HDRUK
Health Data Research UK

Utilising the power of SNOMED CT to evidence the impact of the pandemic on cancer patients

Monica Jones
Chief Data Officer – University of Leeds
Associate Director & National Strategic Lead - HDRUK

MISSION: to unite the UK's health data to enable discoveries that improve people's lives
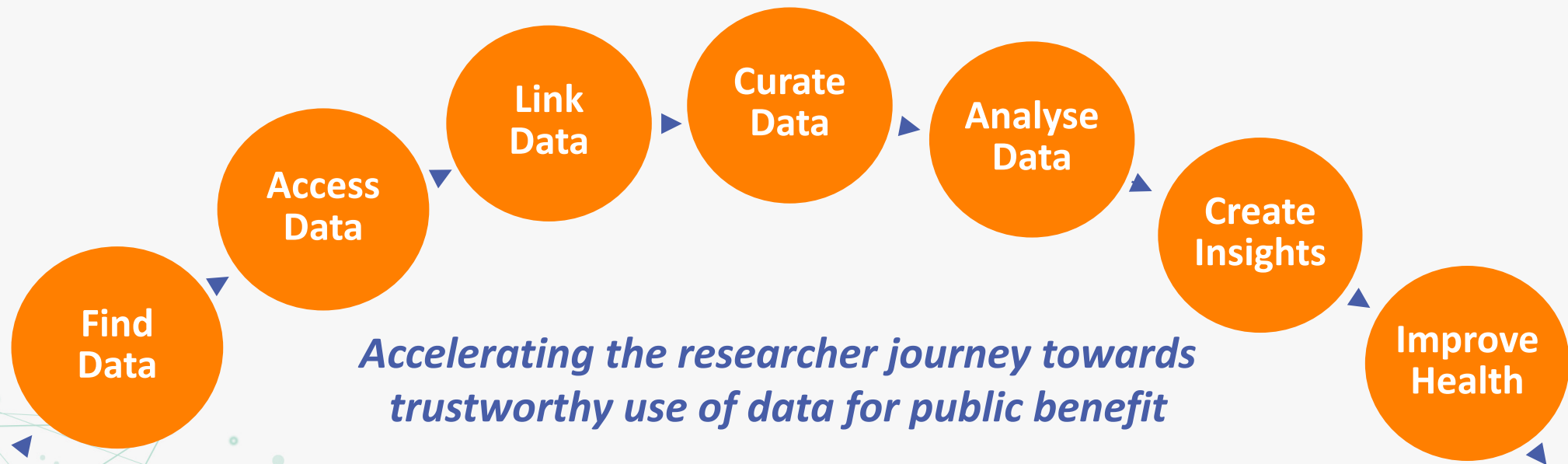
VISION: for large-scale data and advanced analytics to benefit every patient interaction, clinical trial and biomedical discovery, and to enhance public health
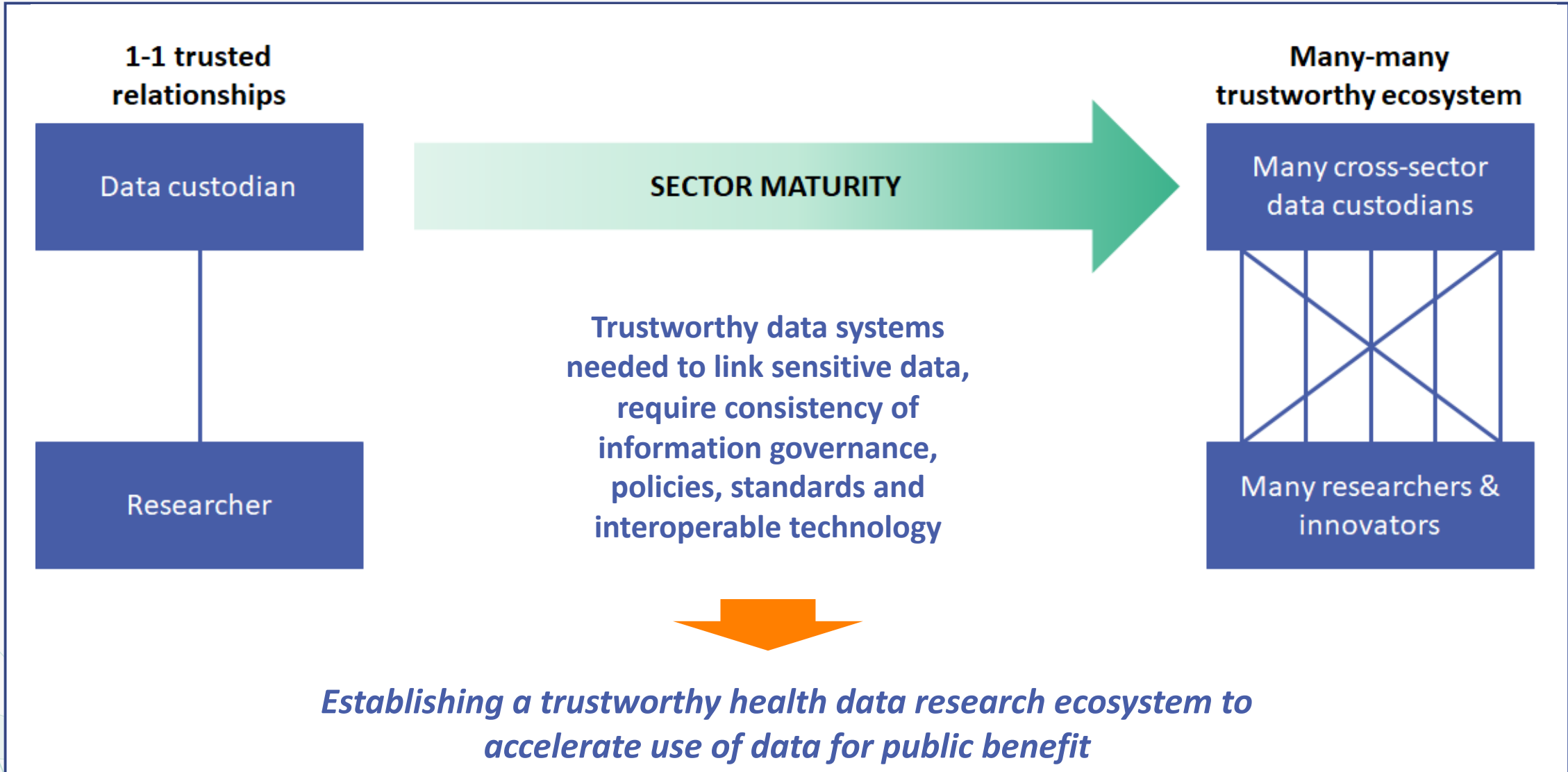
What are we about?

