

Members educational session
“What does your health data
actually look like”

Friday 22nd April 2022

Good morning

The session is due to start at 10:00



Members educational session
“What does your health data
actually look like”

Friday 22nd April 2022

10:00 - 11:00

Chris Carrigan, Expert Data Adviser

Areas to cover

- Outlining the types of health data that may exist about you and your healthcare
- We can't cover all of these.....!
- Looking in more detail at how health data about you is created, along a typical “pathway”, and what it actually looks like
- How much of your data can you actually see?
- What's changing

Starting with points in life – Child & Maternal

- Health data is generated at many points in life, for instance:
 - Maternal health, pregnancy and birth
 - NHS (England, Wales, Isle of Man)
 - HCN (Northern Ireland)
 - CHI number (Scotland)
 - Early years
 - School age children
 - Young people
 - During childhood and teenage years

...which could also be seen as “themes”

- Breastfeeding
- Children and young people's mental health and wellbeing
- Health behaviours in young people
- Healthcare use
- Long term conditions and complex health needs
- Mortality
- Child measurement and child obesity
- Oral health
- Perinatal mental health
- Unintentional injuries
- Vaccinations and immunisations
- Vulnerable children and young people
- <https://fingertips.phe.org.uk/profile/child-health-profiles>

But lets focus on data – from consultation to dataset

- This is based on a generic set of circumstances and events, and is in no way reflective of any individual here or elsewhere
- What this session tries to demonstrate is how data about you is generated, where and by who. And in particular, what does it look like, and what happens to it once it has been created?

The start of this data journey

- Logon to your GP Practice system, and make an appointment
- Or give them a call, and ask for an appointment
- Or go through an online intermediary (e.g. Doctorlink)
- If you are registered with a Practice, they will already have your details on their Practice Computer system



* use MY data
n26 WY 99f9

What is in your GP record?

- Contact details
- Height and weight
- Allergies, for example to a medicine like penicillin or t
- Vaccinations and immunisations, for example tetanu
- Examinations and screening
- Medicines
- Illnesses or diagnoses
- Operations
- Test results, such as blood and urine tests, peak flo
- X-rays and scans
- Notes about your appointments with doctors and
- Letters from hospitals, community nurses, such a that look after you
- Lifestyle information, for example whether you exercise



Clinician viewed	28 Dec 2018
Result type	Radiology
Tests	Ankle X-ray
Filed by	Andrew Marshall at The Manchester Rd Surgery (NHS Sheffield CCG) - 31 Dec 2018 08:25
Result	Normal
What you need to do	No Further Action

The Manchester Rd Surgery (NHS Sheffield CCG) - 04 Jun 2019 14:56

Specimen
 Specimen Type: Type Unspecified
 Specimen Reference#: 1
 Collected: 28 Dec 2018
 Received: 28 Dec 2018
 Provider Sample ID: 22700234

Pathology Investigations

Ankle X-ray XR Ankle Lt
 XR Ankle Lt

Report Summary / Clinical History
 Pain in left ankle below lateral malleoli, worse on running,
 no trauma.

pain above left patella.
 ?oa left knee.
 ?OA left ankle ??stress fracture.
 XR Ankle Lt

No bony abnormality.
 Reported by: DR. DAVID MOORE Report Date: 29/12/2018
 Consultant Radiologist (GMC No: C2309419)

Reviewed by:
 Reported by : Dr. David Moore / EXTERNAL
 Pain in left ankle below lateral malleoli, worse on running, no
 trauma.

pain above left patella.
 ?oa left knee.
 ?OA left ankle ??stress fracture.
 Pain in left ankle below lateral malleoli, worse on running, no
 trauma.

pain above left patella.
 ?oa left knee.
 ?OA left ankle ??stress fracture.

