

Getting Back on Track: Follow the Science, Follow the Data

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Driver Programme

Chair, International Cancer Benchmarking Partnership

Co-Lead, All Island Cancer Research Institute (AICRI)

Co-Lead, AICRI Start an All Island Partnership of Scale (HEA North
South Research Programme (NSRP))

Co-Lead, All Island eHealth Emerging Hub of Excellence for Cancer



Windsor Castle, December 2024



Global Alliance
for Genomics & Health

THE LANCET
Oncology

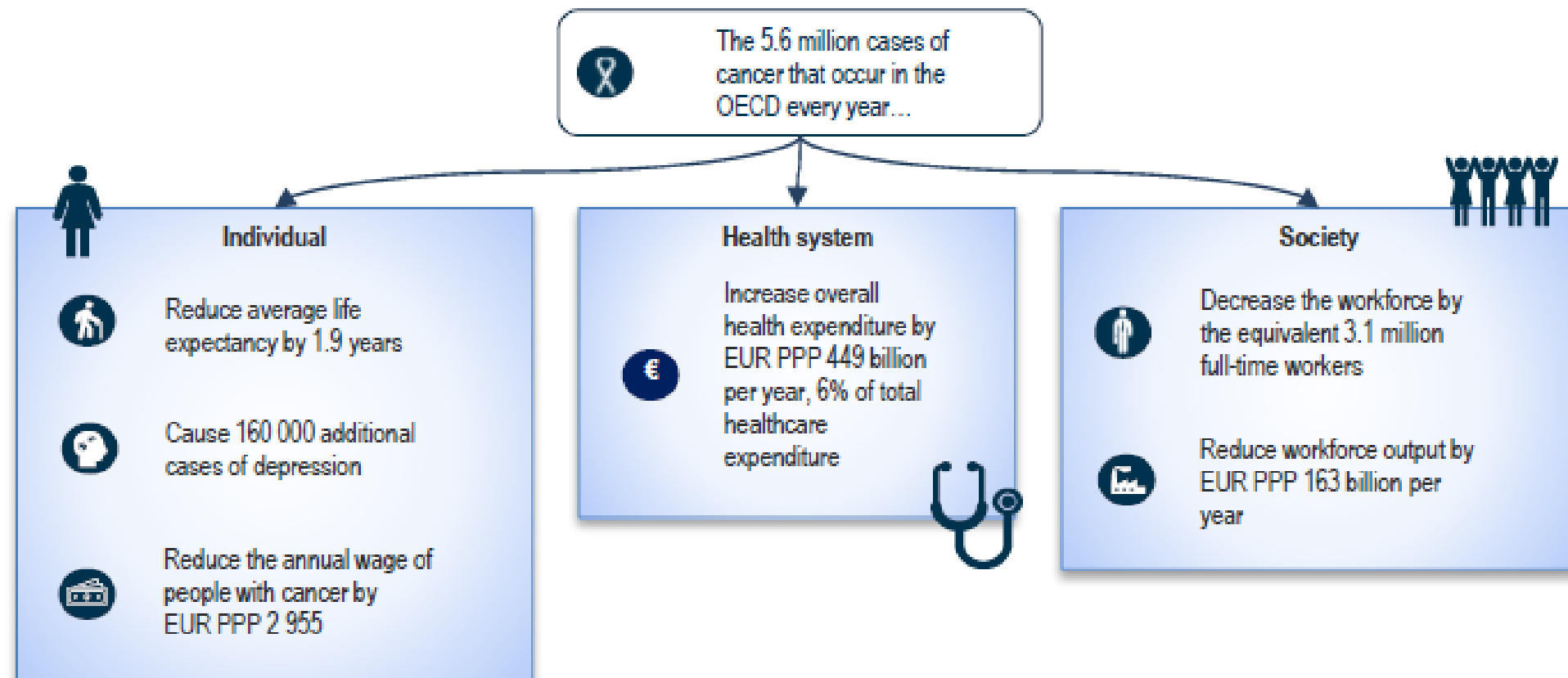
DATA-CAN
The Health Data Research Hub for Cancer