Improve health and boost UK science by making it easier for researchers to find, access and use diverse, high quality data

Provide leadership to fix difficult technical problems, by creating innovative solutions needed for researchers to use large-scale data safely and securely
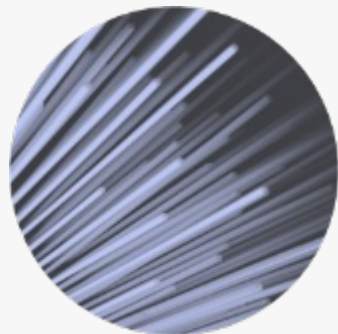
Accelerate & streamline health data science by developing open collaborations that connect data, people and organisations across the UK and internationally

Find Data ▶ Access Data ▶ Link Data ▶ Curate Data ▶ Analyse Data ▶ Create Insights ▶ Improve Health

Accelerating the researcher journey towards trustworthy use of data for public benefit

HDRUK
Health Data Research UK

# The problem we are trying to solve

How we do this ?

1. Accelerate Trustworthy Data Use

By implementing a national research data strategy and assembling infrastructure and services aligned to research and innovation needs

2. Empower Researchers

By valuing people with diverse perspectives & skills committed to open and team science to advance scientific discoveries and deliver patient and public benefit
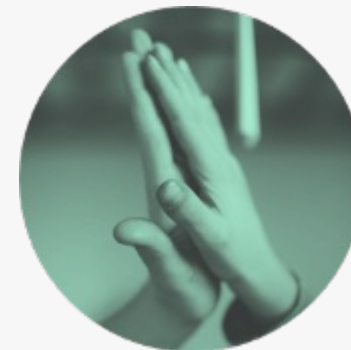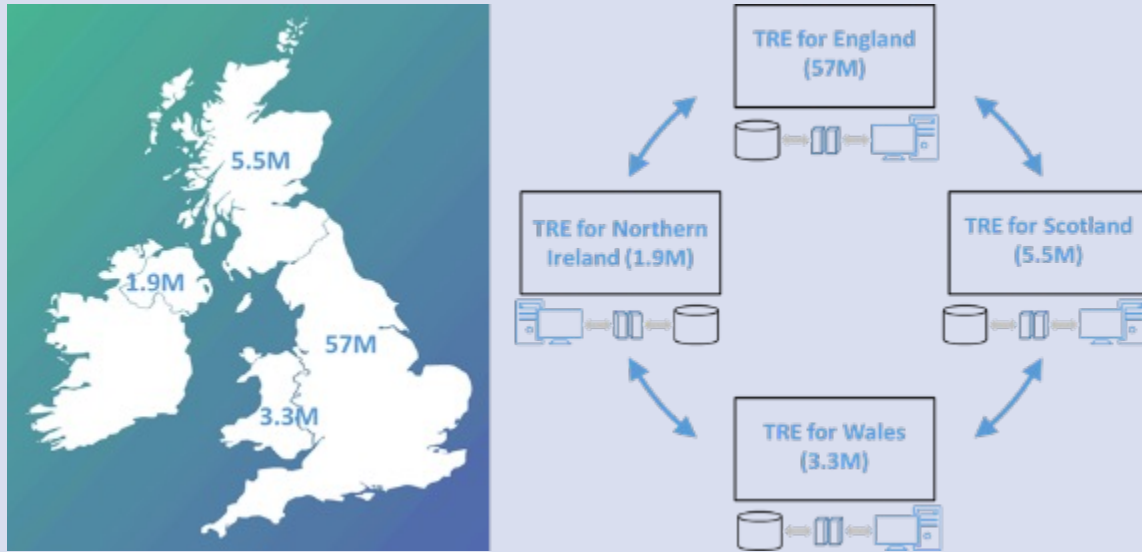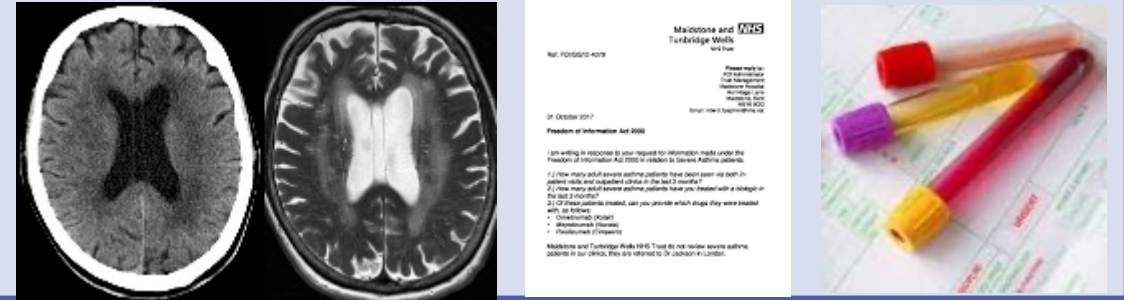
3. Promote Partnerships

By building and maintaining critical partnerships, aligning incentives and reducing complexity across a fragmented landscape to streamline health data science

1. Accelerate Trustworthy Data Use - through a national data strategy

NHS: NATIONALLY COLLATED, POPULATION-WIDE DATA

NHS: REGIONAL DATA

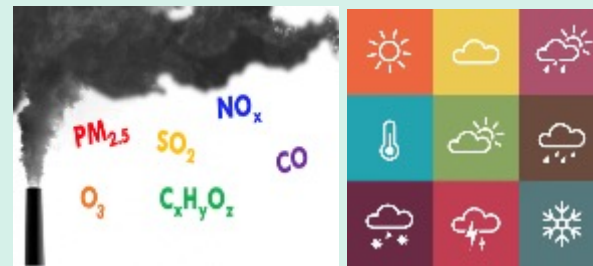## NON-NHS: HEALTH-RELEVANT ADMINISTRATIVE DATA

Census, education, disability, income....

PERSONAL MONITORING DATA

ENVIRONMENTAL DATA

RESEARCH-GENERATED DATA

Longitudinal cohorts & clinical trials, e.g.