General Information

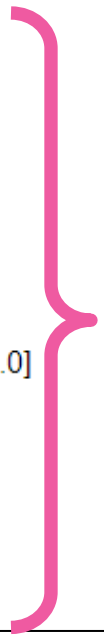


Comment:
 MAY NOT FILE PROPERLY

- 166.0]
]
 0.0 - 400.0]
 5]

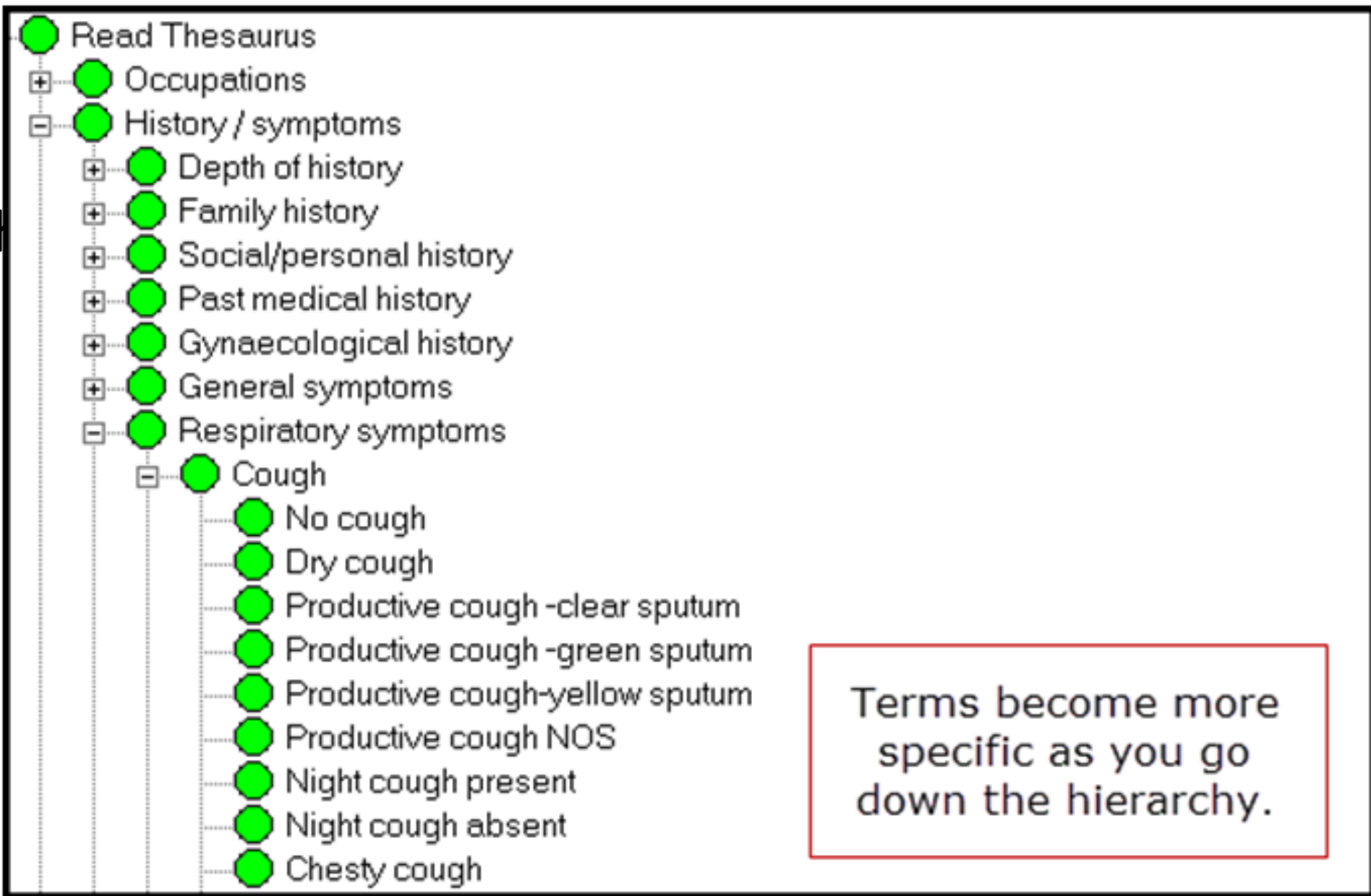
- 33.0]
 /L [335.0 - 370.0]

0.25 - 1.0]
 0.04 - 0.5]



Coded entry Serum creatinine level (XE2q5) 81 umol/L [62 - 106] [Information about this test](#)

• WH



Terms become more specific as you go down the hierarchy.

