NDRS
NATIONAL DISEASE REGISTRATION SERVICE

National Disease Registration Service (NDRS)

COSD Roadshow – Taunton 14th February 2024

Kat Roe, RTDS Project Lead, NDRS

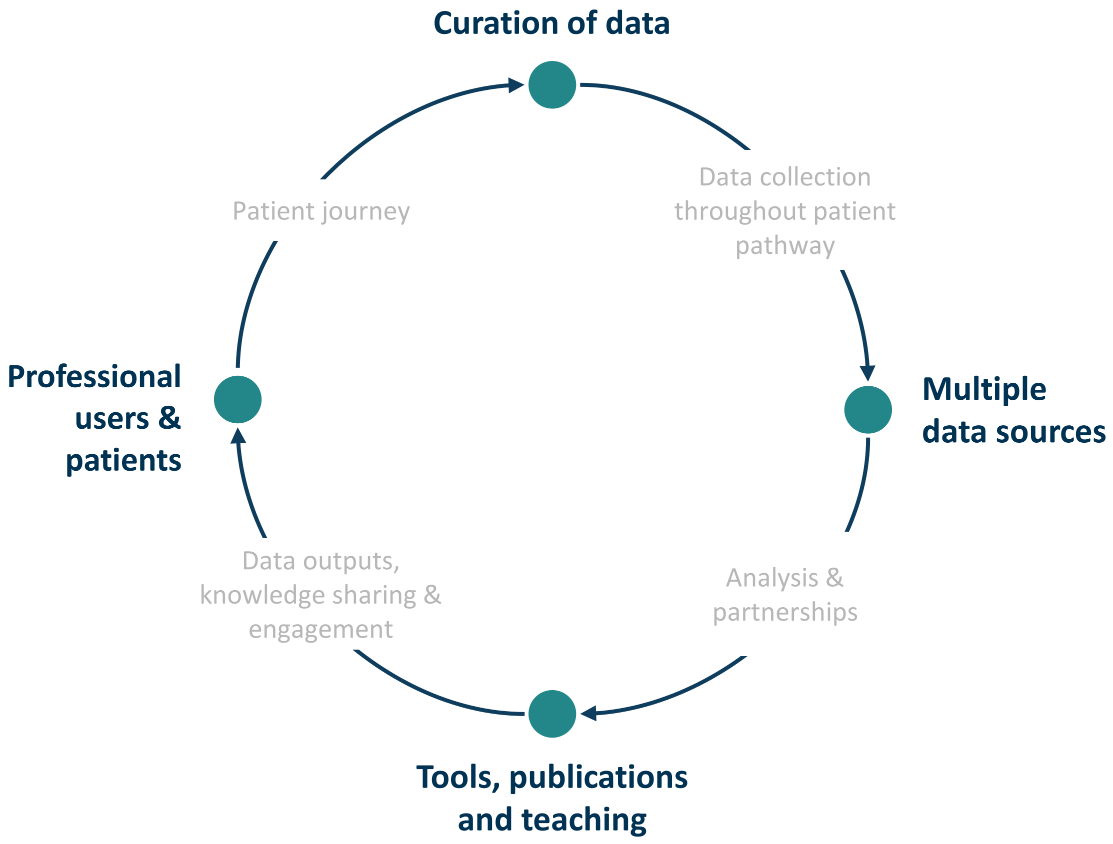
What is the National Disease Registration Service (NDRS)?

The National Disease Registration Service (NDRS) collects and analyses data on patients with cancer, congenital anomalies and rare diseases.

NDRS is a vital resource that helps researchers, healthcare professionals and policy makers make decisions about NHS services and the treatments people receive.

It includes two population disease registration services:

1. **NCRAS** – National Cancer Registration and Analysis Service
2. **NCARDRS** – National Congenital Anomaly and Rare Disease Registration Service



Organisational change

Public Health England

2021

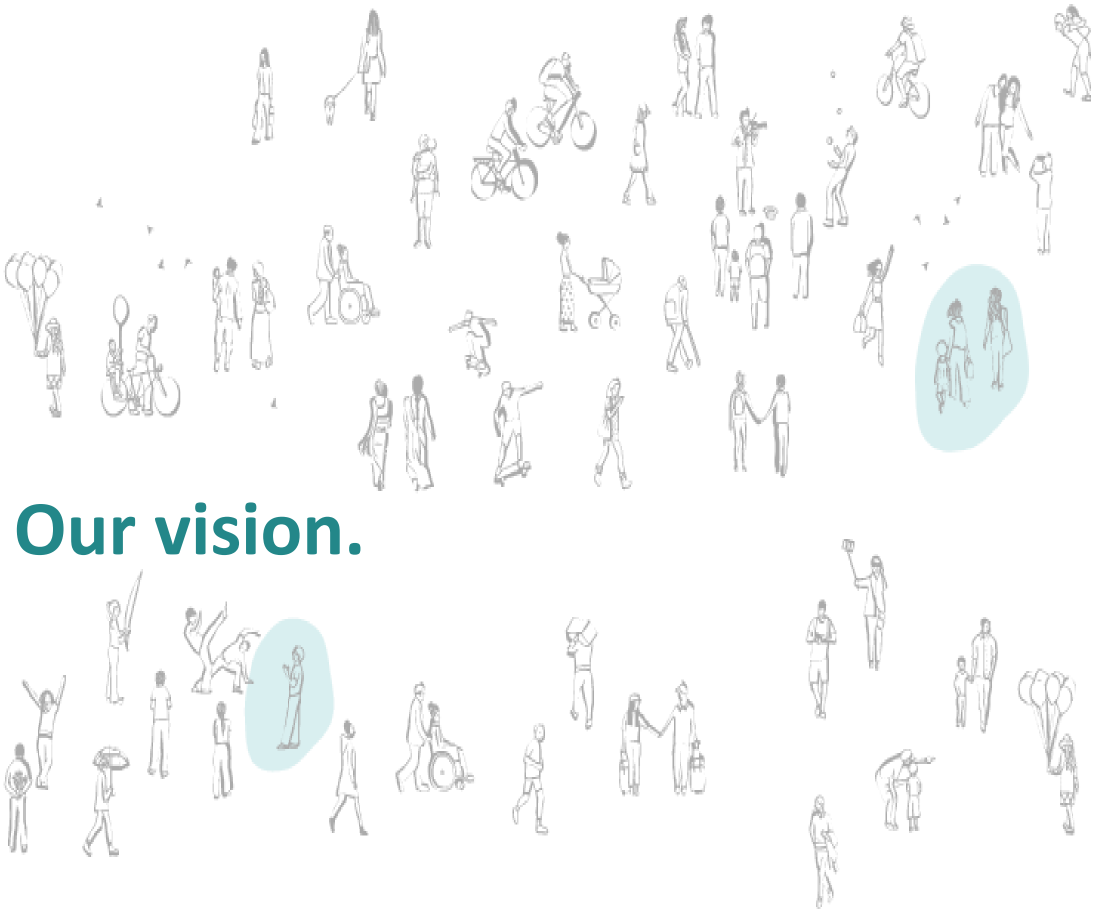
NHS Digital

2023

NHS England

“We will be the best insight-driven, health and care system in the world.”

NDRS vision



Our vision.

To drive improvements in population health and patient outcomes as a globally trusted curator of high-quality disease registration data, enabling and providing expert, timely analysis and insight.

NDRS core business 2024

Trusted and Transparent

Commitment to the National Data Guardian (NDG) Data Transparency Agenda

Protection of Patient Identifiable Data (PID)

Upholding individual right to opt out

Patient self-reporting system for rare disease - test and trial

A user needs led service informed by active stakeholder and public engagement

Supporting Direct Care and Improving Patient Outcomes

Genetic Enquiry Service

Provision of clinical dashboards and Trust level reporting

Cluster Investigation

Identification of patients for targeted screening e.g. Lynch Syndrome and Breast Screening after Radiotherapy (BARD)

Supporting NHSE implementation of Galleri/ GRAIL

Identifying patients vulnerable to public health threats e.g. the COVID shielded patient list

National genomic variant database for cancer and rare disease

Improving population health

Gold Standard Disease Registration Data

National and official statistics on incidence, prevalence, mortality, survival

Epidemiological surveillance

Routes to diagnosis

Reporting on stage of diagnosis

Get Data Out Programme for rare and less common cancers

Support prevention and early detection

Understanding health inequalities

Planning and improving services

Rapid Cancer Registration Dataset

Supporting the NHS National Screening Programmes

Setting and managing data standards

Data rollout to support Rapid Diagnostic Centres

Supporting Clinical Audits

Cancer Drug Fund and Innovative Medicines Fund

Production of data to support local service development and evaluation of treatments and interventions