2. Empower Researchers

Valuing people with diverse perspectives committed to **open and team science** to **advance scientific discovery** and deliver **patient and public benefit.**

Driver Programmes

- Driving the design and delivery of a world-leading health data infrastructure

- Generate UK-wide 'research-ready' data foundations for wider re-use

- Deliver health & care impact
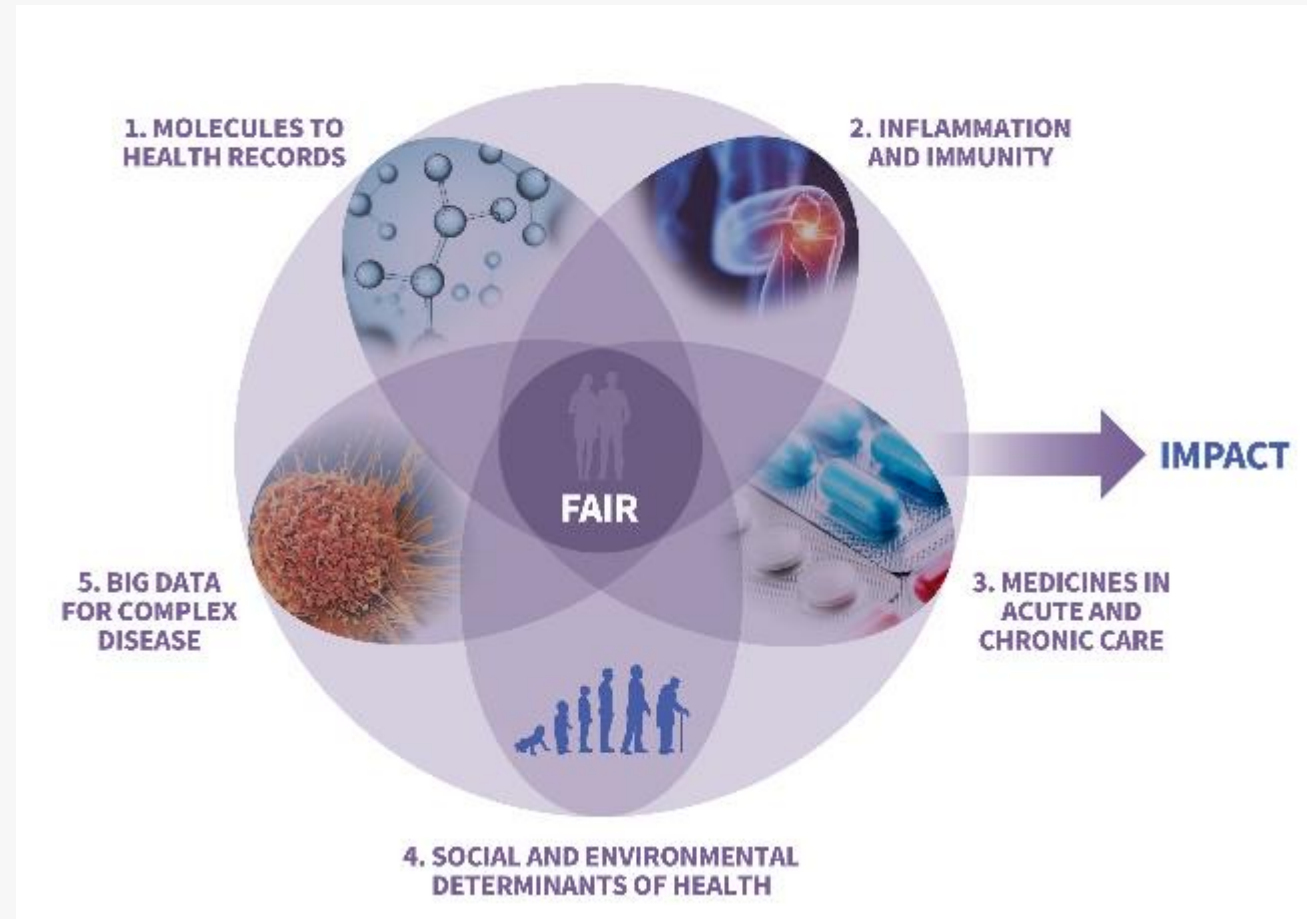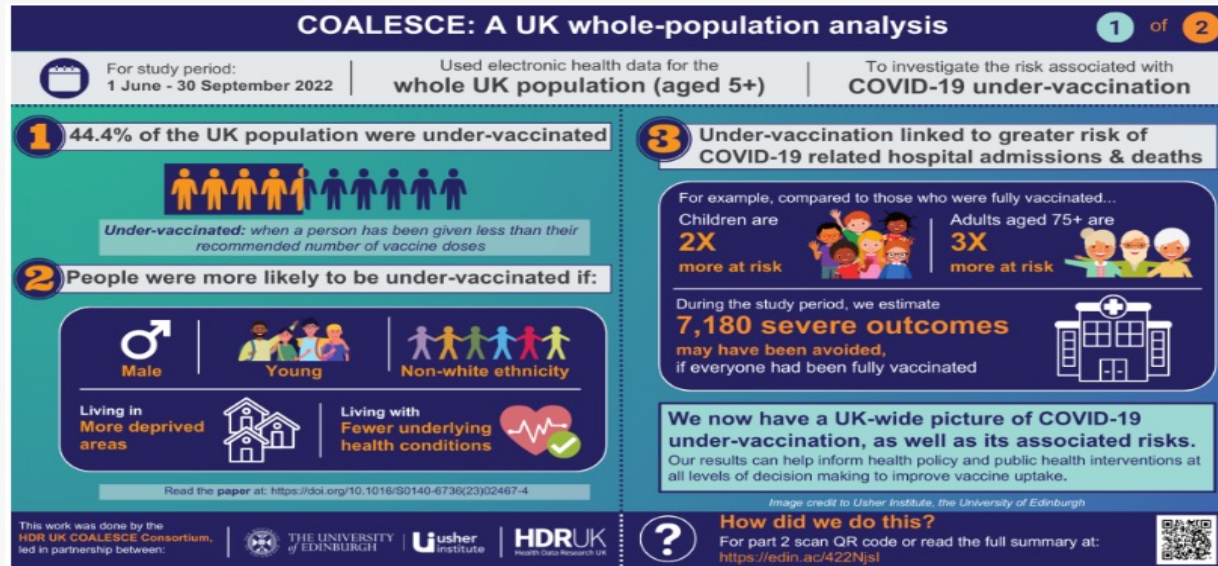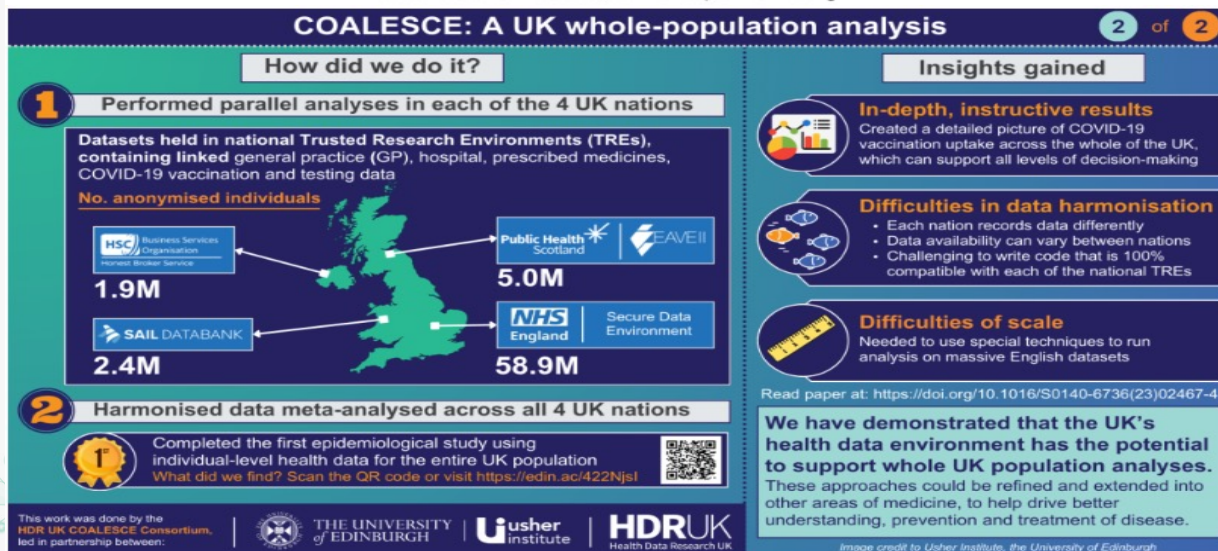
3. Promote Partnerships

