A new unified Cancer Registration Service for England

Jem Rashbass
National Director for Registry Modernisation
Vision

To provide near-realtime, cost effective, comprehensive data collection and quality assurance over the entire cancer care pathway on all patients treated in England.

as a resource for

patient care, quality, safety and performance management, audit, research and outcome monitoring.
Why have things changed?

- Clinical need
- Political push & the Information Revolution
- Patient empowerment
- Cancer is now chronic disease
- Personalised/Stratified Medicine
What needs to happen

- Consistent data processing by registry teams
  - Including staging
  - Extensive data-sets for site specific registries
- Central data clearing-house and processing service
- Real-time QA
- Easily expandable, high granularity data-set (COSD+)
- Improved data access and timely feedback
- Seamless links to cancer screening

- Integral support for
  - Peer review and IOGs
  - National Cancer Audits
  - ONS - National data returns
  - CRUK stratified medicine and beyond
  - National Awareness and Early Diagnosis Initiative (NAEDI)
  - Commissioners, Research, etc
Lessons from the National Brain Tumour Registry

A tale of two workshops
CNS Workshop March 2010 was...

- about input from the expert community
- a reality check
  - Is this what the community wants?
  - can it be made to happen?
  - If it can, then how do we start?
- to identify the champions and early adopters
reasons why this won’t work

“the systems aren’t there to collect the data”

“data in the NHS is rubbish”

“there is no money”

“we all do things differently”

“I already have my own database, thanks”

“nice idea – but you are mad if you think it can be achieved”

“I have been here before – it didn’t work last time and won’t this time.”

“we are all too busy”

“I have been here before – it didn’t work last time and won’t this time.”

“we don’t have the IT expertise in our Trust”

“it isn’t allowed – it breaches patient confidentiality”

Tuesday, 20 September 11
• Work from what you can do now, not from what you like to do eventually (80/20 rule)

• Apply the KISS principle:
  – Keep it simple, stupid

• Provide expert input to help get data flowing

• Only address the real show-stoppers

• Share best practice

• Provide timely and relevant feedback and audit of data to improve quality etc
CNS Workshop March 2011

- Phase 1 volunteers
- 17 Trusts volunteered to be pilot sites
- Caldicott Guardian permission sought
- Trusts and MDT’s visited
- Data teams visited
- Data feeds methods established & tested
- Data arrives!!
- Database
- Data feedback
- Second wave Trust permissions obtained
Phase 1 sites

- Birmingham
- Bristol
- Cambridge
- Hull
- Leeds
- Liverpool
- Manchester
- Middlesbrough
- Newcastle – upon-Tyne
- Nottingham
- Queen’s Romford
- Sheffield
- Southampton

**London**
- Charing Cross
- Great Ormond Street
- Kings
- Queens Square
<table>
<thead>
<tr>
<th>Organisation</th>
<th>Location</th>
<th>Caldicott Contacted</th>
<th>Caldicott Permission</th>
<th>MDT Meeting</th>
<th>Data Meeting</th>
<th>Data Transfer set up</th>
<th>Data Received</th>
</tr>
</thead>
<tbody>
<tr>
<td>University Hospitals Birmingham QE Hospital</td>
<td>Birmingham</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>North Bristol NHS Trust Frenchay Hospital</td>
<td>Bristol</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>University Hospitals Bristol NHS Foundation Trust</td>
<td>Bristol</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Cambridge University NHS Foundation Trust</td>
<td>Cambridge</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Hull &amp; East Yorkshire Hospitals NHS Trust</td>
<td>Hull</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Leeds Teaching Hospitals NHS Trust</td>
<td>Leeds</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td><strong>Pending</strong></td>
<td>Yes</td>
</tr>
<tr>
<td>The Walton Centre NHS Foundation Trust</td>
<td>Liverpool</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Great Ormond Street Hospital for Children (UCH)</td>
<td>London</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Imperial College Healthcare NHS Trust</td>
<td>London</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>The National Hospital for Neurology etc</td>
<td>London</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>King's College Hospital</td>
<td>London</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Salford Royal NHS Foundation Trust, Hope Hospital</td>
<td>Manchester</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Christie NHS Foundation Trust</td>
<td>Manchester</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>The Newcastle Upon Tyne Hospitals NHS Trust</td>
<td>Newcastle</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Nottingham University Hospitals NHS Trust</td>
<td>Nottingham</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Barking, Havering &amp; Redbridge NHS Trust</td>
<td>Romford</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>Sheffield Teaching Hospitals NHS Foundation Trust</td>
<td>Sheffield</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td><strong>Pending</strong></td>
</tr>
<tr>
<td>Wessex Neurological Centre, Southampton General</td>
<td>Southampton</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td>Yes</td>
</tr>
<tr>
<td>South Tees Hospitals NHS Foundation Trust</td>
<td>Middlesbrough</td>
<td>Yes</td>
<td>Yes</td>
<td></td>
<td></td>
<td><strong>Pending</strong></td>
<td></td>
</tr>
</tbody>
</table>
Data sources - patient-level data