Supporting Research and Innovation

Molecular data collection and analysis for cancer and rare diseases

Support for health emergency research/response

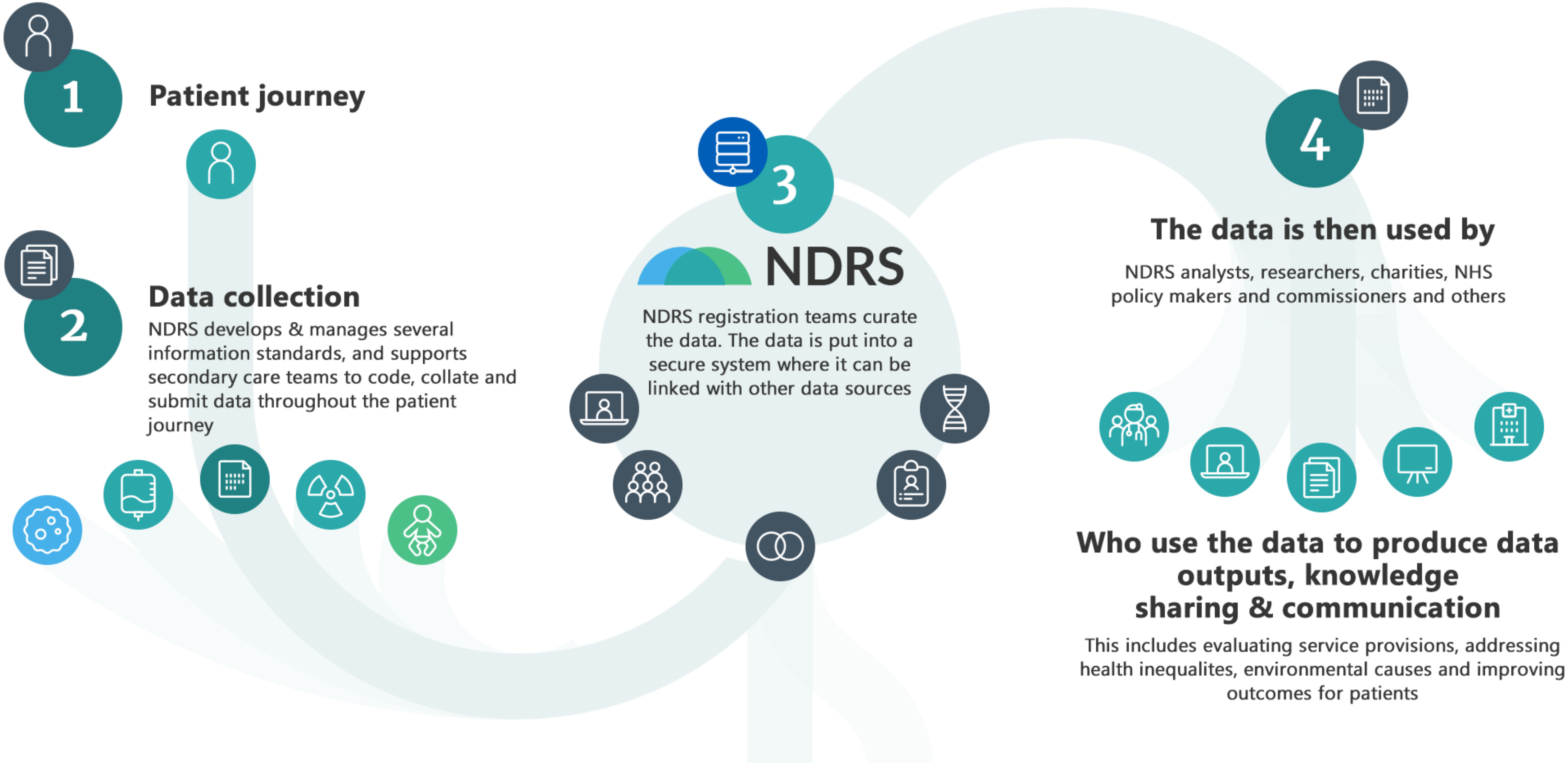
Evaluate introduction of Non-Invasive Prenatal Testing (NIPT) within FASP

Supporting clinical trials and studies

Drive innovation and improvements in data collection and curation to reduce burden

Collaboration on international research and surveillance

NDRS Data Flow



1 **Patient journey**

2 **Data collection**

NDRS develops & manages several information standards, and supports secondary care teams to code, collate and submit data throughout the patient journey

3 **NDRS**

NDRS registration teams curate the data. The data is put into a secure system where it can be linked with other data sources

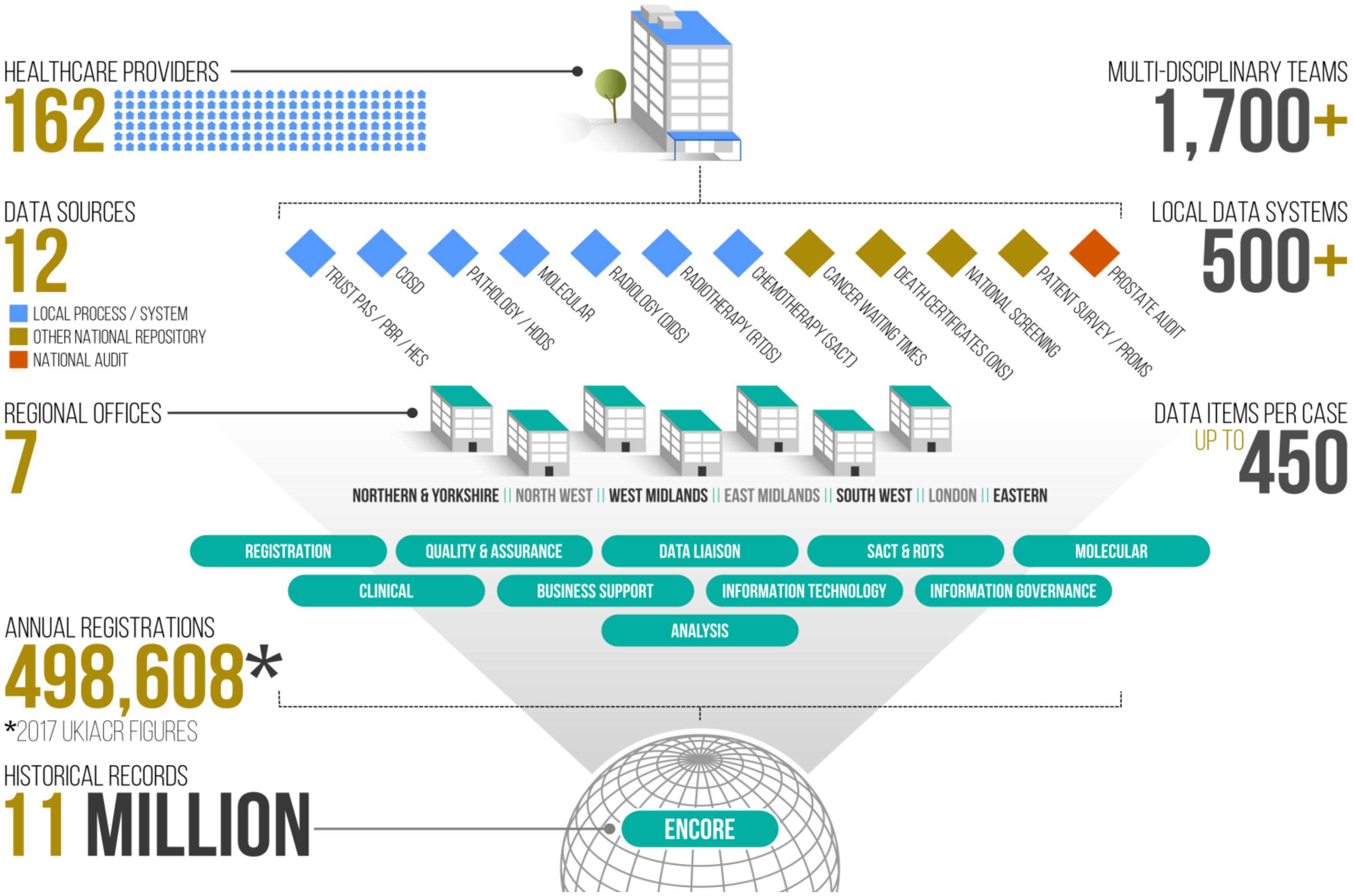
4 **The data is then used by**

NDRS analysts, researchers, charities, NHS policy makers and commissioners and others

Who use the data to produce data outputs, knowledge sharing & communication

This includes evaluating service provisions, addressing health inequalites, environmental causes and improving outcomes for patients

Data Flows



HEALTHCARE PROVIDERS
162

MULTI-DISCIPLINARY TEAMS
1,700+

DATA SOURCES
12

- 🟦 LOCAL PROCESS / SYSTEM
- 🟨 OTHER NATIONAL REPOSITORY
- 🟧 NATIONAL AUDIT

LOCAL DATA SYSTEMS
500+

TRUST PAS / PBR / HES
COSD
PATHOLOGY / HODS
MOLECULAR
RADIOLOGY (DIDS)
RADIOTHERAPY (RTDS)
CHEMOTHERAPY (SACT)
CANCER WAITING TIMES
DEATH CERTIFICATES (ONS)
NATIONAL SCREENING
PATIENT SURVEY / PROMS
PROSTATE AUDIT

