Public Health England

Protecting and improving the nation's health

The National Cancer Registration and Analysis Service (NCRAS) England

Data collection for tumour agnostic treatments

Dr Alice Turnbull
Programme manager, Public Health England

What I will discuss:

1

The National Cancer Registration and Analysis Service (NCRAS) England

- A brief background

2

NCRAS principles for data collection

- How does this facilitate monitoring of tumour agnostic treatments?

1983 Mainframe Compute

Hospital Records are on Paper

Very little cohesive data on cancer across the

- Difficult to understand the burden of cancer
- Difficult to assess service delivery
- Lack of co-ordination of data, knowledge, intelligence

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England

ACHIEVING WORLD-CLASS CANCER OUTCOMES

A STRATEGY FOR ENGLAND
2015-2020
Executive Summary

Report of the Independent Cancer Taskforce

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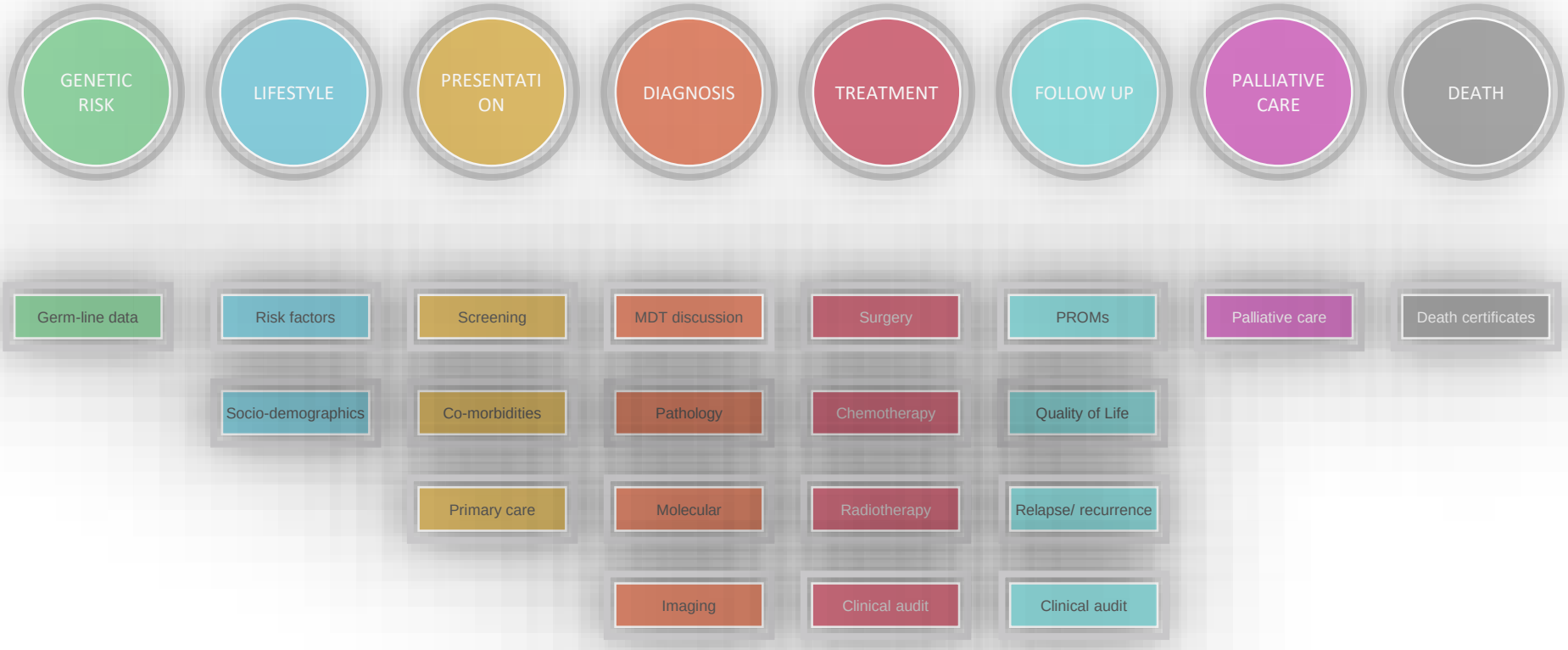
Our vision…

- To provide near-real time, cost-effective, comprehensive, quality-assured data services covering the entire cancer and rare disease care pathways on all patients in England

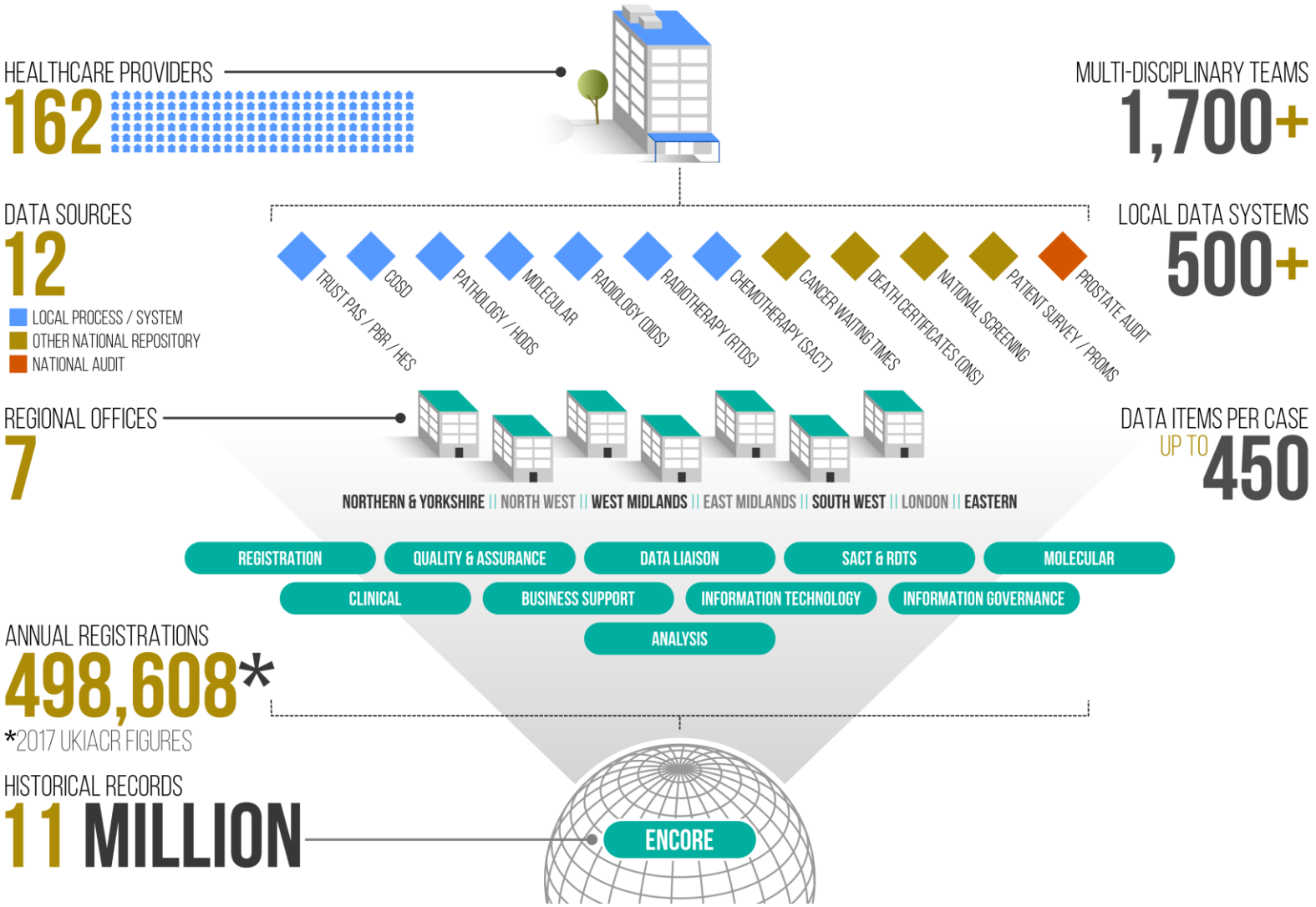
as a resource for

- population and public health, patient care, research, quality, safety, clinical team and service performance management, audit, outcome monitoring and commissioning.

Collecting data across the cancer patient pathway



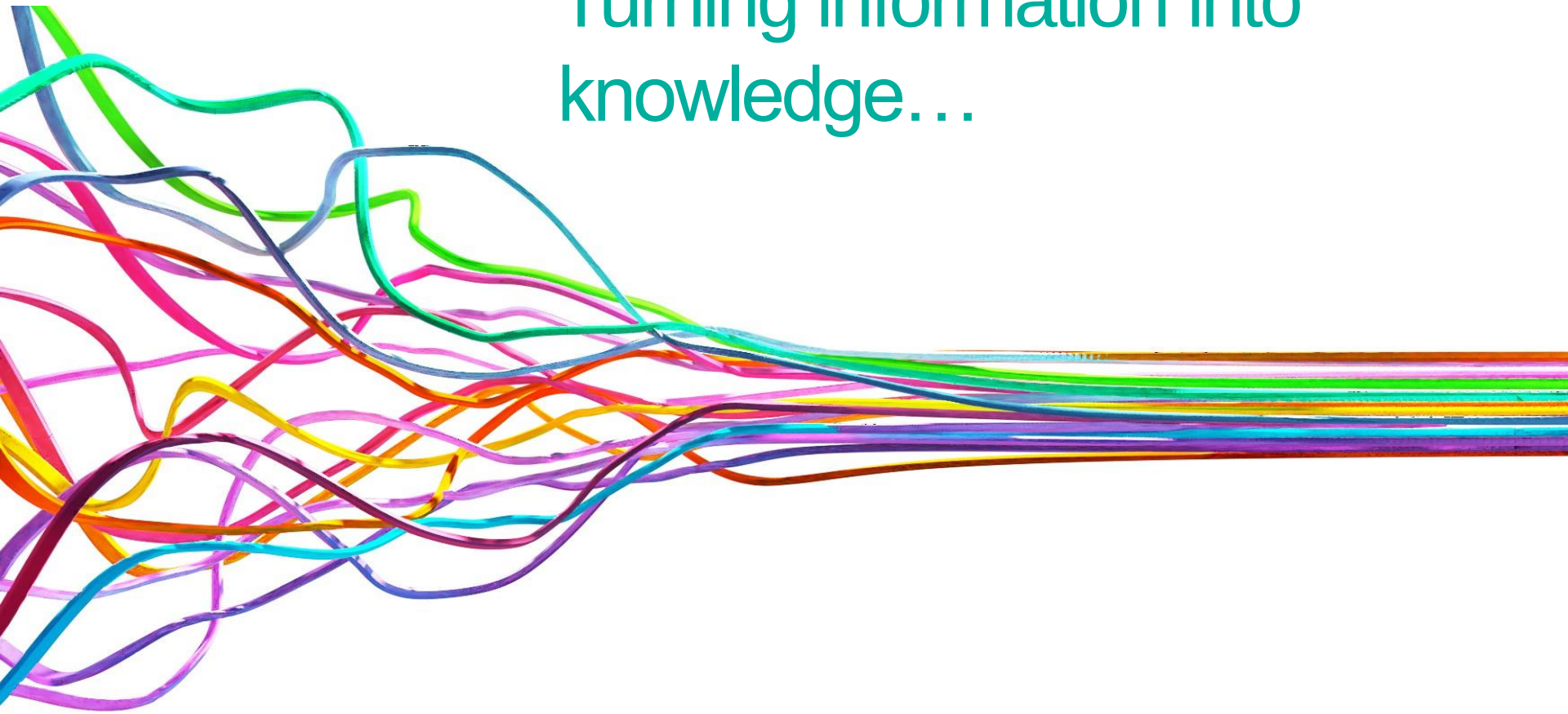
An idea of scale:



Data in the English National Health Service (NHS)

There is plenty of it…..

Turning information into knowledge…



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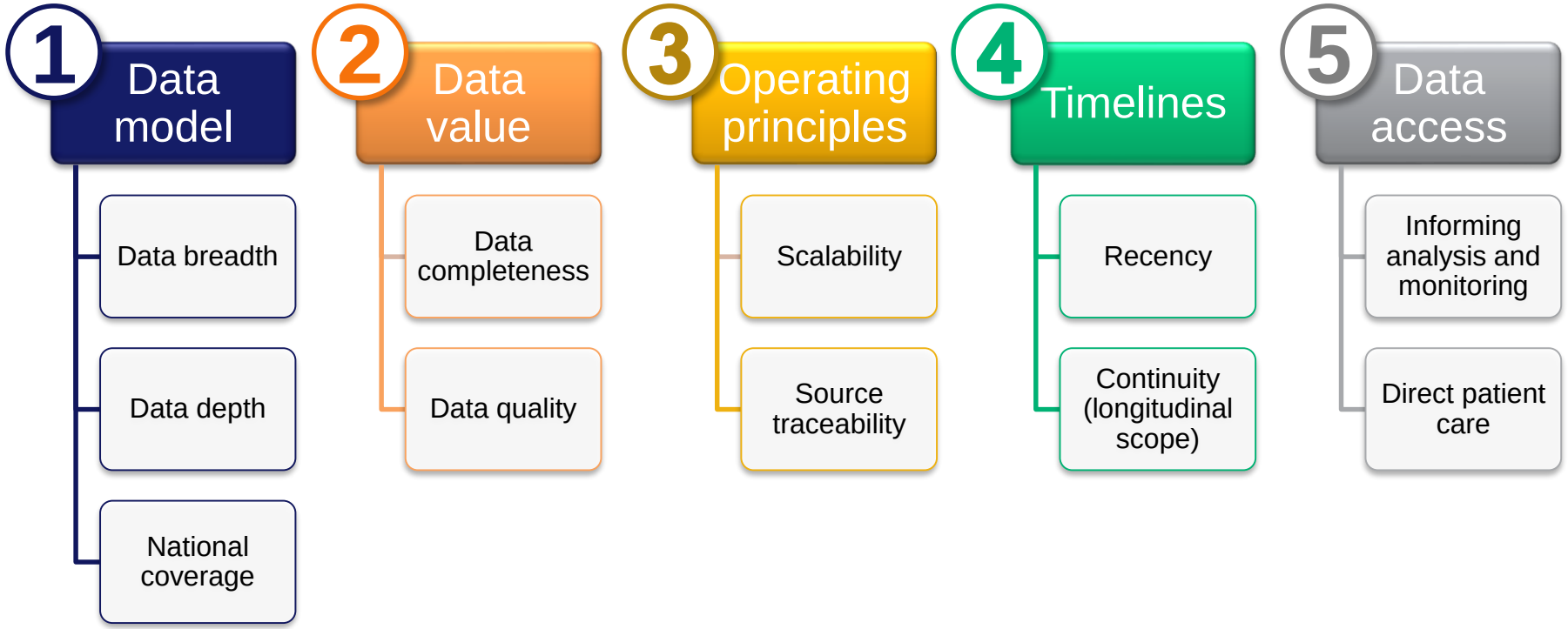
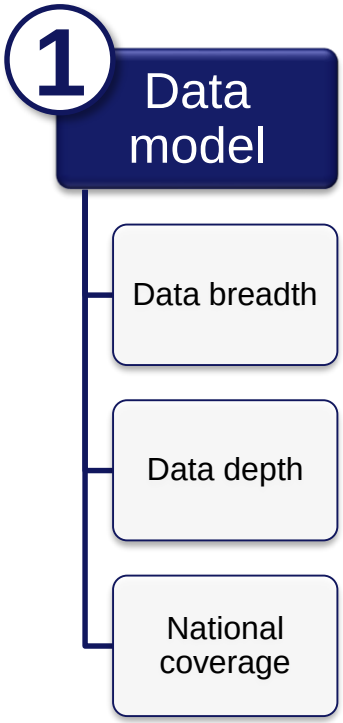
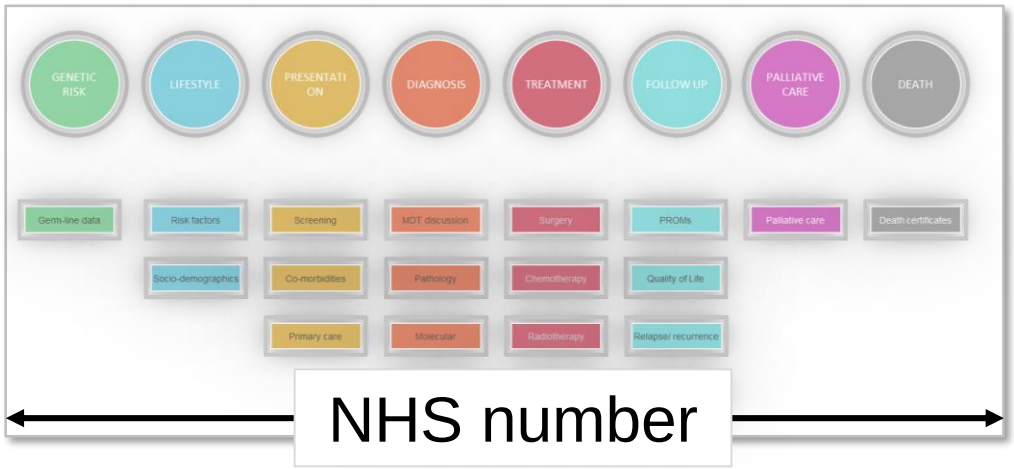
Principles for cancer data collection:



Principles for cancer data collection:



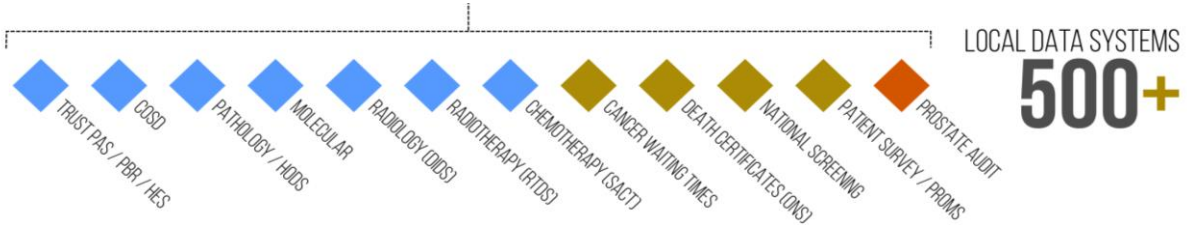
Data breadth



Data across the cancer patient pathway…

AND depth

Captured in tailored datasets



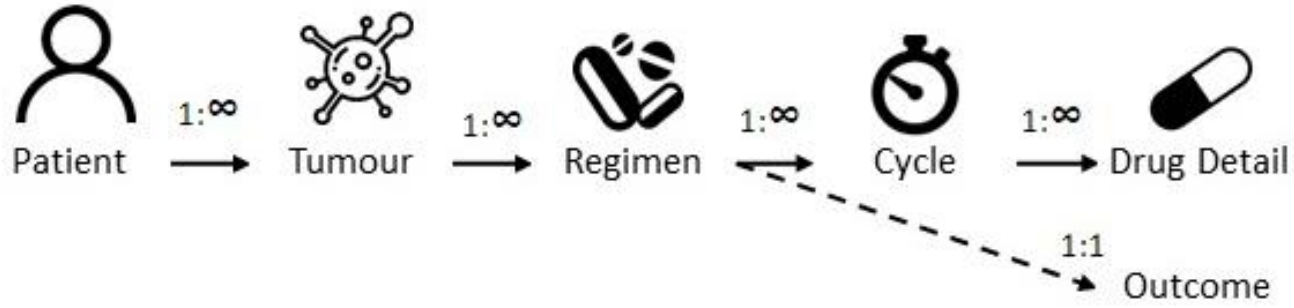
SACT dataset:

