

# Future Direction for Cancer Registries

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# In Ye Olde Days....

- 8 regional cancer registries
- Variation in practice
  - Different coding systems
  - Different data sources
  - Data hard to compare
- Difficulties of doing national work
  - Duplications
  - Timeliness
  - Data comparability

# One National Cancer Registration Service



## Solves these problems:

- Single England wide system
- Common standards and processes including data quality
- National datasets available for external analysis and research

# One National Cancer Registration Service



## And takes us further!

- All systems development now done once instead of 8 times!
  - Opportunity for all to reach standard of the best
  - And to improve on that!
- COSD compliant
- Rapid processing of many data sources
- Direct feedback of data to clinical teams
- Support for (near) real-time surveillance, cancer audit and analysis

# Data sources - patient-level data

## National Feeds



Radiotherapy Data (RTDS)

Cancer Waiting Times

Chemotherapy Dataset (SACT)

ONS - Cancer and non-cancer deaths

Cancer screening programmes - Bowel, Cervix and Breast

National PET-CT imaging

National cancer audits - Lung, Head and Neck, Upper GI and Colorectal

Hospital Episode Statistics (HES)

## Local Feeds



Data from MDT software systems

Pathology full-text reports



Local imaging systems



Patient Administration Systems



Local clinical data systems

## National Pilots

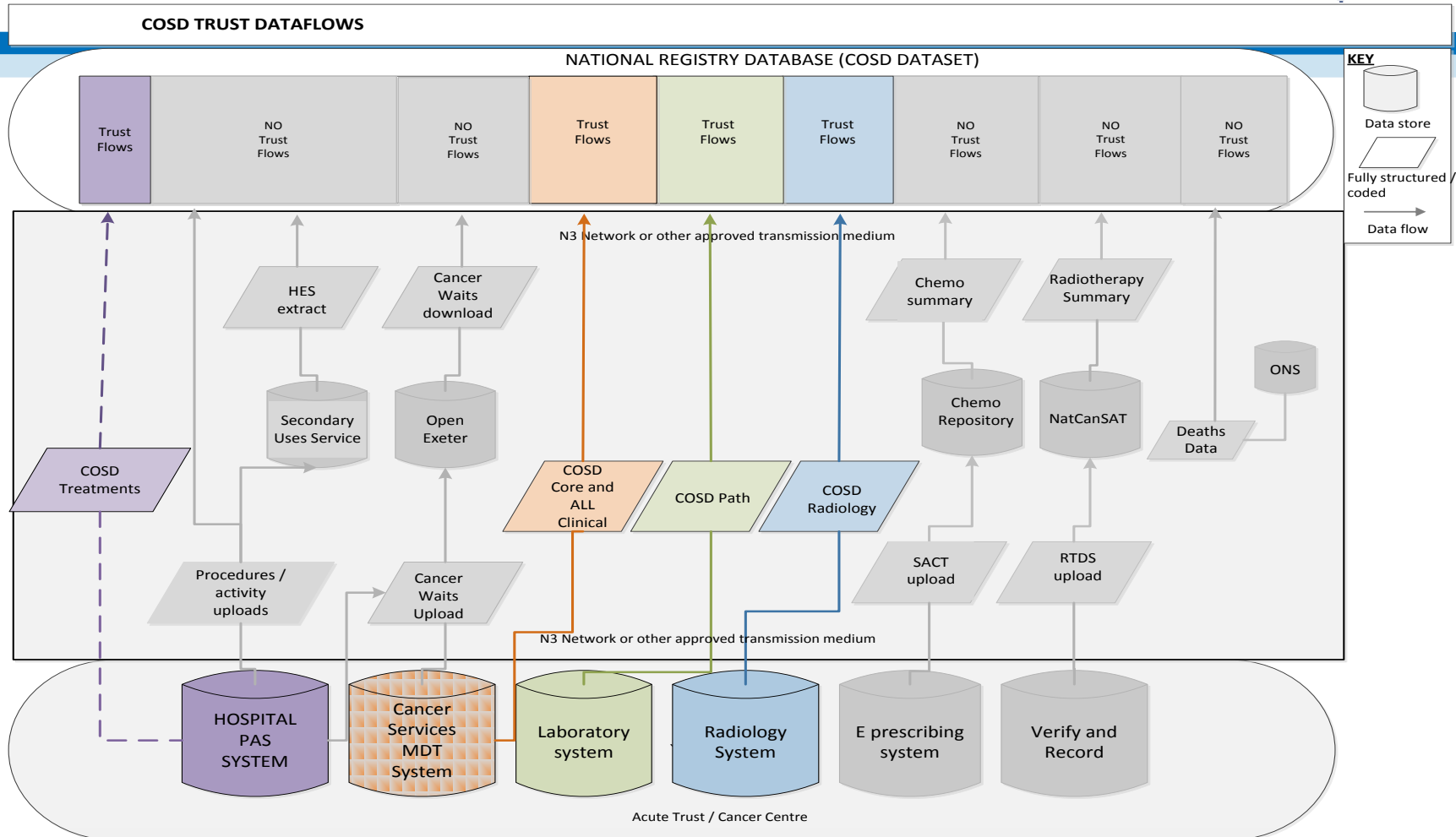
Recurrent/Meta static Breast Audit Pilot