REGIONAL OFFICES
7

DATA ITEMS PER CASE
UP TO **450**

NORTHERN & YORKSHIRE || NORTH WEST || WEST MIDLANDS || EAST MIDLANDS || SOUTH WEST || LONDON || EASTERN

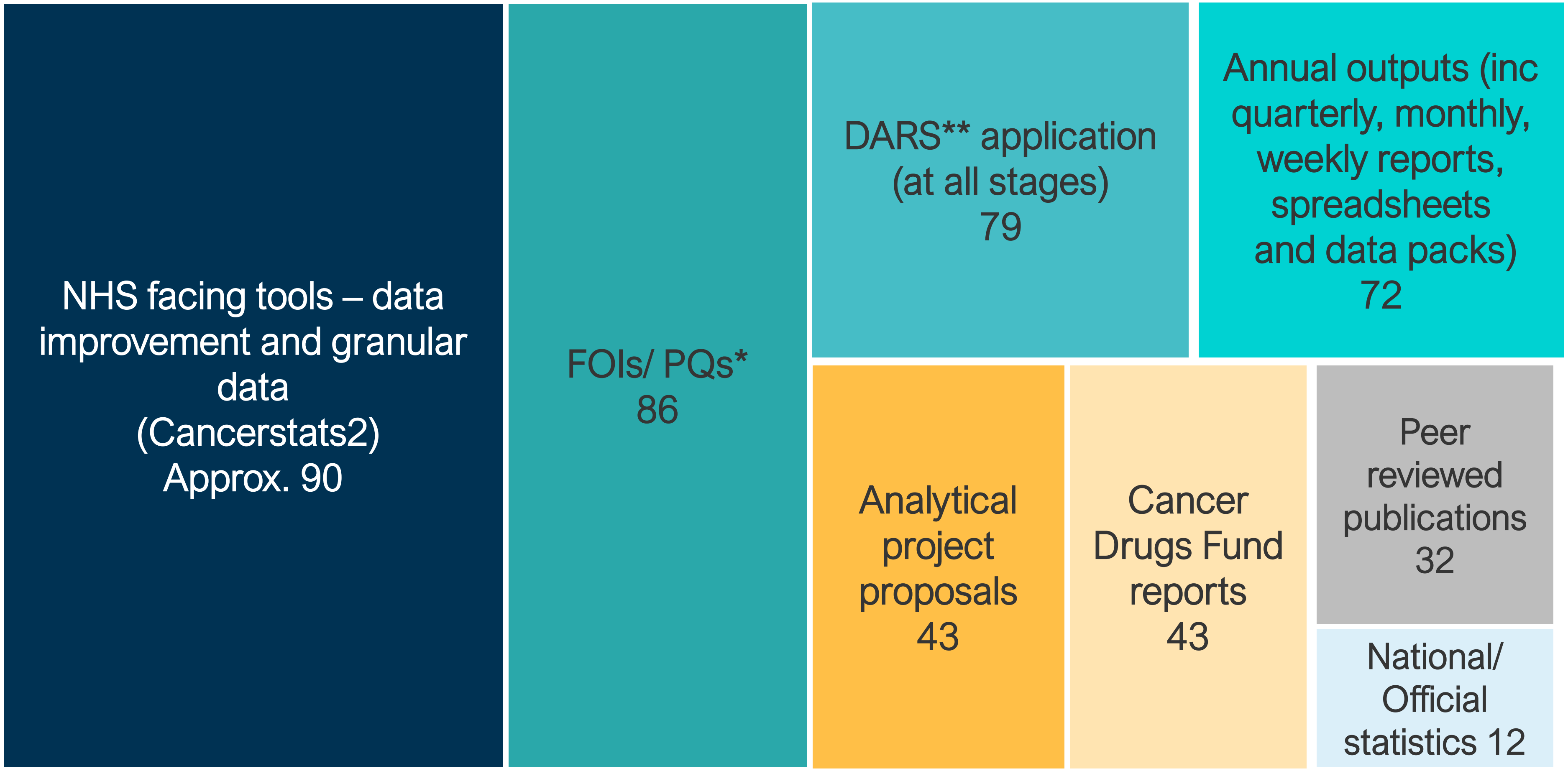
REGISTRATION
QUALITY & ASSURANCE
DATA LIAISON
SACT & RDTS
MOLECULAR
CLINICAL
BUSINESS SUPPORT
INFORMATION TECHNOLOGY
INFORMATION GOVERNANCE
ANALYSIS

ANNUAL REGISTRATIONS
498,608*
*2017 UKIACR FIGURES

HISTORICAL RECORDS
11 MILLION

ENCORE

A breakdown of major NDRS outputs and publications for 2023

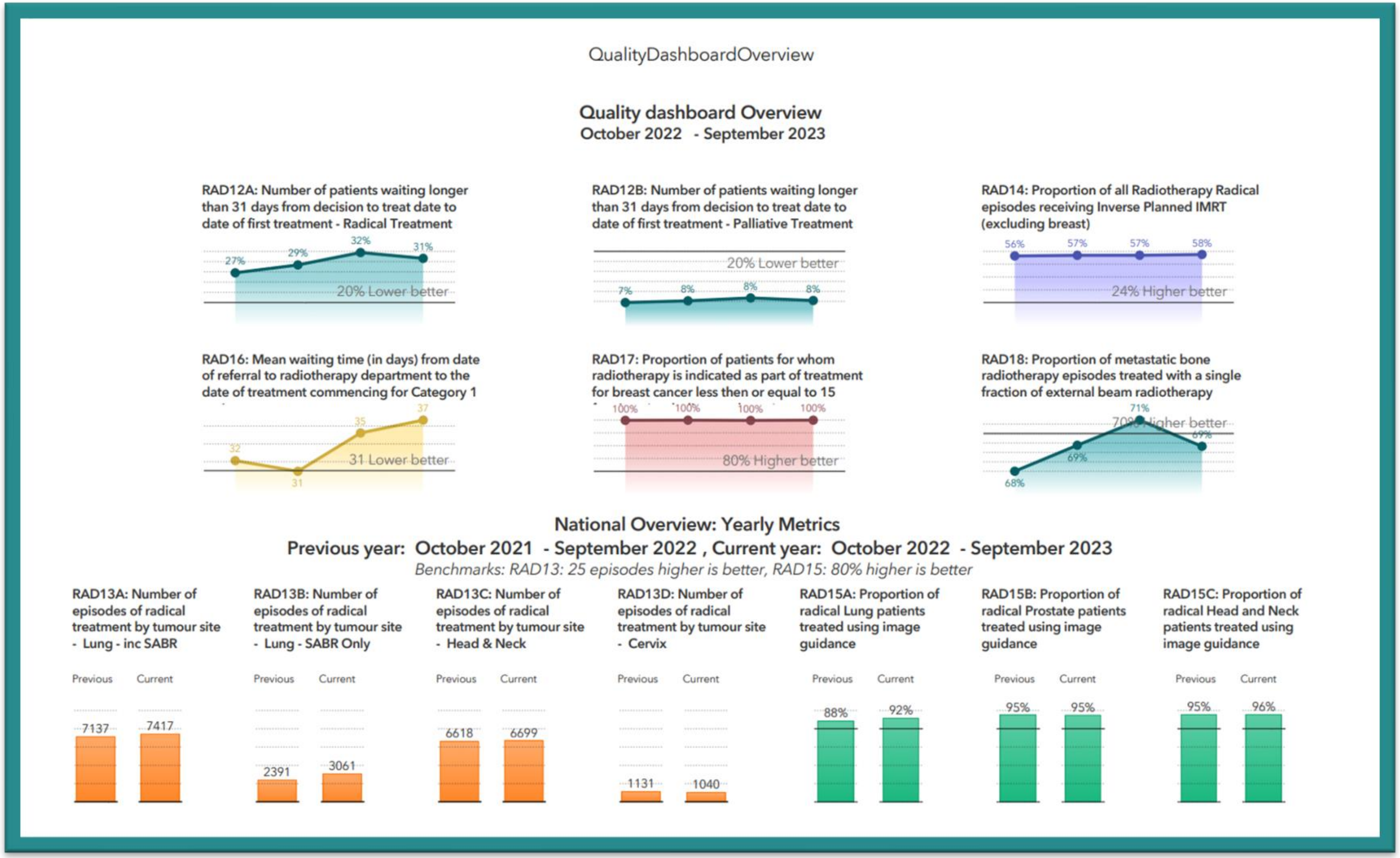


As well as regular webinars, presentations, networking events and public information resources
*Freedom of Information requests/Parliamentary Queries; **Data Access and Release Service

