



The National Brain Tumour Registry

.....one year on

Jem Rashbass

A National Registry for Brain, CNS, Skull-base and Pituitary tumours

- National population-based tumour registry
- With 100% ascertainment
- Covering all tumours in these groups
- Containing quality assured data
- Including details of treatment, outcome, co-morbidity and long term follow-up

It will be the national resource underpinning clinical care, audit and research for this group of tumours

National Brain Tumour Registry

- has a registry database and processing system
- is be able to hold all the data items in existing and new cancer datasets
- has expertise in CNS tumour classification
- has expertise in electronic data processing methods
- is covered by the Information Governance framework for English cancer registries

The case for perfection

- Relatively small work-load
- Limited number of expert centres
- Cohesive expert professional groups
 - Neurosurgery, oncology, pathology, radiology, specialist nurses etc
- Timely
 - IOG and neuroscience MDTs
- Has the potential to deliver significant benefits

The Brain and CNS SSCRG has permission from the NCIN to run a national pilot to implement new data collection for a national site specific registry.

This project will act as an exemplar for “rare” tumour groups.

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

Last March 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.

an opportunity that could only happen with
your support and input.

Overview

- Phase 1 volunteers
- 17 Trusts volunteered to be pilot sites
- Caldicott Guardian permission sought
- Trusts and MDT's visited
- Data teams visited
 - Mini report of each visit for nbtr team
- Data feeds methods established & tested
- Data arrives!!
- Database
- Second wave Trust permissions obtained