ICBP
International Cancer
Benchmarking Partnership

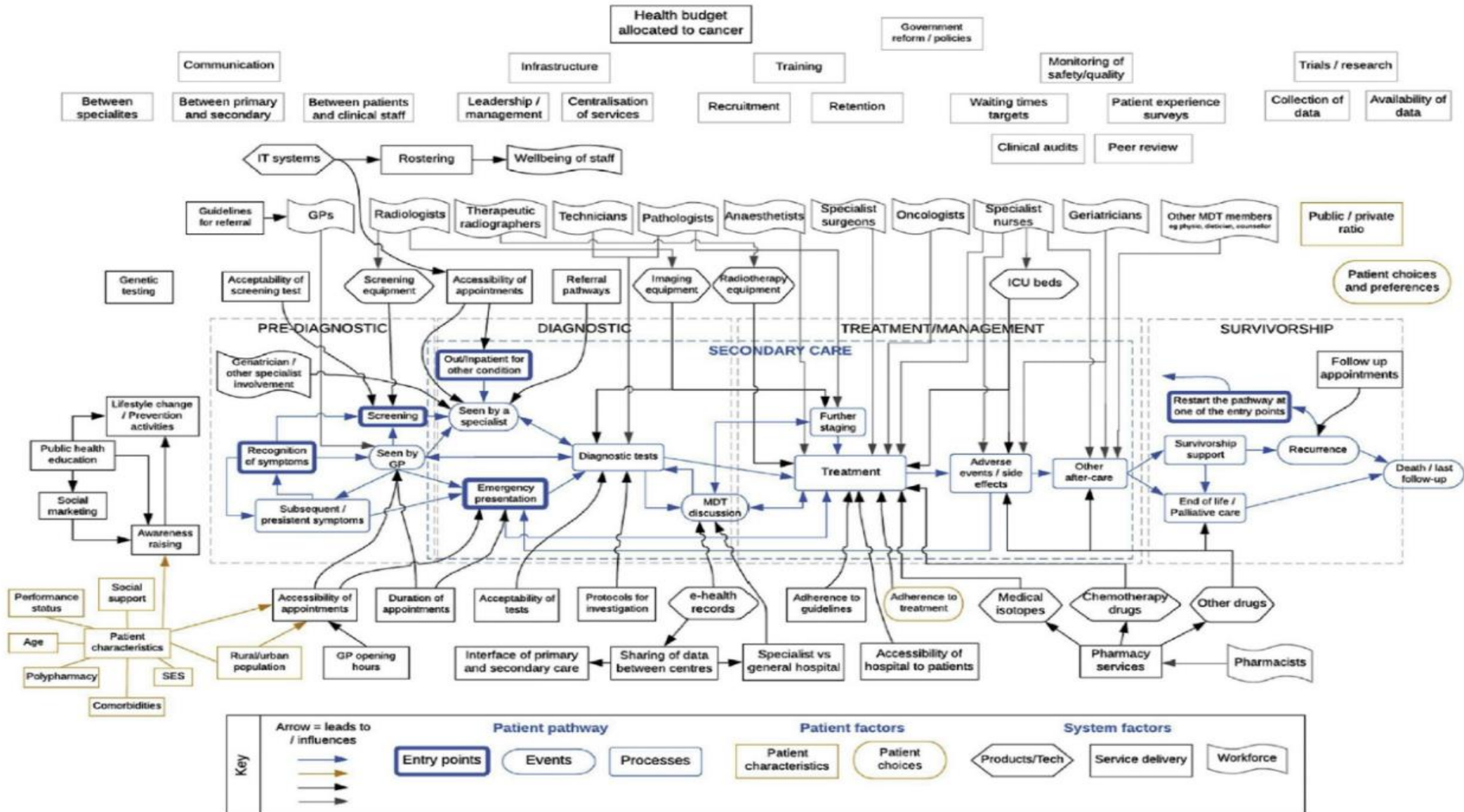


Cancer: The Greatest Challenge in Human and Societal Health

Figure 1.1. The burden of cancer on individuals, health systems and society



The Complex Continuum of Cancer Care: Why we really need a National Cancer Plan!