Supporting Direct Care and Improving Patient Outcomes

- Provision of clinical dashboards and Trust level reporting
- Identification of patients for targeted screening e.g. Lynch Syndrome and Breast Screening after Radiotherapy (BARD)
- Genetic Enquiry Service
- Cluster Investigation
- Supporting NHSE implementation of Galleri/ GRAIL
- Identifying patients vulnerable to public health threats e.g. the COVID shielded patient list
- National genomic variant database for cancer and rare disease

RTDS NHSE Quality Dashboard



QualityDashboardOverview

Quality dashboard Overview
October 2022 - September 2023

RAD12A: Number of patients waiting longer than 31 days from decision to treat date to date of first treatment - Radical Treatment

RAD12B: Number of patients waiting longer than 31 days from decision to treat date to date of first treatment - Palliative Treatment

RAD14: Proportion of all Radiotherapy Radical episodes receiving Inverse Planned IMRT (excluding breast)

RAD16: Mean waiting time (in days) from date of referral to radiotherapy department to the date of treatment commencing for Category 1

RAD17: Proportion of patients for whom radiotherapy is indicated as part of treatment for breast cancer less then or equal to 15

RAD18: Proportion of metastatic bone radiotherapy episodes treated with a single fraction of external beam radiotherapy

National Overview: Yearly Metrics
Previous year: October 2021 - September 2022 , Current year: October 2022 - September 2023
Benchmarks: RAD13: 25 episodes higher is better, RAD15: 80% higher is better

RAD13A: Number of episodes of radical treatment by tumour site - Lung - inc SABR

RAD13B: Number of episodes of radical treatment by tumour site - Lung - SABR Only

RAD13C: Number of episodes of radical treatment by tumour site - Head & Neck

RAD13D: Number of episodes of radical treatment by tumour site - Cervix

RAD15A: Proportion of radical Lung patients treated using image guidance

RAD15B: Proportion of radical Prostate patients treated using image guidance

RAD15C: Proportion of radical Head and Neck patients treated using image guidance

Breast screening After Radiotherapy Data set (BARD)

BARD - Background and aims

- Receiving radiotherapy (RT) to breast tissue under the age of 36, increases the subsequent risk of breast cancer (up to 5 times that of an unirradiated person)
- In 2003 the Department of Health recommended – patient consultation to discuss risk and screening arranged according to a nationally agreed protocol
- Stakeholders agreed that a single national system for identifying women at risk and arranging screening referrals would be helpful
- BARD became fully operational in 2021 and is the first national targeted screening programme
- BARD is an exemplar project that the NHS Screening Director is planning to emulate in other patient groups

BARD project aim and eligibility criteria

- Aim: to identify patients who are eligible for very high-risk (VHR) annual breast screening due to receiving radiotherapy to breast tissue

- Criteria:
    - Women
    - With a lymphoma diagnosis
    - Who received radiotherapy to breast tissue when aged between 10-35 years

BARD collaborative project

The Christie
NHS FOUNDATION TRUST

MANCHESTER
1824
The University of Manchester

NDRS
NATIONAL DISEASE REGISTRATION SERVICE

NHS
Cancer Screening Programmes

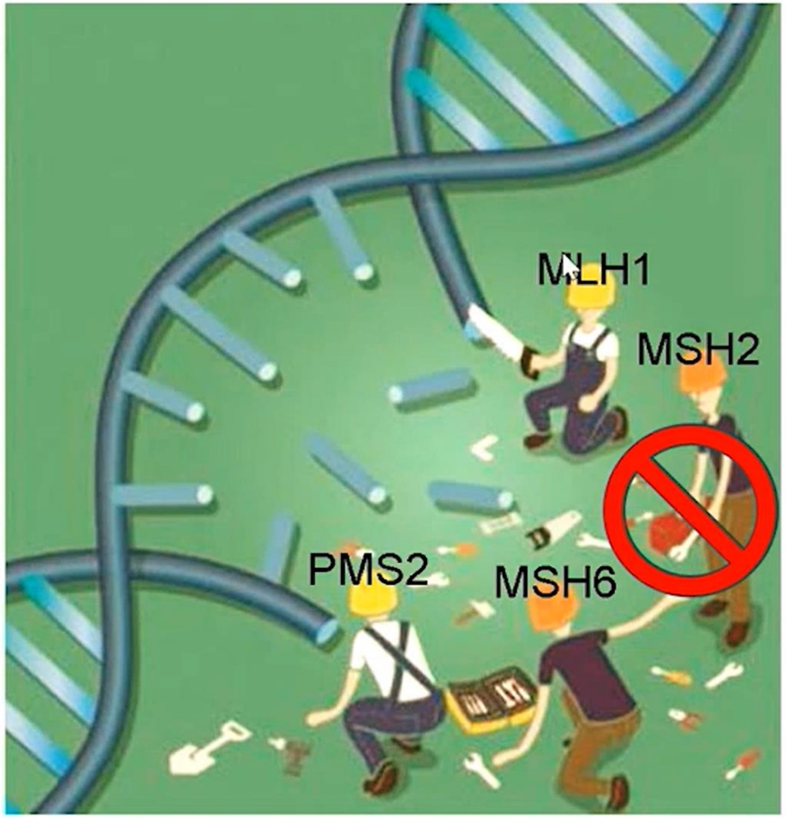
BARD Cohorts

Cohort	Diagnosis years	Diagnosis data source	Data linkage
1	1962-2002	ICR - National recall exercise and associated study dataset	Hospital records
2	2003-2013	Cancer registry	NDRS and manual data return from RT providers
3	2014-2019	Cancer registry	NDRS via COSD, RTDS and data return from RT providers
Next…	2020+	Cancer registry	NDRS, via COSD, RTDS / Data from RT providers
Other	All	Non-lymphoma referral form / Hospital records outside England or from private healthcare setting	Non-lymphoma referral form / Hospital records outside England or from private healthcare setting

Lynch syndrome

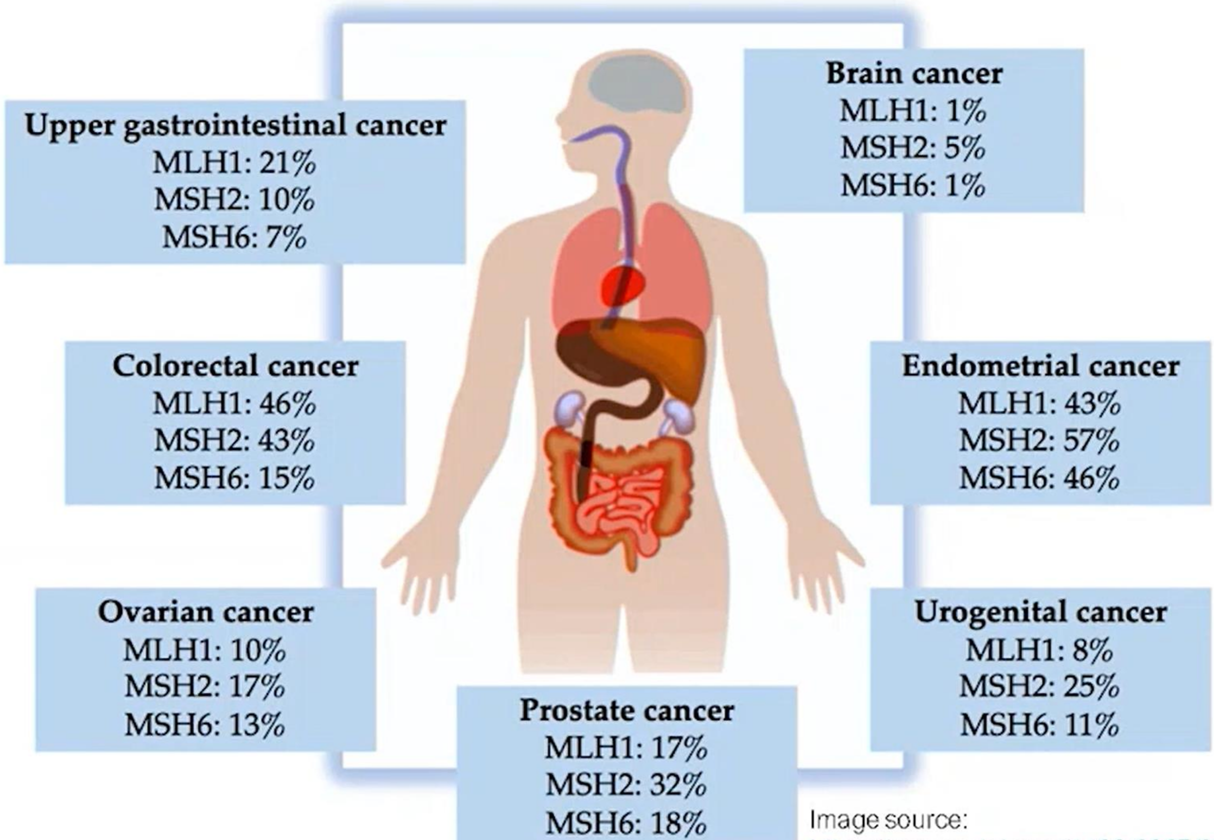
Lynch syndrome - Introduction

- Autosomal dominantly inherited cancer predisposition syndrome, caused by pathogenic variants in a DNA mismatch repair gene:



Lynch syndrome

- Cancer risk depends on the:
  - Gene
  - Variant
  - Gender
  - Cancer site
- Tumours usually display neo-antigens, so are often amenable to immunotherapy



Upper gastrointestinal cancer
MLH1: 21%
MSH2: 10%
MSH6: 7%

Brain cancer
MLH1: 1%
MSH2: 5%
MSH6: 1%

Colorectal cancer
MLH1: 46%
MSH2: 43%
MSH6: 15%

Endometrial cancer
MLH1: 43%
MSH2: 57%
MSH6: 46%

Ovarian cancer
MLH1: 10%
MSH2: 17%
MSH6: 13%

Urogenital cancer
MLH1: 8%
MSH2: 25%
MSH6: 11%

Prostate cancer
MLH1: 17%
MSH2: 32%
MSH6: 18%

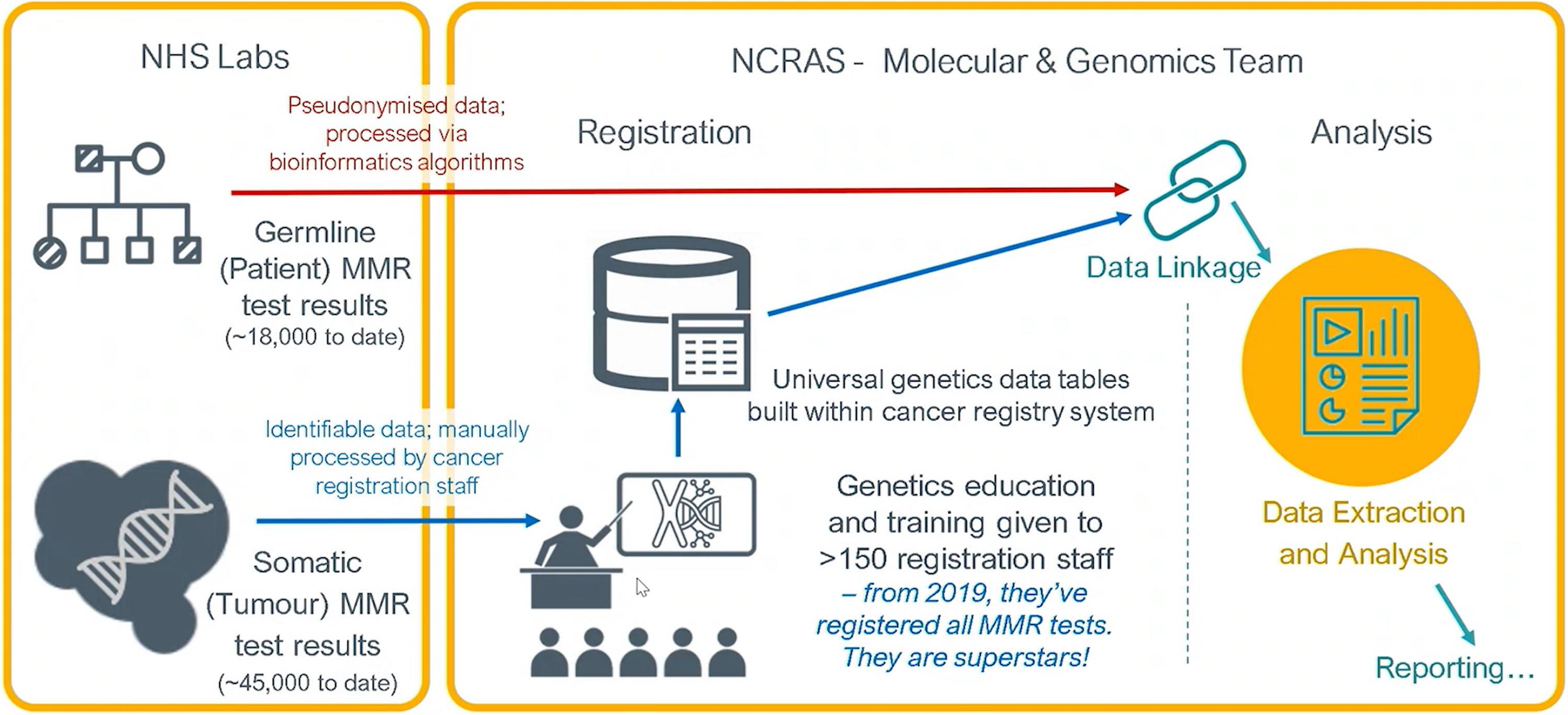
Image source:
https://www.mdpi.com/1422-0067/22/2/531

Lynch syndrome - NICE Guidelines

- Lynch syndrome is underdiagnosed – only 5% of cases identified
- NICE Feb 2017 – National Guidance for Colorectal cancer (CRC) and endometrial cancer (EC) in Oct 2020:

All CRC and EC should be tested for (mis match repair) MMR deficiency.

NDRS Cancer Data Pathway – Lynch syndrome molecular tests



NHS Labs

Pseudonymised data; processed via bioinformatics algorithms

Germline (Patient) MMR test results (~18,000 to date)

Identifiable data; manually processed by cancer registration staff

Somatic (Tumour) MMR test results (~45,000 to date)

NCRAS - Molecular & Genomics Team

Registration

Universal genetics data tables built within cancer registry system

Genetics education and training given to >150 registration staff *– from 2019, they've registered all MMR tests. They are superstars!*