CRUK Stratified Medicine (Sept 2011)



Encore

# Direct Provider data flows



# One National Cancer Registration Service



## To have:

- Single cancer registration service for England
- Near real-time comprehensive data collection and quality assurance
- For entire cancer pathway
- For all patients diagnosed and treated

## Providing:

- Near real-time feedback for providers and clinical teams (months not years)
- QA, completeness, clinical indicators, etc
- Stronger partnerships between Registries and Trusts

**Local data collection at MDTs is key to success**

# Information Governance

- S251 NHS Act exemption
  - All cancer registries covered – one annual application
  - Annual renewal through National Information Governance Board (NIGB) and corresponding statutory instrument
- Caldicott Guardian
  - sign-off required to allow transfer of data to and from organisations
  - existing signoff covers COSD

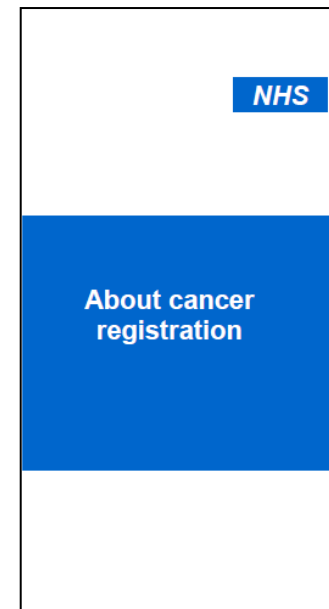


# Information Governance

## ■ Data Protection Act

- All cancer registries are registered under the DPA.
- Fair processing notices, including rights to withdraw consent, are provided through the UKACR Patient Information Leaflet
- Leaflet available from:

[www.orderline.dh.gov.uk/ecom\\_dh/public/home.jsf](http://www.orderline.dh.gov.uk/ecom_dh/public/home.jsf)  
ACR078 About Cancer Registration



# Staging Completeness

- Focus on improving staging data quality
  - In 2010, some registries staged over 70% of cases, others less than 30%
- Need to understand stage of disease to understand
  - Appropriate treatments
  - Expected outcomes
  - Case mix adjust fairly
- Historically, registry data focussed on  
Lung, breast, colorectal

# Staging Completeness

- It is possible to collect Ann Arbor staging data for lymphomas
- The Eastern Cancer Registry prioritised this as a valuable data item
  - 86% with known stage for Non Hodgkin's
  - 93% with known stage for Hodgkin's
- Not historically a priority in other areas of the country
- Now mandated by COSD – should start to see national staging data.

# Improved coding systems

- Currently variation in coding systems used to collect information on tumours
- One national system will see all tumours coded in ICD O3
- This separates out coding for site and morphology
- Greatly improved lymphoma data
  - not just 'it is a lymphoma' but 'this is a lymphoma and this is where it is'