Aligning incentives and **reducing complexity** across a fragmented landscape to streamline health data science

UK population study reveals impact of COVID-19 under-vaccination

Credit: Usher Institute, University of Edinburgh*

Published in *The Lancet*, the COALESCE study suggests that more than 7,000 hospitalisations and deaths might have been averted in summer 2022 if the UK had had better vaccine coverage.

With COVID-19 cases on the rise and a new variant strain recently identified, this research provides a timely insight into vaccine uptake and hesitancy which could inform policy-makers.

This study marks a significant milestone in HDR UK's mission to **unite the UK's health data to enable discoveries that improve people's lives** and demonstrates the value and potential of population-wide health data studies.

Data Standards and Quality

The Data Improvement work supports researchers and custodians across multiple areas of the "FAIR" approach (Findable, Accessible, Interoperable, Reusable).

Across the institute, HDR UK has made great progress in ensuring data is **F**indable and **A**ccessible, the focus now in Data Improvement will be on make data **I**nteroperable and **R**eusable.

Standards and data quality improvements will support research taking place in a federated manner across data custodians, as there must be consistency in data standards and use of data elements for analysis across multiple datasets.
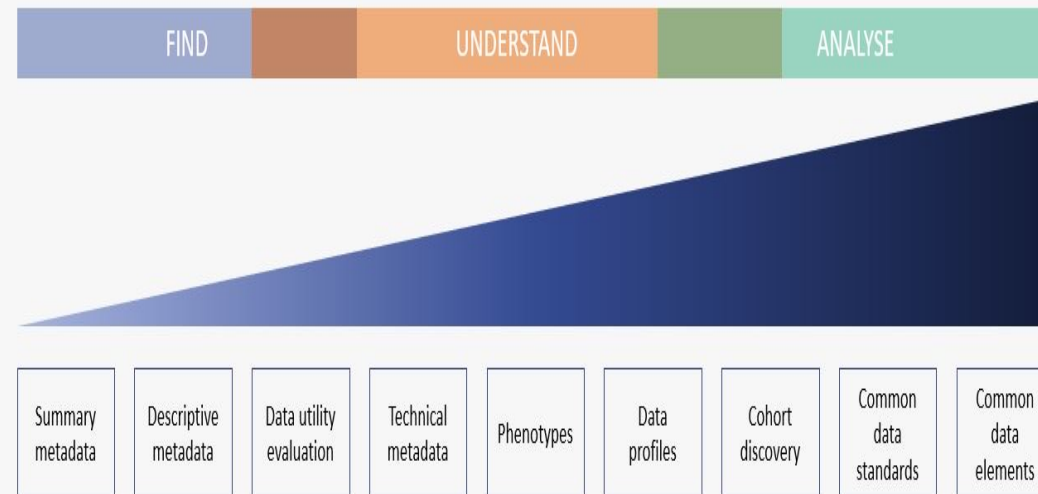

Fig 1. Metadata maturity gradient - information availability for a dataset.

Data Utility Framework - Development

Objectives The value of healthcare data is being increasingly recognised, including the need to improve health dataset utility. There was no established mechanism for evaluating healthcare dataset utility making it difficult to evaluate the effectiveness of activities improving the data.

To describe the method for generating and involving the user community in developing a proposed framework for evaluation and communication of healthcare dataset utility for given research areas.

Conclusion The process resulted in a user centred designed framework for objectively evaluating the likely utility of specific healthcare datasets, and therefore, of value both for potential users of health data, and for data custodians to identify the areas to provide the optimal value for data curation investment.