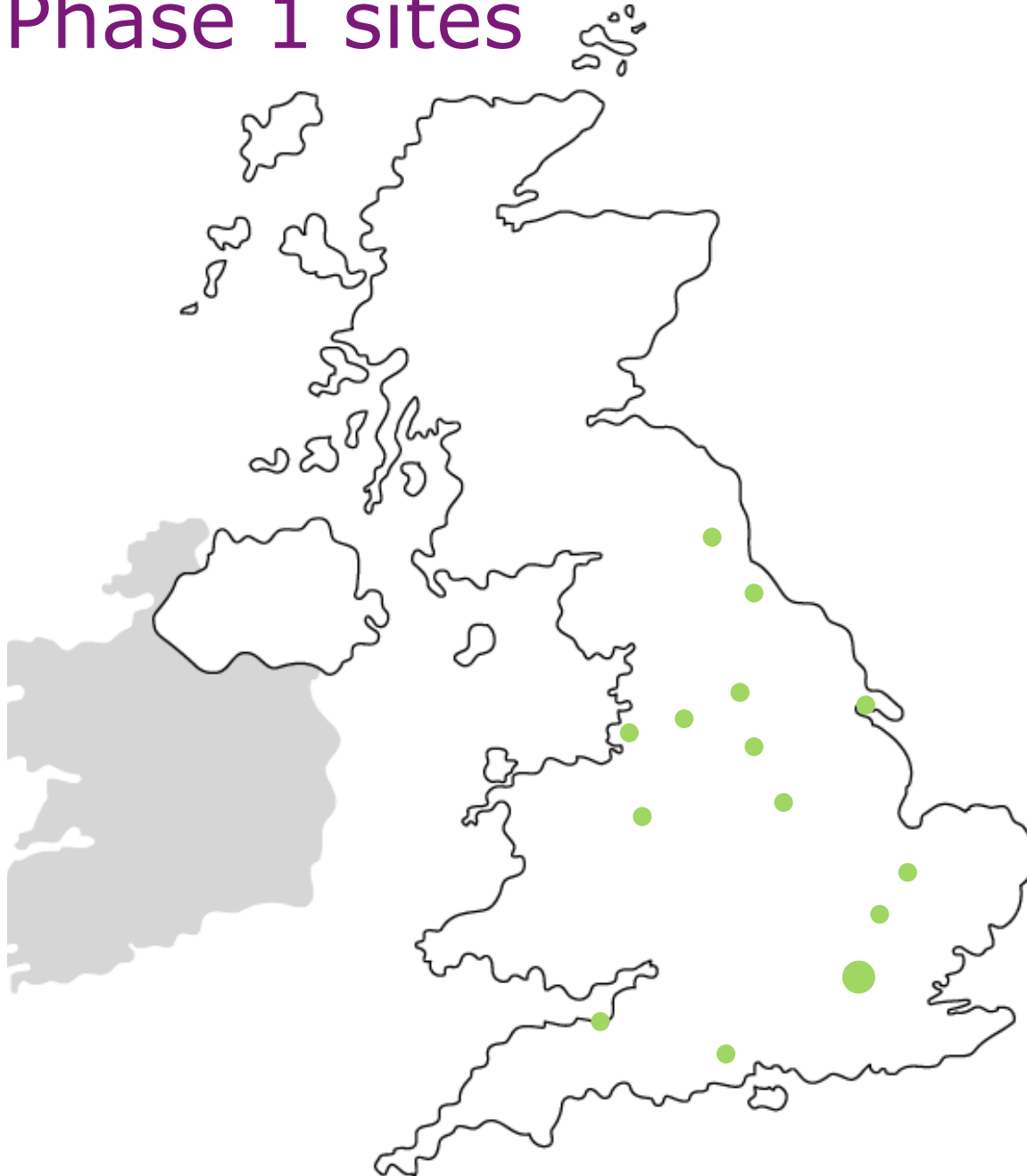
Phase 1 sites



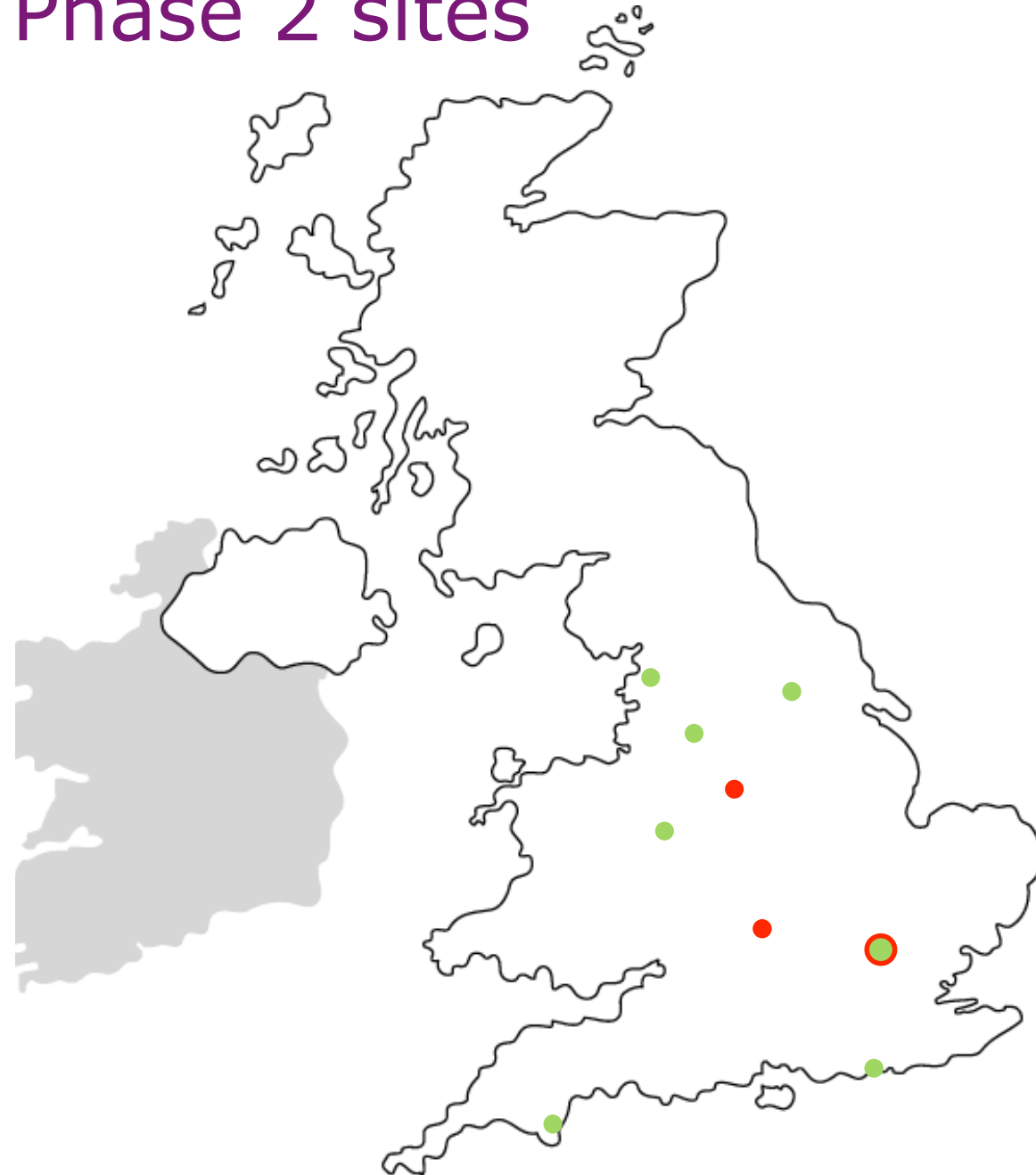
Birmingham
Bristol
Cambridge
Hull
Leeds
Liverpool
Manchester
Middlesbrough
Newcastle – upon-Tyne
Nottingham
Queen's Romford
Sheffield
Southampton