Analysis

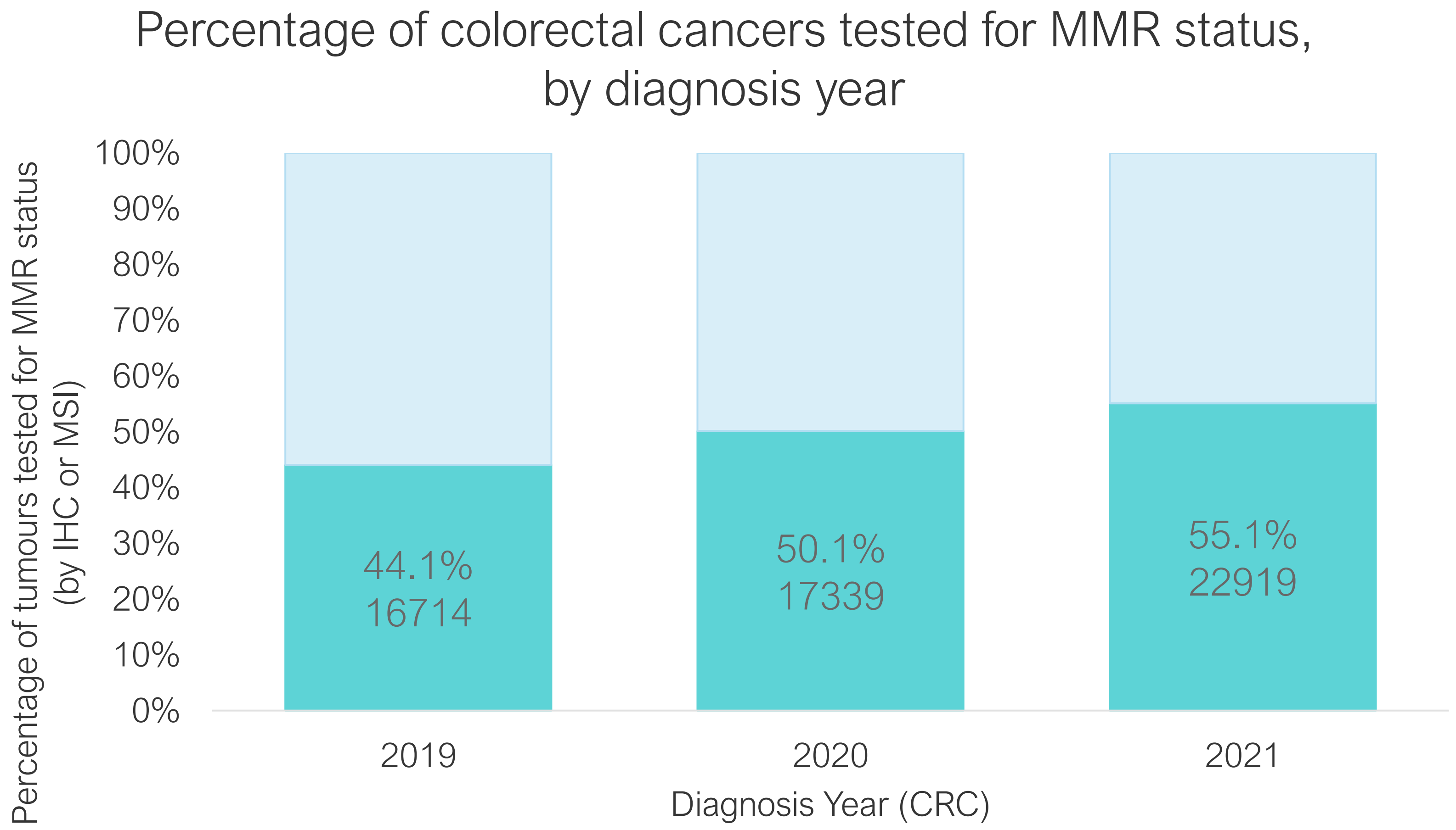
Data Linkage

Data Extraction and Analysis

Reporting…

Figures from the Lynch dashboard

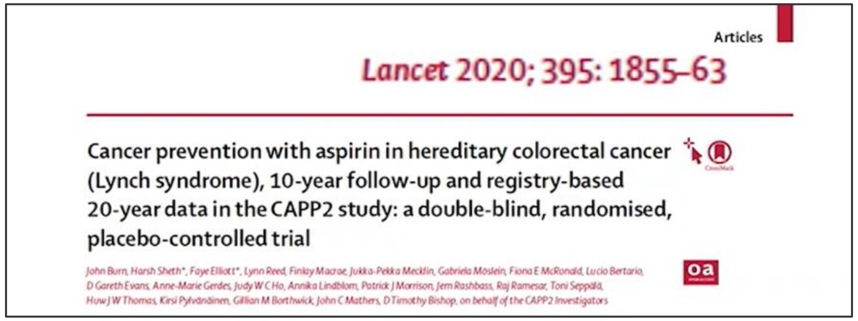
Proportion of tumours tested increased from 2019-2021 (despite the pandemic).



CaPP2 clinical trial

- NDRS data was used for the long term follow up in collaboration with Newcastle University Professor John Burn.
- Clinical trial giving aspirin and resistant starch to patients.
- People with Lynch syndrome who take aspirin for 2 years have a 50% reduction in CRC over the next two decades.
- Recognised by ASCO as a major cancer prevention advance of 2020

https://www.sciencedirect.com/science/article/pii/S0140673620303664?via%3Dihub

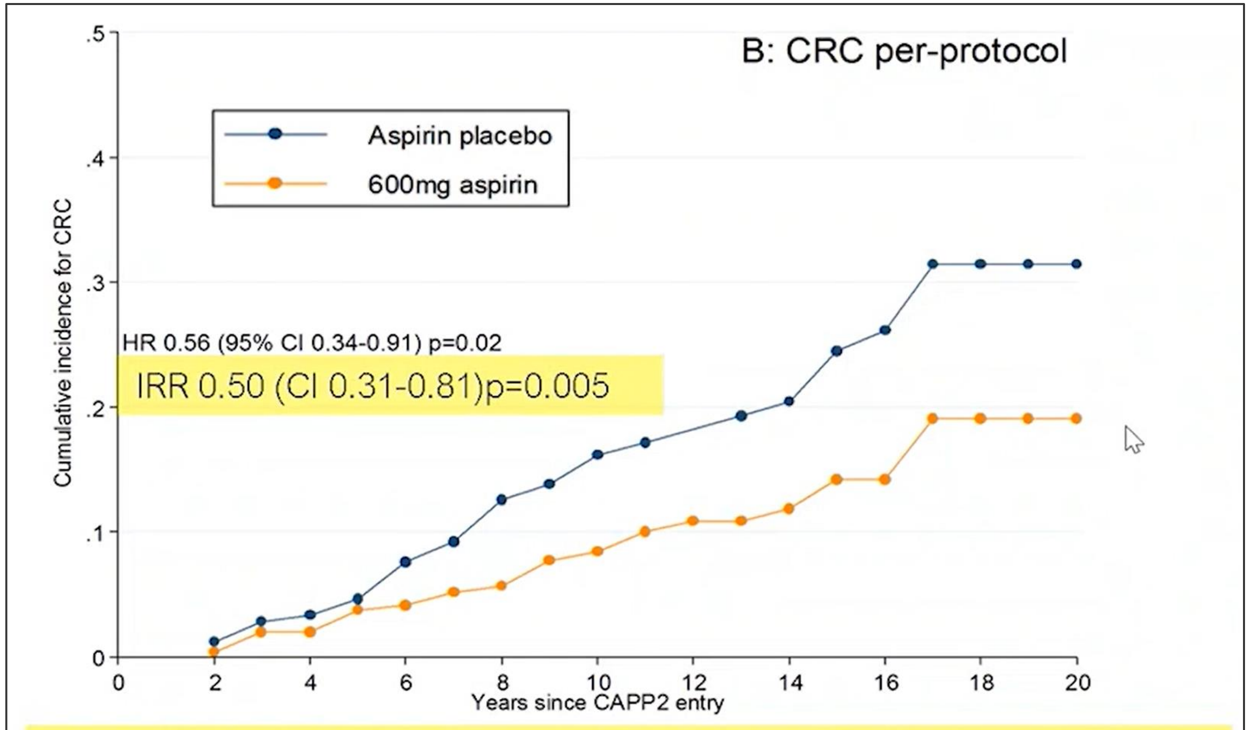


Articles

Lancet 2020; 395: 1855–63

Cancer prevention with aspirin in hereditary colorectal cancer (Lynch syndrome), 10-year follow-up and registry-based 20-year data in the CAPP2 study: a double-blind, randomised, placebo-controlled trial

John Burn, Harsh Sheth, Faye Elliott*, Lynn Reed, Finlay Macrae, Jukka-Pekka Mecklin, Gabriela Möslein, Fiona E McRonald, Lucio Bertario, D Gareth Evans, Anne-Marie Gerdes, Judy W C Ho, Annika Lindblom, Patrick J Morrison, Jem Rashbass, Raj Ramesar, Toni Seppälä, Huw J W Thomas, Kirsi Pylvänäinen, Gillian M Borthwick, John C Mathers, D Timothy Bishop, on behalf of the CAPP2 Investigators*



HR = Hazard Ratio (counts first cancer). IRR = Incident Rate Ratio (counts all cancers)

English National Lynch Registry

- NDRS is working in collaboration with Institute for Cancer Research (ICR) and NHS screening on the creation of a national Lynch registry for all of England
- Including both retrospective (historical data) such as:
  - Clinical genetics
  - Genetics labs
- And prospective data (real time and future data) for which we have created a secure online portal for clinical services to submit the lynch syndrome data to NDRS.

NDRS national genomic datasets & services

Universal genetics data tables

Genetics education programme developed

Rare Disease/Congenital Anomaly dataset

Provide **official statistics** on cytogenetic disorders e.g. T13/18/21

Measuring **quality and outcomes** for the NHS Fetal Anomaly Screening Programme (FASP)

Providing data and intelligence to support the **NIPT evaluative rollout**

Somatic dataset

Data on **tumour DNA** tests from 2016 onwards

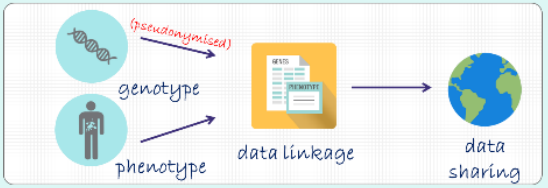
~**300,000** unique tumours tested

Over **1 million** genetic test results recorded

Matching tumour molecular profile to **targeted therapies**

Germline dataset

Pseudonymised genetic data from over **150,000** individuals at high familial risk of cancer



Data sharing supports **variant interpretation** in the UK and **globally**

Working with our **partners** to understand genetic cancer risk

Genetic Enquiries

Over **20,000** cancer family history diagnoses checked and verified per year

We provide a vital service to NHS **genetic counselling** units

> *"It's a fantastic, easy to use service"*
> (Feedback from NHS Genetics Clinic)

With accurate counselling, families can make **informed choices**

Clinical Examples of Using the Routine Data Collected -Breast Metrics

Metrics – Universal Conditions

- Only using RTDSv5 data
- External beam radiotherapy delivered at an English NHS Provider
- Curative (adjuvant) radiotherapy episode starting between 1 January 2020 and 30 June 2022
- Female patients
- Breast cancer, invasive ICD10 C50 or in-situ ICD10 D05

Metrics – Clinical Definition

Metric 1a: Use of 26Gy in 5# for adjuvant breast and chest wall RT for invasive breast cancer

- Numerator: Number of episodes receiving adjuvant 5 fraction breast or chest wall radiotherapy for invasive breast cancer (ICD10 C50)
- Denominator: All episodes receiving adjuvant breast or chest wall radiotherapy for invasive breast cancer (ICD10 C50) excluding patients receiving nodal treatment