Development of a data utility framework to support effective health data curation | BMJ Health & Care Informatics

DATA-CAN: The vision

- **Improve access to existing data**
  - Clinical, academic & commercial

- **Improve quality of data**
  - Better data at the point of care
  - Enhanced curation of current data

- **Improve UK coverage**
  - Four nations of the UK

- **Add new datasets at scale**
  - Genetic/molecular, imaging, pathology
  - Primary care, PROMs

DATA-CAN: The Health Data Research Hub for Cancer

HDRUK
Health Data Research UK

Clinical data
High quality curated data
Structured and plain text (NLP)

Radiology
Application of AI and Machine Learning
to digital radiology images

Genetic and molecular
IHC to single gene
Whole genome sequencing

Pathology
Application of AI and Machine Learning
to digital pathology images

Ensure fair value
NHS & UK
Trusts & CCGs
Patients & public

The impact of COVID-19 on cancer, using open standards such as SNOMED CT, in both local and national cancer data

Covid-19 was shown to **impact cancer referrals** and have a significant **impact on projected excess deaths**. [1]

Access to the National SDE holding over **12 billion rows** of data and more than **50 million patients** in England
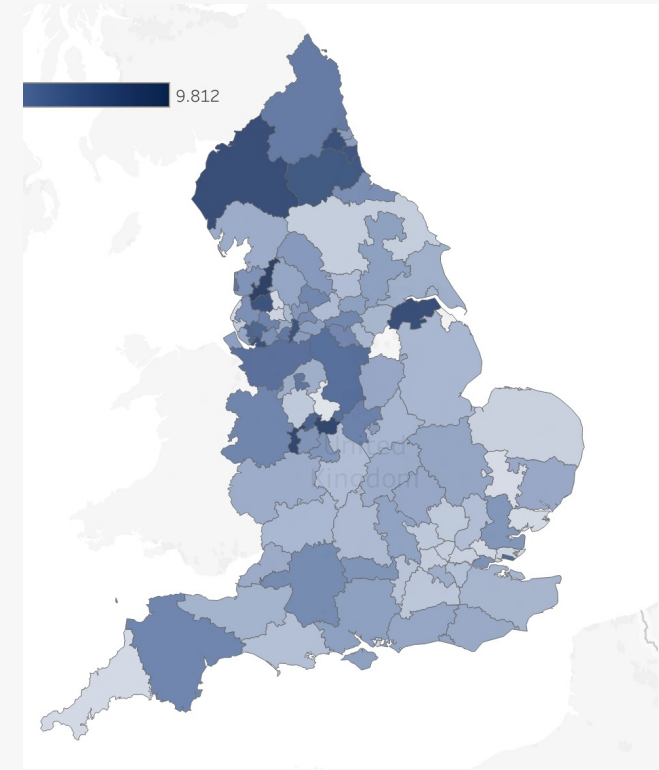
Leeds

Royal Free

UCLH

N.I.
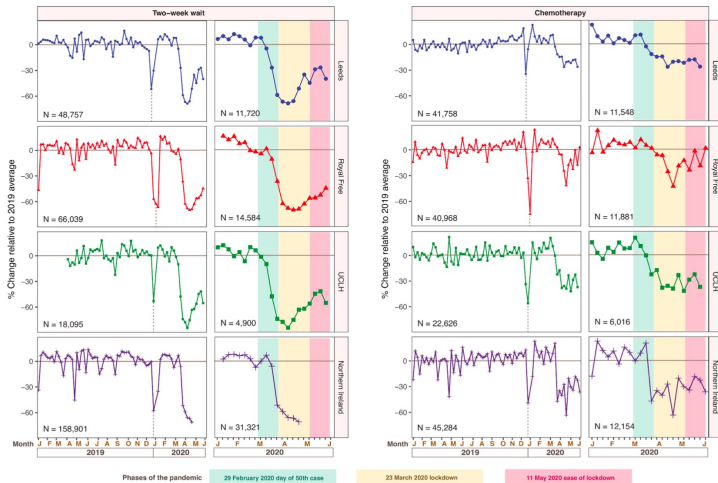
1. Lai AG, Pasea L, Banerjee A, Jones M, et al. Estimated impact of the COVID-19 pandemic on cancer services and excess 1-year mortality in people with cancer and multimorbidity: near real-time data on cancer care, cancer deaths and a population-based cohort study. **BMJ Open 2020;10:e043828**

COVID-19 and Cancer: "Real Time" Data analysis

- **DATA-CAN** researchers analysed data from Hospital Trusts across the UK
- **Looked at two measures to determine the effect of the pandemic on cancer services:**
  - **2 Week Waiting** Time for Cancer Referrals (early warning system for suspicion of cancer) - **7 out of 10 people with suspicion of cancer were not getting referred to cancer specialist services**
  - **Chemotherapy attendances** (proxy measure of the "health" of the cancer treatment service) - **4 out of 10 cancer patients were not getting access to their chemotherapy**
- **First data that drew attention of the government, academia, NHS and the public to the disastrous effect of COVID-19 on cancer services and cancer patients**

Lai AG, … Jones M, Lawler M, Hemingway H. Estimated impact of the COVID-19 pandemic on cancer services and excess 1-year mortality in people with cancer and multimorbidity: near real-time data on cancer care, cancer deaths and a population- based cohort study. *BMJ Open.* 2020;