London

Charing Cross
Great Ormond Street
Kings
Queens Square



Phase 2 sites



Brighton

Coventry

Leicester

Oxford

Plymouth

Preston

Stoke on Trent

York

London

The Royal Free

Bart's & The London

St George's

Royal Marsden

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			Yes	Yes
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				
King's College Hospital	London	Yes	Yes	Yes	Yes	Yes	Pending
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			

Organisation	Location	Caldicott Contacted	Caldicott Permission	MDT Meeting	Data Meeting	Data Transfer set up	Data Received
Brighton and Sussex University Hospitals NHS Trust	Brighton	Yes	Yes	Yes	Yes		Yes
University Hospitals Coventry & Warwickshire	Coventry	Yes	Yes		Yes	Yes	Yes
University Hospitals of Leicester NHS Trust	Leicester	Yes	Yes				
Barts and The London NHS Trust	London	Yes	Yes				
St Georges NHS Trust	London	Yes	Yes				
Plymouth Hospitals NHS Trust	Plymouth	Yes	Yes				
Royal Preston Hospital	Preston	Yes	Pending				
York Hospital	York	Yes	Yes				Yes
Oxford Radcliffe Hospitals NHS Trust	Oxford	Yes	Yes	Yes	Yes		
Royal Free Hospital NHS Trust*	London	Not yet					
Royal Marsden Hospital NHS Trust*	London	Not yet					
North Staffordshire Hospital Trust*	Stoke on Trent	Not yet					

*** No lead clinician identified**

The nbtr system

- Uses the National Cancer Registry database (Encore)
 - Supports near real-time electronic data processing
 - Expandable
- Local data sources
 - MDT: Somerset, Dendrite, Infoflex, Excel
 - Pathology (full text)
 - PAS
 - Local collections
 - Import routines for all other incoming data
- National feeds
 - CWT data monthly
 - PET-CT (National North/South Contracts)
 - National radiotherapy monthly
 - Chemotherapy from 2012
 - Cancer deaths/non cancer deaths

Metastases

- Details of brain metastases are recorded
 - Somerset these are coded as C793
- Do not collect details of the primary (if known)
 - This will change with the roll-out of the National Cancer Registry

Data Completeness (Fields sent)	Manches ter	Nottingh am	Romford	Southam pton	Walton Centre (all Somerse t)	Imperial – Charing X
Patient identifiers (name, dob, NHS number, address, postcode)	Yes	Yes	Yes	Yes	Yes	Yes
Tumour Details (code, description, location, side)	Yes	Yes	Yes	Yes	Yes	Yes
Referral Information (referring hospital, date, type of referral)	Yes	Yes	Yes	Yes	Yes	
MDT Information (date, notes, diagnosis at MDT, care plan)	Yes	Yes	Yes		Yes	
Diagnosis Information (date, hospital, histology, scan, basis)	Yes	Yes	Yes	Yes	Yes	Yes
Treatment Information (surgery, chemo, radio, dates, fractions)	Yes	Yes	Yes	Yes	Yes	Yes
Any additional information: (Karnofsky score, handedness, tumour location, Mets, GBM, detailed information on treatments or MDT)	Yes	Yes	Yes		Limited	Limited
Historical data		Yes				Yes

