

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”

“I already have my own database, thanks”

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

“we all do things differently”

“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”

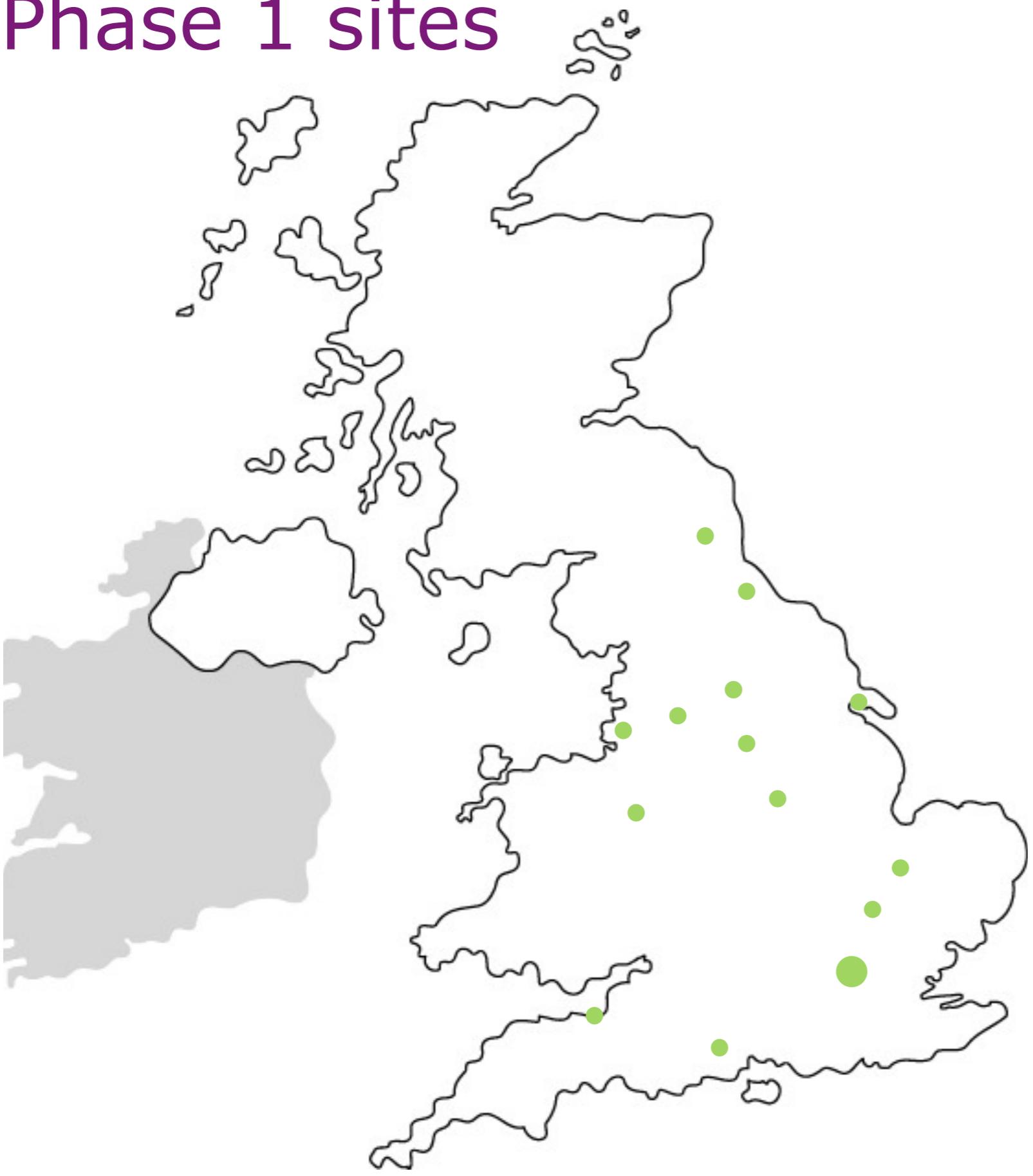
J_(f)di!

