endorsed by Cancer Reform Strategy – Dec 2007
- Coordinating Team begins - January 2008
- NHS Contract for Acute Services mandates collection of Cancer Registration Dataset – April 2008
- Coordinating Team and Steering Groups established – Jan to June 2008
- Launch Conference – June 2008
- Clinical Reference Groups --2009
- Second Annual Conference – June 2009, again with an extraordinary series of cancer public health breakthroughs announced

# Short and longer term challenges for NCIN in the coming years



- **NHS Connecting for Health Programmes in NPfIT**
- **Information Governance**
- **Training E-Health Records Researchers**
- **Public Engagement and Communications**



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## Short and longer term challenges for NCIN in the coming years



- NCIN will not achieve its full potential unless these other initiatives and organisations succeed
- They will not succeed unless they are fully supported by the research community, including the NCIN

# Short and longer term challenges for NCIN in the coming years



- 2010 (and 2014?) General Election(s)
- Very tight public sector funding environment
- Pressure on charity sector
- NHS on £100bn p.a.?
- Less money in the Universities?
- Continuing Pharma cost pressures
- Knives out for the National Programme for IT
- International competition forges ahead

# Short and longer term challenges for NCIN in the coming years



## NHS Connecting for Health

- Other CfH Programmes
- The Information Centre for Health and Social Care
  - Secondary Uses Service
  - NHS Information Reporting Service
  - GP Extraction Service (GPES)
  - Information Governance Framework
- Research Capability Programme with NIHR

**NHS**  
Connecting for Health



Research Capability Programme

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## On a typical day in November 2008, the National Programme for IT enables:

- 409,000 prescriptions to be transmitted electronically, reducing errors and inefficiencies
- 25,000 Choose & Book electronic bookings to be made, putting patients in charge of their care
  - 2,200 patient records transferred electronically between GP Practices
- Over 1.8 million queries to be recorded on the patient demographic system enabling letters to be posted to the correct address and patient information to be handled more efficiently
- 330 new users to be registered for access to the NHS Care Record Service (NHS CRS)
  - 70,000 unique authenticated users to access the NHS Care Record Service
    - 600 new NHS secure email users to be registered
- 189,000 NHSmail users, each of whom has an email address for life, to send 1 million secure e-mails, one third of which contain confidential patient information
  - 70 NHS National Network (N3) secure broadband connections to be installed
- 8,379 GP practices (28,000 GPs) to use the Quality Management Analysis System (QMAS) to deliver better care to patients under the new GP contract
  - 1.5 million records to be added to the Secondary Uses Service (SUS)



## Key NPfIT delivery systems – where are we now?

|  |   |
|--|---|
| • NHS Care Records Service                     | - 653,924 registered users                                      |
| • Summary Care Records                         | - 280,213 created   |
| • Choose and Book                              | - 15,533,441 bookings made                                      |
| • Electronic Prescription Service (EPS)        | - 200,324,521 prescription messages issued                      |
| • N3 Network for the NHS                       | - Over 32,000 connections                                       |
| • NHSmail                                      | - Over 350,000 registered users, 1.6million messages sent daily |
| • Picture Archiving and Communications Systems | - 100% of hospital trusts in England now use PACS               |
| • GP IT - GPsoc                                |   |
| ➤ Quality Management and Analysis System       | - 100% GP site deployment                                       |
| ➤ GP2GP record transfer                        | - 587,917 record transfers                                      |

# NHS Care Records Service (NHS CRS)



Will provide individual  
electronic NHS Care  
Record for **50+ million**  
patients