The referral from your GP to the hospital

- Electronic communication (from the Practice System to the hospital system)
- Phone call
- Letter / Secure email
- The request details sit on both the GP and the hospital system
- The hospital creates an appointment for you; date, time, clinic, instructions**

“Structured data”

A pink arrow points from the text "Structured data" to the first bullet point "Electronic communication (from the Practice System to the hospital system)". Another pink arrow points from "Structured data" to the third bullet point "Letter / Secure email".

“Unstructured data”

A pink arrow points from the text "Unstructured data" to the fifth bullet point "The hospital creates an appointment for you; date, time, clinic, instructions**".

* use MY data

Your hospital appointment

- “What’s your name, address and date of birth?”
 - Not for the first time, so why?
 - “Collect data once”
- The hospital records (or checks) your details, and records you as attending

Your hospital record.....



Your hospital* record.....

- Hand-written notes are typed-up by medical secretary or hospital medical records staff, into your electronic hospital record
- Some are directly entered by clinical teams
- In some hospitals, your attendance, lab results, radiology and pathology results are on the same system. In others, they are on separate systems, and the main hospital system holds summary details of the test results
- Images (e.g. X-rays) are held on separate systems, but can be viewed by the clinical teams
 - Single CT scan is around 30Mb*

Your hospital record.....

- Your electronic data is largely held in codes
- But there is still a large amount of free-text
- Text is easier to read
- Codes are easier to analyse, but:
 - There are several different coding systems
 - Disease classifications
 - Clinical terminology
 - Treatment codes for different types of treatment
- What, where, how, how much

174.5: Malignant breast

SACT submissions for NHS No 458nnnnnn

NHS Number	458nnnnnn	4587098523	4587098523	4587098523	4587098523	4587098523	4587098523	4587098523	4587098523	4587098523
Date of birth	dd/mm/yyyy	dd/mm/yyyy	dd/mm/yyyy	dd/mm/yyyy	dd/mm/yyyy	dd/mm/yyyy	dd/mm/yyyy	dd/mm/yyyy	dd/mm/yyyy	dd/mm/yyyy
Gender current	1	1	1	1	1	1	1	1	1	1
Ethnicity	A	A	A	A	A	A	A	A	A	A
Patient postcode	YO8 9JZ	YO8 9JZ	YO8 9JZ	YO8 9JZ	YO8 9JZ	YO8 9JZ	YO8 9JZ	YO8 9JZ	YO8 9JZ	YO8 9JZ
Registered GP	B82097	B82097	B82097	B82097	B82097	B82097	B82097	B82097	B82097	B82097
Practice Code										
Consultant GMC code	3582666	3582666	3582666	3582666	3582666	3582666	3582666	3582666	3582666	3582666
Consultant speciality code	370	370	370	370	370	370	370	370	370	370
Organisational code of provider	RCB55	RCB55	RCB55	RCB55	RCB55	RCB55	RCB55	RCB55	RCB55	RCB55
Primary diagnosis	C189	C189	C189	C189	C189	C189	C189	C189	C189	C189
Morphology										
Stage of disease	300	300	300	300	300	300	300	300	300	300
Programme number	1	1	1	1	2	2	300	300	300	300
Regimen number	1	1	1	1	1	1	2	2	2	2
Intent of treatment	A	A	A	A	A	A	A	A	A	A
Regimen	Capecitabine	Capecitabine	Capecitabine	Capecitabine	Fluorouracil + Folinic Acid (Mayo)	Fluorouracil + Folinic Acid (Mayo)	Fluorouracil + Folinic Acid (Mayo)	Fluorouracil + Folinic Acid (Mayo)	Fluorouracil + Folinic Acid (Mayo)	Fluorouracil + Folinic Acid (Mayo)
Height at start of regimen	1.7	1.7	1.7	1.7	1.7	1.7	1.7	1.7	1.7	1.7
Weight at start of regimen	83.9	83.9	83.9	83.9	91.9	91.9	91.9	91.9	91.9	91.9
Performance status at start of regimen						1	1	1	1	1
Comorbidity adjustment	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Date decision to treat	03/06/2014	03/06/2014	03/06/2014	03/06/2014	14/10/2014	14/10/2014	14/10/2014	14/10/2014	14/10/2014	14/10/2014
Start date of regimen	30/06/2014	30/06/2014	30/06/2014	30/06/2014	20/10/2014	01/12/2014	01/12/2014	01/12/2014	01/12/2014	01/12/2014
Clinical trial	N	N	N	N	N	N	N	N	N	N
Chemo radiation	N	N	N	N	N	N	N	N	N	N
Number of cycles planned	8	8	8	8	2	4	4	4	4	4
Cycle number	1	2	3	4	1	2	2	2	2	2
Start date of cycle	30/06/2014	21/07/2014	11/08/2014	02/09/2014	20/10/2014	01/12/2014	01/12/2014	01/12/2014	01/12/2014	01/12/2014
Weight at start of cycle	83.9	83.9	83.9	83.9	91.9	91.9	91.9	91.9	91.9	91.9
Performance status at start of cycle						1	1	1	1	1
OPCS procurement code	X702	X702	X702	X702		X702				
Drug Name	CAPECITABINE	CAPECITABINE	CAPECITABINE	CAPECITABINE	FLUOROURACIL	FLUOROURACIL	FLUOROURACIL	FLUOROURACIL	FLUOROURACIL	FLUOROURACIL
Actual dose per administration	2500	2500	2500	2500	850	750	750	750	750	750
Administration	2	2	2	2						