- 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 I 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

Organisation	Location	Caldicott Contacted	Caldicott Permission	MDT Meeting	Data Meeting	Data Transfer set up	Data Received
University Hospitals Birmingham QE Hospital	Birmingham	Yes	Yes			Yes	Yes
North Bristol NHS Trust Frenchay Hospital	Bristol	Yes	Yes	Yes	Yes	Yes	Yes
University Hospitals Bristol NHS Foundation Trust	Bristol	Yes	Yes	Yes	Yes	Yes	Yes
Cambridge University NHS Foundation Trust	Cambridge	Yes	Yes	Yes			Yes
Hull & East Yorkshire Hospitals NHS Trust	Hull	Yes	Yes	Yes	Yes	Yes	Yes
Leeds Teaching Hospitals NHS Trust	Leeds	Yes	Yes	Pending			
The Walton Centre NHS Foundation Trust	Liverpool	Yes	Yes			Yes	Yes
Great Ormond Street Hospital for Children (UCH)	London	Yes	Yes	Yes	Yes	Yes	Yes
Imperial College Healthcare NHS Trust	London	Yes	Yes			Yes	Yes
The National Hospital for Neurology etc	London	Yes	Yes	Yes	Yes	Yes	Yes
King's College Hospital	London	Yes	Yes	Yes	Yes	Yes	Yes
Salford Royal NHS Foundation Trust, Hope Hospital	Manchester	Yes	Yes	Yes	Yes	Yes	Yes
Christie NHS Foundation Trust	Manchester	Yes	Yes	Yes	Yes	Yes	Yes
The Newcastle Upon Tyne Hospitals NHS Trust	Newcastle	Yes	Yes	Yes	Yes	Yes	Yes
Nottingham University Hospitals NHS Trust	Nottingham	Yes	Yes	Yes	Yes	Yes	Yes
Barking, Havering & Redbridge NHS Trust	Romford	Yes	Yes	Yes	Yes	Yes	Yes
Sheffield Teaching Hospitals NHS Foundation Trust	Sheffield	Yes	Yes	Yes	Yes	Yes	Pending
Wessex Neurological Centre, Southampton General	Southampton	Yes	Yes	Yes	Yes	Yes	Yes
South Tees Hospitals NHS Foundation Trust	Middlesbro'	Yes	Yes	Pending			

Data sources - patient-level data

Local Feeds

National Feeds

Radiotherapy Data

Hospital Episode Statistics (HES)

Cancer Waiting Times

MDT data
Somerset, Infoflex etc

Pathology full-text reports

Local imaging systems

Patient administration systems (pre-HES)

Local clinical data systems

National Pilots

CRUK Stratified Medicine (Sept 2011)

Breast Recurrence Audit Pilot



Encore

National cancer audits - Lung, Head and Neck, Breast and Bowel

Chemotherapy (from April 2012)