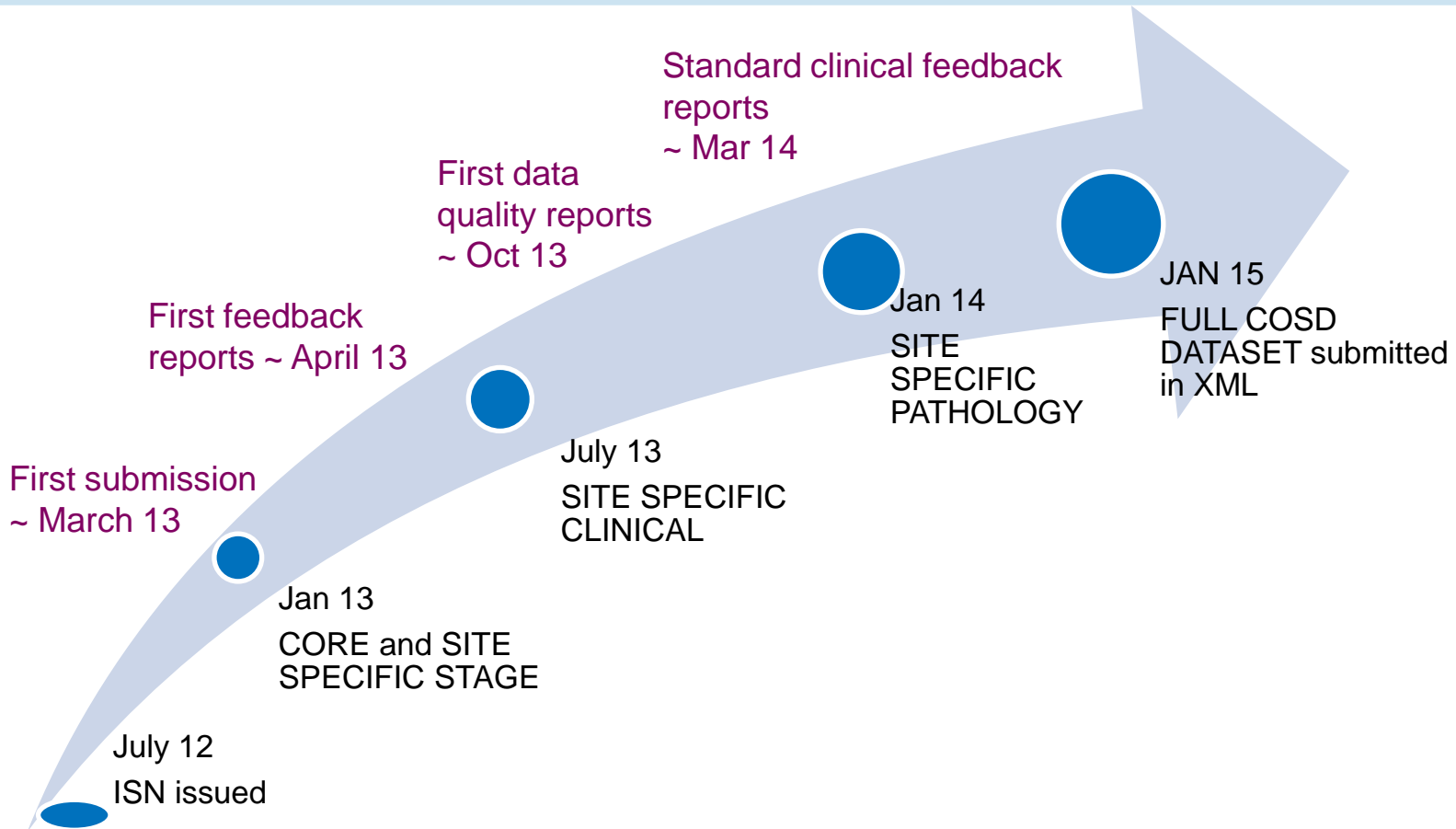
# Richer data from COSD

- Site specific fields
- Selected by the SSCRG who had to justify the value of each one
- Examples:
  - Platelet count (for CML, CLL, Myeoldysplasia)
  - White blood cell count (for AML, ALL, Hodgkin's)
  - Hasford Index and Sokal Index (for CML) etc etc
- Will be collected and coded consistently around the country.

# Feedback for Providers and Clinical Teams

- Monthly Conformance Report
  - Extract files received, number of cases, timeliness etc
- Data Quality
  - Initial completeness eg NHS number, stage
- Summary Information Indicators
  - Eg COSD data item completeness
- Clinical and Performance Indicators
  - NICE Quality Standards etc