174.6: Malignant breast

174.8: Malignant breast female

174.9: Malignant breast

S-4.6 codes agreed with the NHS Classifications

26/09/2012

Recommendation

OPCS-4.6 Code

Special

S62.2 Liposuction of subcutaneous tissue NEC

site code

In addition one of the following ICD-10 codes is assigned: I97.2 Postmastectomy lymphoedema syndrome or I89.0 Lymphoedema, not elsewhere classified or Q82.0 Hereditary lymphoedema.

CENTRAL NERVOUS SYSTEM

Special

One of the following OPCS-4 codes is selected as appropriate:
L29.2 Intracranial bypass to carotid artery NEC
L29.6 High flow interposition extracranial to intracranial bypass from external carotid artery to middle cerebral artery
L29.7 Bypass of carotid artery by anastomosis of superficial temporal artery to middle cerebral artery

L34.2 Anastomosis of cerebral artery

Plus the following code:

Y08.8 Other specified laser therapy to organ NOC

Note: It is not possible to classify 'without temporary arterial occlusion' using OPCS-4.

DIGESTIVE SYSTEM

Special

One of the following OPCS-4 codes is selected as appropriate:

G21.5 Insertion of stent into oesophagus NEC
G15.4 Fiberoptic endoscopic insertion of tubal prosthesis into oesophagus
G15.6 Fiberoptic endoscopic insertion of expanding metal stent into oesophagus NEC
G15.7 Fiberoptic endoscopic insertion of expanding covered metal stent into oesophagus

Special

T85.2 Block dissection of axillary lymph nodes
Y76.3 Endoscopic approach to other body cavity or
T86.2 Sampling of axillary lymph nodes
Y76.3 Endoscopic approach to other body cavity or
T87.3 Excision or biopsy of axillary lymph node



BASELINE DATA

Participant Number:

--	--	--	--	--	--	--

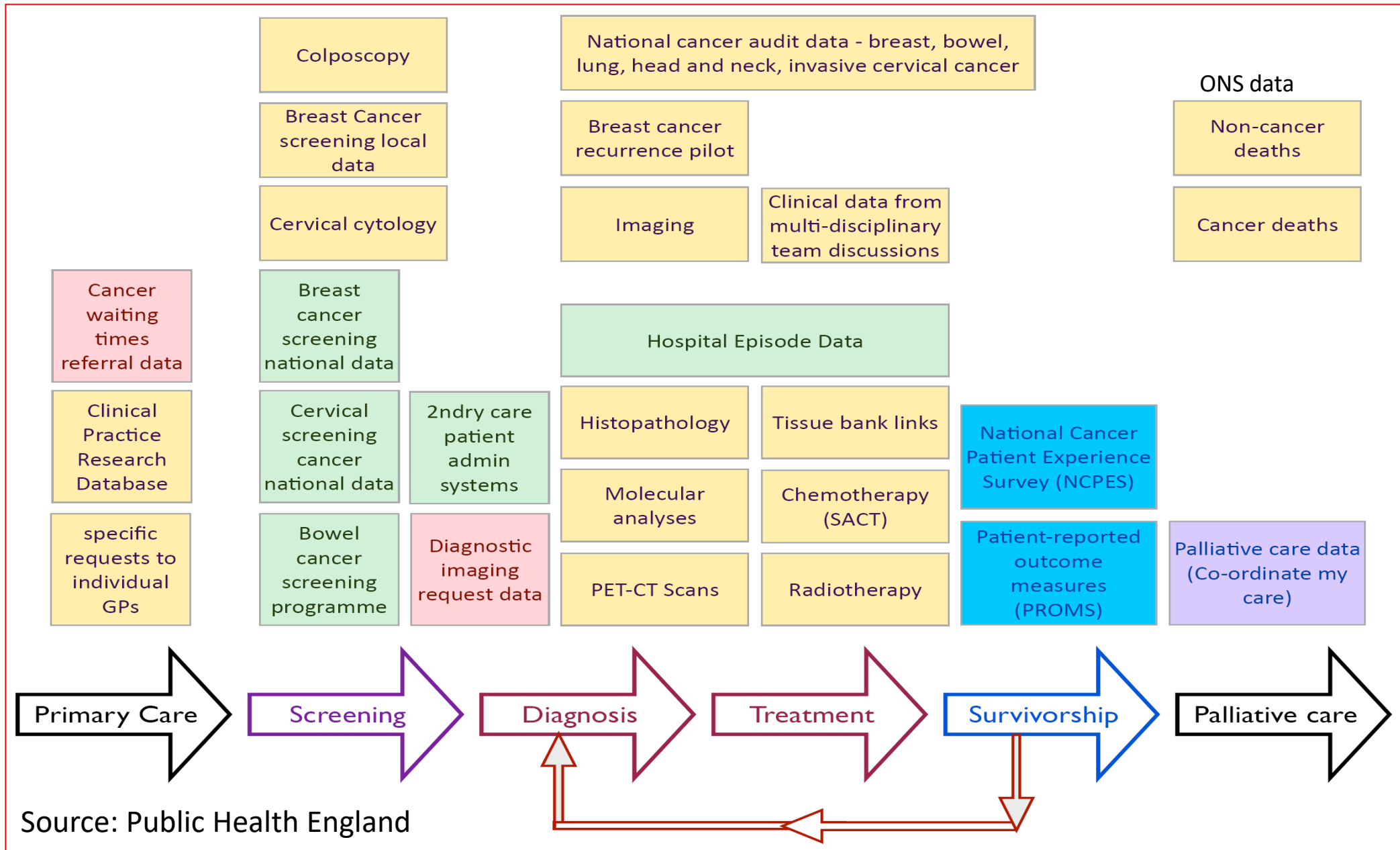
If you are on a
clinical trial....

PARTICIPANT INFORMATION																							
Participant Number	<table border="1"> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>																						
Study Group	_____																						
Study Site (Health Centre Name)	_____																						
Inclusion/exclusion criteria <small>*Patient must meet all criteria to eligible for the study</small>	Met all <input type="checkbox"/>	Not met* <input type="checkbox"/>																					
Date of Informed Consent	<table border="1"> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>																						
Date of Birth	<table border="1"> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>																						Or estimated age _____
Gender	<input type="checkbox"/> Male <input type="checkbox"/> Female																						
Pregnant	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown																				
If pregnant, Estimated Gestational Age _____ weeks																							
Date of Enrolment	<table border="1"> <tr> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> <td></td> </tr> </table>																						
Had malaria in the last 28 days	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown																				
Had antimalarial in the last 28 days	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unknown																				

The NHS deals in “activity” data

- Cumulative
- Replicated*
- Activity is grouped by:
 - Episodes of care (e.g. Hospital Episode Statistics – HES)
 - Cost groupings (e.g. Healthcare Resource Groups – HRG)
- Data is used for things like:
 - Invoice validation**
 - Risk Stratification**

An example – cancer data along a “pathway” ...



Getting access to your health data

- From your GP system
 - What you can expect, or ask for....
 - What are the difficulties
 - What is changing?
- From your hospital record
 - The legalities vs. the practicalities
 - What's changing and what isn't?

What do you find if you do get access?