1. Patient and tumour characteristics

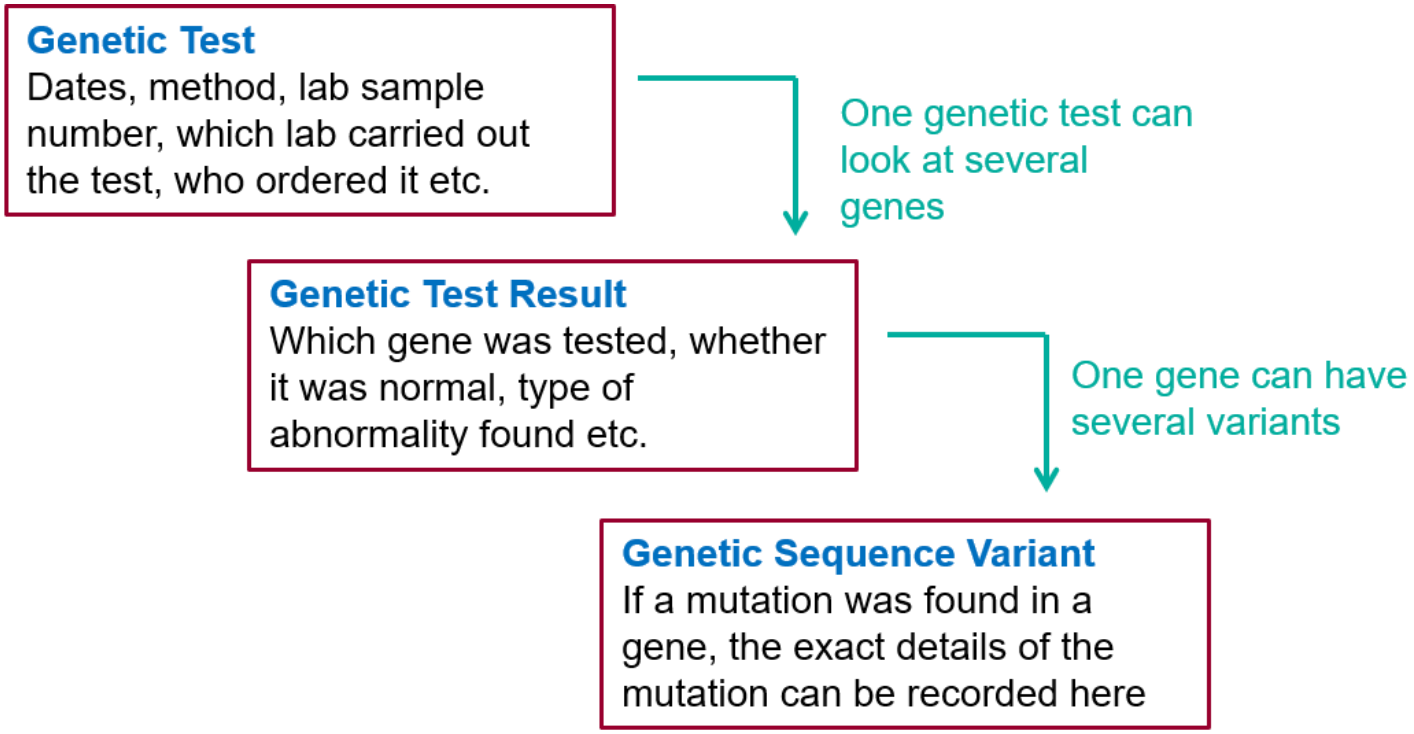
2. Trust and consultant details

3. Treatment characteristics including drug names and drug combinations (regimens)

Data structure:

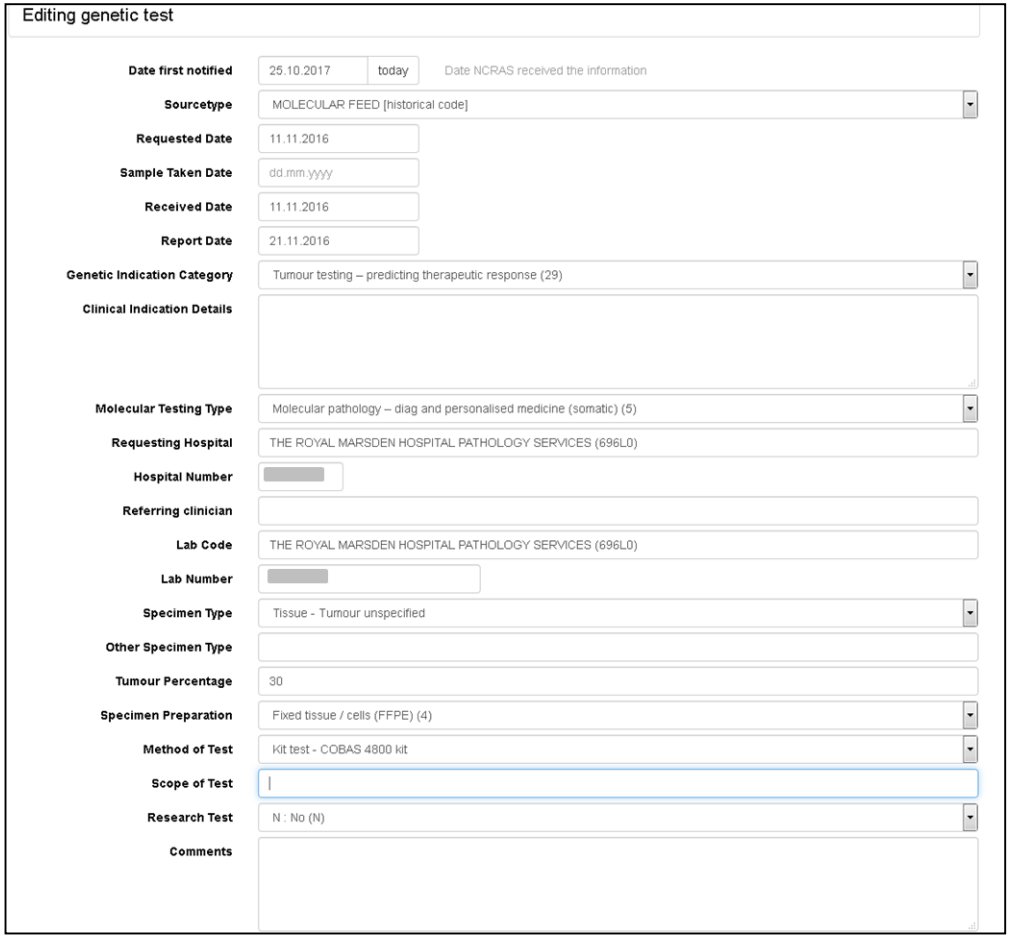


Molecular dataset:



Genetic Test
Dates, method, lab sample number, which lab carried out the test, who ordered it etc.

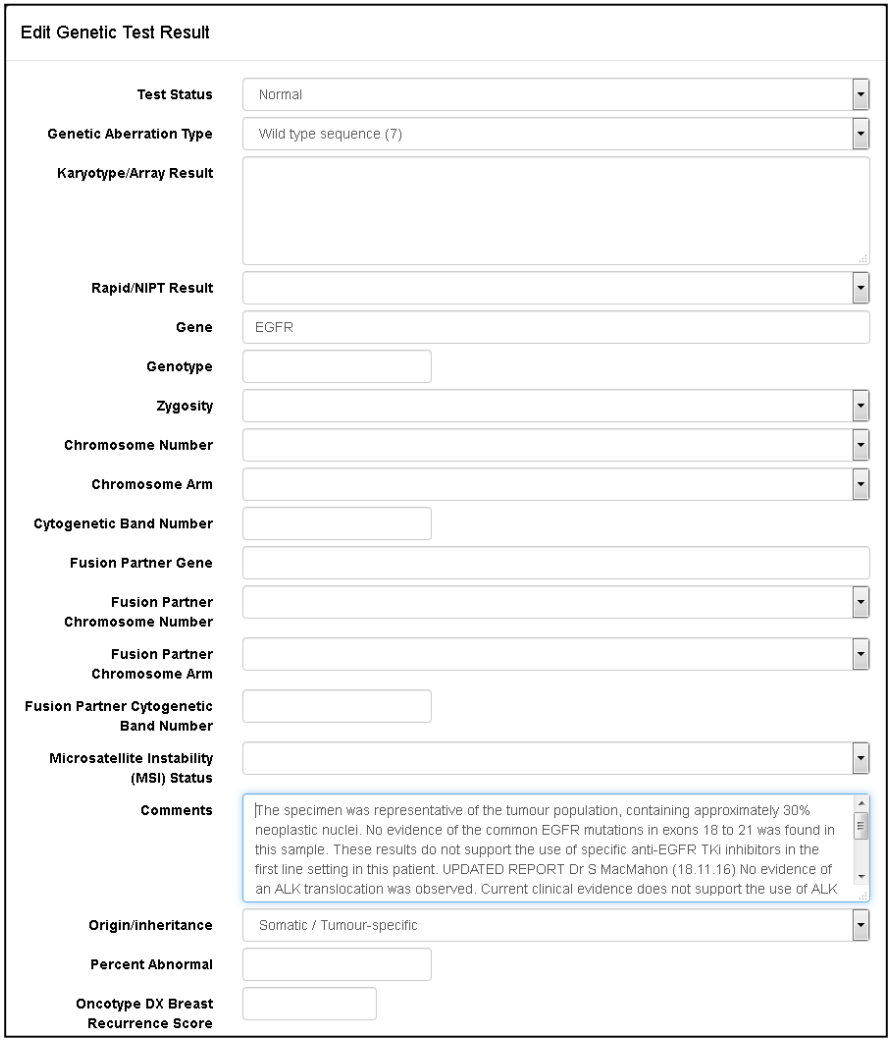
- Dates:
  - Test Requested
  - Sample Taken
  - Sample received
  - Report authorised date
- Reason for referral
- Hospital/Lab demographics
- Specimen type
- Tumour %
- Methodology / technology



Genetic Test Result

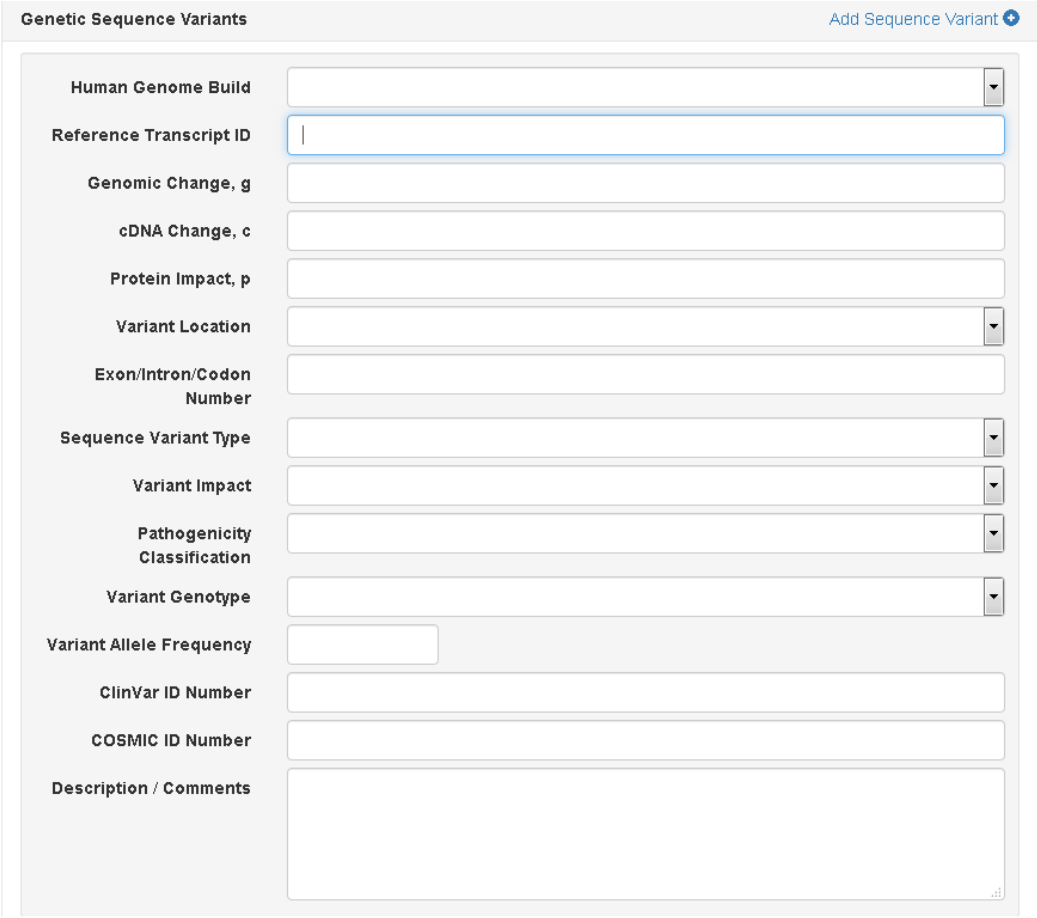
Which gene was tested, whether it was normal, type of abnormality found etc.

- Test status
  - Normal
  - Abnormal
- Aberration type
  - DNA sequence variant
  - Fusion
  - Amplification
  - Etc.
- Gene tested
  - EGFR
  - BRAF
  - KRAS
  - Etc.

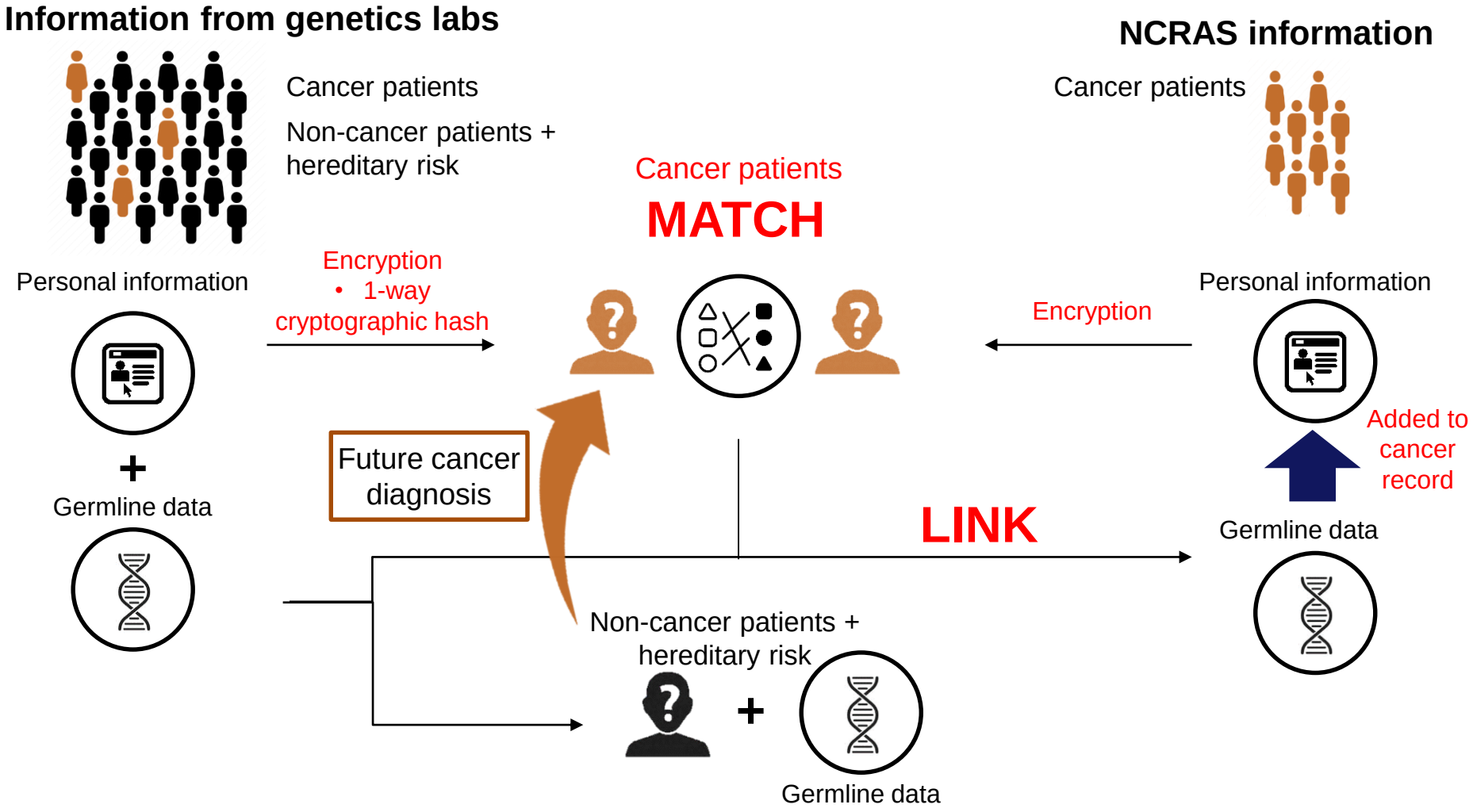


Genetic Sequence Variant
If a mutation was found in a gene, the exact details of the mutation can be recorded here

- Genome Build
- Transcript ID (incl. version number)
- Sequence variant details in HGVS where available
- Exon/intron/codon number where specific details not given:
  - E.g. ‘BRAF codon 600 mutation detected’