The European Cancer Pulse: Tracking Inequalities in Cancer Care in Europe

- Interactive data visualisation tool **mapping and tracking inequalities in cancer** across the WHO European region **and their resolution**
- Bringing together in **one place** multi-stakeholder data intelligence for:
 - EU and non-EU European countries
 - All areas of cancer pathway
 - Cancer policies
 - Social inequalities
 - All types of available data sources
- Currently captures data from **49 European countries**, on **280+ indicators** in **24 inequalities categories**, with **>13,000 data points**.

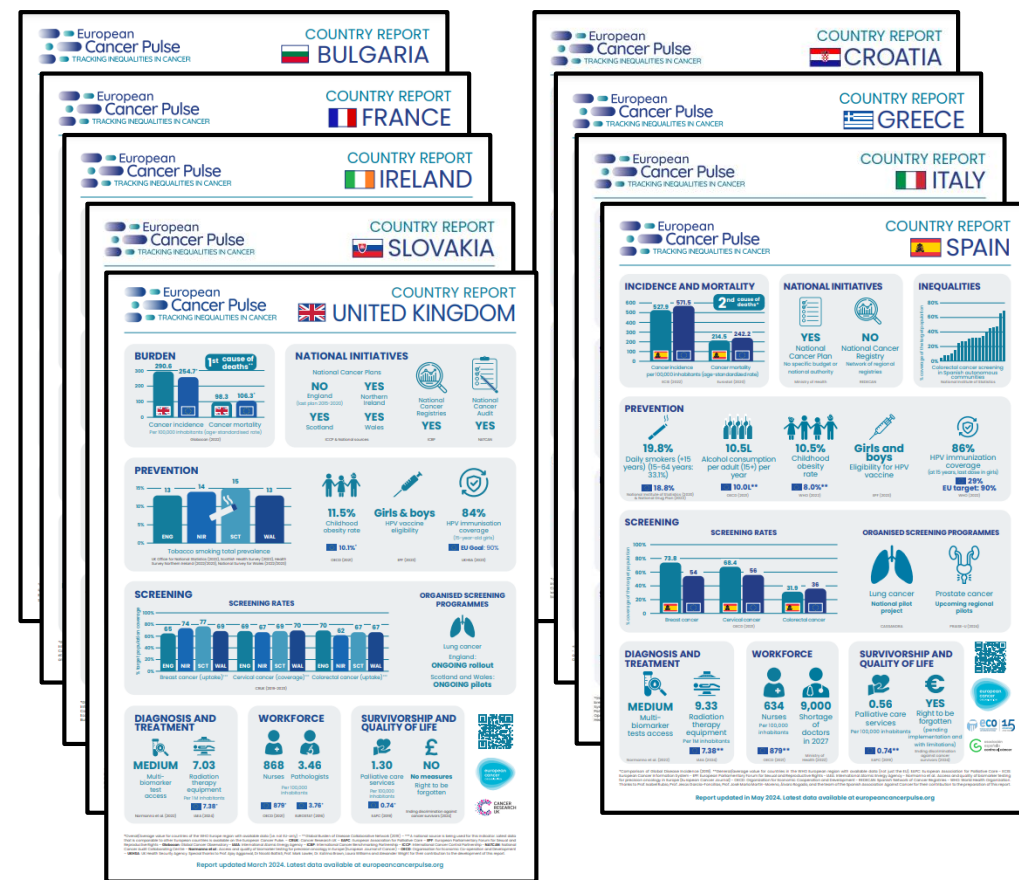


Couespel N, Venegoni E, Lawler M. The European Cancer Pulse: tracking inequalities in cancer control for citizen benefit
Lancet Oncology May;24(5):441-442