Category	Field Names	Comments	Episode 11	Episode12	Episode 13	Episode 14	Episode 15
Clinical; Period of Care	MAINSPEF	defines the specialty under which the consultant is contracted.. 370 = Medical Oncology	370	370	370	370	370
Clinical; Period of Care	TRETSPEF	defines the specialty in which the consultant was working during the period of care. (as above)	370	370	370	370	370
Patient Data	DIAG_01	C17.2 Malignant neoplasm of ileum. C97X Malignant neoplasms of independent (primary) multiple sites C18.5 Malignant neoplasm of splenic flexure	C172	C97X	C97X	C97X	C185

Inconsistent coding of chemo reason.

Field Names	Field Description	Event4	Event5
WITHIN_SIX_MONTHS_FLAG	Did this happen between -6 and +6 months from the diagnosis date	1	1
SIX_MONTHS_AFTER_FLAG	Did this happen between 0 and +6 months from the diagnosis date	1	1
OPCS4_CODE	Coded procedure	S361	
OPCS4_NAME	Plain text of OPCS4_CODE	FULL THICKNESS AUTOGRAFT OF SKIN TO HEAD OR NECK	

?

Systemic Anti-Cancer Treatments (SACT)

Field Names	Comments	Episode 1	Episode 2	Episode 3	Episode 4
ORGANISATION_CODE_OF_PROVIDER	Organisation code (provider)	RCB55	RCB55	RCB55	RCB55
CONSULTANT_SPECIALITY_CODE	370 = MEDICAL ONCOLOGY	370	370	370	370
PRIMARY_DIAGNOSIS	ICD-10 classification of disease C189 = Malignant neoplasm of kidney and other and unspecified urinary organs	C189	C189	C189	C189
STAGE_AT_START	Stage at start of treatment: 300 = T3,N0,M0	300	300	300	300
MERGED_REGIMEN_ID	Pseudonymised regimen ID	434918	434918	434918	434918
HEIGHT_AT_START_OF_REGIMEN	Patient's height (metres (m))	1.7	1.7	1.7	1.7
WEIGHT_AT_START_OF_REGIMEN	Patient's weight (kilograms (kg))	83.9	83.9	83.9	83.9
PERF_STATUS_START_OF_REGIMEN	Performance Status (Adult)				
COMORBIDITY_ADJUSTMENT	An indication of whether a PATIENT's overall physical state (i.e. other diseases and conditions) was a significant factor in deciding on the type of Anti-Cancer Drug Regimen.	Y	Y	Y	Y

Why?
Ask hospital?

Tumour number 1. Centre/Year/Serial: 0301-14-37828

Tumour details[Edit](#) [Stage](#) [Audit Timeline](#)Status of registration **Final****Pre-COSD Mode**

Diagnosis date 30.12.2013

Postcode at diagnosis S17 3PT TRENT CANCER REGISTRY (Y0301)

Primary site **ICD-O-3 (2011)** C494: Connective, Subcutaneous And Other Soft Tissues Of Abdomen

Histology 9680/3: Malignant lymphoma, large B-cell, diffuse, NOS

Grade X

Laterality Not Applicable (8)

Tumour size

Nodes Involved Excised

Excision margin

Multifocal

No scans found false

Staging

Registry	Date			
T	N	M	<u>edition</u>	
TNM Stage Insufficient Info				

Screened
('diagnostic route')

No treatment reason

Lab number* PH054273S/13

Further information

Bypass all validation

Submorphologys +

[None]

Recurrences +

[None]

Original Scans

[None]

Events

Add to this tumour: Pathology Notification Referral Imaging Drug Therapy Radiotherapy Surgery Event Other Treatment

Event	Provider	Hosp #	Practitioner	Date	Source type	
Pathology [Diagnostic]	Sheffield Te...	WR2992	Morley N	30.12.2013	Pathology On Disk	Details
Drug therapy	Royal Hallam...		Morley N	16.01.2014	Cosd Xml	Details
→ Anti Cancer Drug Regimen (Cytotoxic Chemotherapy)						



Registration actions Add

Action initiated	Action date	Place	User	Dt closed	
SEARCH Search Outstanding Information	30.12.2013	Sheffield T...	sue [redacted]	10.09.2014	Details
COMPLETE Complete Registration Complete	10.09.2014 08:08		sue [redacted]	10.09.2014	Details
→ Autogenerated at finalising tumour					