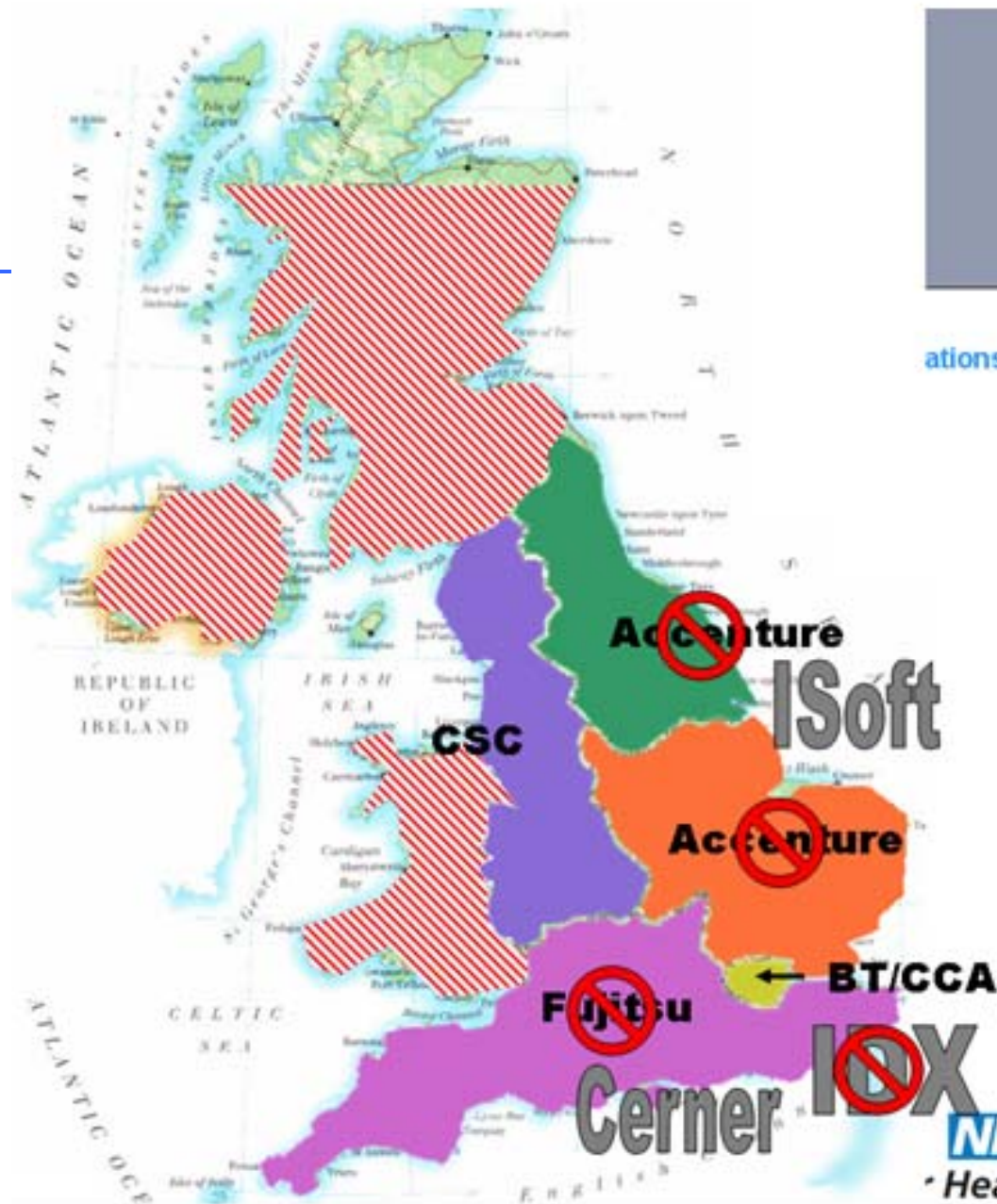
**653,924** NHS Staff  
registered to date

**At the centre** of all new  
systems and services

**280,213** Summary Care  
Records have been  
created to date



ations



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# *What is the Research Capability Programme?*

It is a formal programme of work within NHS CFH looking at how information held in the National Programme for IT systems may be used for research purposes.

It will take forward the recommendations in the “Report of Research Simulations” produced by the UKCRC Advisory Group to NHS CFH.

It has a Senior Responsible Owner, who is a nominee of the DH Director-General of R&D and a Programme Director. A Programme Board and External Reference Group provide strong governance.

The primary objective is to enable research to achieve its full potential as a “core” activity for healthcare, alongside other uses of NHS data that lead to improvements in the quality and safety of care.



## *How will the RCP Vision be realised?*

It will achieve this by:

- Providing a common information infrastructure that will be adaptable and develop in response to the research process and the needs of all stakeholders (including patients);
- Providing a customer-focused set of services that both ensure information is treated and handled in a safe and secure way to protect the rights and confidentiality of patients and individuals under the law, and also meet researchers' needs efficiently. The services will enable high quality research directed towards improving health outcomes: effective treatments, patient safety and quality of life; and
- Providing access to a comprehensive range of technical resources and data sets, under strict protocols of information governance, that will aid the research community to access the data needed to conduct research of the highest methodological standard.