Germline data - pseudonymisation



Primary care prescription data: Data items

~80 million records a month

Pseudo ID (NHS number & DOB)
Prescription form ID

Patient characteristics
Patient age
Sex
Exemption category

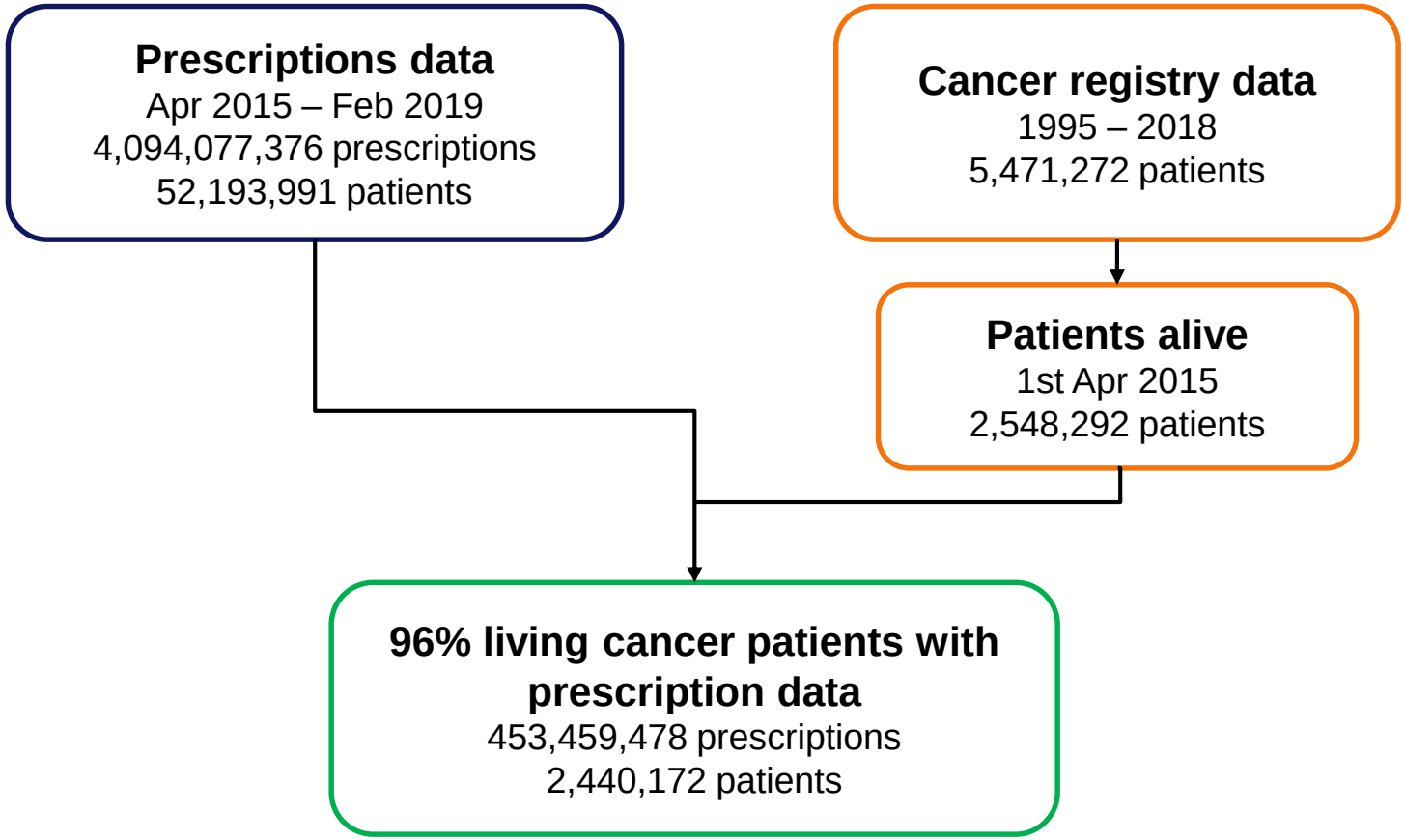
Drug information
Drug name
Dose
Quantity
Form (tablets etc)
BNF code
Net ingredient cost
Standard drug identifiers from dm+d

Prescriber information
Postcode
Practice name
Prescription form type

Dispenser information
Date dispensed
Organisation responsible for payment

Data profile: https://bmjopen.bmj.com/content/8/7/e020980

Linking prescriptions data to cancer records



Identification of Endocrine Therapy

Cancer Epidemiology 61 (2019) 185–189

Contents lists available at ScienceDirect

Cancer Epidemiology

journal homepage: www.elsevier.com/locate/canep

Endocrine therapy in the years following a diagnosis of breast cancer: A proof of concept study using the primary care prescription database linked to cancer registration data

Gabrielle Emanuel[a,*], Katherine E. Henson[a], John Broggio[a], Jackie Charman[a], Kieran Horgan[b],

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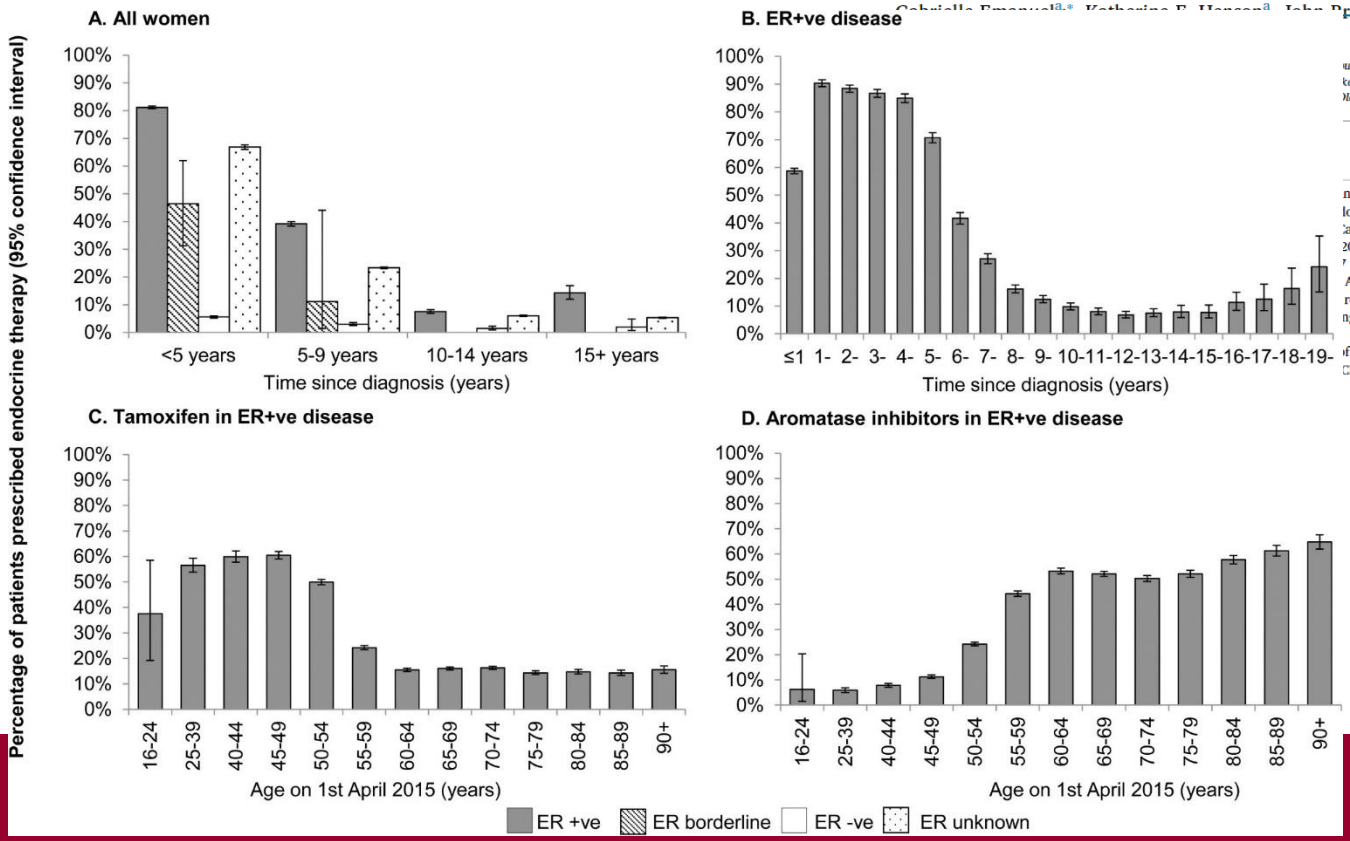
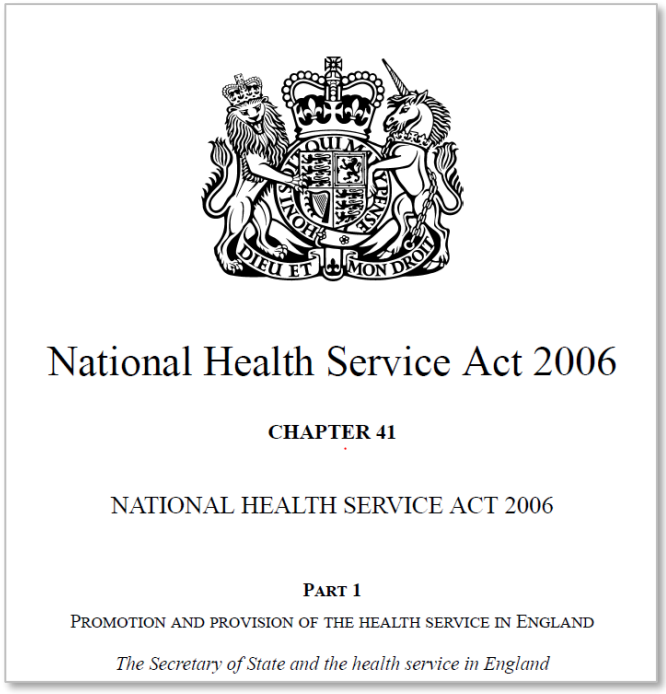
kett St, Leeds, LS9 7TF, United Kingdom
ld Road Campus, Oxford, OX3 7LF, United Kingdom

ncer registration data were linked to the Primary Care Prescription Database (PCPD) in
locrine therapy (ET) prescribed in women after a diagnosis of breast cancer was studied.
cancer registrations for women diagnosed with breast cancer during 1995–2015, who
2015, were linked to ET prescriptions issued during April–July 2015.
survivors of breast cancer diagnosed during 1995–2015, 37% were prescribed ET
Among women whose breast cancer diagnosis was after 31st July 2010, 81% of those
receptor positive (ER + ve) disease were prescribed ET compared with only 6% of those
nger women usually received tamoxifen and older women usually received aromatase

f ET use observed in these data corresponds to that expected. This provides confidence
CPD for epidemiological research.



Coverage - data on all cancer patients



National Health Service Act 2006

CHAPTER 41

NATIONAL HEALTH SERVICE ACT 2006

PART 1

PROMOTION AND PROVISION OF THE HEALTH SERVICE IN ENGLAND

The Secretary of State and the health service in England

- Legal permission to collect information on all cancer patients without consent (NHS Act 2006 Section 251)
- Activity must:
  - Have a medical purpose
  - Be in the public interest or in the interests of improving patient care
  - Be compliant with DPA/GDPR
  - Impracticable to obtain consent and anonymised information cannot be used
- Yearly review with Confidentiality Advisory Group - Health Research Authority

- Data collection embedded in NHS and mandated by contractual requirements

Coverage:

Data on all cancer patients nationally

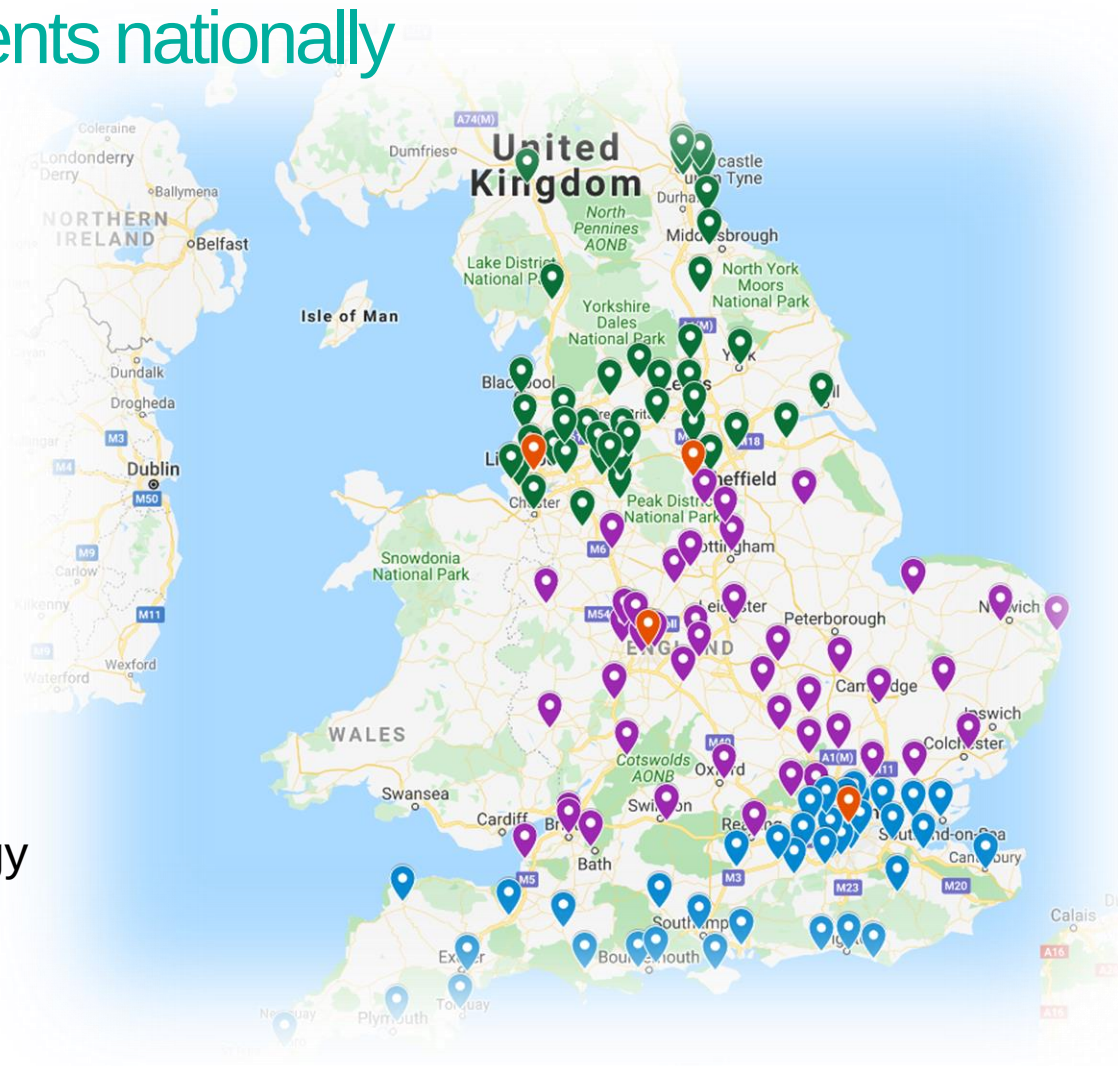
SACT:

Data from **137 NHS trusts** (all centres providing SACT treatment)

Molecular:

Data from

- Regional Molecular Genetics Labs (Somatic and germline)
- Molecular section of Pathology Labs (Somatic)



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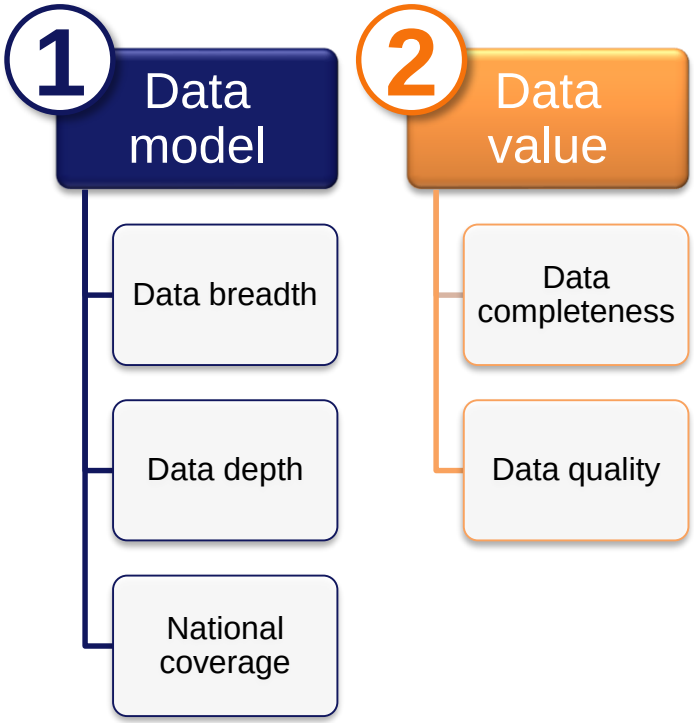
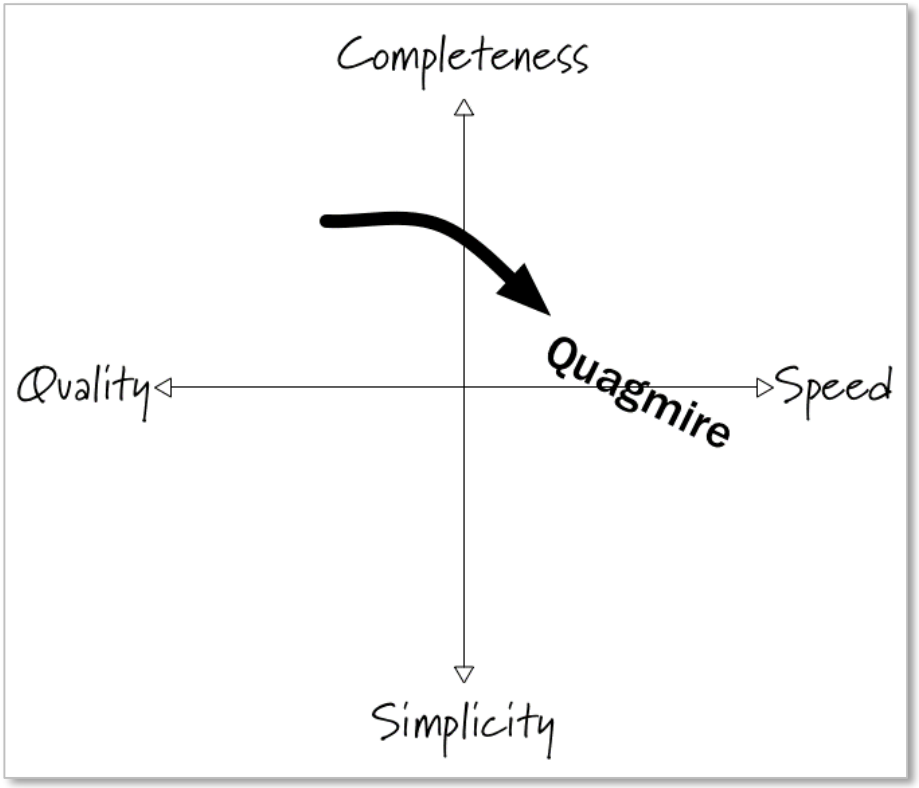


Data completeness ≠ Data quality



Maximising completeness AND quality…

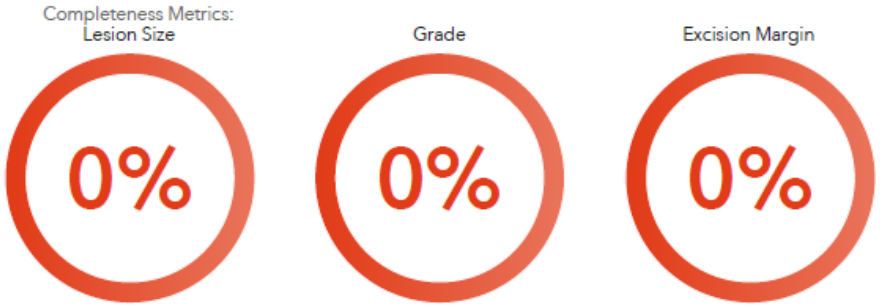
Ensuring high data quality:
Working to support data providers

Ensuring high data quality:
Reporting back to data providers

Pathology Indicators:

Engagement Indicator:
Pathology sent in a suitable format?