Metric 1b: Use of 26Gy in 5# for adjuvant breast RT for ductal carcinoma in situ

- Numerator: Number of episodes receiving adjuvant 5 fraction breast radiotherapy for ductal carcinoma in situ (ICD10 D05)
- Denominator: All episodes receiving adjuvant breast radiotherapy for ductal carcinoma in situ (ICD10 D05)

Metric 1b Results Overview

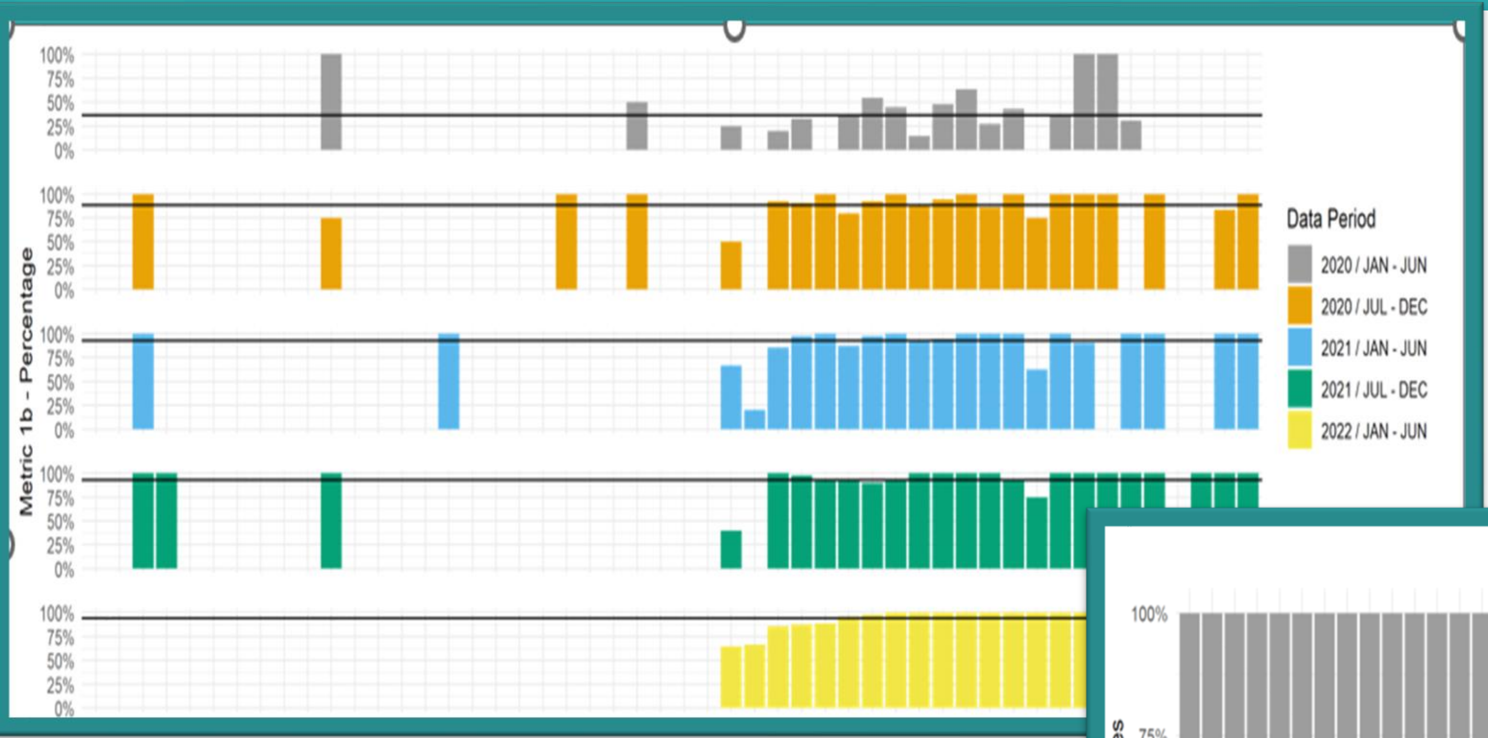
Metric 1b

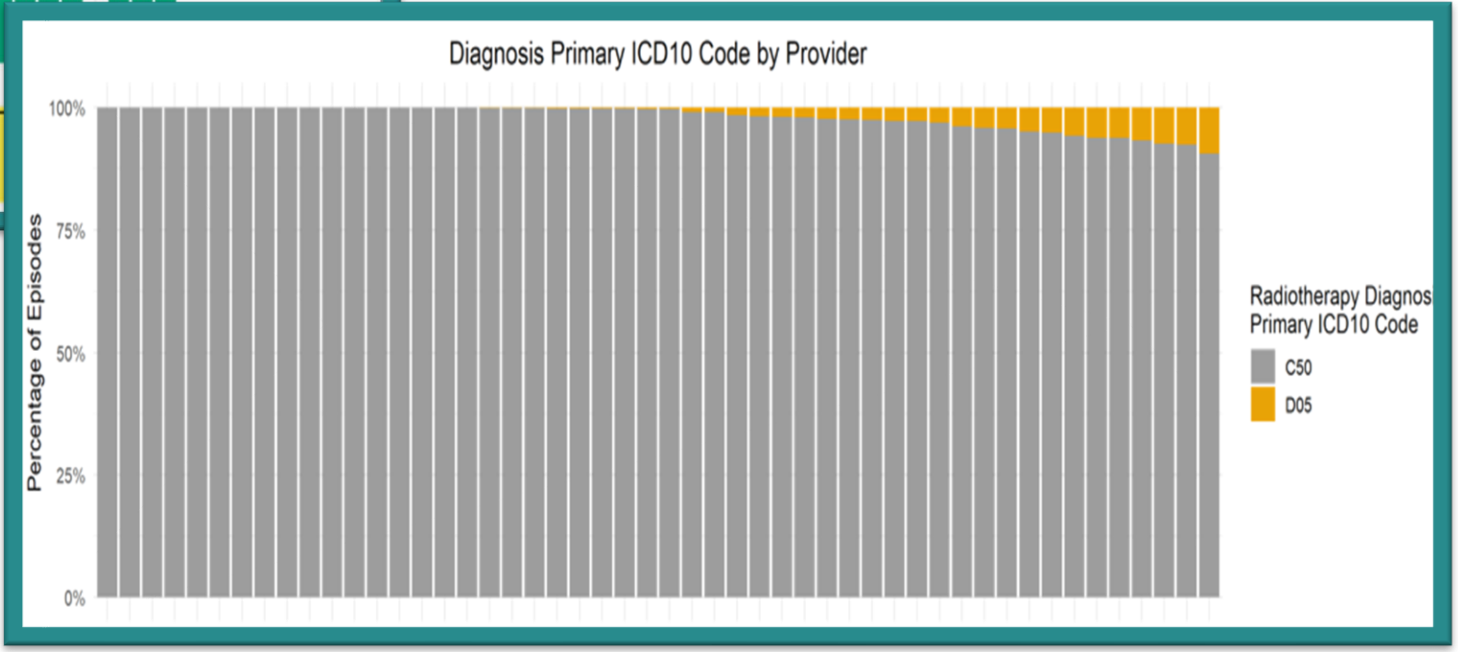
1,393 episodes identified as delivered for DCIS between 1 January 2020 and 30 June 2022

Data Period	England Overall (%)	Lowest Provider (%)	Highest Provider (%)	Median (%)
2020 / JAN - JUN	37	0	100	29
2020 / JUL - DEC	88	0	100	97
2021 / JAN - JUN	93	20	100	100
2021 / JUL - DEC	93	0	100	100
2022 / JAN - JUN	94	0	100	100