National PET-CT imaging

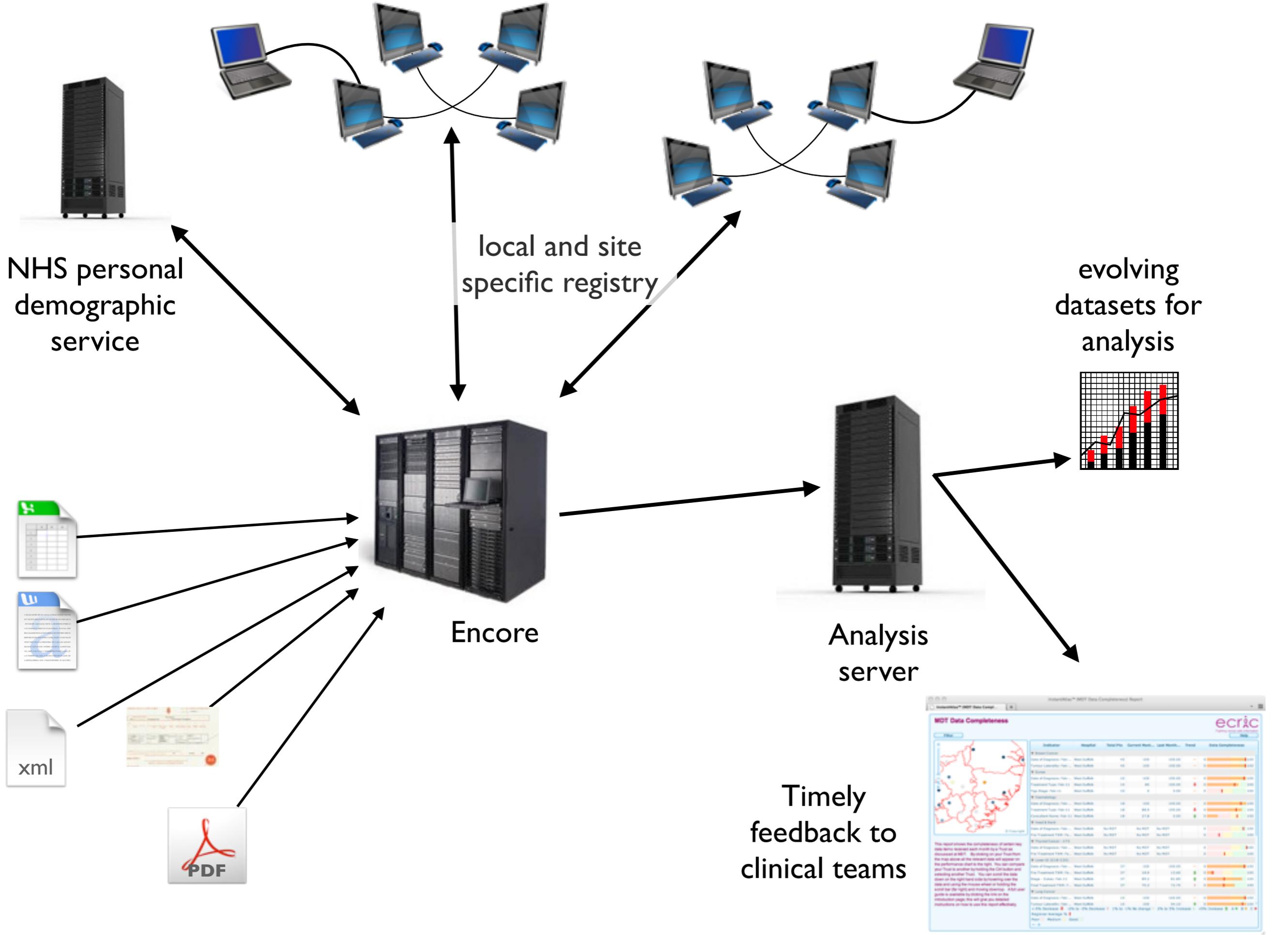
Cancer screening programmes - Bowel, Cervix and Breast

ONS - Cancer and non-cancer deaths

What do the data sources look like?

System	Number	Varieties	Live Feeds	Not live
Pathology	167	33	144	23
MDT	165	22	147	18
PAS [♀]	96	>12	96	63
Imaging	IEP/others	3	Pending	~20

[♀]TCR and SWCIS use Hospital Episode Statistics (HES) as source of data



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...