The data

Next steps

- Data Collection
 - Neuropathology reports
 - Imaging
- Audit and feedback
 - Standardising data quality
- Patient pathways
- IOG clinical lines of enquiry
- Data analysis work programme
 - This is today's activity

Rapid Feedback

- Instant Atlas – a simple web-based graphical interface for data feedback.
- Based on patient-level data
- Drill down
 - by centre,
 - by tumour type
 - by treatment types
- Request a login at:
 - www.nbtr.nhs.uk/staff/IArequest.html



Treatments >> Surgery >> Oct-10



National Brain Tumour Registry (nbtr) CWT Data 2010

Help

Data

Filter

▼ Brain Tumour Diagnosed Patients

► Total Records Received

▼ Tumour Groups

► Malignant Neoplasm of Meninges

► Malignant Neoplasm of Brain

► Malignant Neoplasm of CNS

► Other

▼ Treatments

► Surgery

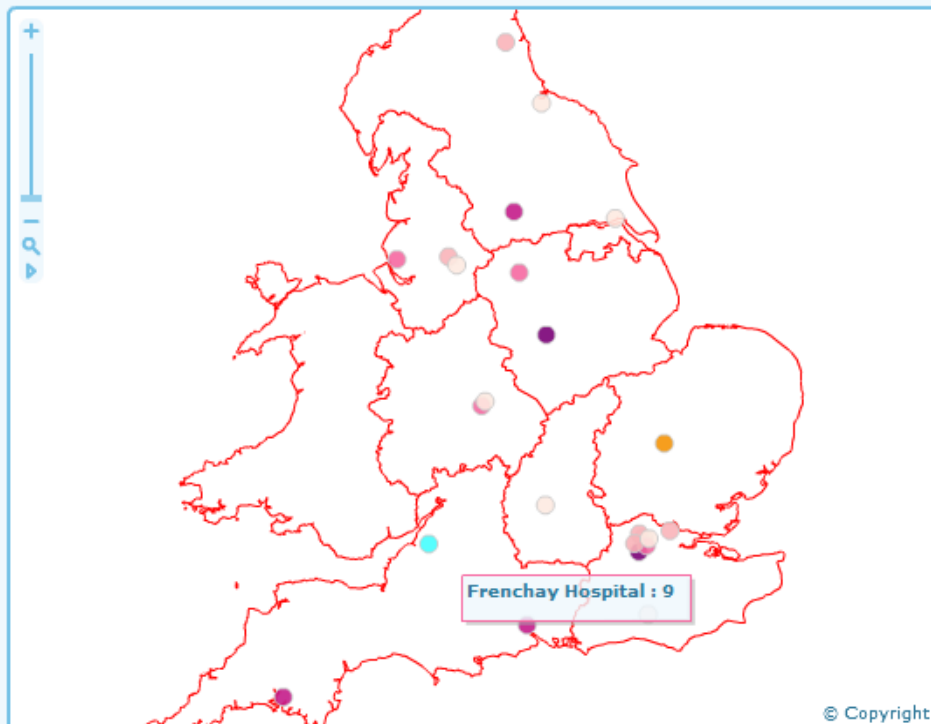
► Radiotherapy

► ChemoRadiotherapy

► Chemotherapy

► Palliative Care

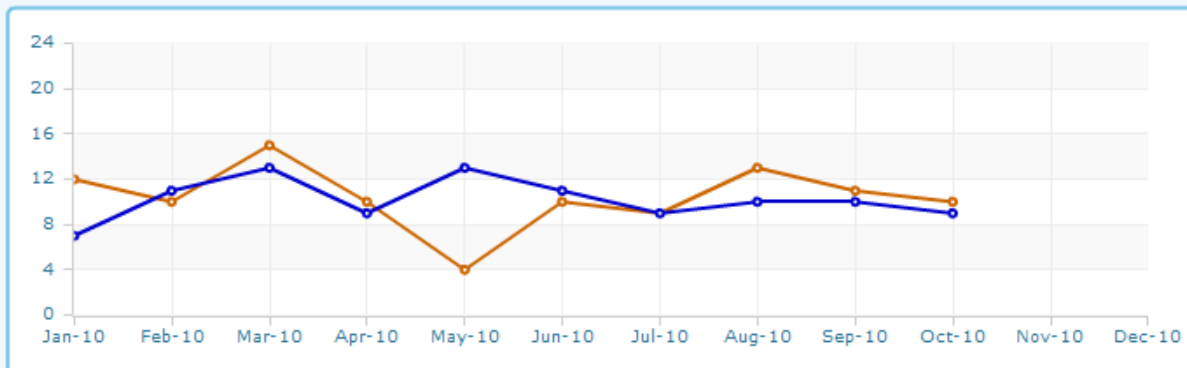
► Active Monitoring



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Name	Indicator
Addenbrooke's Hospital	10
Birmingham Children's Hospital	1
Charing Cross	5
Christie NHS FT	0
Derriford Hospital	11
Essex Neurological Centre	5
Frenchay Hospital	9
Great Ormond Street Hospital for C...	3
Hope Hospital	6
Hull Royal Infirmary	2
Hurstwood Park Neurological Centre	2
James Cook University Hospital	3
John Radcliffe Hospital	1
King's College Hospital	9
Newcastle General Hospital	6
Queen Elizabeth Neuroscience centre	7
Queen's Medical Centre	16
Royal Free Hospital	6
Royal Hallamshire Hospital	7

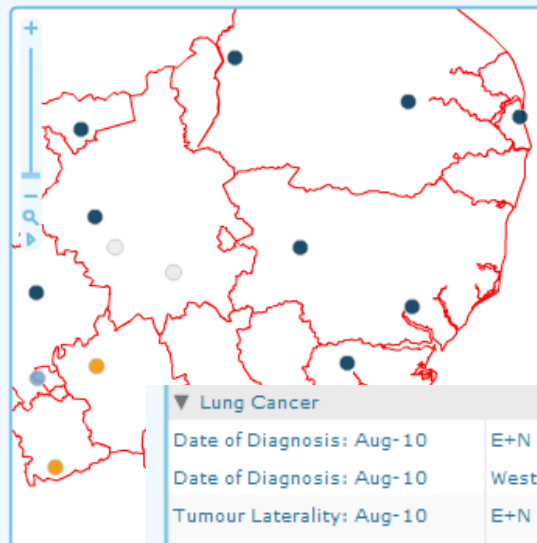
This data has been taken from data submitted by your Trust to the National Cancer Waiting Times Dataset for 2010; any metastatic disease is grouped into 'Other' along with all 'Other Brain Tumours' and 'Cerebral Lymphomas'. The records received and diagnoses will refer to unique patients who received treatment in the month analysed, this will remove duplications, however one patient may have more than one treatment in a month. It is possible that a patient may appear in multiple months if they have received treatment over a long period as the data is looking at individual months at a time. Very occasionally patients have been excluded from the analysis if e.g. the treatment is anything other than those shown (HT or Brachytherapy) and/or if the diagnosis is not for either a brain tumour or treatment of a metastases of a primary elsewhere in the body e.g. Lung or Breast etc.



MDT Data Completeness

Help

Filter



▼ Lung Cancer

Date of Diagnosis: Aug-10	E+N Herts	13	92.3	93.80	—	0	100
Date of Diagnosis: Aug-10	West Herts	12	100	100.00	—	0	100
Tumour Laterality: Aug-10	E+N Herts	13	92.3	68.80	↑	0	100
Tumour Laterality: Aug-10	West Herts	12	75	90.90	↓	0	100
Pre-Treatment TNM: Aug-10	E+N Herts	13	0	18.80	↓	0	100
Pre-Treatment TNM: Aug-10	West Herts	12	25	72.70	↓	0	100