National Feeds

- Radiotherapy Data
- Hospital Episode Statistics (HES)
- National cancer audits - Lung, Head and Neck, Breast and Bowel
- Chemotherapy (from April 2012)
- National PET-CT imaging
- Cancer screening programmes - Bowel, Cervix and Breast

Cancer Waiting Times

MDT data
- Somerset, Infoflex etc

Local Feeds

- Pathology full-text reports
- Local imaging systems
- Local clinical data systems

National Pilots

- CRUK Stratified Medicine (Sept 2011)
- Breast Recurrence Audit Pilot
- ONS - Cancer and non-cancer deaths

Encore

Tuesday, 20 September 11
## What do the data sources look like?

<table>
<thead>
<tr>
<th>System</th>
<th>Number</th>
<th>Varieties</th>
<th>Live Feeds</th>
<th>Not live</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pathology</td>
<td>167</td>
<td>33</td>
<td>144</td>
<td>23</td>
</tr>
<tr>
<td>MDT</td>
<td>165</td>
<td>22</td>
<td>147</td>
<td>18</td>
</tr>
<tr>
<td>PAS</td>
<td>96</td>
<td>&gt;12</td>
<td>96</td>
<td>63</td>
</tr>
<tr>
<td>Imaging</td>
<td>IEP/others</td>
<td>3</td>
<td>Pending</td>
<td>~20</td>
</tr>
</tbody>
</table>

*TCR and SWCIS use Hospital Episode Statistics (HES) as source of data*
NHS personal demographic service

local and site specific registry

evolving datasets for analysis

Encore

Analysis server

Timely feedback to clinical teams
What this is and is not

**NOT**

- An IT project
- Clinical information system
- Big-bang implementation
- Top-down project

**IS**

- Change management
- National Cancer registration service
- Obsessed with high accuracy
- Just automation for speed
Data feedback and use...

Feedback the data to clinical teams and patients
Provide tools to analyse the care pathway
## MDT Data Completeness

### Breast Cancer
- **Date of Diagnosis**: Feb-
- **Tumour Laterality**: Feb-

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Total Pts</th>
<th>Current Mont...</th>
<th>Last Month...</th>
<th>Trend</th>
<th>Data Completeness</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Suffolk</td>
<td>45</td>
<td>100</td>
<td>100.00</td>
<td>-</td>
<td>0</td>
</tr>
</tbody>
</table>

### Gynaecology
- **Date of Diagnosis**: Feb-
- **Treatment Type**: Feb-
- **Figo Stage**: Feb-

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Total Pts</th>
<th>Current Mont...</th>
<th>Last Month...</th>
<th>Trend</th>
<th>Data Completeness</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Suffolk</td>
<td>10</td>
<td>100</td>
<td>100.00</td>
<td>-</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>80</td>
<td>100.00</td>
<td>-</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>10</td>
<td>0</td>
<td>0.00</td>
<td>-</td>
<td>0</td>
</tr>
</tbody>
</table>

### Haematology
- **Date of Diagnosis**: Feb-
- **Treatment Type**: Feb-
- **Consultant Name**: Feb-

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Total Pts</th>
<th>Current Mont...</th>
<th>Last Month...</th>
<th>Trend</th>
<th>Data Completeness</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Suffolk</td>
<td>18</td>
<td>100</td>
<td>100.00</td>
<td>-</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>18</td>
<td>88.9</td>
<td>100.00</td>
<td>-</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>18</td>
<td>27.8</td>
<td>0.00</td>
<td>-</td>
<td>0</td>
</tr>
</tbody>
</table>

### Lung Cancer
- **Date of Diagnosis**: Feb-
- **Tumour Laterality**: Feb-

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Total Pts</th>
<th>Current Mont...</th>
<th>Last Month...</th>
<th>Trend</th>
<th>Data Completeness</th>
</tr>
</thead>
<tbody>
<tr>
<td>West Suffolk</td>
<td>15</td>
<td>100</td>
<td>100.00</td>
<td>-</td>
<td>0</td>
</tr>
</tbody>
</table>

---

Data and using the mouse wheel or holding the scroll bar (far right) and moving down/up. A full user guide is available by clicking the link on the introduction page; this will give you detailed instructions on how to use this report effectively.
Data use...