Other tumours

[None]

Pre-COSD Mode

Organisation Site Code (Pathology Test Requested By)	SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST (RHQ)
Care Professional Code (Pathology Test Requested By)	MORLEY N (C4307907)
Date first notified	11.03.2014 (Date NCRAS received the information)
Source type	Pathology On Disk
Comments	
Primary diagnosis ICD	
Investigation type	
Specimen Source	ROYAL HALLAMSHIRE HOSPITAL
Specimen Type	
Date sample taken	Date on which the specimen was obtained from the patient.
Date sample received	30.12.2013 Date received by path lab
Date of investigation result	30.12.2013 Date path lab wrote the report
Histology SNOMED	TD4000 M95903
Tumour laterality	
Excision margin	
Lab number	PH054273S/13
Full pathology text	Full Text Report Abdomen. NOS

Full pathology text Full Text Report
Abdomen, NOS

Malignant lymphoma, NOS

Andrew SMITH - WR2882 HODS 27346

SPECIMEN

Needle core biopsy from abdominal mass

CLINICAL DETAILS

? Lymphoma. Previous biopsy not diagnostic.

MACROSCOPY

A single core of white tissue measuring 12 mm in length plus an additional fragment.

MICROSCOPY

These are needle core biopsies of largely necrotic abnormal lymphoid tissue consisting of a mixed population of small and large lymphoid cells. Both populations appear to be morphologically abnormal, although morphological interpretation is extensively compromised by necrosis. These cells have the following immunophenotype:

CD10, CD20, bcl2 - Positive

CD3, CD5, CD23, CD30, Cyclin D1, bcl6, MUM1 - Negative

Subject Access Request -What Did We Find?

- Better than a similar exercise in 2013
- A few inconsistent uses of codings
- Some chemotherapy missing (one entire month)
- Some clearly erroneous codes
- Nothing of real significance noted apart from 1 item
- The data has been used externally by 10 organisations
 - Personally Identifiable – 2 organisations (supplied on 3 occasions)
 - De-personalised – 8 organisations (supplied on 18 occasions)
- The data has been used internally by cancer registry analysts

Your data choices....

- GP Payment
 - List size, deprivation, health checks, health promotion, visits, training
- Research databases
 - Prescribing, observational studies
- Summary Care Record
 - Shielded Patient List
 - “Emergencies”

systemonline
PATIENT ONLINE SERVICE

Home Help Logout

Appointments Medication Records Account

Mr Christopher M Carrigan
NHS Number: [REDACTED]
Date of birth: 27 Sep 1962

The Manchester Rd Surgery
The Manchester Road Surgery, 484 Manchester Road,
Sheffield, S10 5PN
Usual GP: Dr Wendy Jaques

General: 01142668265
General: 01142668265

Sharing In

Unit	Status
The Manchester Rd Surgery	This organisation is currently able to view health information recorded in your electronic health record by other health and social care organisations involved in your direct care. If you do not want this organisation to be able to view this information, please contact this care organisation directly and request that this is changed.

Sharing Out

Unit	Start Date	End Date	Status
The Manchester Rd Surgery	05 Jul 1991		Information recorded in your electronic health record by this organisation is currently made available to be shared with other health and social care organisations involved in your direct care. If you do not want your record to be made available, please contact this care organisation directly and request that this is changed.

Back

Your data choices....

- The right to opt-out is different across the UK
- In England, you have the National Data Opt-out
 - <https://your-data-matters.service.nhs.uk/>

NHS

Choose if data from your health records is shared for research and planning

We need to check who you are before you can make your choice

We'll need your:

- name
- date of birth
- postcode or NHS number

We'll use these details to find your contact details from your health records so we can send you a security code.

Continue

[How your data will be processed using this service](#) (opens in new window).

* use MY data
n26 MY d9f9

Take away points

- Health data about you can be generated in many places
- Its not all linked together, either for your care, or for research
- There are lots of Data Standards, and coding systems, which are mandated
- Not all the coding systems are directly “mappable”
- But data quality is not always great
- You can only see a small amount of your health data, but you do have a legal right to see more

Questions?