# Proposed Feedback Timetable



# Feedback Indicators?

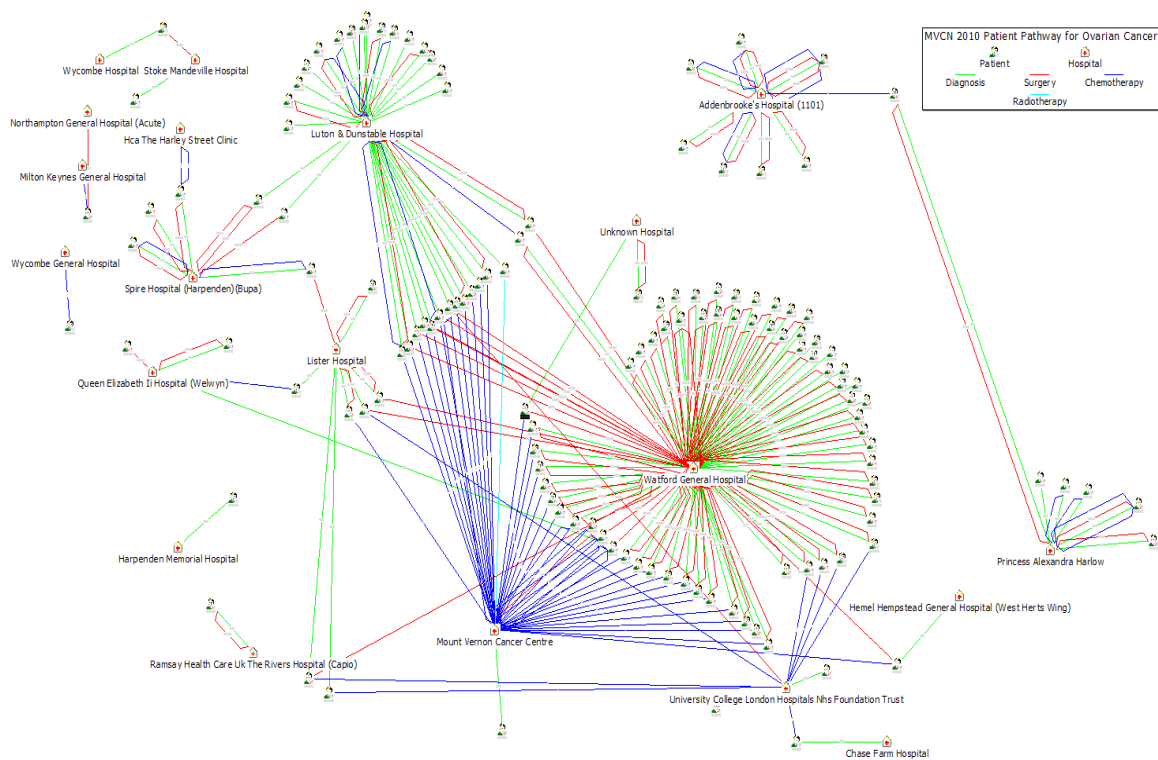
## Completeness Summary - 2011/12 - All Sites (C00-C97)

	No of Records	No of Persons	Full Valid Stage	Partial Stage
<b>North East London</b>				
Barking, Havering & Redbridge Unk. Hospitals NHS Trust	2496	2665	14%	8%
Barts and the London NHS Trust	2164	2163	32%	10%
Homerton University Hospital NHS Trust	479	472	31%	5%
Newham University Hospital NHS Trust	438	438	26%	2%
Whipps Cross University Hospital NHS Trust	1214	1209	30%	12%
<b>North London</b>				
Barnet and Chase Farm Hospitals NHS Trust	2013	1958	11%	21%
Great Ormond Street Hospital for Children NHS Trust	95	95	7%	0%
North Middlesex University Hospital NHS Trust	493	491	2%	5%
Royal Free Hampstead NHS Trust	1228	1228	38%	35%
Royal National Orthopaedic Hospital NHS Trust	227	225	15%	7%
University College London Hospitals NHS Trust	2306	2155	12%	2%
Whittington Hospital NHS Trust	465	460	31%	13%
<b>North West London</b>				
Chelsea and Westminster Hospital NHS Trust	488	485	1%	1%
Ealing Hospital NHS Trust	604	569	27%	13%
Hillingdon Hospital NHS Trust	584	581	3%	4%
Imperial College Healthcare NHS Trust	3075	2921	0%	0%
North West London Hospitals NHS Trust	990	977	14%	3%
West Middlesex Hospital NHS Trust	599	574	1%	1%
<b>South East London</b>				
Guys and St Thomas NHS Foundation Trust	2877	2834	7%	0%
Kings College Hospital NHS Foundation Trust	1852	1824	12%	11%
Lewisham Healthcare NHS Trust	332	331	3%	1%
South London Healthcare NHS Trust	2252	2225	16%	11%
<b>South West London</b>				
Croydon Healthcare NHS Trust	911	903	20%	17%
Epsom and St Helier Hospitals NHS Trust	1412	1391	22%	11%
Kingston Hospital NHS Trust	682	665	11%	5%
Royal Marsden NHS Foundation Trust	5869	5482	39%	3%
St George's Healthcare NHS Trust	1303	1264	5%	6%
<b>Kent and Medway</b>				
Dartford and Gravesham NHS Trust	875	871	7%	4%
East Kent Hospitals NHS Trust	4102	4084	6%	5%
Maldstone and Tunbridge Wells NHS Trust	2517	2512	12%	4%
Medway NHS Foundation Trust	1728	1724	15%	2%
Queen Victoria Hospital NHS Foundation Trust	190	159	2%	1%
<b>Surrey, West Sussex and Hampshire</b>				
Ashford and St Peter's Hospitals NHS Trust	1425	1366	11%	9%
Frimley Park Hospital NHS Foundation Trust	1855	1853	17%	17%
Royal Surrey County Hospital NHS Trust	5192	5156	4%	10%
Surrey and Sussex Healthcare NHS Trust	1907	1888	14%	14%
<b>Sussex</b>				
Brighton and Sussex University Hospitals NHS Trust	4270	4232	20%	20%
East Sussex Hospitals NHS Trust	2679	2620	30%	33%
Western Sussex Hospitals Trust (Worthing Hospital)	2281	2245	16%	25%
<b>Central South Coast</b>				
Western Sussex Hospitals Trust (St Richards Hospital)	1938	1897	12%	13%