# Background

- Dec 2005 – Chancellor's commitment
- Jan 2006 – DH strategy *Best Research for Best Health*
- July 2006 – R&D advisory group to NHS CFH established by UKCRC
- June 2007 – UKCRC R&D advisory group report
- August 2007 – CRDB SUS working group report
- August 2007 – Research Capability Programme initiated
- September 2007 – Health Select Committee Report



The proposed high level capabilities have been defined through six work streams...

All this documentation is available on the RCP website

| RCP work streams                             | Areas of focus   |
|--|--|
| Infrastructure                               | Honest broker(s) and business model,<br>Safe havens  |
| Functional scope                             | Services to be provided centrally;<br>business models  |
| Data quality and standards                   | Data standards, terminologies, options<br>for linkage of datasets                                      |
| Technical architecture                       | How data will be stored and accessed   |
| Information Governance                       | Data security and measures to<br>manage the threats, patient consent                                   |
| Communications and<br>stakeholder engagement | Initial consultation exercise;<br>communications with public/physicians<br>and with research community |

## *RCP Implementation Phase*

- Strategic Outline Case
- Outline Business Case
- Output Based Specification 1
- Output Based Specification 2
- Full Business Case
- Office of Government Commerce, Gateway Reviews
- Financial Approval Processes: NHS CFH, Department of Health, HM Treasury
- Pilot Studies
- Procurement
- Information Governance Framework
- Ongoing role for ERG/OSCHR E-Health Records Research Board
- Funders' Forum and Strategic Coordination Group
- Continuing engagement with the research community
- Ongoing public consultation and communication

## RCP Data Sources?

- Assessing feasibility of:
  - Demographic Data (NHS patient index)
  - Vital events (births, deaths)
  - Primary care clinical records (GP system extracts, research collections)
  - Secondary care clinical records (Hospital system extracts, research collections)
  - NHS National Data Collections (HES/MHMDs)
  - NHS CRS National Systems (Summary Care Record, Choose and Book, Electronic Prescription Service)
  - Disease Registries (National and Regional)
  - Diagnostic data (Laboratory tests)
  - NHS Specialist Collections (Clinical Audit)
  - Other data collections (research datasets, education, social care, deprivation, socio-economic)

## Examples of services that are within the scope of the RCP would include:



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Negotiating agreements with current data custodians for existing databases to be made available through the HRSS

Developing new linkages between a GP database and a secondary care database such that the combined data can be used for research

Providing access to data sources

Providing regular reports from new datasets built on systems being established within the NPfIT