Disruptions to cancer services across the pathway due to COVID-19

- **Disruption was felt across the entire cancer pathway**

- **Presentational Delay, Diagnostic Delay and significant impact on treatment**

- **Significant disruption of cancer research (clinical trials, discovery research, translational research)**
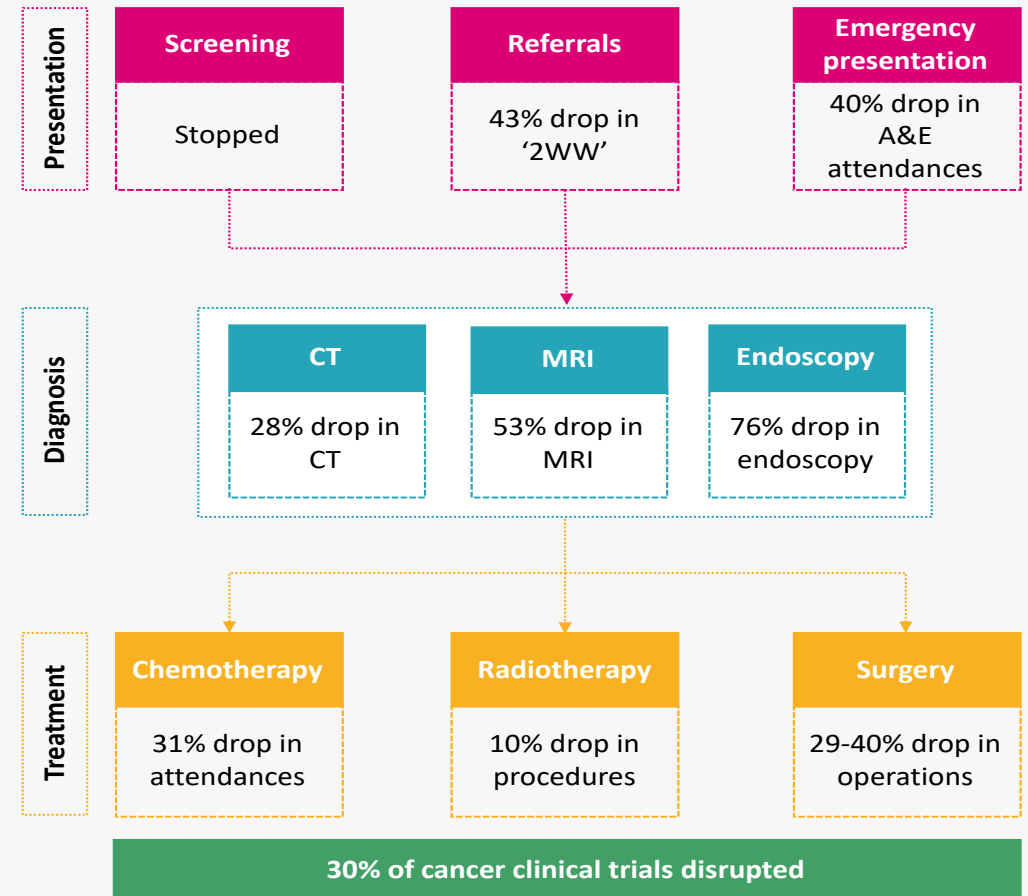
Sud A, Torr B, Loveday C, Jones M, Broggio J, ... McFerran E, Lawler M, Houlston R, Turnbull C. COVID-19 Lockdown and its impact on the two-week wait pathway for suspected cancer *(Lancet Oncology 2020)*

https://www.carnallfarrar.com/life-sciences/life-sciences-insights/disruption-and-recovery-of-cancer-from-covid-19/)

Presentation

Screening	Referrals	Emergency presentation
Stopped	43% drop in '2WW'	40% drop in A&E attendances

Diagnosis

CT	MRI	Endoscopy
28% drop in CT	53% drop in MRI	76% drop in endoscopy

Treatment

Chemotherapy	Radiotherapy	Surgery
31% drop in attendances	10% drop in procedures	29-40% drop in operations

30% of cancer clinical trials disrupted

Covid-19 and Cancer: Excess Mortality

- **Looked at excess mortality on data from nearly 4M citizens through a primary/secondary care linked data set**

- **Modelled different scenarios to determine excess deaths due to pandemic**

- **Used Real Time Data from Hospital Trusts to Inform the Model**

- **Significant predicted excess deaths (England) 7,165 – 17,910 excess deaths**
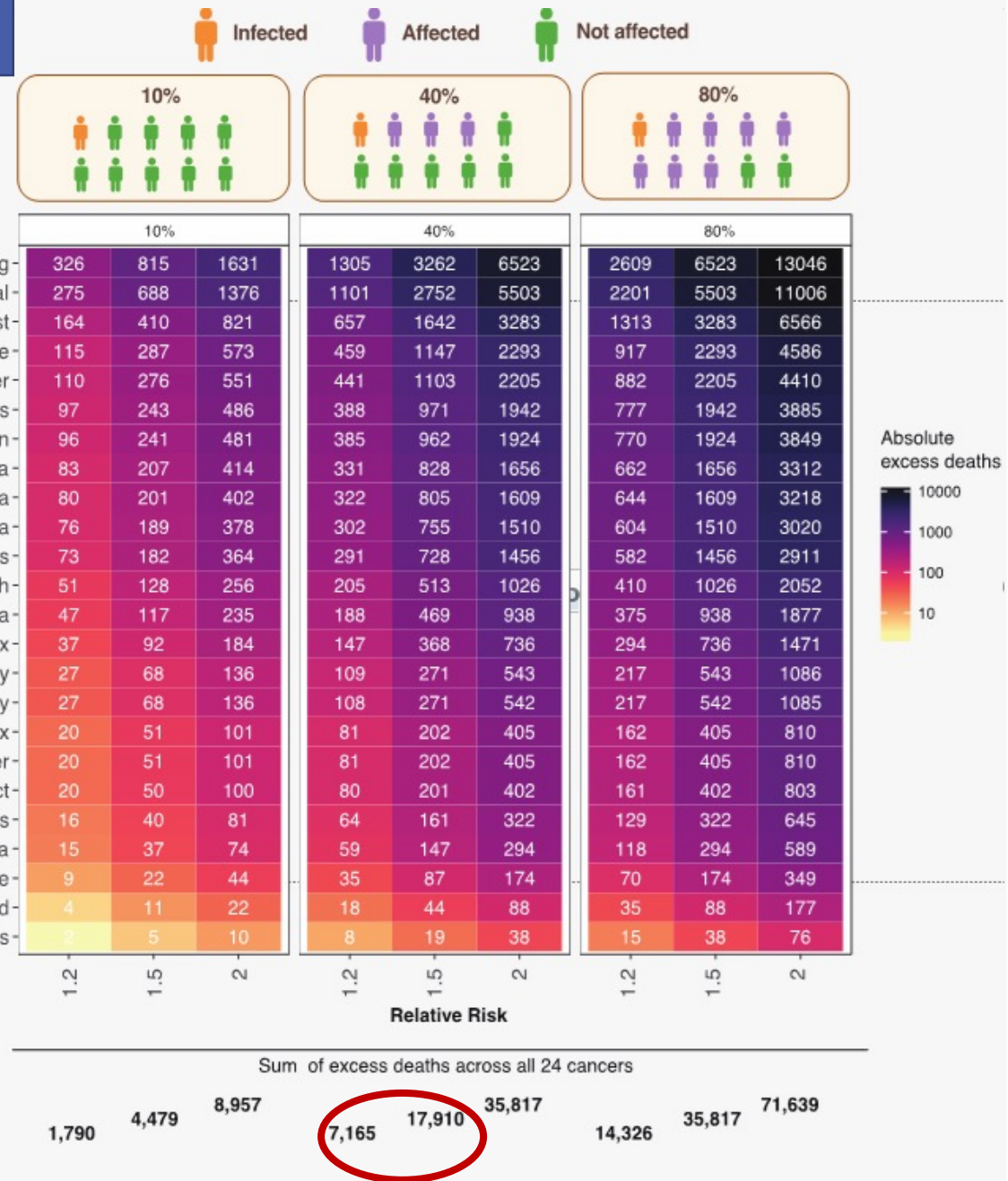
Lai AG, Pasea L, Banerjee A, Hall G, Denaxas S, Chang WH, Katsoulis M, Williams B, Pillay D, Noursadeghi M, Linch D, Hughes D, Forster MD, Turnbull C, Fitzpatrick NK, Boyd K, Foster GR, Enver T, Nafilyan V, Humberstone B,. Neal RD, Cooper M, Jones M, Pritchard-Jones K, Sullivan R, Davie C, Lawler M, Hemingway H *BMJ Open.* 2020;