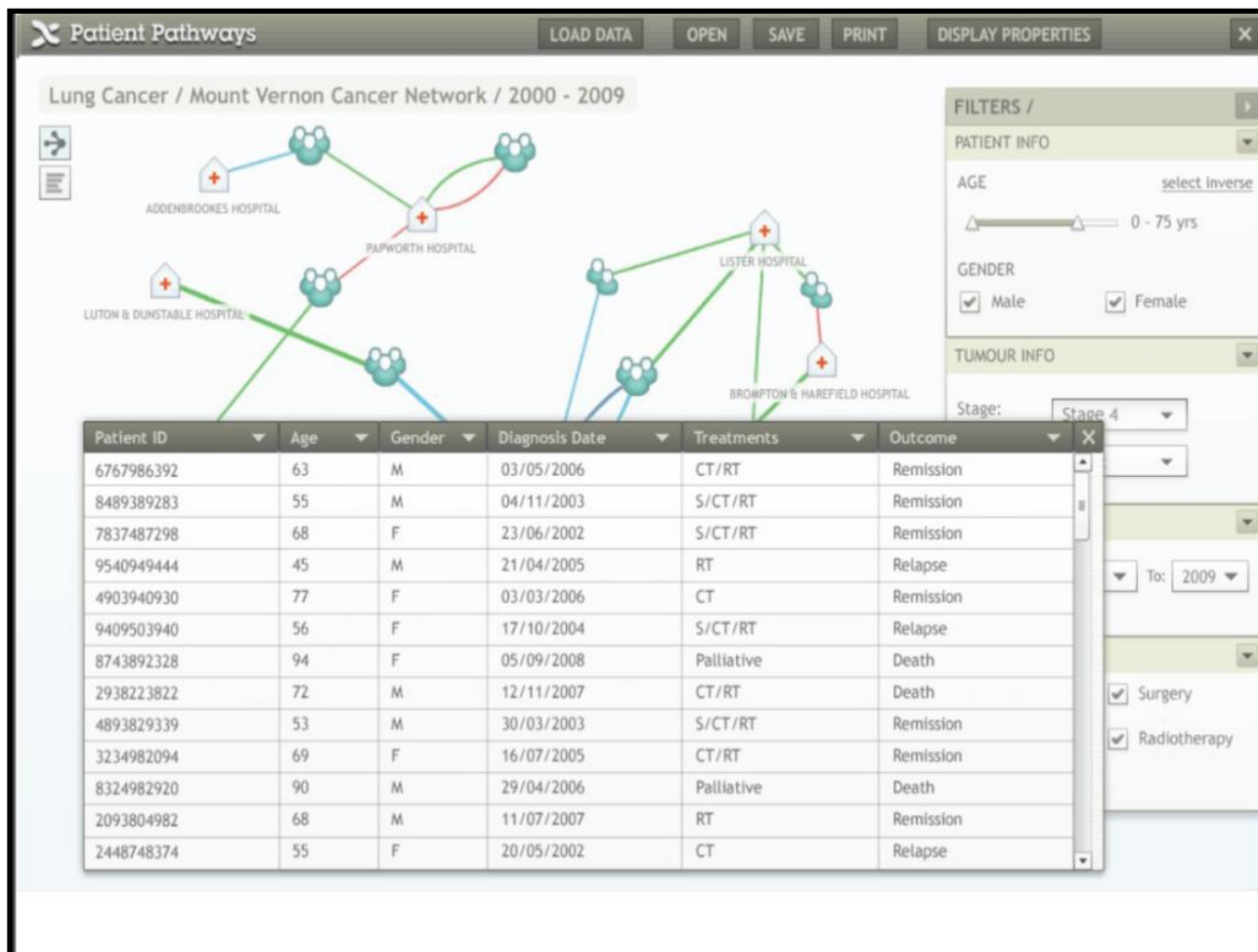




# Feedback Patient Pathways?



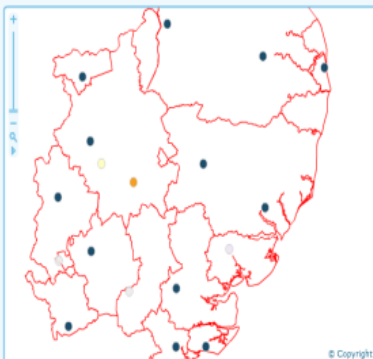
# Feedback Patient Pathways?



# Feedback Interactive tools?

## MDT Data Completeness

Filter



This report shows the completeness of certain key data items received each month by a Trust as discussed at MDT. 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. \*\*\* If the indicator shows 'No Data' or 'No MDT', additional information about a specific Trust can be found by clicking the 'Notes' icon before the the hospital's name in the MDT Discussion InstantAtlas chart. \*\*\*

ecric  
Fighting cancer with information  
Help

Indicator	Hospital	Total Pts	Current Month %	Last Month %	Trend	Data Completeness
<b>▼ Breast Cancer</b>						
Date of Diagnosis: Nov-11	Addenbrookes	57	100	100.00	↔	0   100
Tumour Laterality: Nov-11	Addenbrookes	57	96.5	100.00	↓	0   100
<b>▼ Gynaec</b>						
Date of Diagnosis: Nov-11	Addenbrookes	33	100	100.00	↔	0   100
Treatment Type: Nov-11	Addenbrookes	33	93.9	100.00	↓	0   100
Pigo Stage: Nov-11	Addenbrookes	33	69.7	73.90	↑	0   100
<b>▼ Haematology</b>						
Date of Diagnosis: Nov-11	Addenbrookes	42	100	100.00	↔	0   100
Treatment Type: Nov-11	Addenbrookes	42	97.6	97.00	↔	0   100