Provide tools to analyse the care pathway
# Lung Cancer / Mount Vernon Cancer Network / 2000 - 2009

![Network Diagram](image)

## Patient Pathways

### Filters /

**Patient Info**
- **Age**: select inverse 0 - 75 yrs
- **Gender**:
  - Male
  - Female

**Tumour Info**
- **Stage**: Stage 4
- **To**: 2009
- **Surgery**
- **Radiotherapy**

## Table of Patients

<table>
<thead>
<tr>
<th>Patient ID</th>
<th>Age</th>
<th>Gender</th>
<th>Diagnosis Date</th>
<th>Treatments</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>6767986392</td>
<td>63</td>
<td>M</td>
<td>03/05/2006</td>
<td>CT / RT</td>
<td>Remission</td>
</tr>
<tr>
<td>8489389283</td>
<td>55</td>
<td>M</td>
<td>04/11/2003</td>
<td>S / CT / RT</td>
<td>Remission</td>
</tr>
<tr>
<td>7837487298</td>
<td>68</td>
<td>F</td>
<td>23/06/2002</td>
<td>S / CT / RT</td>
<td>Remission</td>
</tr>
<tr>
<td>9540949444</td>
<td>45</td>
<td>M</td>
<td>21/04/2005</td>
<td>RT</td>
<td>Relapse</td>
</tr>
<tr>
<td>4903940930</td>
<td>77</td>
<td>F</td>
<td>03/03/2006</td>
<td>CT</td>
<td>Remission</td>
</tr>
<tr>
<td>9409503940</td>
<td>56</td>
<td>F</td>
<td>17/10/2004</td>
<td>S / CT / RT</td>
<td>Relapse</td>
</tr>
<tr>
<td>8743892328</td>
<td>94</td>
<td>F</td>
<td>05/09/2008</td>
<td>Palliative</td>
<td>Death</td>
</tr>
<tr>
<td>2938223822</td>
<td>72</td>
<td>M</td>
<td>12/11/2007</td>
<td>CT / RT</td>
<td>Death</td>
</tr>
<tr>
<td>4893829339</td>
<td>53</td>
<td>M</td>
<td>30/03/2003</td>
<td>S / CT / RT</td>
<td>Remission</td>
</tr>
<tr>
<td>3234982094</td>
<td>69</td>
<td>F</td>
<td>16/07/2005</td>
<td>CT / RT</td>
<td>Remission</td>
</tr>
<tr>
<td>8324982920</td>
<td>90</td>
<td>M</td>
<td>29/04/2006</td>
<td>Palliative</td>
<td>Death</td>
</tr>
<tr>
<td>2093804982</td>
<td>68</td>
<td>M</td>
<td>11/07/2007</td>
<td>RT</td>
<td>Remission</td>
</tr>
<tr>
<td>2448748374</td>
<td>55</td>
<td>F</td>
<td>20/05/2002</td>
<td>CT</td>
<td>Relapse</td>
</tr>
</tbody>
</table>
Migration plan

you are here

ECRIC  TrCR  NWCIS  OCIU/SWCIS  WMCIU  NYCRIS  TCR

2011  2012  2013

registrations x10^3

300  225  150  75  0

ECRIC  TrCR  NWCIS  OCIU/SWCIS  WMCIU  NYCRIS  TCR

Tuesday, 20 September 11
Implications for haematology

- Finalise data requirements
- Establish data flows from haematology MDTs
- Develop specific rapid feedback for haematology teams
- Identify supplementary feeds
  - Lab data - for liquid diagnoses
  - FISH?
  - Cytogenetics?
  - Flow?
- Engage commissioners, networks and providers
Just some of the people

ECRIC
David Greenberg
Brian Shand
Tim Gentry
Tom Bacon
Warren Carmody
Jane Richardson
Claire Beattie
Jessica Farrimond
Brian Rous
Clem Brown

NWCIS
Colin Jones
Gavin Flatt
Stavros Abelidis
Steve Potter
Steve Raynor
Roger Hartley
Jane Jones
Jennifer Kennedy

NCIN
Trish Stokes
Chris Carrigan
Di Riley

OCIU
Neil Kennedy
Monica Roche
Kellie Peters
Heather Davies
Pam Thomas

NYCRIS
Sarah Lawton
Dan Farrar
John Wilkinson
Paul Edwards
Christine Head
Sheila Pass

Trent
Carolynn Gildea
Louise Hollingworth
Andy Smith
David Meechan
Alexandra Thackeray
Gillian Gull
James Hitchman
Anne Hailey

WMCIU
Sally Vernon
Alan Macdonald
Mike Porter
Gill Lawrence
Tasha Wood
Gill Barrett
Natalie Pearce
Otis Francis
Paul Davies
Gill Lawrence

SWCIS
Matthew Iles
Paul Eves
Tariq Malik
Gill Christmas

ONS
Bob Seymour
and so...

The registry migration project will transform cancer care, research and clinical practice in England to provide timely, consistent, accurate data on every patient.

to succeed we need the engagement of clinicians, providers, commissioners, patients and public.