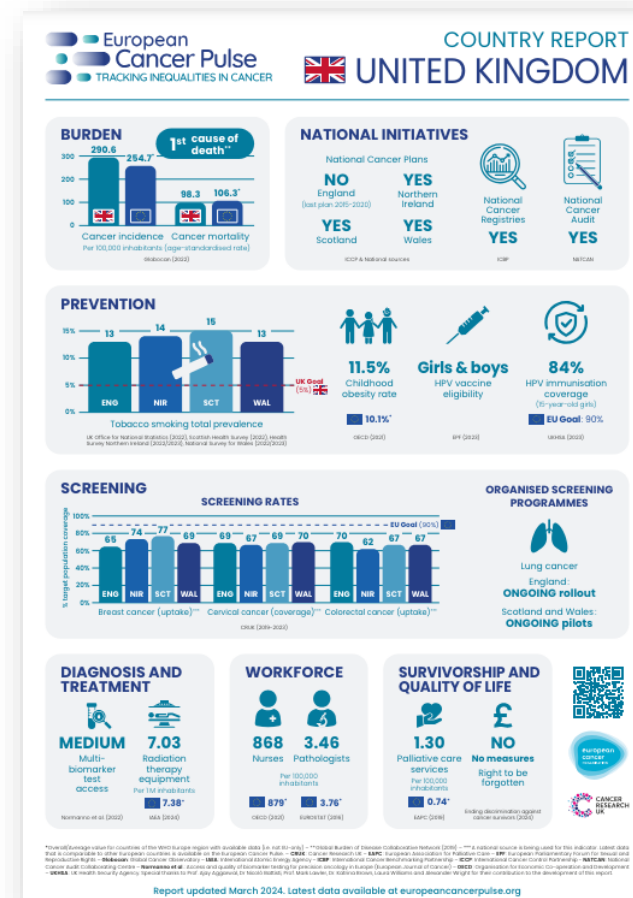
<https://www.europeancancer.org/pulse>

The European Cancer Pulse: Data to Action

- **Country reports** are produced as **national factsheets** (9 countries to date), including **key data** from the Pulse tool
- Reports developed in collaboration with **local institutions and experts**
- Form the basis of country visits of the **‘Time to Accelerate: Together Against Cancer’** pan-European campaign, driving **high media and policy impact** nationally



United Kingdom launch: City of London



- **Key impact:** Highlighting the **cancer workforce crisis** in the UK

UK Cancer Workforce – UNDER PRESSURE

NEW PUBLICATION
A Report on the Cancer Workforce Crisis

**Launch at the
European Cancer Summit**
Wednesday, 20 November 2024

TIME TO **ACCELERATE** FOR OUR WORKFORCE
TOGETHER AGAINST CANCER

europ^{ean} cancer ORGANISATION

UNDER PRESSURE
Safeguarding the health of Europe's oncology workforce

A report and policy action plan of the European Cancer Organisation Workforce Network