Consultant Name: Nov-11	Addenbrookes	42	100	97.00	↑	0   100
<b>▼ Head &amp; Neck</b>						
Date of Diagnosis: Nov-11	Addenbrookes	20	100	100.00	↔	0   100
Pre-Treatment TNM: Nov-11	Addenbrookes	20	85	68.80	↑	0   100
<b>▼ Thyroid Cancer - C73</b>						
Date of Diagnosis: Nov-11	Addenbrookes	3	100	100.00	↔	0   100
Pre-Treatment TNM: Nov-11	Addenbrookes	3	100	100.00	↔	0   100
<b>▼ Liver GI (C18-C20)</b>						
Date of Diagnosis: Nov-11	Addenbrookes	20	100	100.00	↔	0   100
Pre-Treatment TNM: Nov-11	Addenbrookes	20	80	67.70	↑	0   100
Stage - Dukes: Nov-11	Addenbrookes	20	65	64.30	↔	0   100
Rural Treatment TNM: Nov-11	Addenbrookes	20	60	32.30	↑	0   100
<b>▼ Lung Cancer</b>						
Date of Diagnosis: Nov-11	Addenbrookes	13	100	100.00	↔	0   100
Tumour Laterality: Nov-11	Addenbrookes	13	84.6	88.20	↓	0   100
Pre-Treatment TNM: Nov-11	Addenbrookes	13	100	94.10	↑	0   100
<b>▼ Skin - C43</b>						
Date of Diagnosis: Nov-11	Addenbrookes	14	100	100.00	↔	0   100
Breast/Thickness: Nov-11	Addenbrookes	14	92.9	90.00	↑	0   100
Rural TNM: Nov-11	Addenbrookes	14	92.9	70.00	↑	0   100
<b>▼ Upper GI</b>						
Date of Diagnosis: Nov-11	Addenbrookes	22	100	100.00	↔	0   100
Pre-Treatment TNM: Nov-11	Addenbrookes	22	99.1	64.00	↑	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 |  
 - +