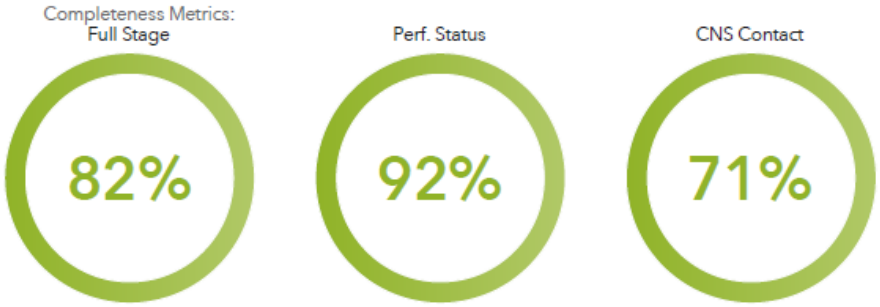
Non Compliant



COSD Indicators:

Engagement Indicator:
COSD sent in the correct format and version?

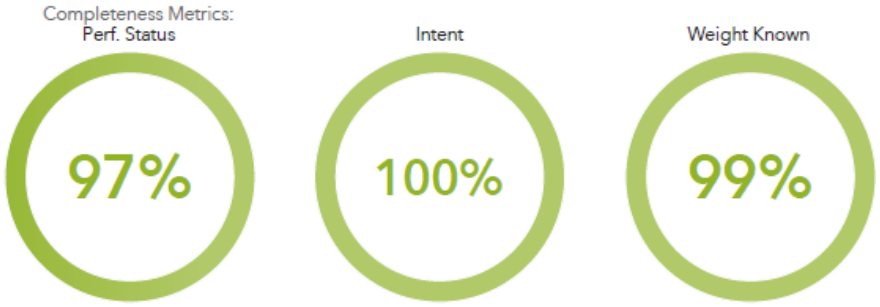
Compliant



SACT Indicators:

Engagement Indicator:
SACT sent in on time?

Compliant

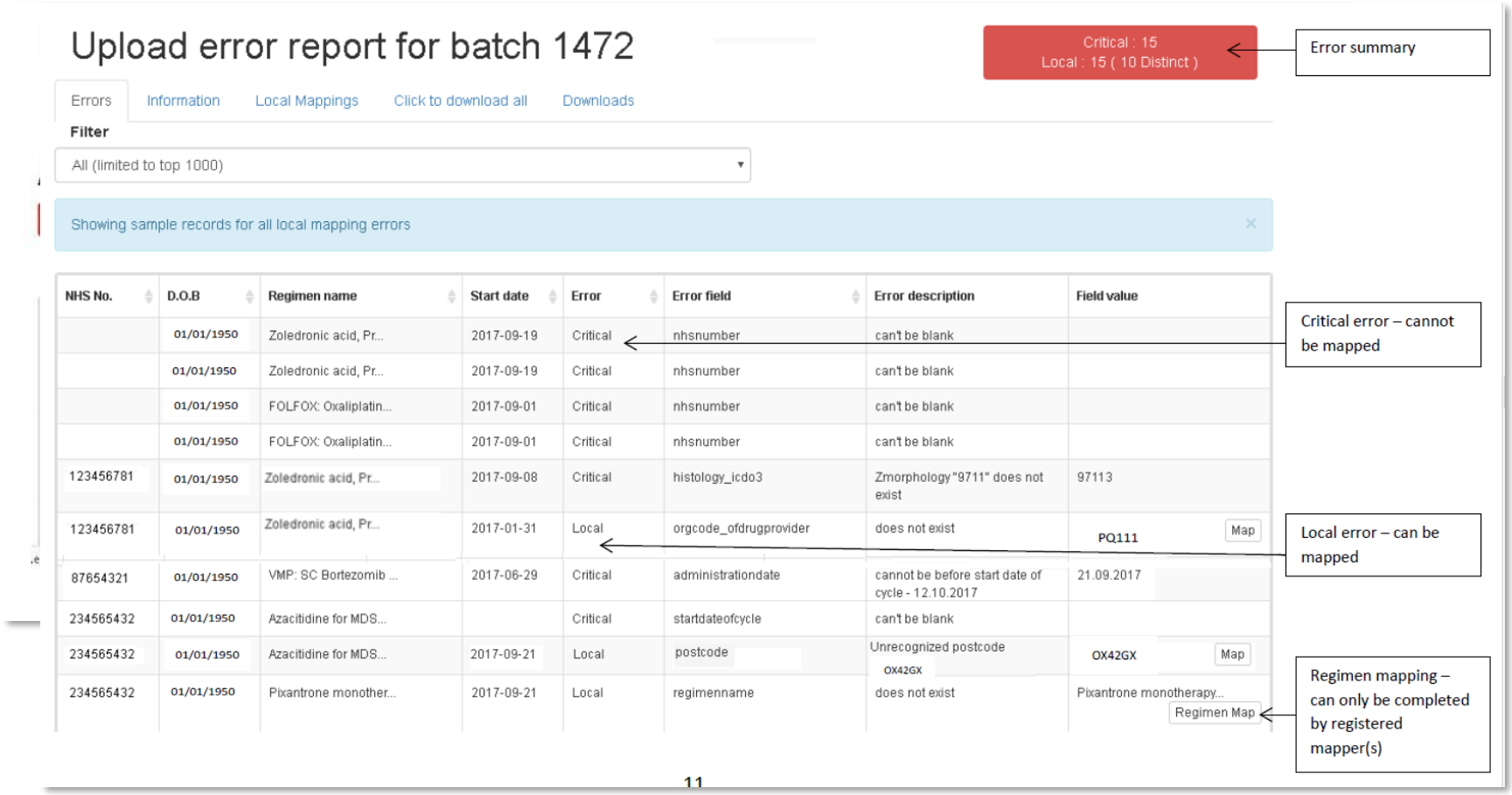


RTDS Indicators:

Engagement Indicator:
RTDS sent in a full year of data?

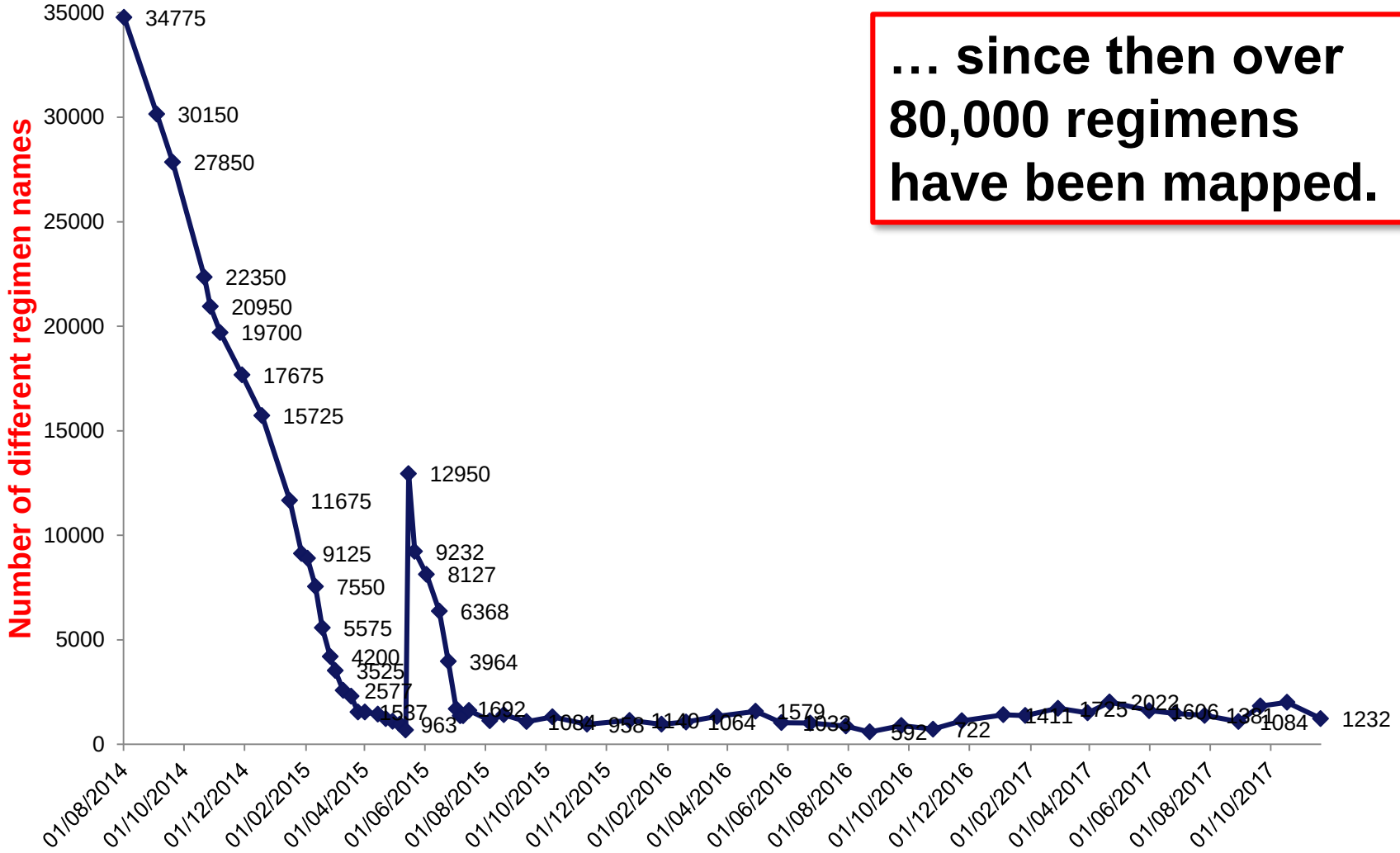
Compliant

Ensuring high data quality:
Validating data on submission



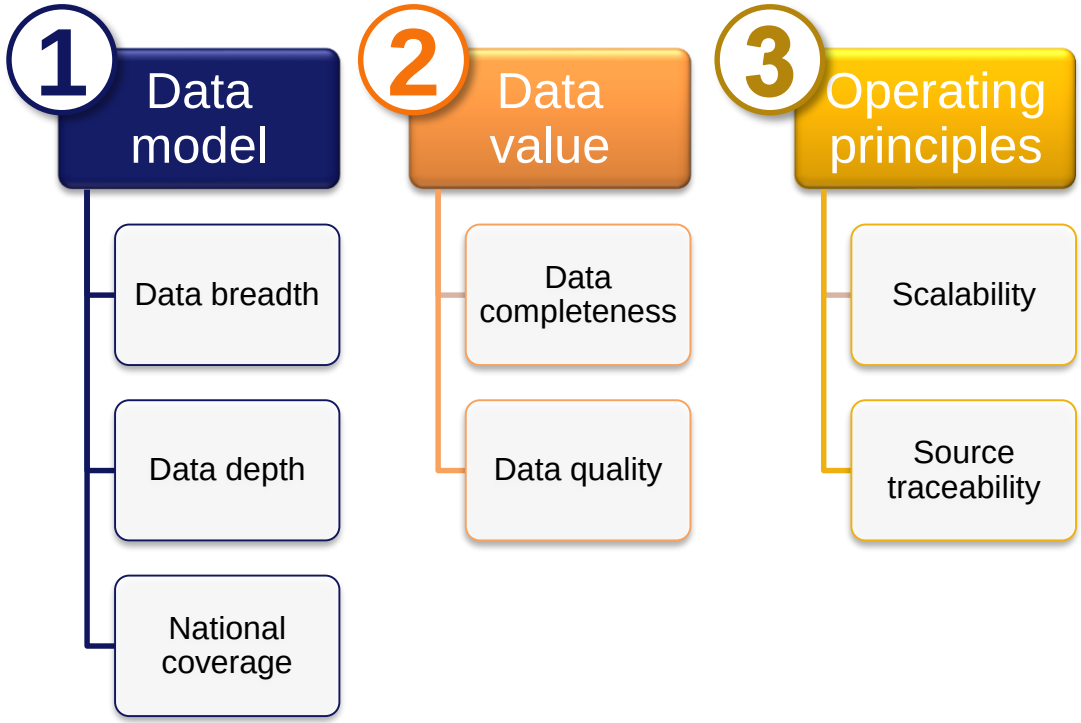
Ensuring high data quality:

Mapping regimens since August 2014



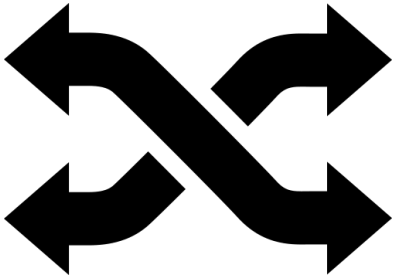
… since then over 80,000 regimens have been mapped.

Principles for cancer data collection:



Scalability and generalisability:

All patients



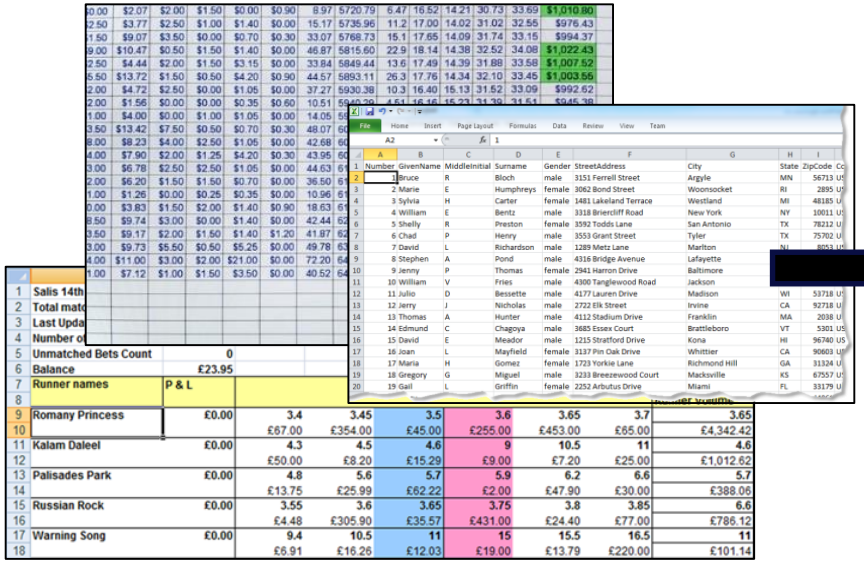
All data providers

Approaches:

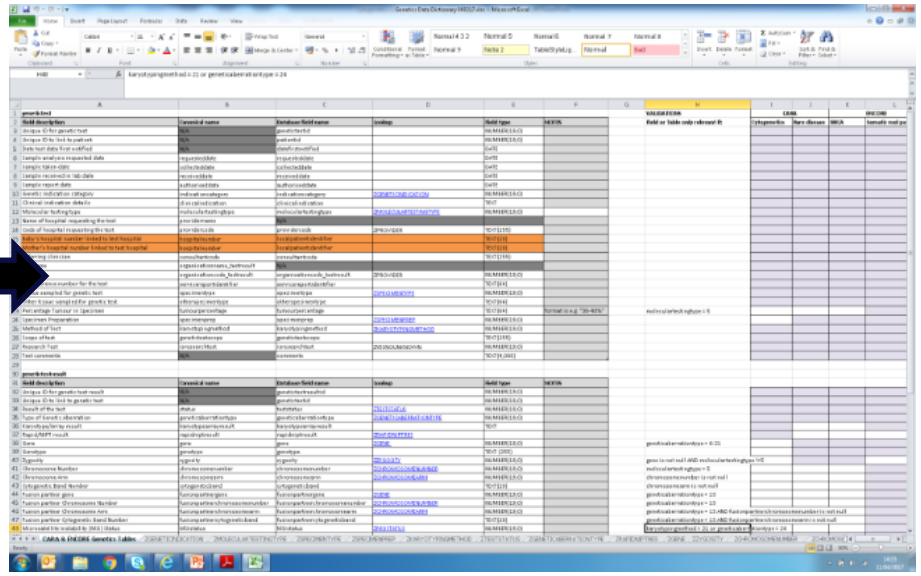
- Schema specification
- Supplementary data collection

- Minimal submission burden
- **Adaptation to local systems**

Adapting to local systems:

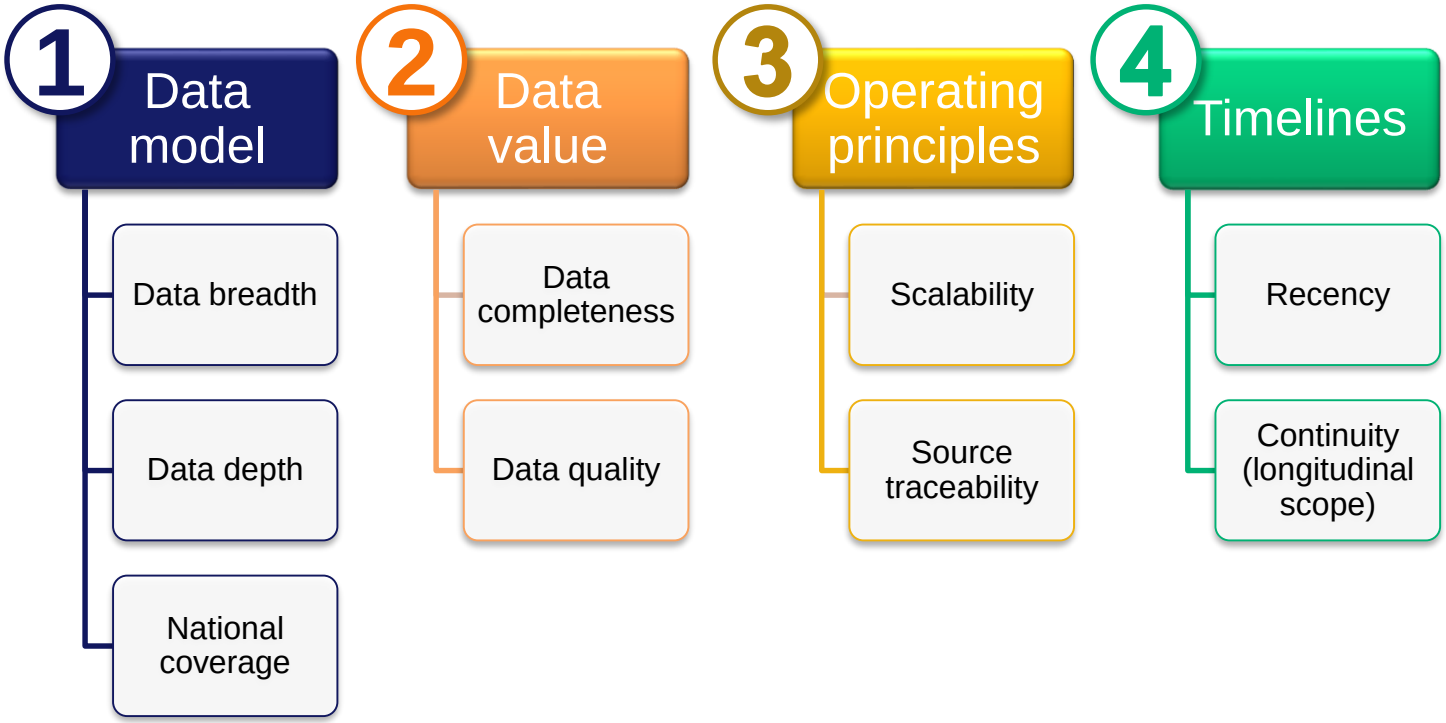


1. Input data:
Electronic data from labs
Each data extract in a unique format…

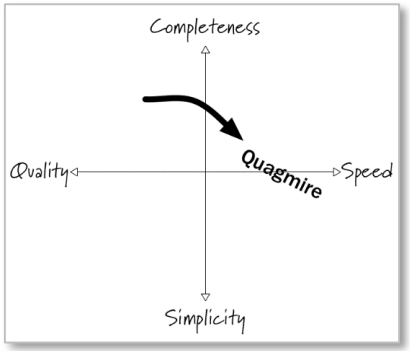


2. Transformation mapping:
Transform data into standard schema for cancer registration system (ENCORE)

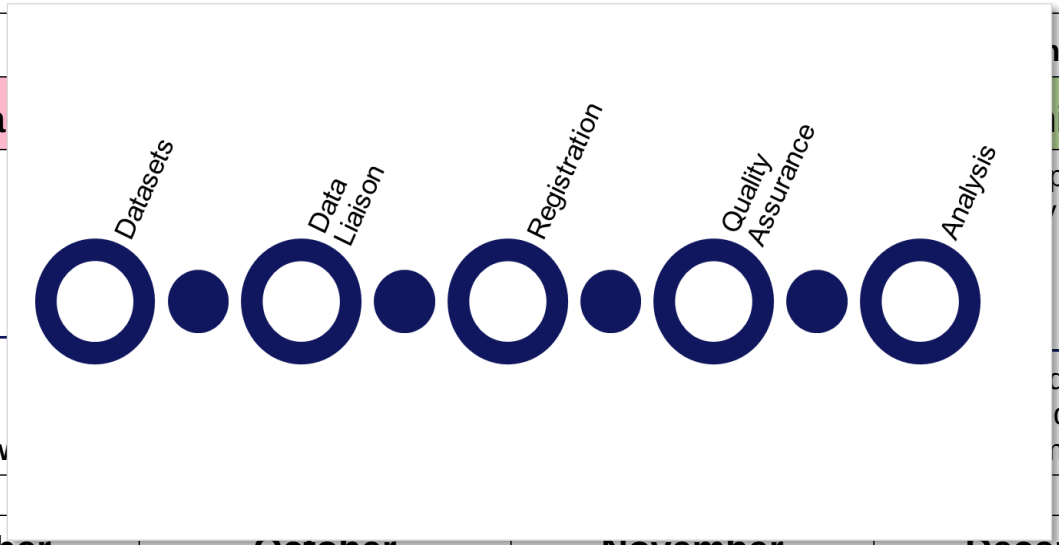
Principles for cancer data collection:



Recency:



SACT monthly data submission

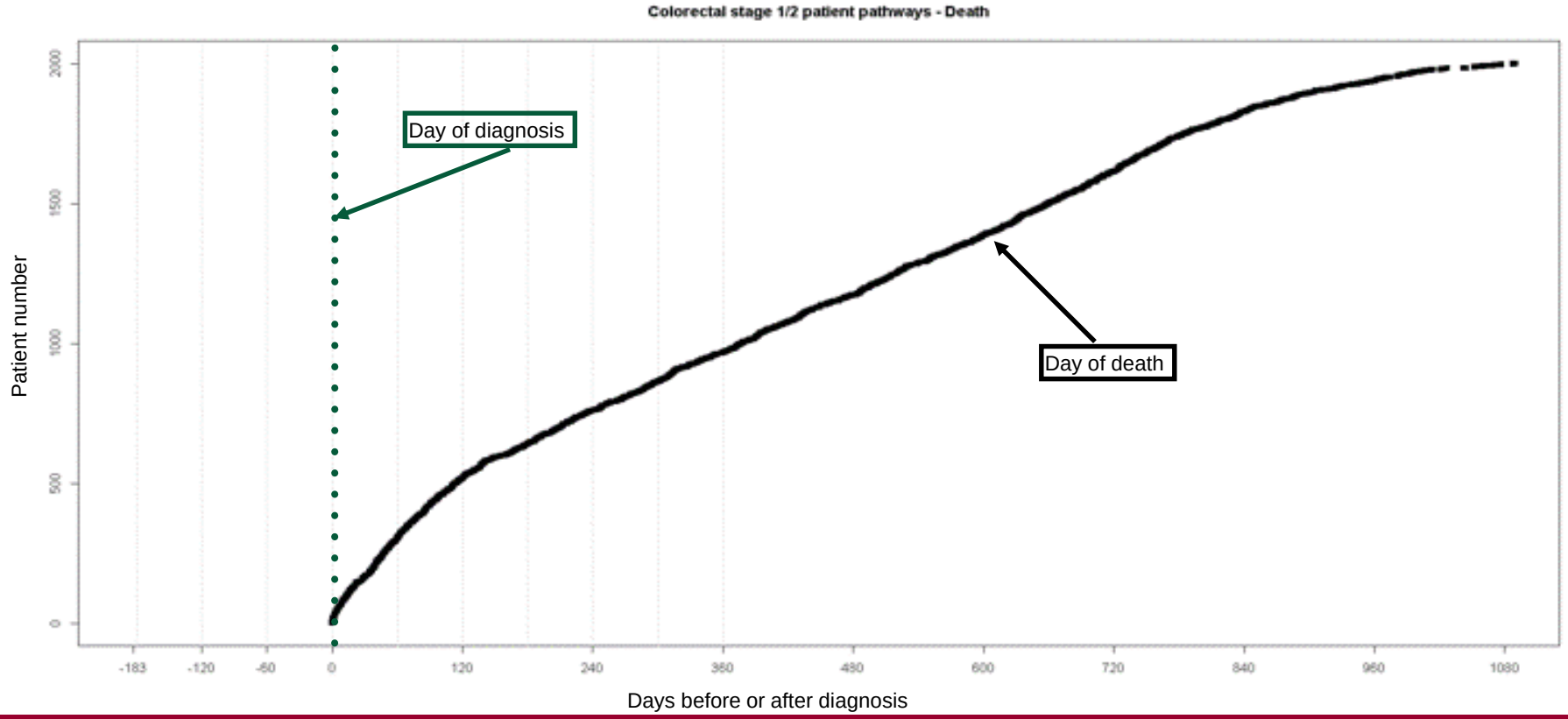


Example:

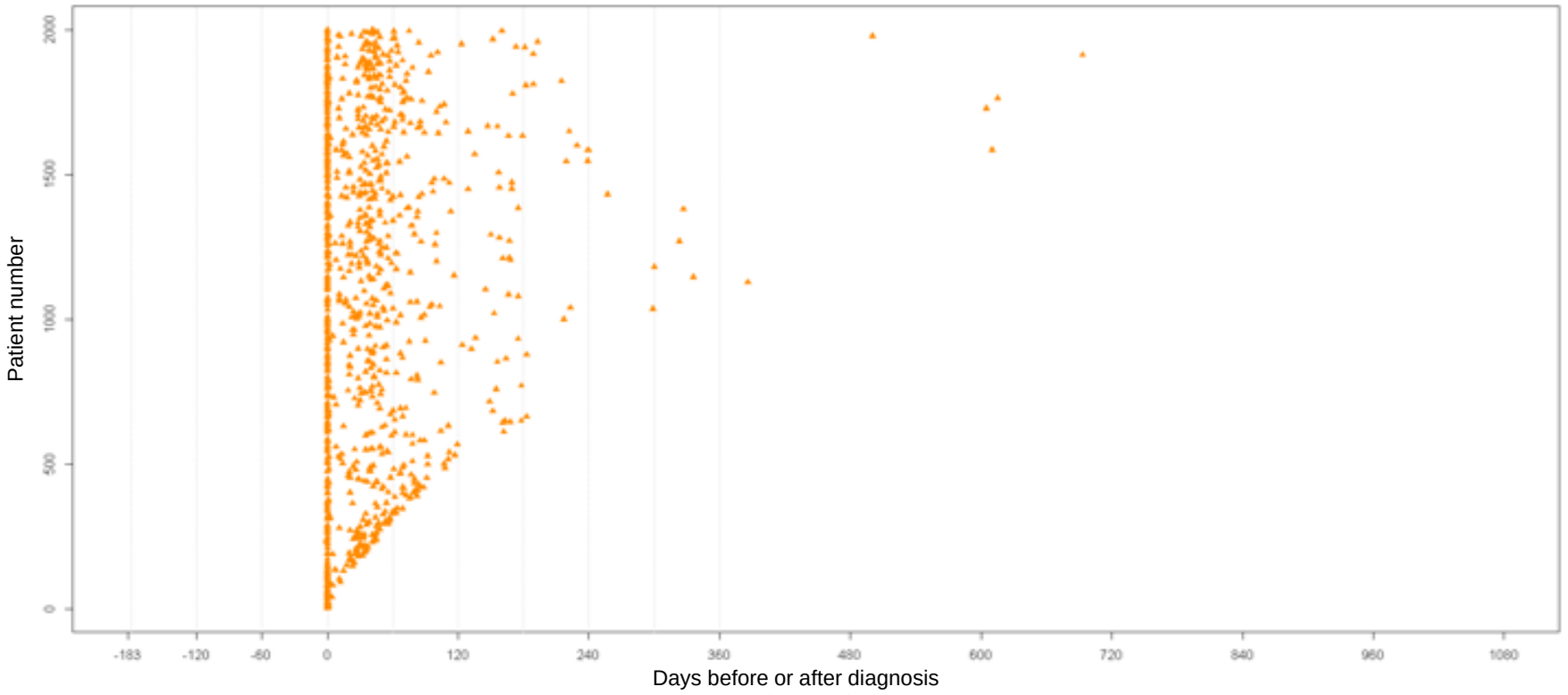
September	October	November	December
Treatment activity	DQ & DC checks	**Upload**	Submission

Continuity:

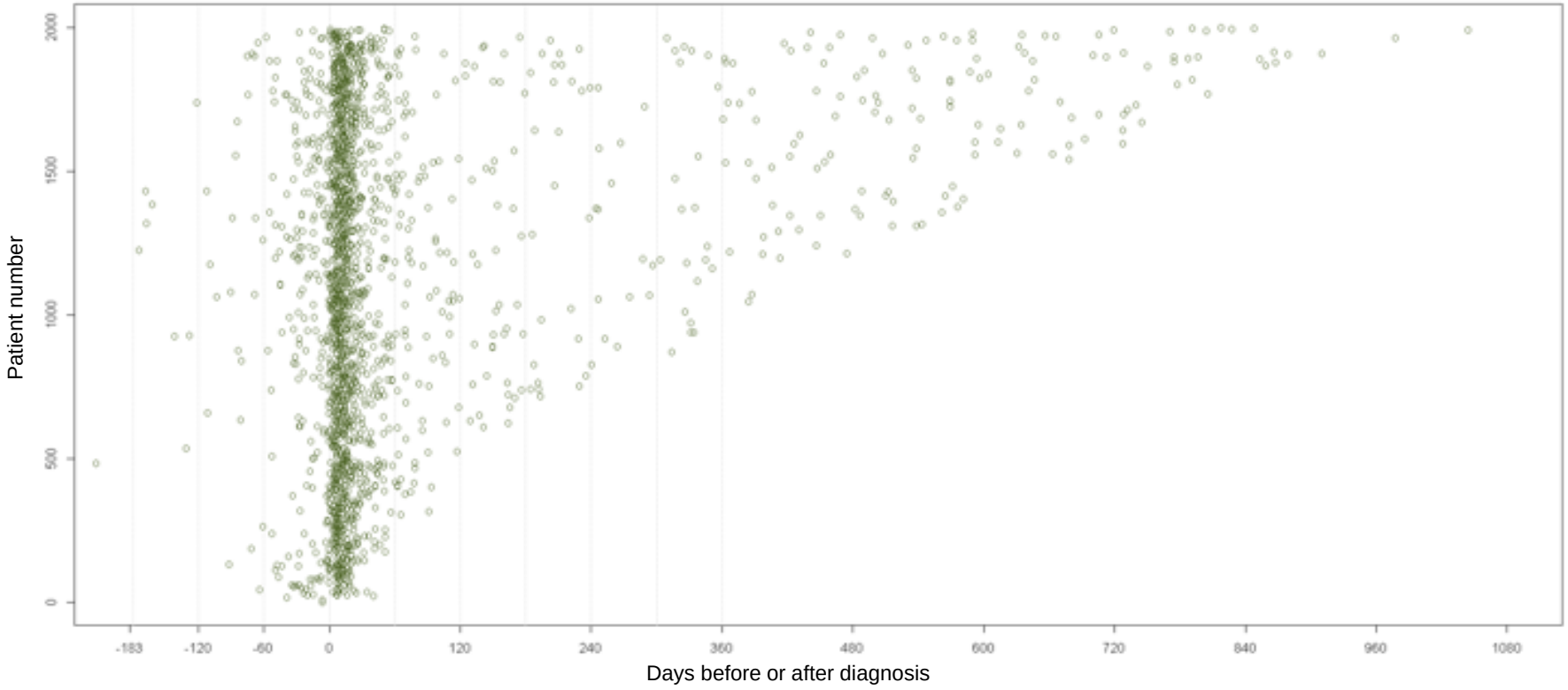
Ongoing monthly data collection collecting the complete patient pathway:



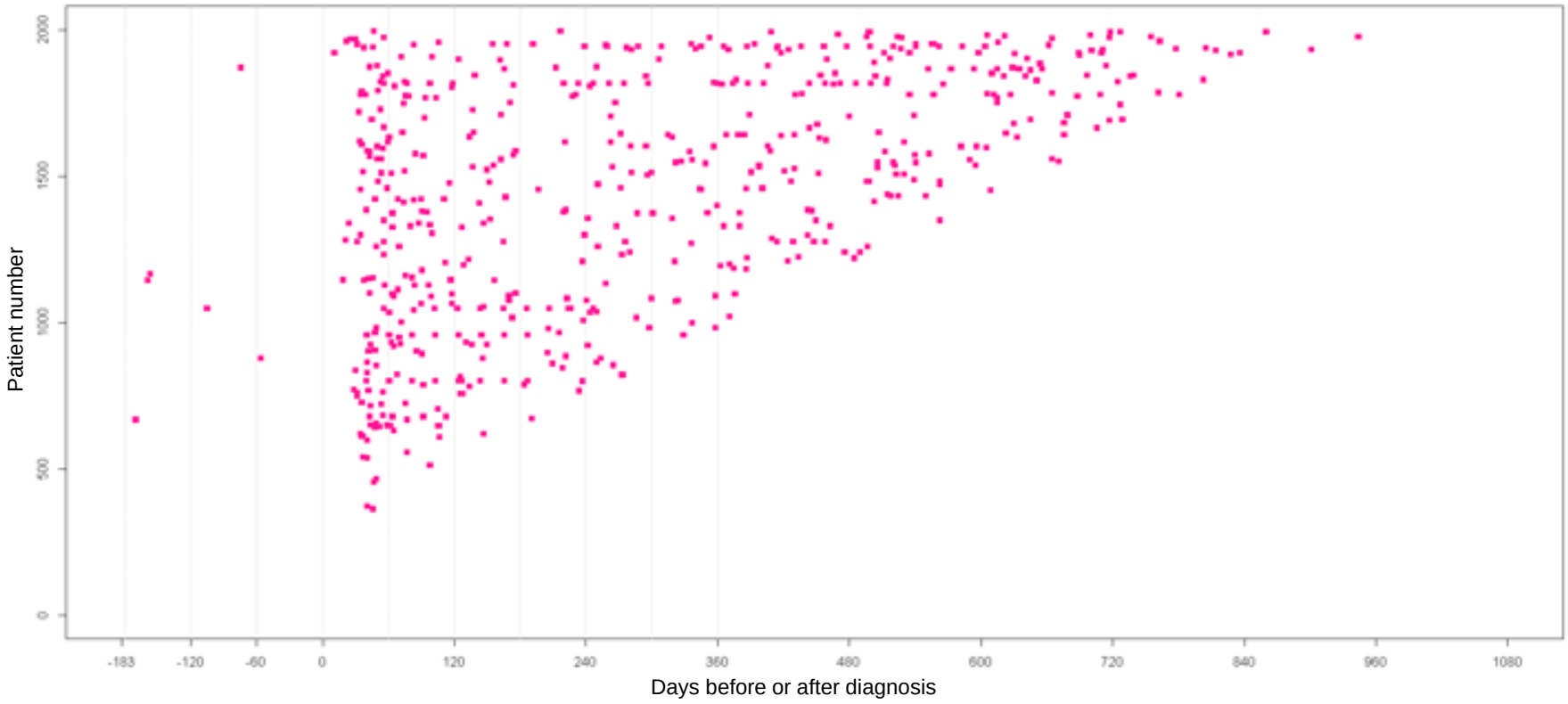
Patients have surgery



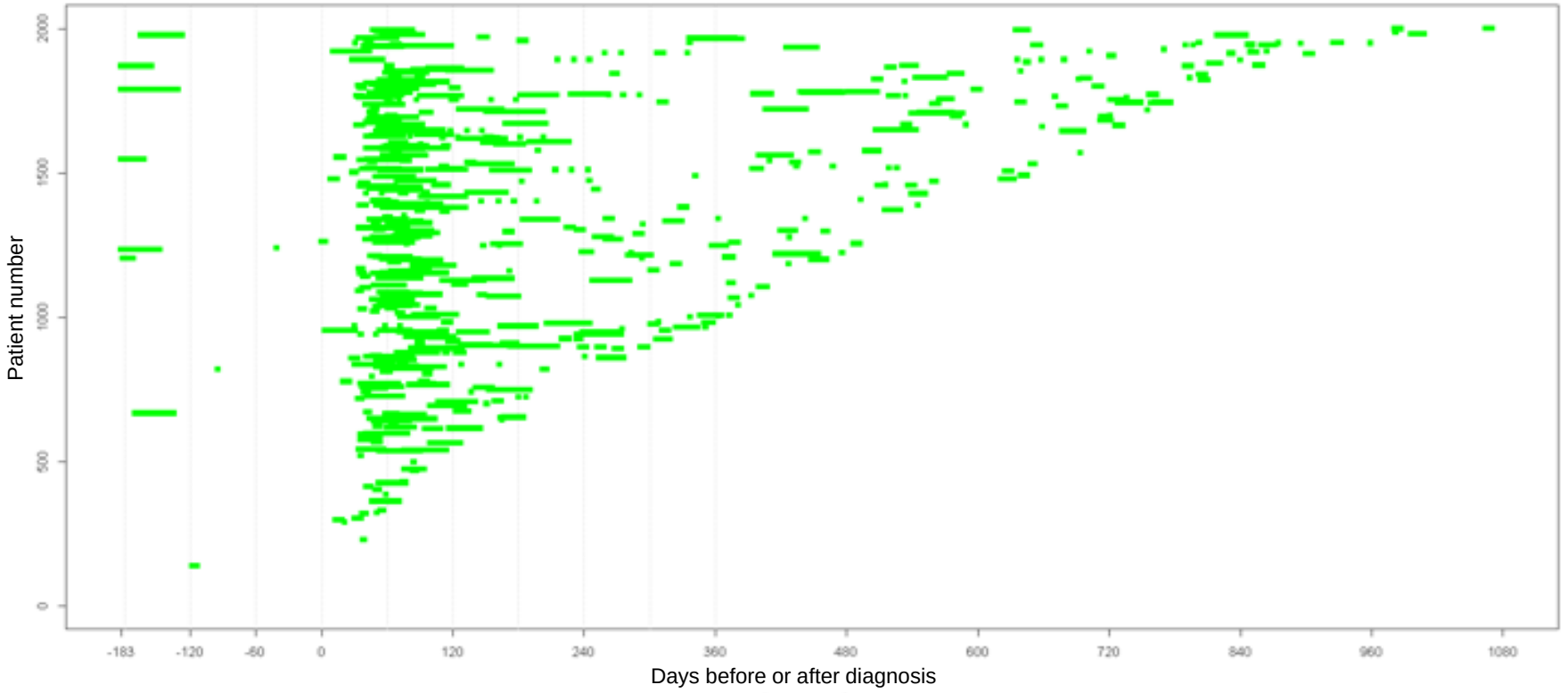
Patients are discussed at a multi-disciplinary team meeting