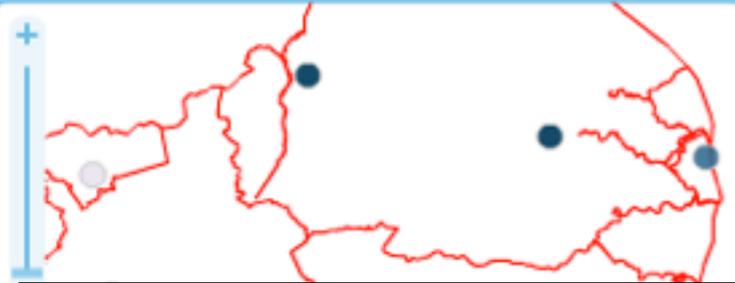
Feedback the data to clinical teams and patients
Provide tools to analyse the care pathway

MDT Data Completeness



Filter

Help



Indicator	Hospital	Total Pts	Current Mont...	Last Month...	Trend	Data Completeness
▼ Breast Cancer						
Date of Diagnosis: Feb-...	West Suffolk	45	100	100.00	—	0 100
Tumour Laterality: Feb-...	West Suffolk	45	100	100.00	—	0 100
▼ Gynae						

Indicator	Hospital	Total Pts	Current Mont...	Last Month...	Trend	Data Completeness
▼ Breast Cancer						
Date of Diagnosis: Feb-...	West Suffolk	45	100	100.00	—	0 100
Tumour Laterality: Feb-...	West Suffolk	45	100	100.00	—	0 100
▼ Gynae						