# Feedback

# Direct querying?!

Utilities - Mozilla Firefox

File Edit View History Bookmarks Tools Help

Utilities

gnpy https://gnpy.utilities/

enCORE Search Index Reports ESources Utilities Account Development Andrew Murphy Log out

### Tumour Near-natural Query Language (from: Tink)

\* Structure

status *	behaviour	stage	site group / icd code	tumours *	action *	unprocessed data filters
all	non-invasive	unstaged	brain	tumours	diagnosed	with unprocessed records
final	invasive	unknown stage	breast		tracked	
provisional	metastatic	stage 1	lower-gi			
referenced	behaviour 2	stage 2	lung			
	etc...	etc...	C209			
			C20			
			C18 C19 and C20			
			C18 C19 C20			
			etc...			

\* required  
\* required when query contains "date / date range" and/or "provider / cancer network"

Examples

TIQL  Search

TIQL: final invasive stage 3 lung tumours diagnosed at Addenbrookes hospital Search

6940 Tumours SQL statement

	MRN number	Name	Date of birth	Vital status	Site & M18	ICD 10/O-3	Date of
1			12.11.1929	Dead on 14.03.2005	C342 8046/3		01.06
2			01.08.1951	Dead on 01.03.2006	C341 8041/3		08.06
3			18.02.1941	Dead on 23.09.2008	C341 8140/3		15.06
4			21.04.1937	Dead on 30.04.2009	C341 8046/3		13.03
5			24.05.1941	Dead on 15.01.2005	C340 8041/3		08.06
6			01.08.1923	Dead on 27.09.2004	C343 8046/3		08.06
7			19.11.1921	Dead on 02.08.2004	C343 8140/3		18.06
8			12.07.1942	Dead on 24.01.2006	C349 8046/3		20.09
9			04.06.1924	Dead on 30.08.2007	C340 8010/3		12.05
10			08.08.1928	Dead on 23.08.2007	C341 8046/3		15.03

« Previous 1 2 3 4 5 6 7 8 9 10 11 12 Next »

# Future Feedback?

- No point providing feedback if no-one is reading it!
- Needs to be
  - Easy to use
  - Engaging
  - Answering the questions clinicians, nurses and service managers care about!
- Important to work with the users to develop tools that are best for them
- Not necessarily one size fits all

# Conclusions

- A single cancer registration system (ENCORE) for England
- COSD compliant
- Routine, timely feedback
- Provide powerful data for local, national and international analysis

Any further questions, feel free to contact me

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or the lead cancer registry for Haematology

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# Haematology Specific (1)