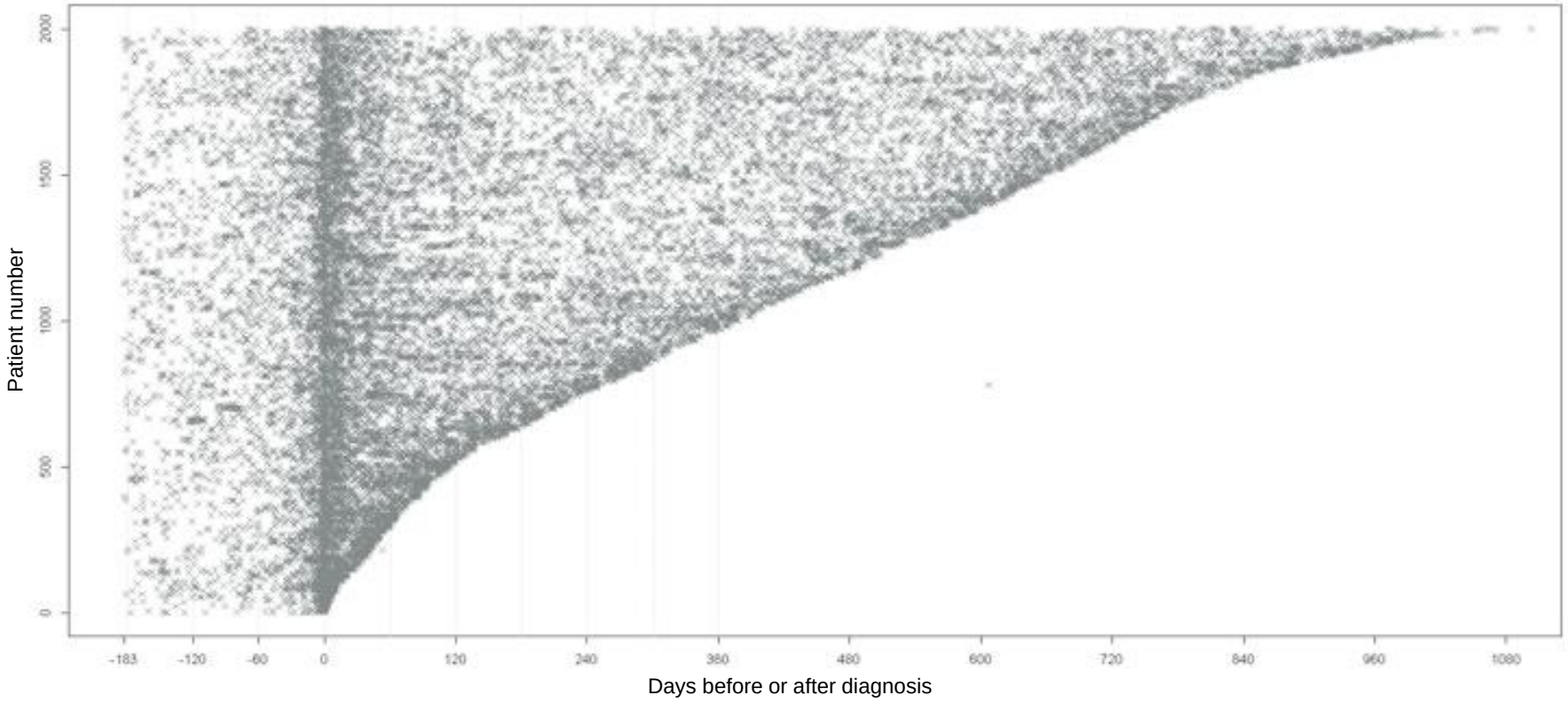
Patients have SACT



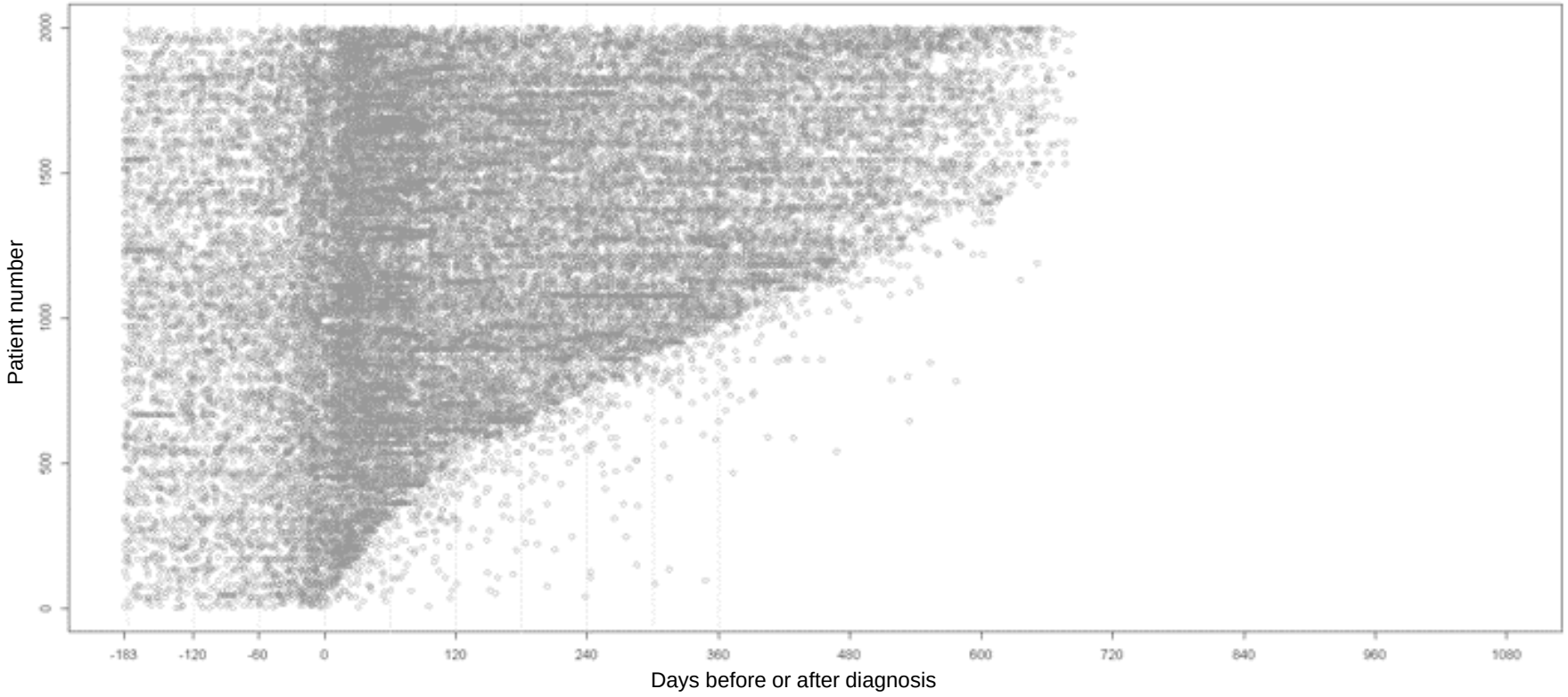
Patients have radiotherapy



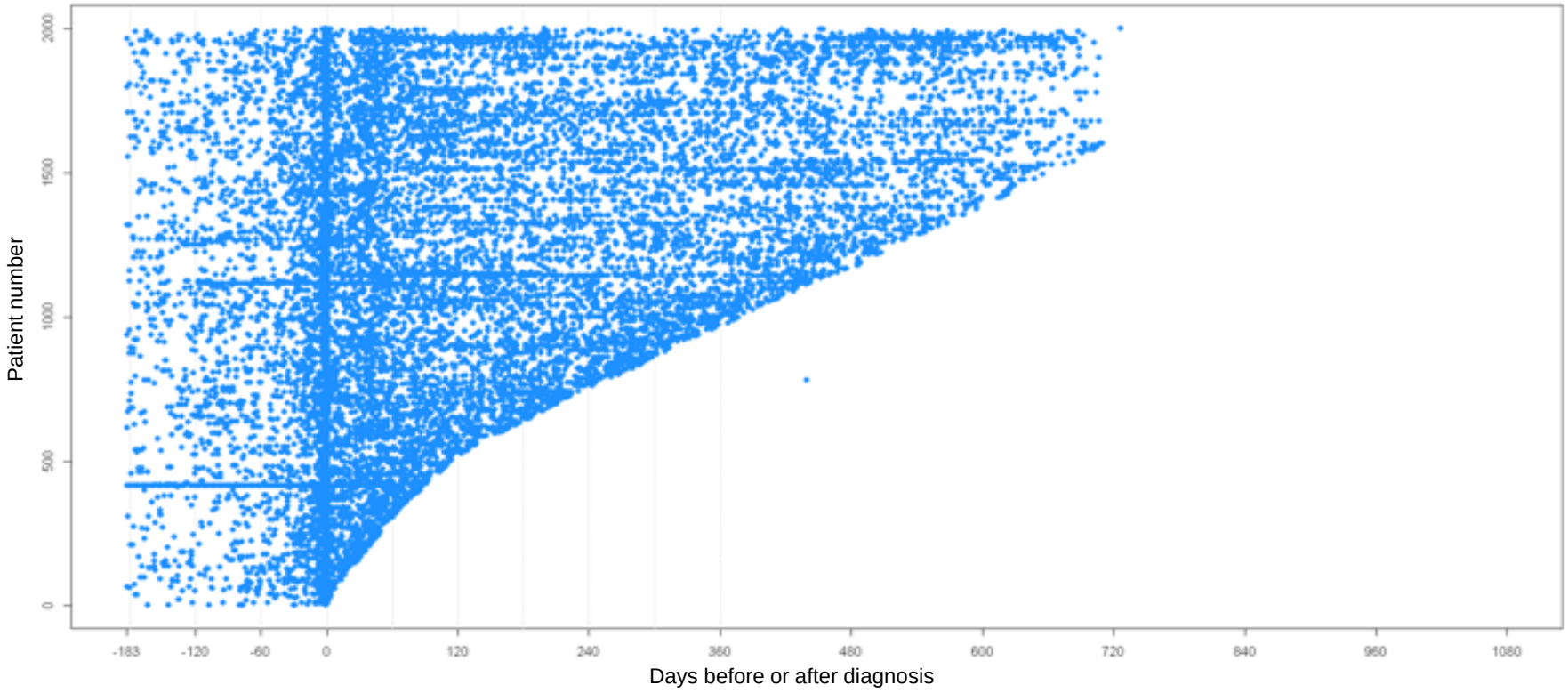
Patients have imaging investigations



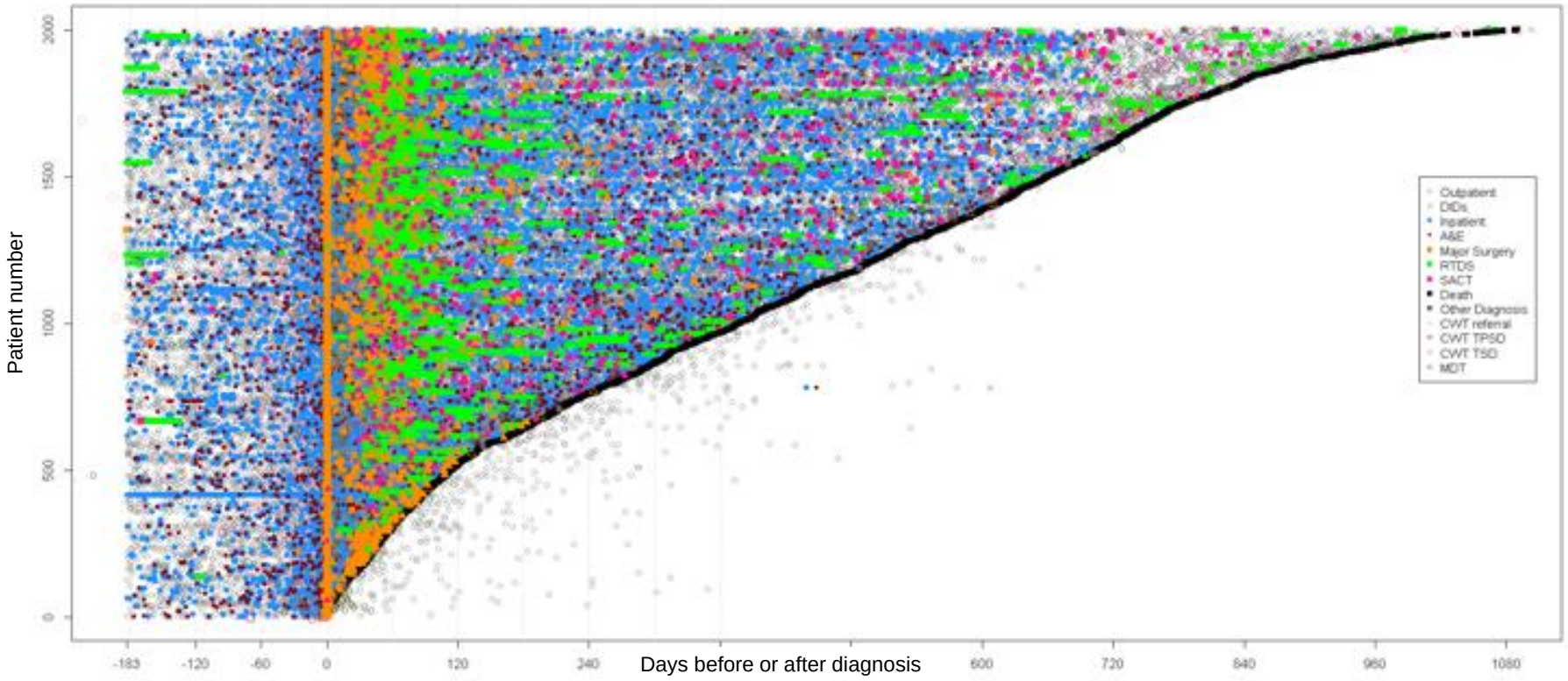
Patients get given out-patient appointments



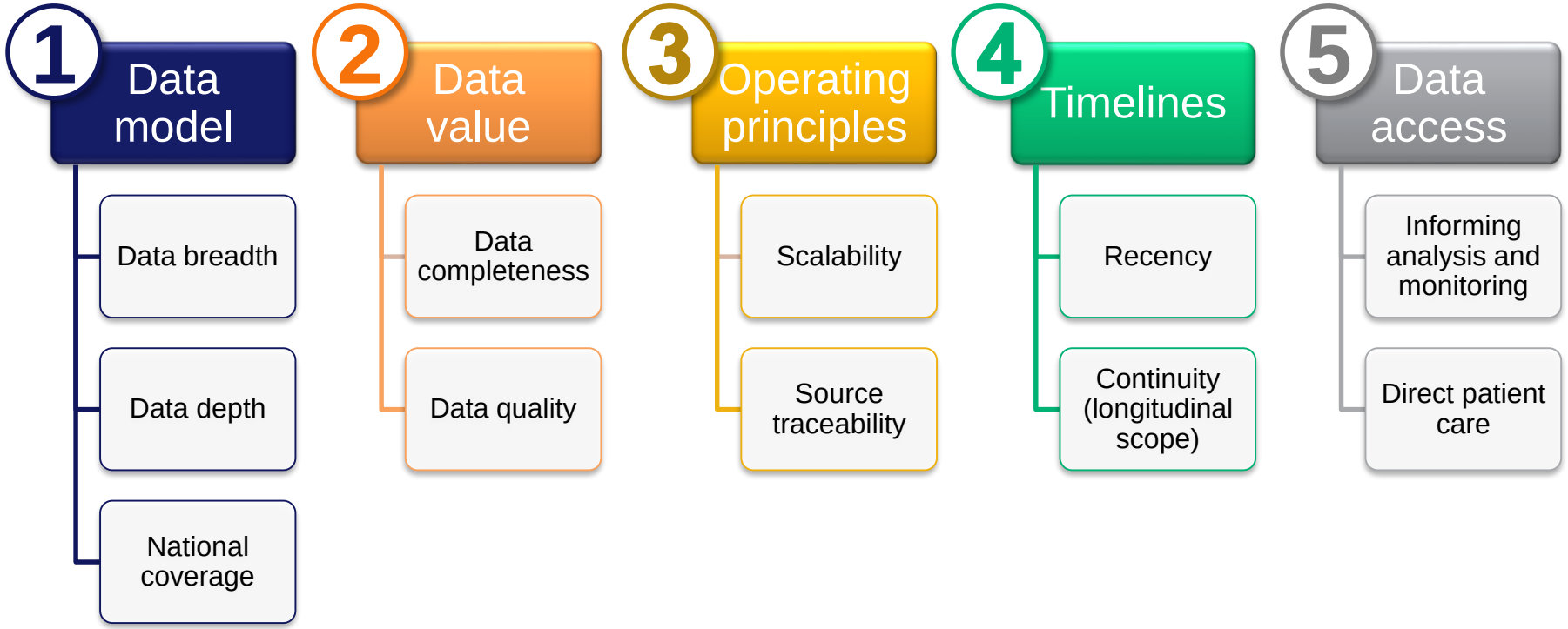
Patients come to their out-patient appointments