Covid-19 and Cancer: Excess Mortality and Comorbidities

- **Additional risk of excess deaths with at least one additional underlying health condition (comorbidities)**

  - **Cardiovascular Disease**

  - **Hypertension**

  - **Diabetes**

  - **COPD**
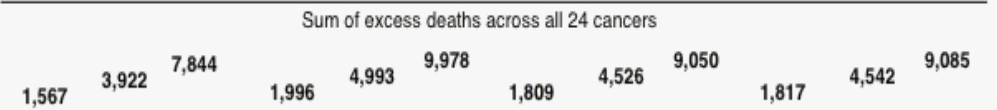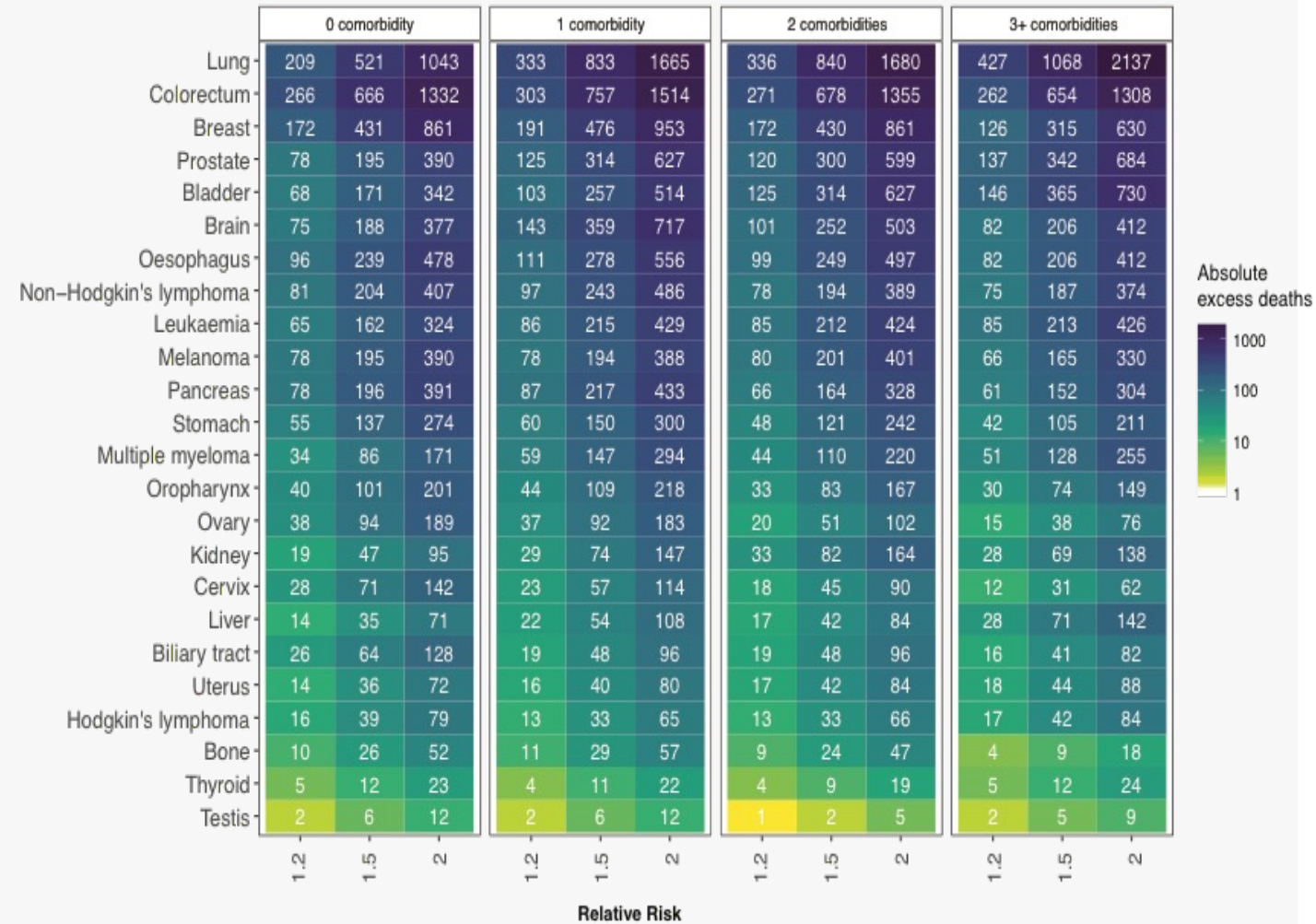
Lai AG, Pasea L, Banerjee A, Hall G, Denaxas S, Chang WH, Katsoulis M, Williams B, Pillay D, Noursadeghi M, Linch D, Hughes D, Forster MD, Turnbull C, Fitzpatrick NK, Boyd K, Foster GR, Enver T, Nafilyan V, Humberstone B,. Neal RD, Cooper M, Jones M, Pritchard-Jones K, Sullivan R, Davie C, Lawler M, Hemingway H *BMJ Open.* 2020;

One Step Forwards … Two Steps Backwards

- **Following months of disruption, stage shift in detection of cancer i.e. detecting cancer later rather than earlier due to disruptions to the cancer pathway significantly affected five-year survival**

- **For certain cancers e.g. colorectal the COVID-19 pandemic set us back nearly a decade**

https://www.carnallfarrar.com/life-sciences/life-sciences-insights/disruption-and-recovery-of-cancer-from-covid-19/)

Five-year survival anticipated (England)