Date of Diagnosis: Feb-...	West Suffolk	10	100	100.00	—	0 100
Treatment Type: Feb-11	West Suffolk	10	80	100.00	↓	0 100
Figo Stage: Feb-11	West Suffolk	10	0	0.00	—	0 100
▼ Haematology						
Date of Diagnosis: Feb-...	West Suffolk	18	100	100.00	—	0 100
Treatment Type: Feb-11	West Suffolk	18	88.9	100.00	↓	0 100
Consultant Name: Feb-11	West Suffolk	18	27.8	0.00	↑	0 100

... 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.

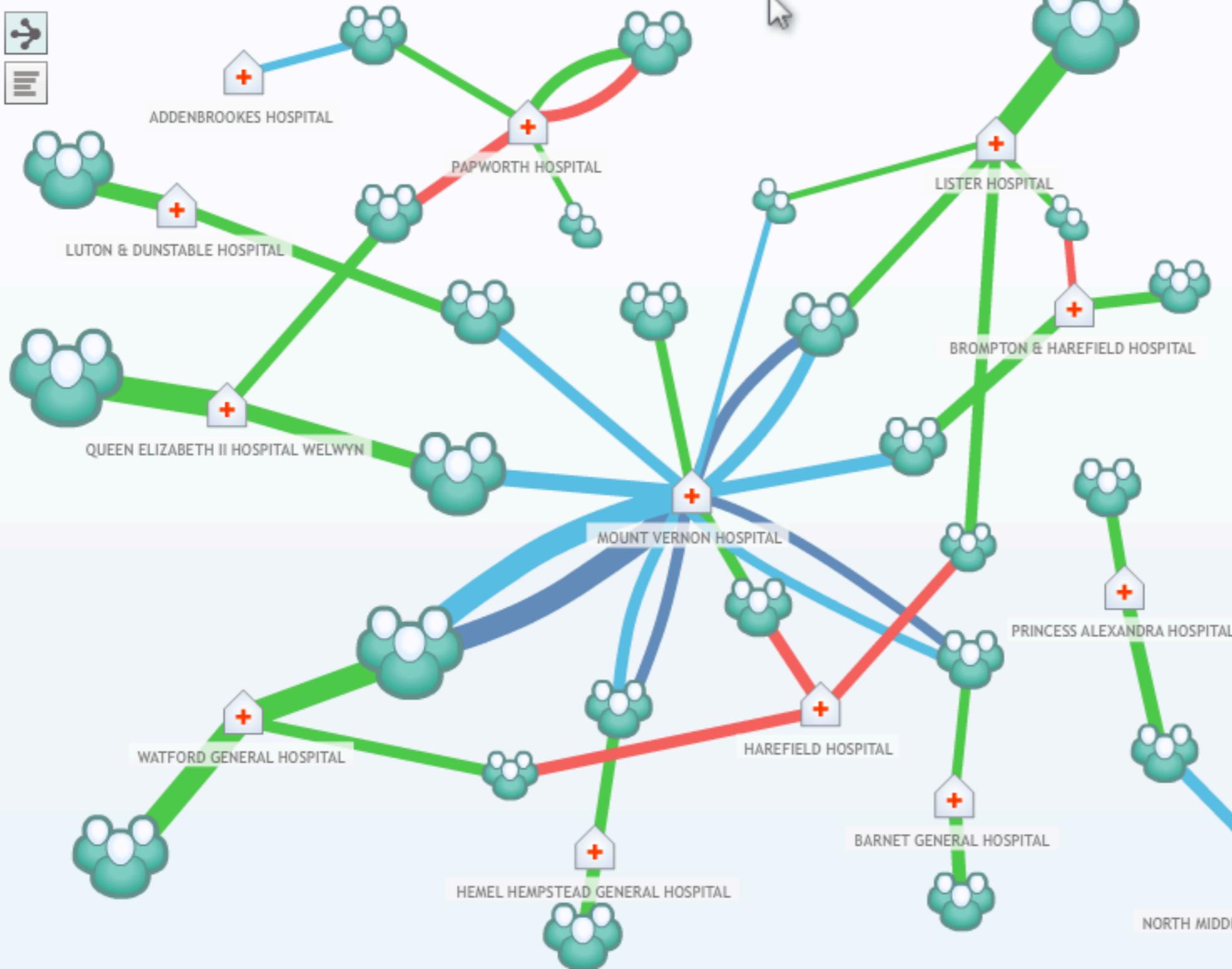
Final Treatment TNM: F...	West Suffolk	37	70.3	72.70	↓	0 100
▼ Lung Cancer						
Date of Diagnosis: Feb-...	West Suffolk	15	100	100.00	—	0 100
Tumour Laterality: Feb-...	West Suffolk	15	100	94.10	↑	0 100