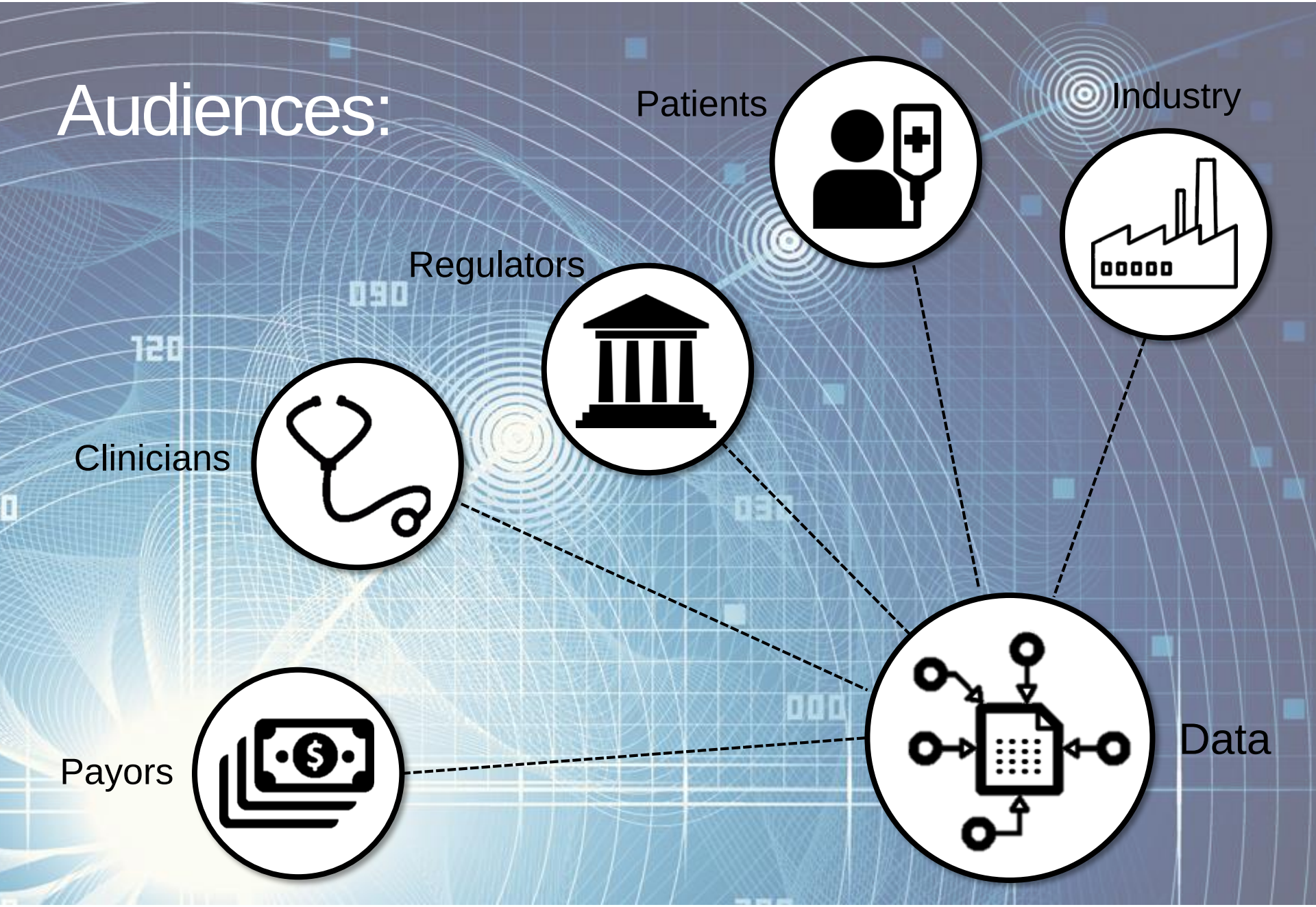
Putting it all together ….



Principles for cancer data collection:

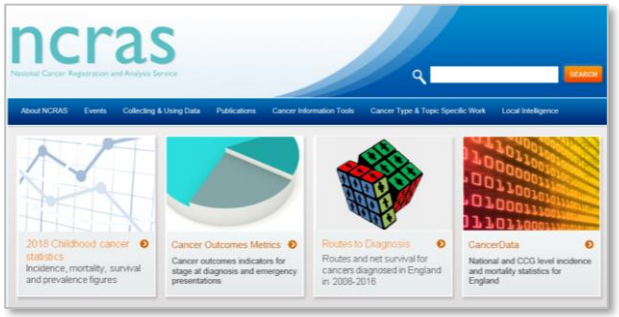


Audiences:



Our responsibilities as a data custodian are two-fold

Routes to access data:



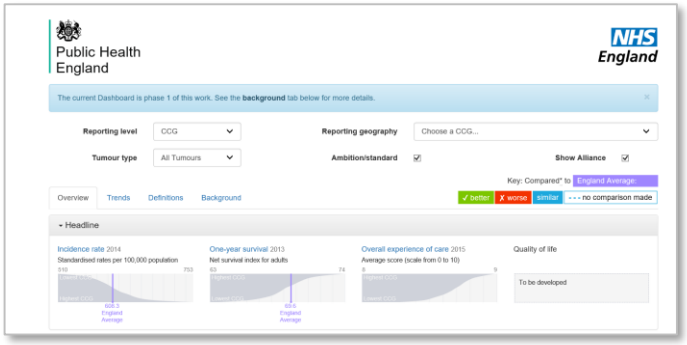
NCRAS homepage

- Overview of NCRAS datasets and ongoing work
- Links to reports and all sources listed below

Reports to data providers (CancerStats2)

- Dynamic reporting portal for users within the NHS
- Includes reports on many NCRAS datasets: COSD, Radiotherapy (RTDS), SACT, Incidence/Mortality, National Audits, Cancer Alliance Reporting (CADEAS)

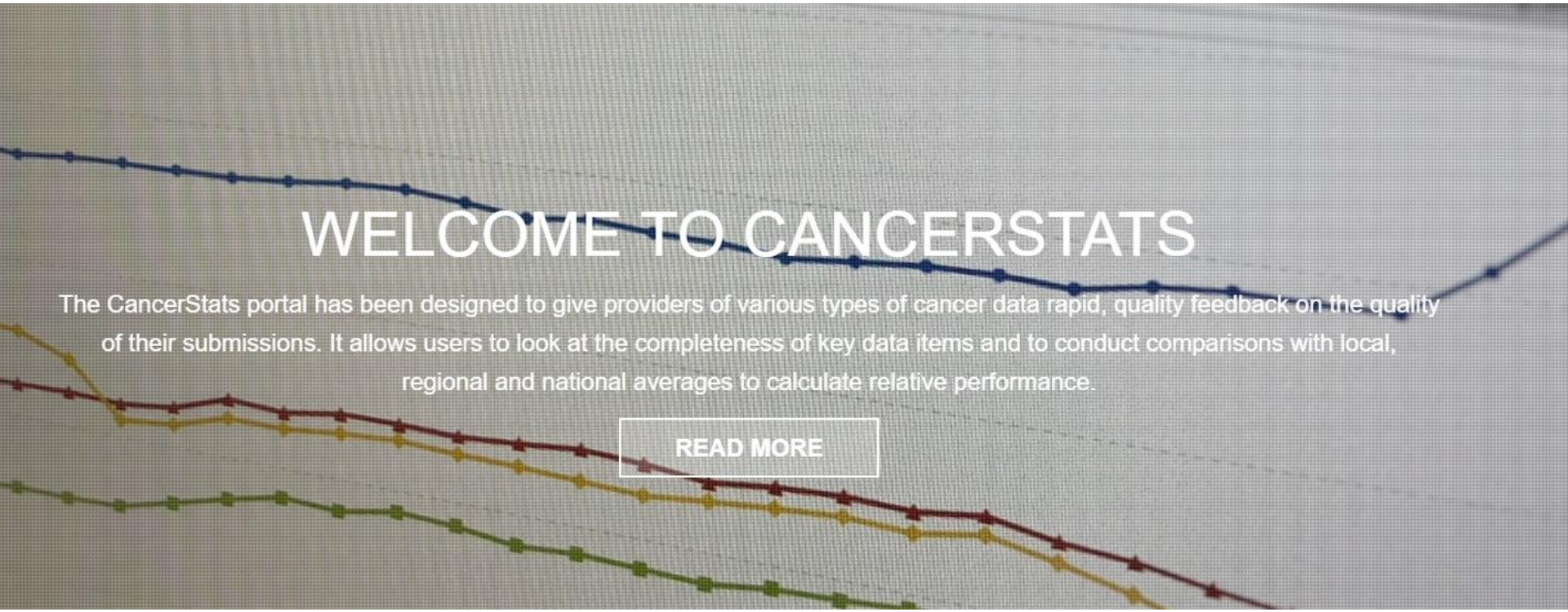
CancerStats



Public reports (CancerData)

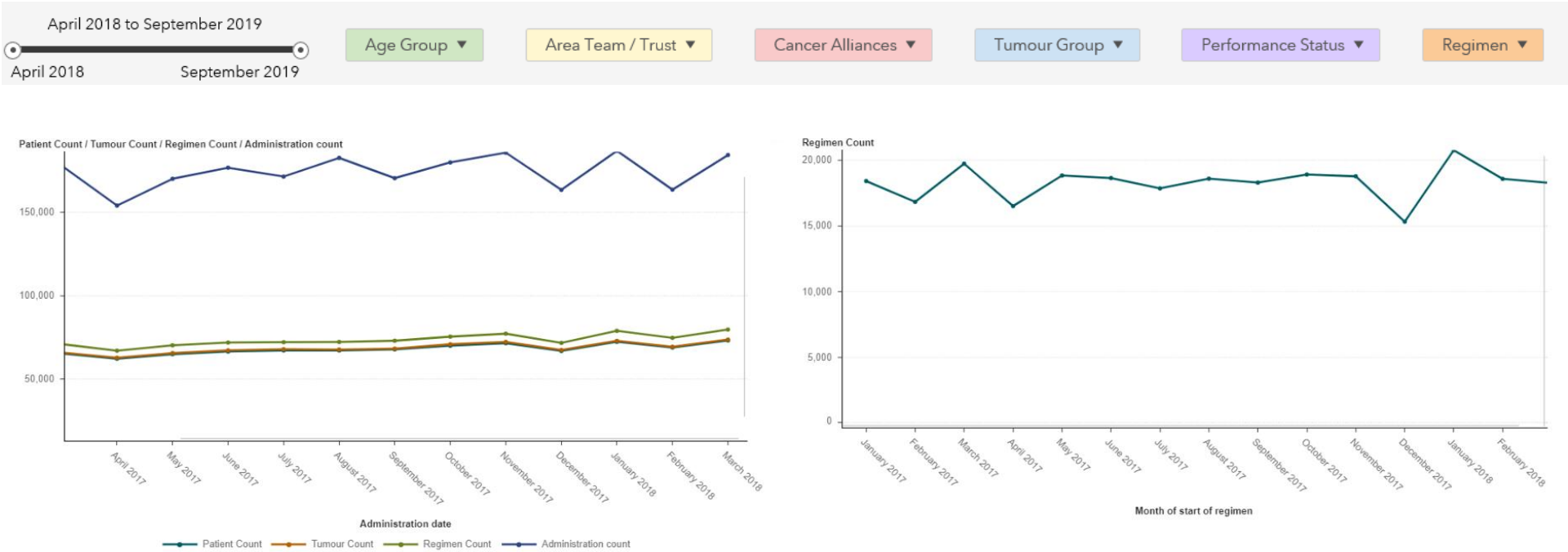
- Open access tool reporting routine incidence and mortality data, as well as hosting the National Cancer Taskforce Dashboard which includes a number of metrics
- Aggregate data released under Open Government Licence

Trust reports



Trust reports:
SACT treatment activity

Patient, tumour regimen and administration count by month



New regimens by month

Trust reports:

SACT treatment activity

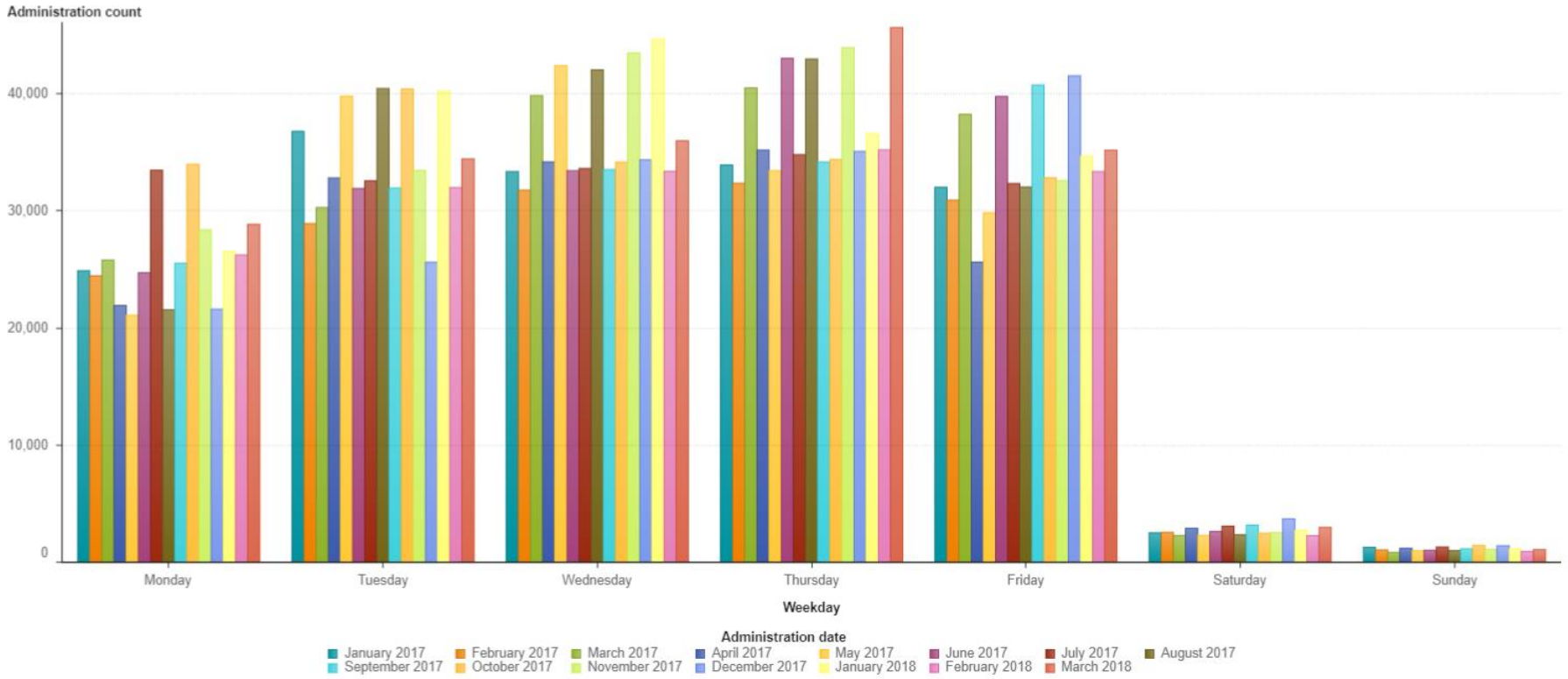
Treatment activity by day of the week

April 2018 to September 2019

April 2018 September 2019

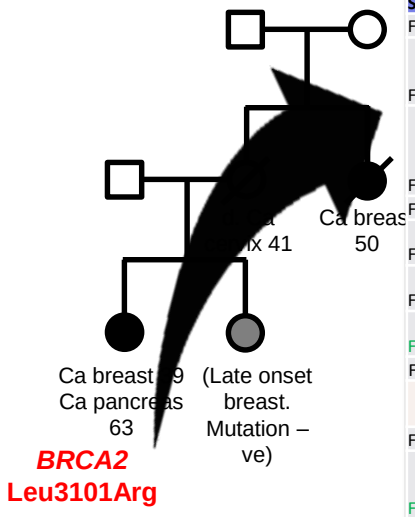
Age Group ▼ | Area Team / Trust ▼ | Cancer Alliances ▼ | Tumour Group ▼ | Performance Status ▼ | Regimen ▼

Number of treatment administrations (n) per day split by month of treatment activity.



Direct patient care:

Supporting variant interpretation by genomics labs



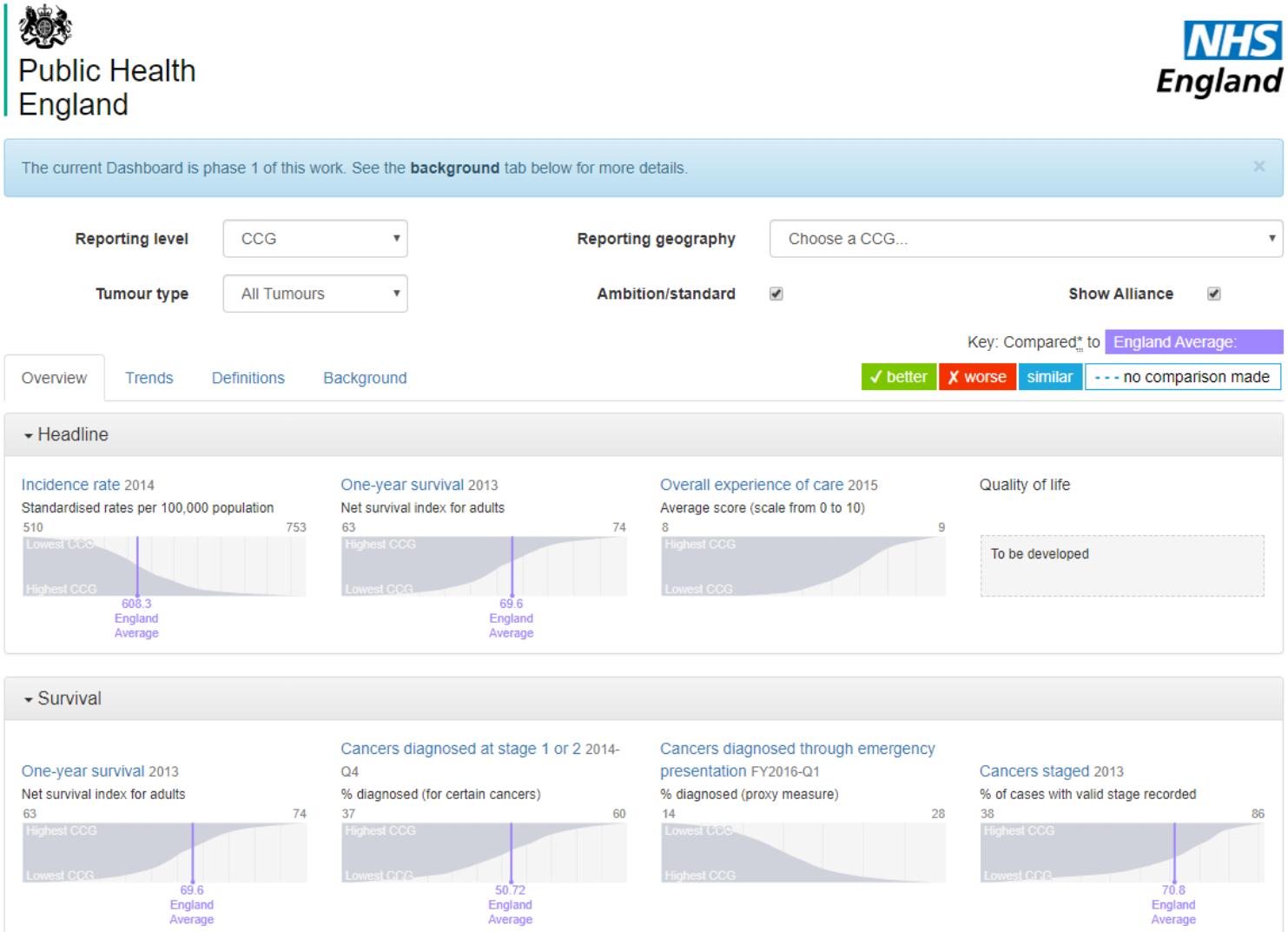
National collation of evidence

Identifying variant in NCRAS data

Sex	Ethnicity	Age at Dx	Tumour site	Tumour details	Family history / other notes	Lab	Molecular Test Type	Test Scope	Year of BRCA test
F	White British	36	breast, R	G3 IDC, TNBC	Grandmother Hx Ca breast in 40s	1	Diagnostic	Full Screen	2017
		31	humerus, R	G2 chondrosarcoma					
		34	breast, R	G3 IDC, ER+ PR+					
F	White British	34	breast, R	G2 LC, ER+ PR+		1	Diagnostic	Full Screen	2016
				SCC					
		26	cervix	G3 adeno					
		41	breast, L	G3 adeno, MMR+, MSS,					
F	White British	47	caecum	KRAS-wt		2	Diagnostic	Full Screen	2012
F	White British	37	breast	G2 IDC.		2	Diagnostic	Full Screen	2016
F	White British	45	breast, R	G3 IDC. ER- HER2 borderline IHC		2	Diagnostic	Full Screen	2014
F	White British	67	tubo-ovarium or primary peritoneal origin	high grade serous cystadenocarcinoma	FH of breast and ovarian ca	2	Diagnostic	Full Screen	2012
F	White British	74	oesophagus	SCC.	Same maiden name as case above.	2	Family Studies	Targeted test	2013
F	White British	33	breast, R	G2 IDC, ER+ PR+ HER2-		2	Diagnostic	Full Screen	2015
				(No match to NCRAS)		2	Family Studies	Targeted test	2012
F	Not stated	40	breast, R	G3 IDC		3	Diagnostic	Full screen	2014
	Any Other White	42	breast, L	DCIS					
F	Background	48	breast, R	LCIS		3	Predictive	Targeted test	2014
F	White British	55	breast, L	G3 IDC, TNBC		3	Diagnostic	Full screen	2016
		43	breast, R	G2 IDC					
F	White British	47	skin	BCC		3	Predictive	Targeted test	2016
F	White British	55	ovary, bilateral	high grade serous adenocarcinoma	FH ovarian/breast Ca. Diagnosed following risk reduction Lap BSO.	3	Diagnostic	Full screen	2016
F	White British	75	female genital tract, NOS	high grade serous cystadenocarcinoma	surname in common with case above	3	Predictive	Targeted test	2016
F	White British	55	breast, R	G3 IDC. ER+, HER2-	underwent risk reduction surgery. TLH BSO.	3	Predictive	Targeted test	2016
		51	probably peritoneal; possibly left fallopian tube or ovary	high-grade serous carcinoma					
F	White British	51	endometrium	G1 adenocarcinoma		4	Diagnostic	Full Screen	2015
		60	breast, L	G3 IDC					
F	White British	68	ovary	high grade serous carcinoma		5	Diagnostic	Full screen	2013
F	Unknown	71	breast, L	G3 IDC.		6	Diagnostic	Full screen	2009

Public reports

Incidence and survival statistics



Routes to access data:

Ad hoc data requests (NCRAS enquiries)

- Responds to routine enquiries for aggregate data requiring <0.5day analytical work
- Data release under Open Government Licence

Direct data access (Office for Data Release)

- Responds to requests to access identifiable or de-personalised data PHE data for secondary purposes - which could not be openly released
- Data can be:
  - individual-level
  - aggregate-level
- Data releases reported through the Data Release Register

Office for Data Release:
Data Release Register

Content:

- Applicant's organisation
- Applicant's organisation type
- Technical summary
- **Lay summary overview**
- **Why is this project being conducted?**
- **How will the data be used?**
- **Anticipated public health benefit(s) and/or impact of conducting the project**
- Funders and collaborators
- Data source
- Type of data
- **Legal basis for the release of personally identifiable data**
- National data opt-out programme applied
- Date of release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Data Release Register April 2017 - July 2019

Version 2.2

Office for Data Release:

The PHE Office for Data Release (ODR) is responsible for providing a common governance framework for responding to requests to access PHE data for secondary purposes, including service improvement, surveillance and ethically approved research.

The ODR approval process ensures that Public Health England can continue to support our stakeholders to fairly and lawfully access personally identifiable or de-personalised data collected and managed by Public Health England to:

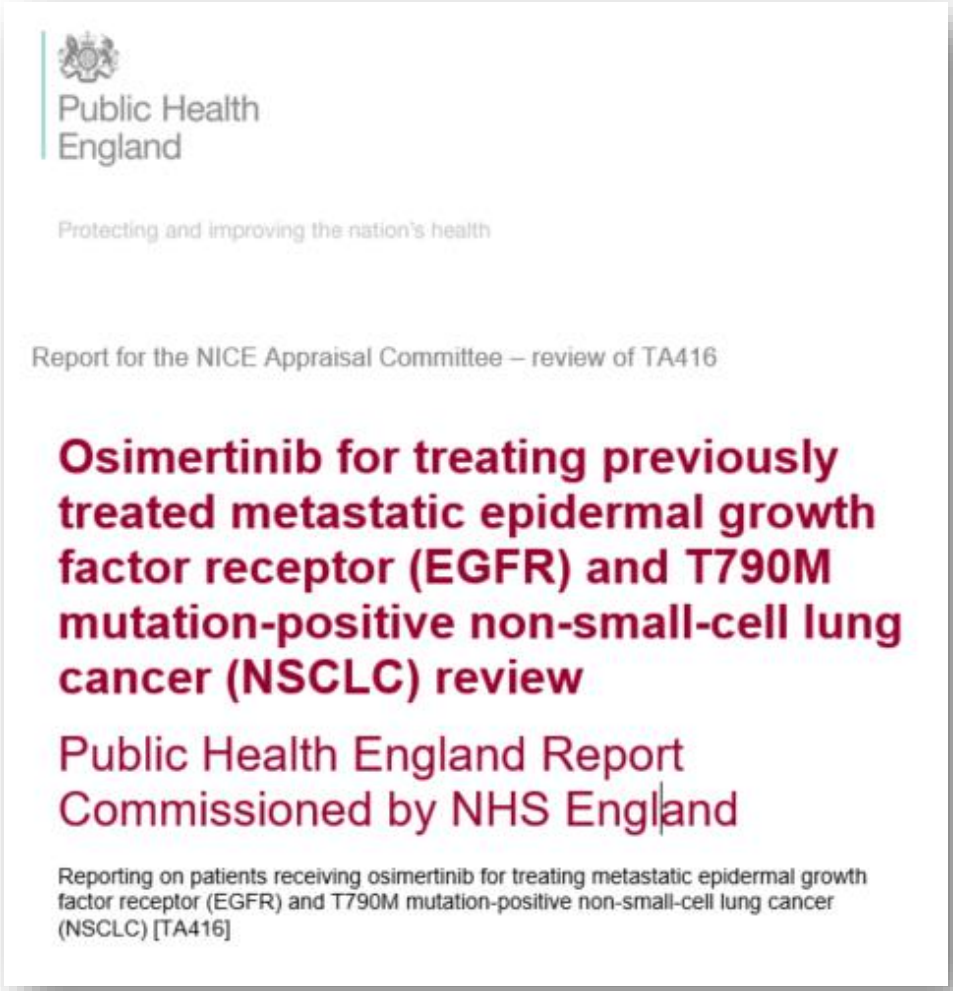
Routes to access data:

Analytical partnerships

- Partner analysts embedded in NCRAS to conduct projects which align with PHE's overall objectives

Reports to inform HTA appraisal:

The Cancer Drugs Fund
Reporting to NICE


Public Health England

Protecting and improving the nation's health

Report for the NICE Appraisal Committee – review of TA416

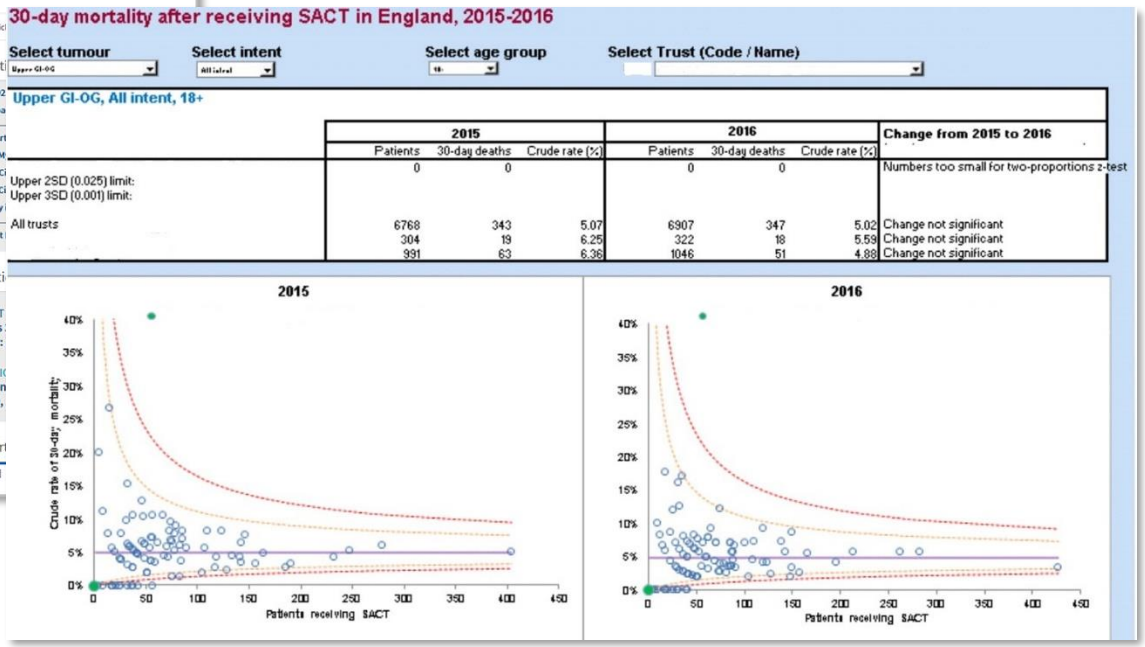
Osimertinib for treating previously treated metastatic epidermal growth factor receptor (EGFR) and T790M mutation-positive non-small-cell lung cancer (NSCLC) review

Public Health England Report
Commissioned by NHS England

Reporting on patients receiving osimertinib for treating metastatic epidermal growth factor receptor (EGFR) and T790M mutation-positive non-small-cell lung cancer (NSCLC) [TA416]

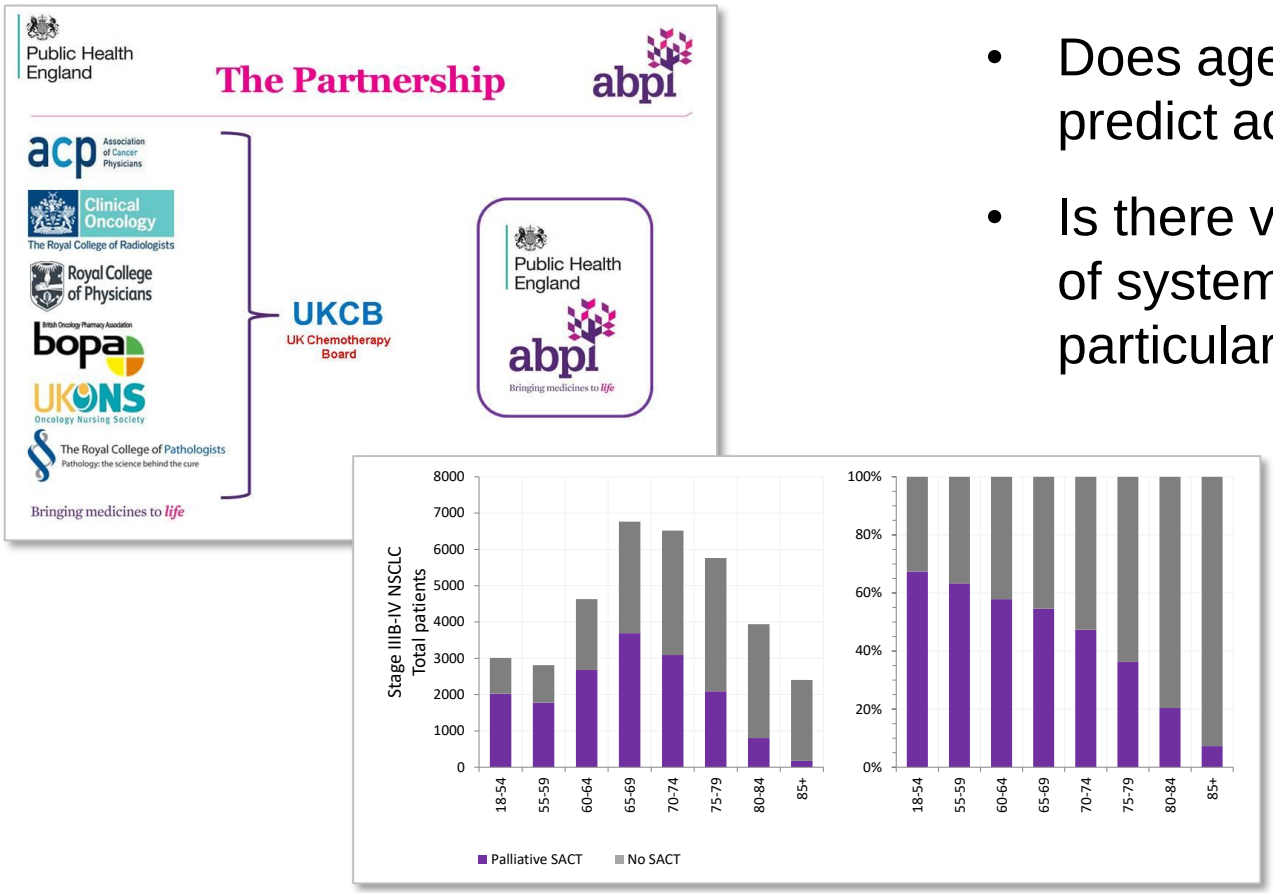
Analysis outputs

30 day mortality post SACT



Analysis outputs

Age is not a barrier to chemotherapy



- Does age independently predict access to SACT?
- Is there variable prescribing of systemic therapy particularly to the elderly?

What I will discuss:

1

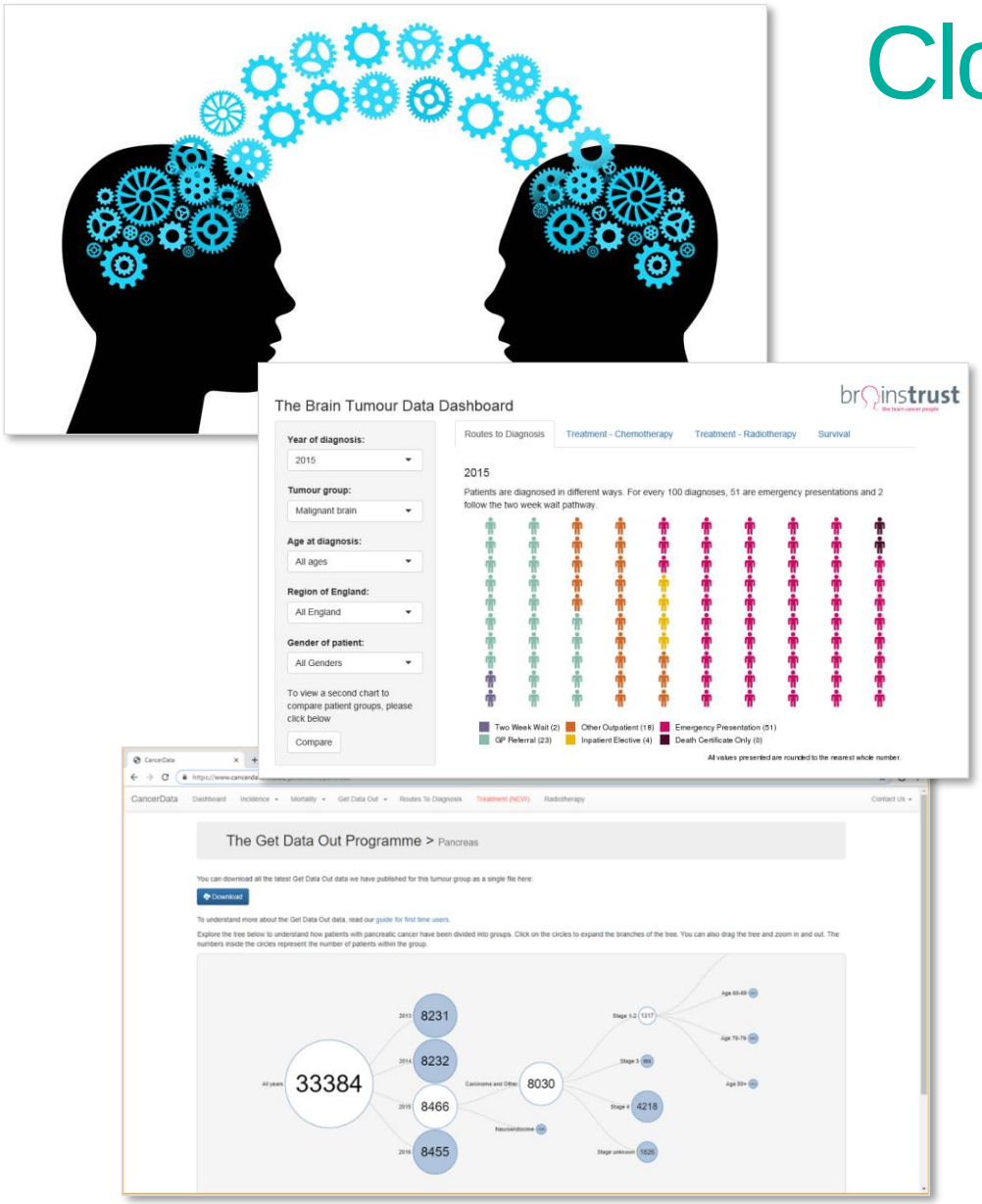
The National Cancer Registration and Analysis Service (NCRAS) England

- A brief background

2

NCRAS principles for data collection

- How does this facilitate monitoring of tumour agnostic treatments?



Closing the loop:

- Collecting high quality data relies on co-operation from many individuals across the healthcare infrastructure
- We often focus on getting the data in
- Must consider how you will get data back out – particularly to providers

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Any questions?

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