Indicator	Hospital	Total Pts	Current Month %	Last Month %	Trend	Data Completeness
Date of Diagnosis: Aug-10	E+N Herts	16	100	94.40	↑	0 100
Date of Diagnosis: Aug-10	West Herts	8	100	100.00	—	0 100
Pre-Treatment TNM: Aug-10	E+N Herts	16	0	0.00	—	0 100
Pre-Treatment TNM: Aug-10	West Herts	8	0	0.00	—	0 100
Stage - Dukes: Aug-10	E+N Herts	16	50	44.40	↑	0 100
Stage - Dukes: Aug-10	West Herts	8	0	0.00	—	0 100
Final Treatment TNM: Aug-10	E+N Herts	16	0	27.80	↓	0 100
Final Treatment TNM: Aug-10	West Herts	8	12.5	28.60	↓	0 100
▼ Lung Cancer						
Date of Diagnosis: Aug-10	E+N Herts	13	92.3	93.80	—	0 100
Date of Diagnosis: Aug-10	West Herts	12	100	100.00	—	0 100
Tumour Laterality: Aug-10	E+N Herts	13	92.3	68.80	↑	0 100
Tumour Laterality: Aug-10	West Herts	12	75	90.90	↓	0 100
Pre-Treatment TNM: Aug-10	E+N Herts	13	0	18.80	↓	0 100
Pre-Treatment TNM: Aug-10	West Herts	12	25	72.70	↓	0 100
Breslow Thickness: Aug-10	West Herts	9	0	0.00	—	0 100
Final TNM: Aug-10	E+N Herts	17	0	0.00	—	0 100
Final TNM: Aug-10	West Herts	9	0	0.00	—	0 100
▼ Upper GI						
Date of Diagnosis: Aug-10	E+N Herts	5	80	85.70	↓	0 100
Date of Diagnosis: Aug-10	West Herts	4	100	100.00	—	0 100
Pre-Treatment TNM: Aug-10	E+N Herts	5	0	0.00	—	0 100
Pre-Treatment TNM: Aug-10	West Herts	4	0	0.00	—	0 100
▼ Pancreatic Cancer						
Date of Diagnosis: Aug-10	E+N Herts	1	100	100.00	—	0 100
Date of Diagnosis: Aug-10	West Herts	0	n/a	n/a	—	0 100
Pre-Treatment TNM: Aug-10	E+N Herts	1	0	0.00	—	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

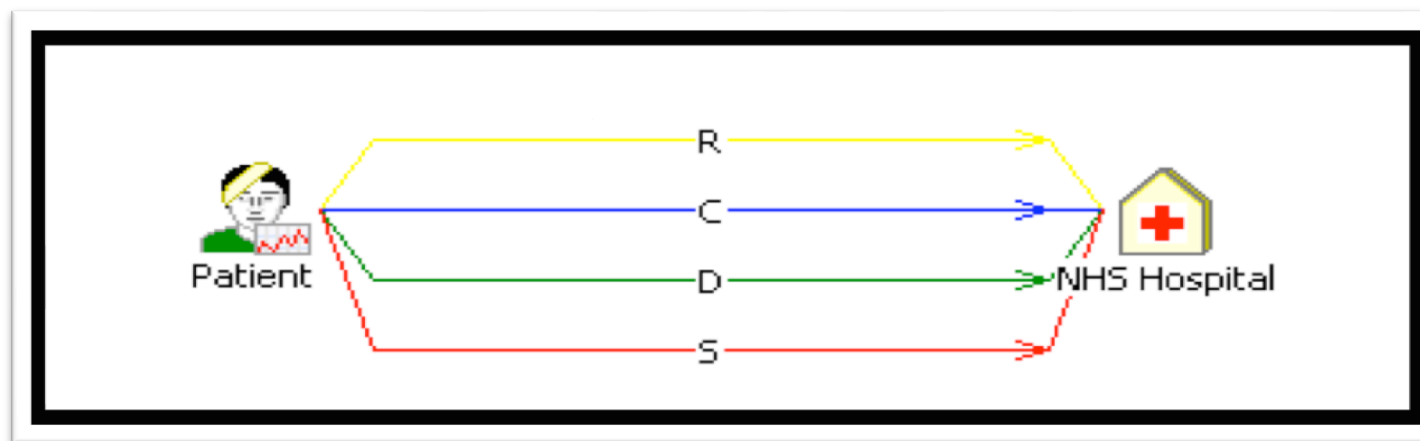
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This report shows data for each Trust that has received each indicator. By clicking on your Trust from the map above all the relevant data will appear on the performance chart to the right. You can compare your Trust to another by holding the Ctrl button and selecting another Trust. You can scroll the data down on the right hand side by hovering over the 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.