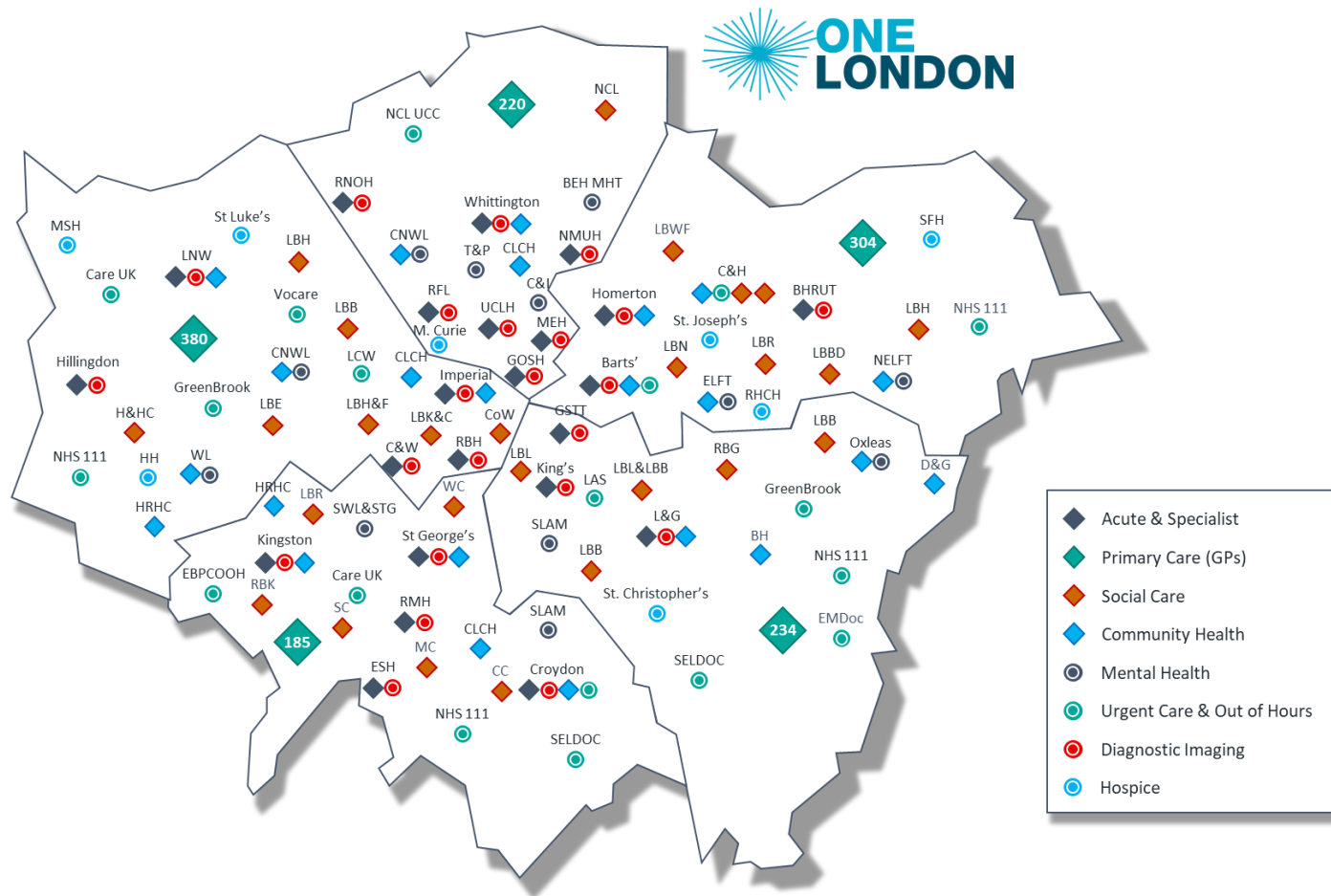
europ^{ean} cancer ORGANISATION

european-cancer.org/workforce-crisis

- **49%** of UK cancer professionals often feel that their **workload seems endless**
- **45%** of UK cancer professionals feel that **administrative rules** and **procedures** make their job **too difficult**
- **45%** of UK cancer professionals often feel that their **work exhausts them**
- **18%** of UK cancer professionals experience **high levels of burnout**
- *Former UK Cancer Minister, Steve Brine, said; "When I wrote the last cancer plan for England, I **regretted not getting an accompanying workforce strategy out at the same time**. The **two go hand in hand** so this is an important report from the European Cancer Organisation."*

Launched at European Cancer Summit November 2024

Vignette I: Addressing the workforce crisis – The Impact of Digital Transformation