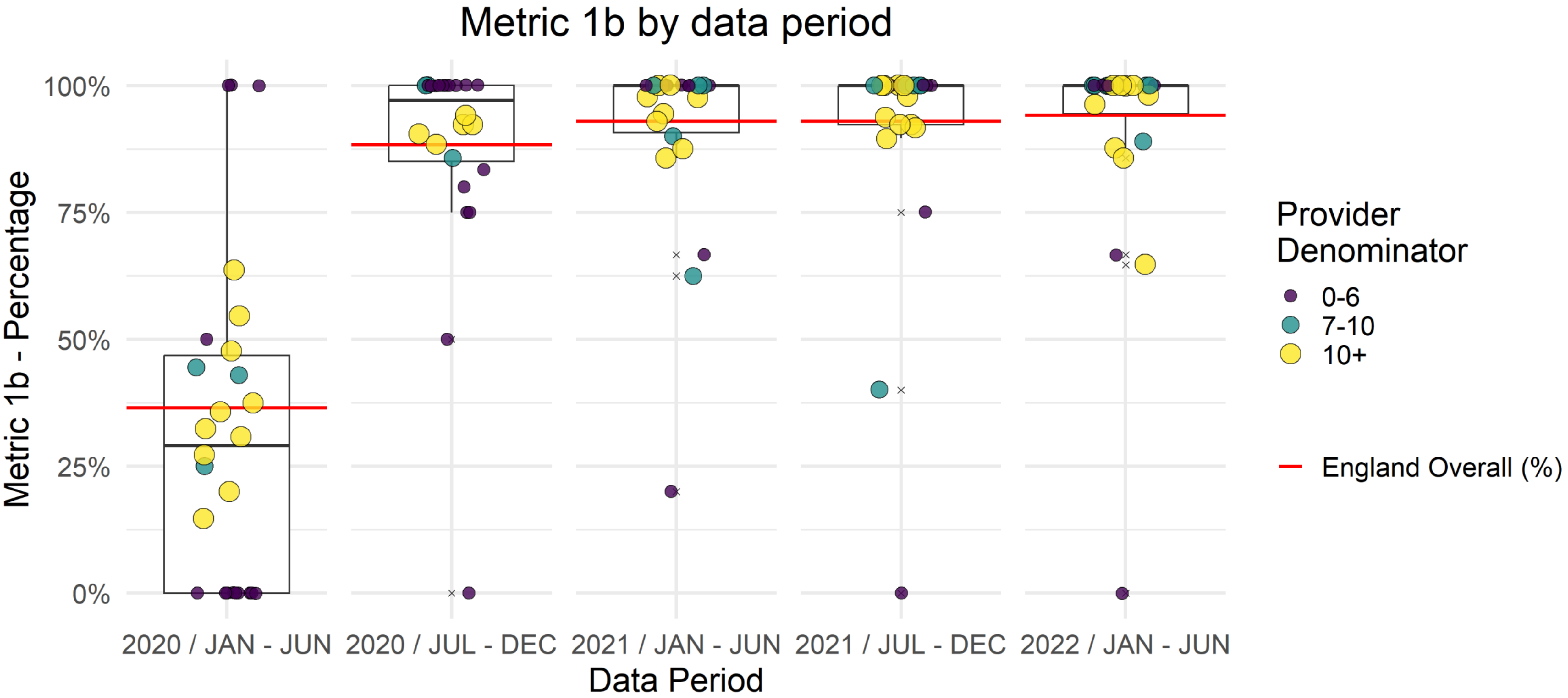
* Data quality around submitted radiotherapy diagnosis ICD10 codes will be discussed later in the presentation

Breast Metrics Data Quality





Metric 1b results by provider



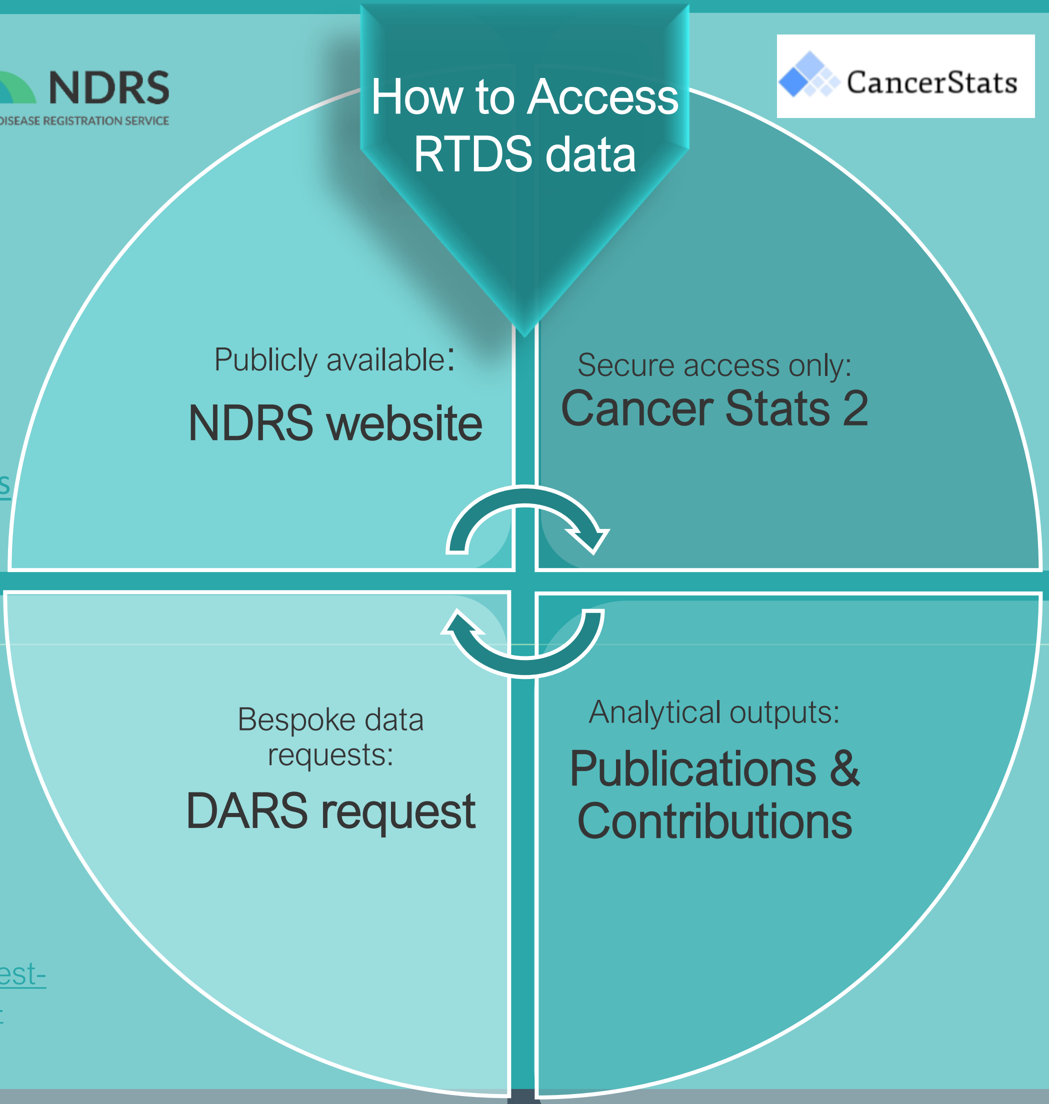
Methods to Access Data

NDRS site

Publicly available content

- **Background** information
- Data submission information
- **Bitesize series** – video guide of available content
- Dashboards:
  - COVID-19/ Dose and Fractionation Dashboard
  - RTDS/ IMRT Episode Dashboard

https://digital.nhs.uk/ndrs/data/data-sets/rtds



How to Access RTDS data

Publicly available:

NDRS website

Secure access only:

Cancer Stats 2

Bespoke data requests:

DARS request

Analytical outputs:

Publications & Contributions

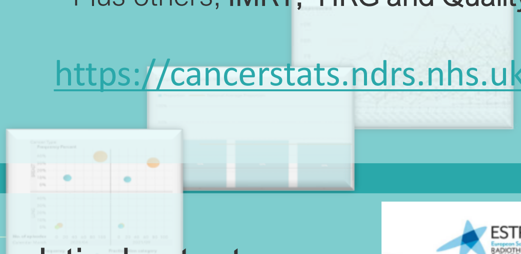
Cancer Stats 2 site

Permission required to access

Suite of 8 dynamic reports including:

- **Events**; Attendance, Episode and Prescription
- **Machine attendance** information for;
  - Linac, Brachy & Kilovoltage machines
- **Working day profile** - machine attendances
- **Dose and fractionation** details
- Plus others; **IMRT**, **HRG and Quality Dashboard**

https://cancerstats.ndrs.nhs.uk/



Data Access Request Service (DARS)

For other data requests/ bespoke analysis contact the Data Access Request Service (DARS).

Applications should be made online:
https://digital.nhs.uk/services/data-access-request-service-dars/data-access-request-service-dars-process

Analytical outputs

- Specialised services Quality Dashboard **(SSQD)** metrics
- Contribution to the Health economics in Radio-Oncology (**HERO**) project
- Out for comment- **90-day and 30-day mortality**
- Examples of RTDS used in **published analysis**:
  - The impact of the COVID-19 pandemic on radiotherapy services in England, UK: a population-based study. (Spencer et al. 2021)
  - Stereotactic Ablative Body Radiotherapy Versus Radical Radiotherapy: Comparing Real-World Outcomes in Stage I Lung Cancer (Phillips et al. 2019)

Image from: https://www.cancer.gov/about-cancer/treatment/types/radiation-therapy/external-beam

Thank you for listening

Please get in touch: ndrsenquiries@nhs.net & visit our new website for more information https://digital.nhs.uk/ndrs

This work uses data that has been provided by patients and collected by the NHS as part of their care and support. The data are collated, maintained and quality assured by the National Disease Registration Service, which is part of NHS England.

NDRS
NATIONAL DISEASE REGISTRATION SERVICE