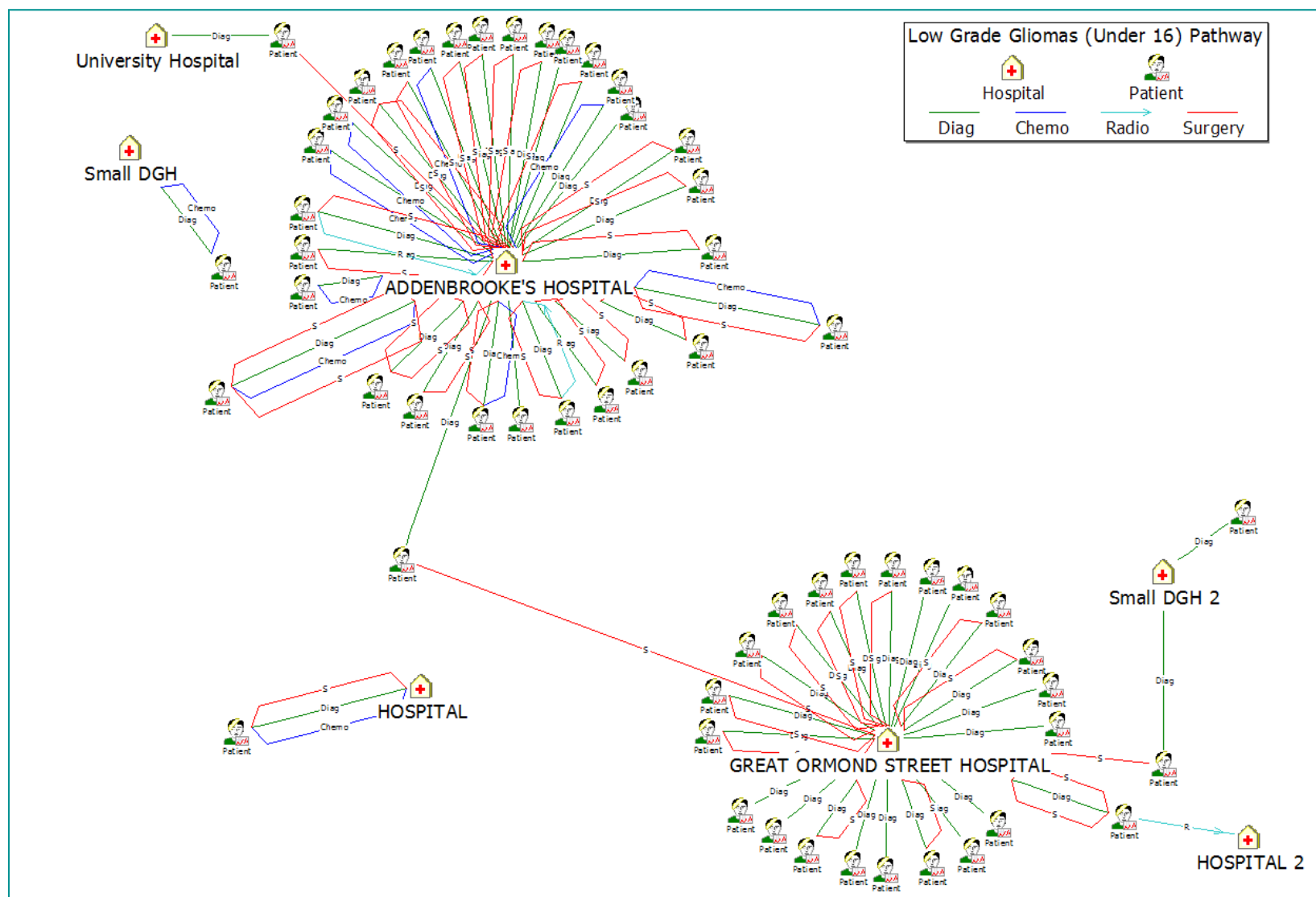
i₂ Patient Visualisation software

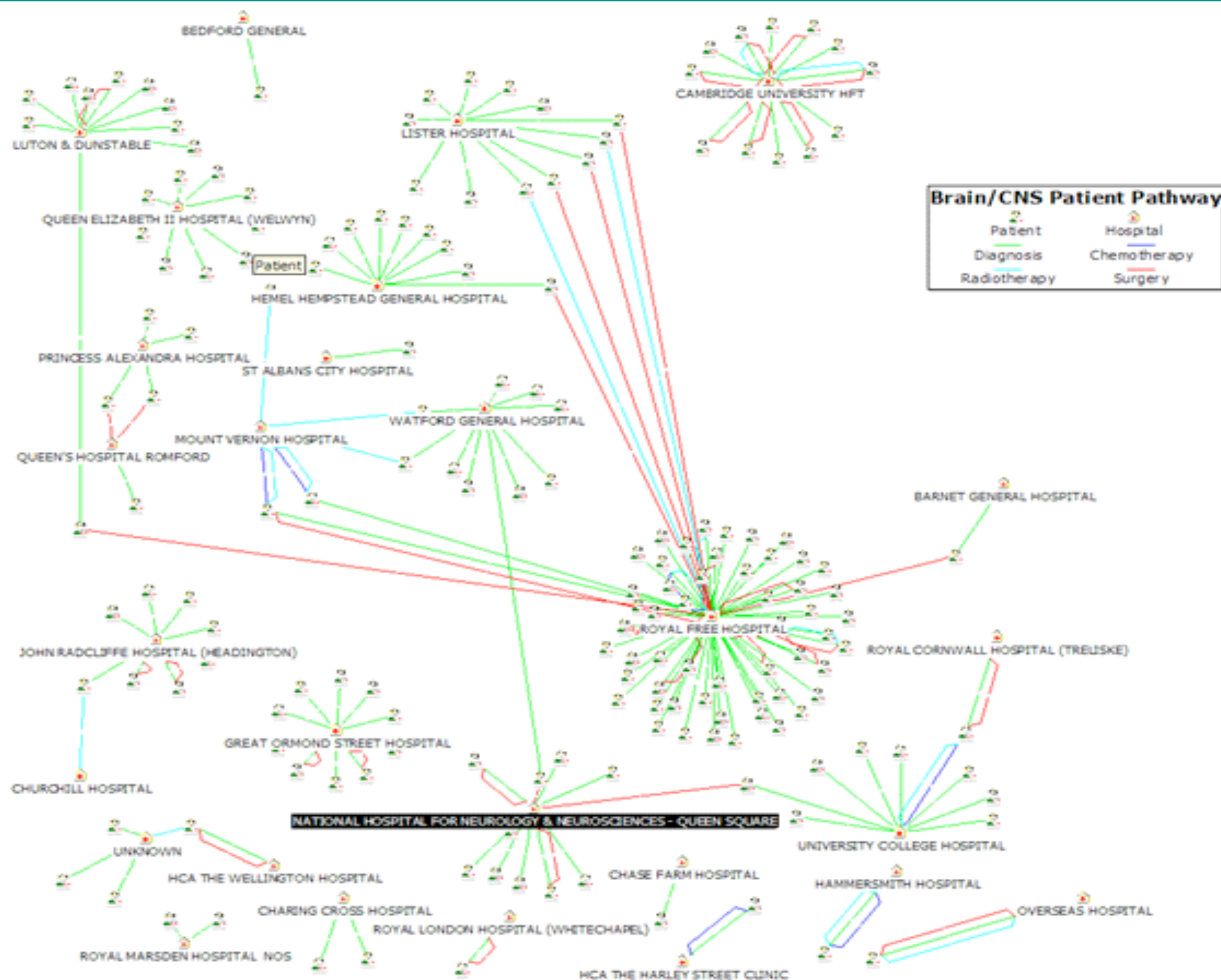
- i₂ allows visualisation of each part of the patient journey
- Shows effectiveness of new regional care plans
- Highlights possible anomalies in care delivery

Key:  Diagnosis  Chemo  Hormone Therapy
  Surgery  Radiotherapy  Other



Low Grade Gliomas (0-16)





Summary

The National Brain Tumour Registry is now a reality.

It is a resource to be used to support high quality equitable care across the NHS, audit and research.

The aim of today is to begin to define the work programme.