Lung													
7.4%	7.6%	8.0%	8.3%	8.9%	10.4%	11.0%	12.4%	13.0%	13.5%	14.2%	15.3%	15.4%	16.2%
2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2020*	2017

Breast													
78.1%	78.8%	79.6%	80.1%	80.7%	83.6%	82.8%	83.5%	84.1%	85.6%	85.0%	85.0%	85.3%	85.0%
2005	2006	2007	2008	2009	2010	2011	2020*	2012	2013	2014	2015	2016	2017

Colorectal													
50.8%	51.5%	52.5%	53.5%	54.7%	56.1%	57.9%	58.3%	59.6%	59.6%	59.4%	59.0%	59.1%	58.4%
2005	2006	2007	2008	2009	2020*	2010	2011	2012	2013	2014	2015	2016	2017

SOURCE: CF analysis, Office for National Statistics, Cancer survival in England, adults diagnosed
* Anticipated 5-year survival for 2020, calculated from 2017 figures

Covid-19 and Cancer: Influence and Impact

- **Results shared** pre-submission with governmental/NHS stakeholders including all four CMOs, National Cancer Director and SAGE, **contributed to decision** to start restoring cancer services

- **Association of British Pharmaceutic Industries:** DATA-CAN should be supported to help "restore standards of care in cancer."

- **Research Community** – Over 24,000 hits on ResearchGate and 127 citations in further research

- **Media/Public: Main story** Guardian, Telegraph; **significant coverage** Daily Mail, Financial Times, Sun, Sunday Independent, Wall Street Journal, others including print/online in France, Germany and Spain

- **Lead story** on Sky News; Interviews with BBC, ITV, Channel 4, NBC News, SBS News, multiple local radio

- **Media Question to Prime Minister** on his first press briefing post return from COVID-19 hospitalisation

- Featured prominently in **BBC Panorama** and **BBC Spotlight** programmes on Cancer and COVID

- **Quoted extensively** in report from **Carnall Farrar** and the **Institute for Public Policy Research**

- Won the **Royal College of Physicians (RCP)** research award **#EPCA2021** for original research that has contributed to significant improvements in health outcomes or the quality of patient care

The impact of COVID-19 on cancer - Analysis

Enumerating the impact of COVID-19 on cancer pathways: a robust evaluation of the NHS England Secure Data Environment (SDE)

DATA-CAN delineated the precise impact of the COVID 19 pandemic on cancer systems and cancer patients. This required access to both historical data (pre-2020) and near real-time data on patients referred with (i) a suspicion of cancer and (ii) those diagnosed with and/or managed for cancer.

The emphasis was on data on cancer referral, cancer diagnosis, cancer treatment and cancer outcomes, examining the impact of age, ethnicity, deprivation, comorbidity and concurrent medication.

WP 2.1 - Indirect impact of COVID-19 on cancer:

WP 2.2 - Influence/associations of cancer on COVID-19 outcomes (such as admissions to hospital, admission to ITU, mechanical ventilation and death):

WP 2.3 - Influence/associations of cancer risk factors on COVID-19 outcomes:

WP 2.4 - Influence/associations of cancer medications on COVID-19 outcomes:

WP 2.5 - Direct impact of COVID-19 disease on cancer disease occurrence, re-occurrence and outcomes in short, medium and long term:

These analyses required access to linked data from the personal demographic service, primary care, hospital emergency, inpatient and outpatient care, intensive care, registered deaths by cause, cancer registries and COVID-19 laboratory testing. All data are accessed by named, approved researchers in the Cancer SDE within NHS England.

Utilising the power of SNOMED CT to evidence the impact of the pandemic on cancer patients

HDRUK and DATA-CAN used live and historic comorbidity data coded using SNOMED CT to highlight the effect of the COVID-19 pandemic on cancer wait times, treatment attendance and outcomes

Lifesaving researchers: HDRUK and DATA-CAN

Health Data Research UK (HDRUK) is the national health data science institute, with a vision that "every health and care interaction and research endeavour will be enhanced by access to large scale data and advanced analytics."
Previous projects have included using healthcare data to understand causes of deaths of homeless people, understanding suicide risk and identifying why ethnic minority groups were at greater risk from COVID-19.

DATA-CAN is HDRUK's cancer hub; a unique partnership of NHS organisations, patients, charities, academic institutions, and industry working across all four nations of the United Kingdom. DATA-CAN works to use the nation's healthcare data that is accessible to researchers and healthcare professionals working with cancer, to improve outcomes. The organisation also contributes to funded cancer research and produces quality cancer datasets for this purpose.

Chief Data Officer at University of Leeds and HDRUK Associate Director, Monica Jones

The impact of COVID-19 on cancer patients

The COVID-19 pandemic was an uncertain and challenging time for the entire world, and many patients across the health and care system were impacted directly or indirectly as a result. One cohort of patients who encountered many challenges across the health and care system were patients affected by cancer, including those with a suspected or existing diagnosis. These patients were identified as being vulnerable, and at a higher risk from having severe symptoms or dying from the virus.
Because of this, NHS cancer services were forced to adopt new operating practices, introduce enhanced safety measures, and review priorities, all of which significantly changed the patient experience.

HDRUK and DATA-CAN, 2024

"Using information recorded using SNOMED CT meant this critical comorbidity data was accessible in real-time from a range of care settings and sources. This information was then used as the basis to highlight how people with cancer were more likely to die from COVID-19, and how their interactions with lifesaving services were affected by the pandemic"

1. Cancer 2WW referrals - Dramatic fall
2. Cancer diagnoses - Significant fall
3. Mode of presentation - Increase emergency, decrease 2WW, loss screening
4. Stage at presentation - Stage shift (more advance disease)
5. Surgery - Decrease in number and complexity
6. Chemotherapy - Decrease in use, especially adjuvant, decrease intensity
7. Radiotherapy - Decease in use, lower numbers of fractions
8. Survival - Negative impact on 30-day, 90-day and 1, 2 & 5 year survival
9. PROMs - Not possible in real time
10. End of life - Shift from hospital and hospice to home

https://nhsengland.kahootz.com/gf2.ti/f/762498/196619525.1/PDF/-/SNOMED%20Implementation_Case%20Studies_HDRUK%20Case%20Study%20v3.0.pdf

QUESTIONS ?
NOW OR
LATER

Monica Jones FBCS CITP MInstLM
www.linkedin.com/in/monicacmjones
m.c.m.jones@leeds.ac.uk