-5% Decrease ↓ -2% to -5% Decrease ↓ 1% to -1% No change — 2% to 5% Increase ↑ <5% Increase ↑ A ● B ● C ●
 Regional Average % |
 Poor ■ Medium ■ Good ■
 — +

Data use...

Provide tools to analyse the care pathway

Lung Cancer / Mount Vernon Cancer Network / 2000 - 2009



FILTERS /

PATIENT INFO

AGE select inverse

GENDER

Male Female

TUMOUR INFO

Stage:

Grade:

TIMESCALE

Dates: From: To:

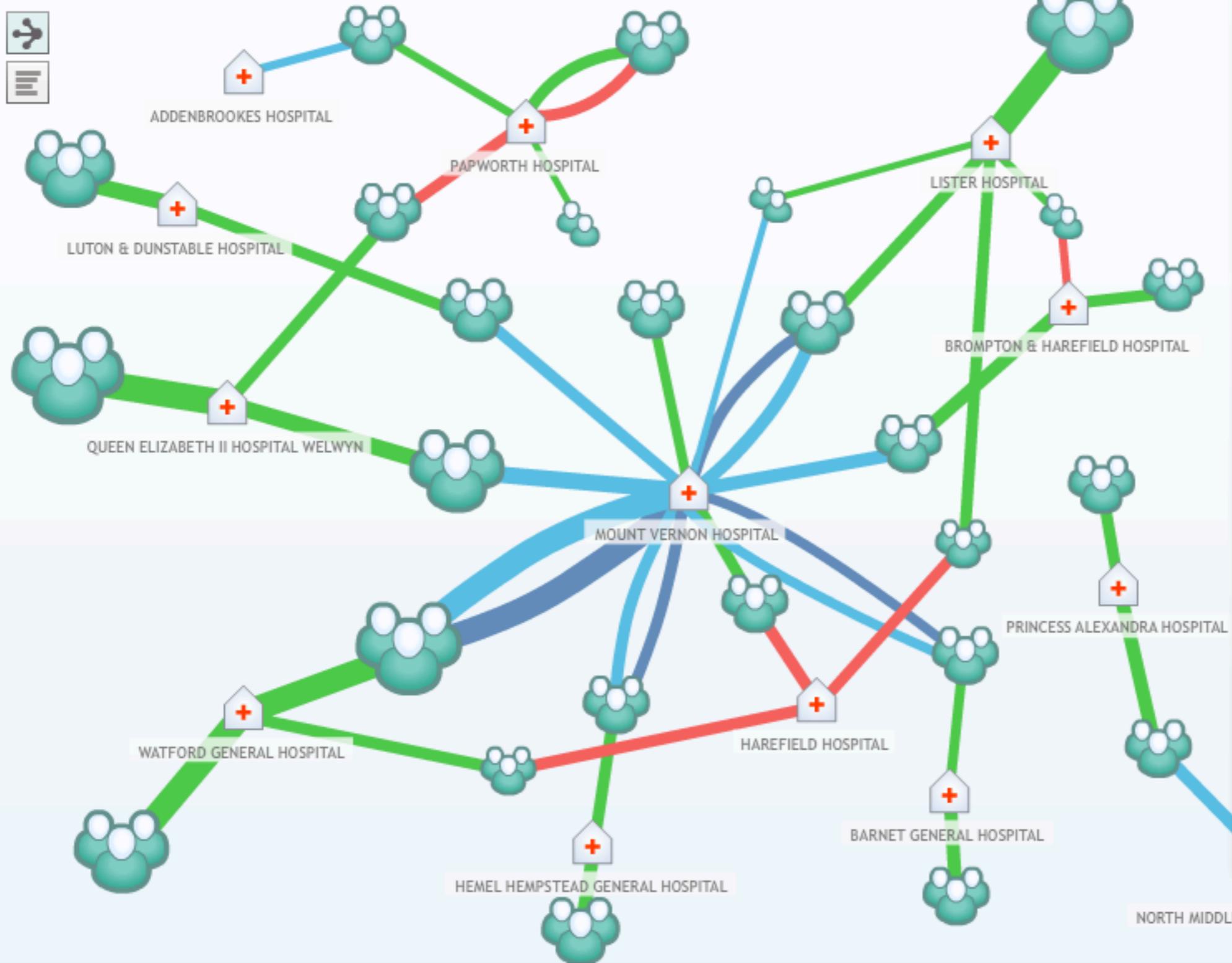
EVENTS

Diagnosis Surgery

Chemotherapy Radiotherapy

Other

Lung Cancer / Mount Vernon Cancer Network / 2000 - 2009



FILTERS /

PATIENT INFO

AGE select inverse

GENDER

Male Female

TUMOUR INFO

Stage: Stage 4

Grade: Stage 1

Stage 2

Stage 3

TIMESCALE

Dates: From: 2000 To: 2009

EVENTS

Diagnosis Surgery

Chemotherapy Radiotherapy

Other

Lung Cancer / Mount Vernon Cancer Network / 2000 - 2009



FILTERS /

PATIENT INFO