Storing and archiving data

Verifying data

Providing cohort management services

Anonymising or coding data

Re-identifying individuals from coded data

# ...but these cannot be seen in isolation: they build upon what we have now and what is being developed



*Connecting for Health*

## Examples

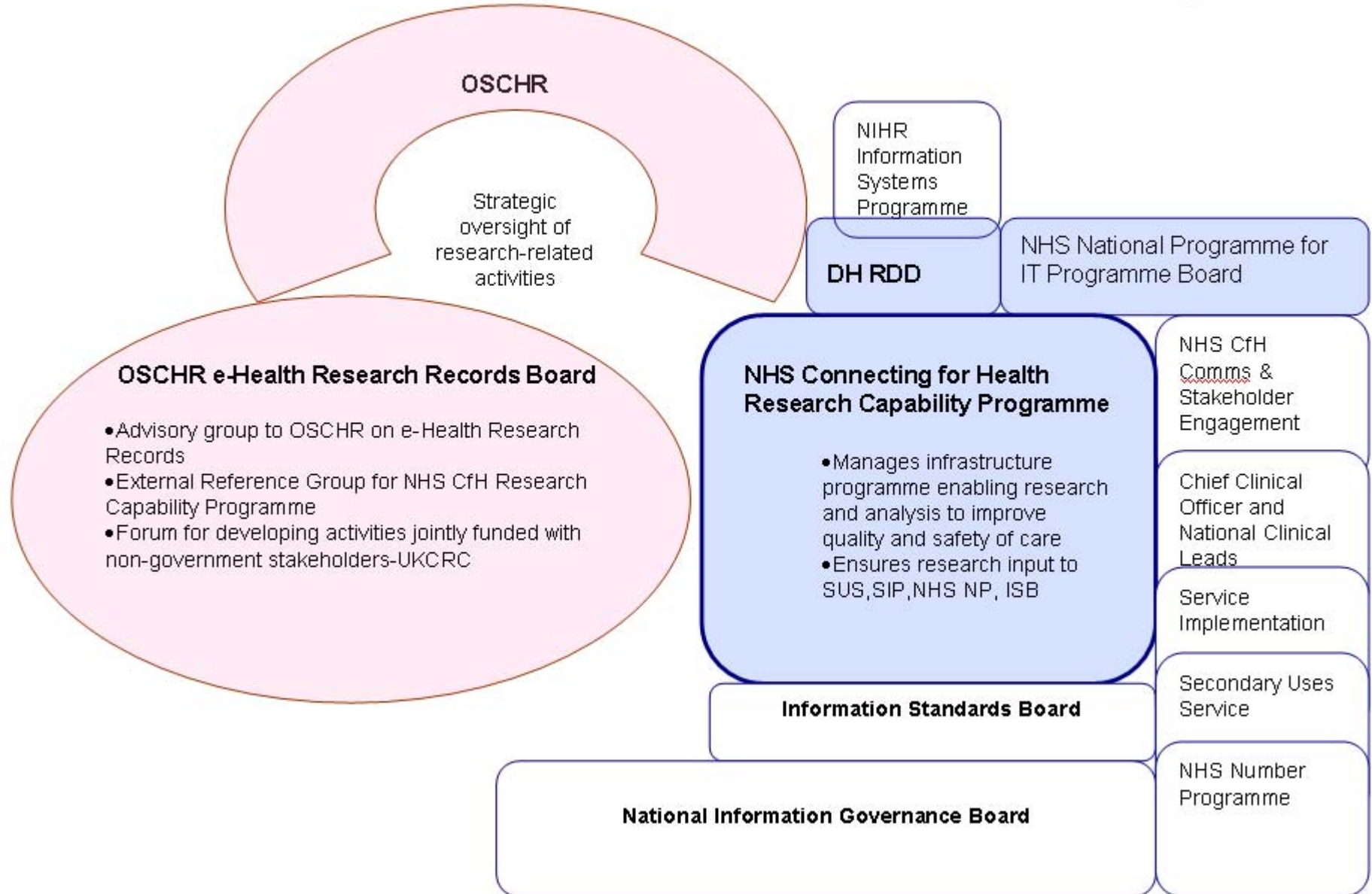
| <b>Building on what we have now:</b> | <b>Building on what is coming...</b> |  |                                      |
|--------------------------------------|--------------------------------------|--|--------------------------------------|
|                                      | <b>...through RCP</b>                | <b>...elsewhere in CfH</b>                   | <b>...other initiatives</b>          |
| Excellent primary care data          | Honest broker                        | Information on prescriptions dispensed (ETP) | Standard costs for clinical trials   |
| Some hospital data, eg HES           | Infrastructure                       | Imaging data (PACS)                          | Streamlined study approval processes |
| Clinical Research Networks           | Linkage and anonymisation services   | Use of a unique patient identifier           |                                      |
| Governance on use of data            | Access to data sets                  |  |                                      |
|                                      | Catalogues and advice                |  |                                      |

## **INFORMATION GOVERNANCE**

- National Information Governance Board (NIGB)/PIAG
- DH Information Policy Unit
- Information Commissioner
- General Medical Council
- BMA/Medical Insurers
- Caldicott Guardians
- SHA Chief Information Officers
- NHS CFH Information Governance Board
- DH Information Director
- Director, NPfIT
- Chief Statistician etc, etc, etc

...all set against a bewildering assortment of legislation..... and Parliamentary Statements as to what the laws are supposed to mean.....and conflicting views as to how the Parliamentary Statements are then to be interpreted





## *RCP Key Partnerships*

### **Established Players** (in no particular order):

- Other NHS CFH Programmes
- NIHR IT Programme
- UK Biobank
- Secondary Uses Service
- The Information Centre for Health and Social Care
- GP Research Database/MHRA
- QResearch and other primary care datasets
- GP Extraction Service (IC)
- Office for National Statistics/Registrar General
- Public Health Observatories
- National Cancer Intelligence Network
- Janet/N3 Forum
- Public Health Researchers
- Observational Epidemiologists
- Clinical Trialists
- Health Services Researchers
- Pharmacovigilantes

..... and many, many others.

## *What should be achieved by 2012?*

- 2009: Pilot Studies; IG Framework; joint working with the NIGB, IC.
- 2010: HRSS; Integrated Training and Programmatic support through the “Funders’ Forum” and OSCHR E-Health Records Research Board; earliest publications using RCP facilities; steadily increasing utilisation by research community.
- 2011: HRSS moves to “Business as Usual” mode; continuing Public Engagement work; initial outputs from the Wellcome Trust/Research Councils 2008-09 funding competition.
- 2012: First PhD students trained around the RCP complete.
- 2012 onwards: Continuing monitoring of the Programme’s agreed “Inputs, Outputs, Outcomes and Impacts” Metrics.