Data Item Section	Data Item Name
<b>HAEMATOLOGY - LABORATORY RESULTS</b>	
HAEMATOLOGY - LABORATORY RESULTS - CML, CLL, MYELOYDYSPLASIA	PLATELET COUNT
HAEMATOLOGY - LABORATORY RESULTS - AML, ALL, HODGKIN	WHITE BLOOD CELL COUNT (HIGHEST PRE TREATMENT)
HAEMATOLOGY - LABORATORY - HODGKIN, CLL, MYELOYDYSPLASIA, FOLLICULAR	BLOOD HAEMOGLOBIN CONCENTRATION
HAEMATOLOGY - LABORATORY RESULTS - MYELOYDYSPLASIA	BONE MARROW KARYOTYPE
HAEMATOLOGY - LABORATORY RESULTS - MYELOYDYSPLASIA	BONE MARROW BLASTS PERCENTAGE
HAEMATOLOGY - LABORATORY RESULTS - MYELOYDYSPLASIA	NEUTROPHIL COUNT
HAEMATOLOGY - LABORATORY RESULTS - MYELOMA, HODGKIN	ALBUMIN
HAEMATOLOGY - LABORATORY RESULTS - MYELOMA	BETA2 MICROGLOBULIN LEVEL
HAEMATOLOGY - LABORATORY RESULTS - HODGKIN	BLOOD LYMPHOCTYE COUNT
HAEMATOLOGY - LABORATORY RESULTS - FOLLICULAR, DLBCL, OTHER LYMPHOMAS	LACTATE DEHYDROGENASE LEVEL
HAEMATOLOGY - LABORATORY RESULTS - CLL	BLOOD MYELOBLASTS PERCENTAGE
HAEMATOLOGY - LABORATORY RESULTS - CML	BLOOD BASOPHILS PERCENTAGE
HAEMATOLOGY - LABORATORY RESULTS - CML	BLOOD EOSINOPHILS PERCENTAGE
HAEMATOLOGY - LABORATORY RESULTS - AML	CYTOGENETIC GROUP (ACUTE MYELOID LEUKAEMIA)
<b>HAEMATOLOGY - CANCER CARE PLAN</b>	
HAEMATOLOGY - CANCER CARE PLAN - FOLLICULAR	NUMBER OF ABNORMAL NODAL AREAS
HAEMATOLOGY - CANCER CARE PLAN - FOLLICULAR, DLBCL, OTHER LYMPHOMAS, HODGKIN	PRIMARY EXTRANODAL SITE
HAEMATOLOGY - CANCER CARE PLAN - DLBCL	NUMBER OF EXTRANODAL SITES CODE
<b>HAEMATOLOGY - CML CANCER CARE PLAN</b>	
HAEMATOLOGY - CANCER CARE PLAN - CML	SPLEEN CM BELOW COSTAL MARGIN
HAEMATOLOGY - CANCER CARE PLAN - CML	HASFORD INDEX (CHRONIC MYELOID LEUKAEMIA)
HAEMATOLOGY - CANCER CARE PLAN - CML	SOKAL INDEX (CHRONIC MYELOID LEUKAEMIA)



# Haematology Specific (2)

Data Item Section	Data Item Name
<b>HAEMATOLOGY - MYELOYDYSPLASIA CANCER CARE PLAN</b>	
HAEMATOLOGY - CANCER CARE PLAN - MYELOYDYSPLASIA	IPSS (MYELOYDYSPLASIA)
<b>HAEMATOLOGY - CLL CANCER CARE PLAN</b>	
HAEMATOLOGY - CANCER CARE PLAN - CLL	HEPATOMEGALY INDICATOR
HAEMATOLOGY - CANCER CARE PLAN - CLL	SPLENOMEGALY INDICATOR
HAEMATOLOGY - CANCER CARE PLAN - CLL	NUMBER OF LYMPHADENOPATHY AREAS
HAEMATOLOGY - CANCER CARE PLAN - CLL	RAI STAGE
HAEMATOLOGY - CANCER CARE PLAN - CLL	BINET STAGE
<b>HAEMATOLOGY - FOLLICULAR CANCER CARE PLAN</b>	
HAEMATOLOGY - CANCER CARE PLAN - FOLLICULAR	FLIPI INDEX SCORE
<b>HAEMATOLOGY - DLBCL CANCER CARE PLAN</b>	
HAEMATOLOGY - CANCER CARE PLAN - DLBCL	(R)IPI INDEX for DLBCL
<b>HAEMATOLOGY - MYELOMA CANCER CARE PLAN</b>	
HAEMATOLOGY - CANCER CARE PLAN - MYELOMA	ISS STAGE for MYELOMA
<b>HAEMATOLOGY - HODGKIN CANCER CARE PLAN</b>	
HAEMATOLOGY - CANCER CARE PLAN - HODGKIN	HASENCLEVER INDEX
<b>HAEMATOLOGY - ACUTE LYMPHOCYTIC LEUKAEMIA CANCER CARE PLAN</b>	
HAEMATOLOGY - CANCER CARE PLAN - ACUTE LYMPHOCYTIC LEUKAEMIA	HASENCLEVER INDEX
<b>HAEMATOLOGY - STAGING</b>	
HAEMATOLOGY - STAGING - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	ANN ARBOR STAGE
HAEMATOLOGY - STAGING - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	ANN ARBOR SYMPTOMS
HAEMATOLOGY - STAGING - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	ANN ARBOR EXTRANODALITY
HAEMATOLOGY - STAGING - HODGKIN, FOLLICULAR, DLBCL, OTHER LYMPHOMAS	ANN ARBOR BULK