AGE select inverse

GENDER

Male Female

TUMOUR INFO

Stage: Stage 4

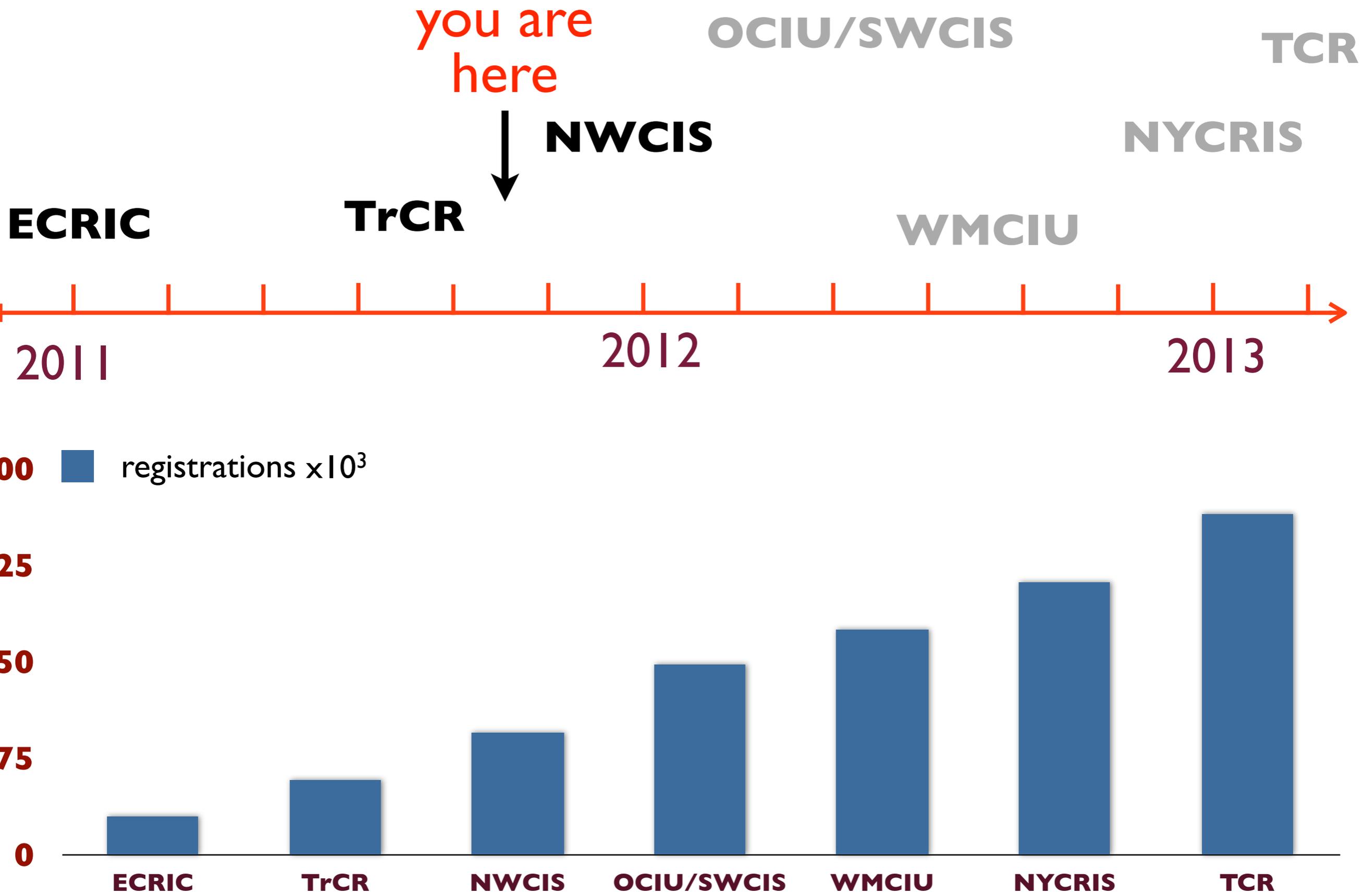
To: 2009

Surgery

Radiotherapy

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

Migration plan



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

NCIN

Trish Stokes
Chris Carrigan
Di Riley

OCIU

Neil Kennedy
Monica Roche
Kellie Peters
Heather Davies
Pam Thomas

NWCIS

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

NYCRIS

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

SWCIS

Matthew Iles
Paul Eves
Tariq Malik
Gill Christmas

Tariq Malik
Tina Ball
Carlos Rocha

Thames

Vivian Mak
Steve Richards
Maggie Barker
Pat Mcdade
Barry Plewa

WMCIU

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

Trent

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

CCRG

Mike Murphy

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.