## Wellcome Training Grant Research Questions



UNIVERSITY OF LEEDS

The plan is to design and validate training courses for clinical research, industrial and NHS informatics staff to aid the exploitation of digital information resources.

**1. Can focussed training of academic and NHS database developers/administrators help:**

- record alignment between research databases and clinical systems
- support strategic research

**2. How can awareness of best practice in information systems development and management be best increased within the research and clinical IT communities?**



"You did say you wanted HL7 format?"

## NCRI ONIX

- ONcology Information eXchange
- Internet portal connecting data sets and data sources from around the world
- Similar adoption / training issues as e-health records research:
  - New
  - Outwardly, seemingly complex
  - Daunting due to confidentiality concerns
- These present challenges in uptake - but can be offset with appropriate training



# What Does the ONIX Portal look like?



**NCRI ONCOLOGY INFORMATION EXCHANGE**

Welcome Robin  
X Logout of ONIX

HOME  
RESOURCES  
Cancer InfoMatrix  
Resource Catalogue  
SEARCHING  
VOCABULARIES  
DOCUMENT REPOSITORY  
USER OPTIONS  
FUNDERS SECTION  
RESOURCE OWNER  
ONIX ADMINISTRATION

Home > Resources > Resource Catalogue

### Resource Catalogue

Catalogue

My filters

First Previous page 1 of 13 [showing results 1 to 10 of 121] Next Last

| Resource Name             | Interop Level | Country        | Project Type      | Metadata | Data |
|---------------------------|---------------|----------------|-------------------|----------|------|
| BioMart                   | 4             | International  | Tools             | n/a      | n/a  |
| BMRR                      | 4             | International  | Semantic tool     | n/a      | n/a  |
| COSMIC                    | 4             | United Kingdom | Multidisciplinary | n/a      | n/a  |
| EMBL-EBI-ArrayExpress     | 4             | European       | Multidisciplinary | n/a      | n/a  |
| EMBL-EBI-IntAct           | 4             | European       | Tools, Data sets  | n/a      | n/a  |
| EMBL-EBI-PRIDE            | 4             | European       | Tools, Data sets  | n/a      | n/a  |
| GeneCards®                | 4             | Israel         | Multidisciplinary | n/a      | n/a  |
| HealthAgents              | 4             | European       | Semantic tool     | n/a      | n/a  |
| Human Protein Atlas (HPA) | 4             | Sweden         | International     | n/a      | n/a  |
| Human Variome Project     | 4             | International  | Consortium, Tools | n/a      | n/a  |

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PS103

Internet

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## *How to Find Out More*

The ONIX prototype is available to try out!

- Production data and functionality
- BUT contents and functions to be significantly expanded (full launch 17<sup>th</sup> July 2009)

Contact

- [Stuart.bell@ncri.org.uk](mailto:Stuart.bell@ncri.org.uk)
- Or read more on:  
<http://www.cancerinformatics.org.uk/onix.html>
- Or just dive in:  
<http://www.ncri-onix.org.uk/>

# Determining the effectiveness of ONIX as an educational tool: preliminary analysis

Stuart Bell, Alan Hogg, See Wah Cheng, Ekaterini Blaveri, Robin Clark  
(NCRI Informatics Initiative)

Barbara Pedley, Richard Begent et al  
(UCL Cancer Institute)

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Last but by no means least...

## Challenges to NCIN from the Patient Perspective

Lynn Faulds Wood

President, European Patients' Coalition

President, MDT Co-ordinators Task Force



# NCIN Core Objectives



1. Promoting efficient and effective data collection throughout the cancer journey
2. Providing a common national repository for cancer datasets
3. Producing expert analyses, based on robust methodologies, to monitor patterns of cancer care
4. Exploiting information to drive improvements in standards of cancer care and clinical outcomes
5. Enabling use of cancer information to support audit and research programmes



# National Cancer Data Repository



## Registry-HES linkage: 1995-2004 (England)

- Commissioned by NCIN
- 8.5 million tumour records from Registries
  - c. 30 fields of data
- 34 million hospital in patient episodes
  - c. 150 fields of data
- Enables novel analytical approaches
  - ethnicity, comorbidity, surgery, bed-stay
  - non-cancer outcomes, hospital “footprints”
  - end of life resource use