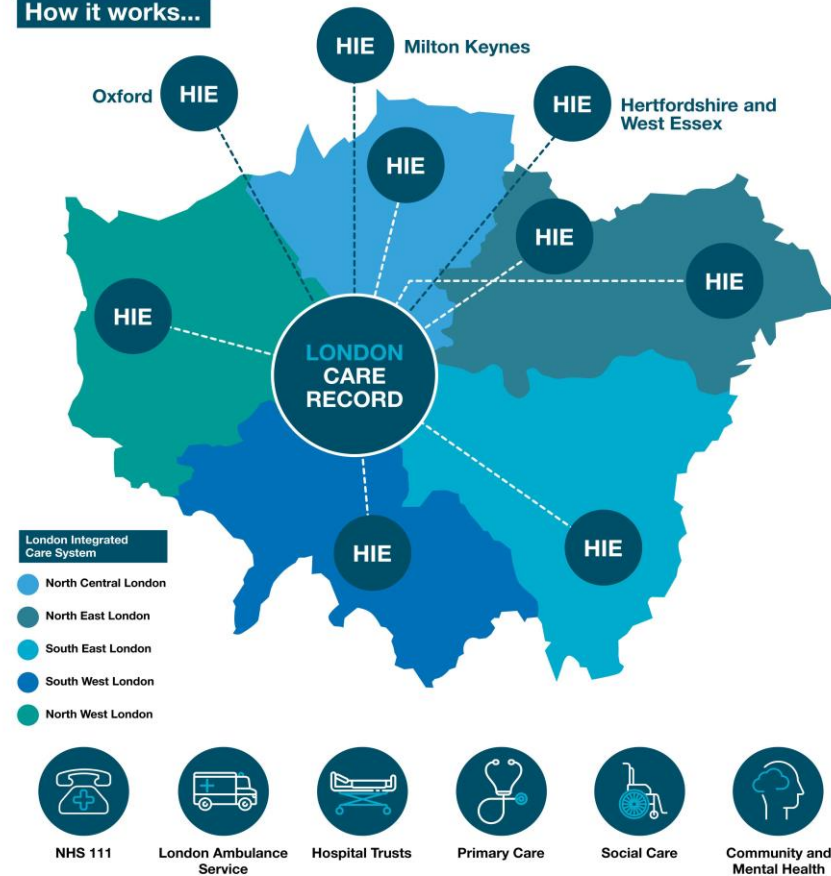
- Almost 10 million population
- 5 Integrated Care Systems
- 40+ NHS Trusts, 1,400 general practices, 33 local authorities

The London Care Record: Creating a Digital London



London Care Record

How it works...



- London Care Record
- Connects London up digitally
- Used >17.7 million times by frontline health and care staff during 2023
- >100,000 staff use the London Care Record per month
- Viewed around 2 million times a month

HIE Health Information Exchange
A shared care record brings together separate records from the different organisations involved in your health and care. The shared care records in London are based on a product called the Health Information Exchange (or HIE) from Cerner.

Access is ☒ Logged ☒ Monitored ☒ Audited

Summary of Impact with a particular focus on the workforce



Estimated monthly savings potentially **~£2M**



Since its Launch, OneLondon is estimated to have **saved the equivalent of £44.4 million**



FTE staff time saved: **1.3M minutes / per month**



Average time-based saving per system access
£0.29 - £1.61



Overall, the OneLondon initiative presents **significant benefits** by **improving staff and systems efficiency, reducing costs, and enhancing patient safety** in the healthcare system.



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Economic Analysis of Digital Health Infrastructure:

The Case of OneLondon's Impact on Time Efficiency and Safety in Healthcare Services



Authors: Ethna McFerran, Sanjay Gautama, Emma Pace, Sally Wiltshire, Jocelyn Palmer, Phil Koczan, Luke Readman, Mark Lawler

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£0.20



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significant benefits by **improving staff and systems efficiency, reducing costs, and enhancing patient safety** in the healthcare system.



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Economic Analysis of Digital Health Infrastructure:

The Case of OneLondon's Impact on Time Efficiency and Safety in Healthcare Services



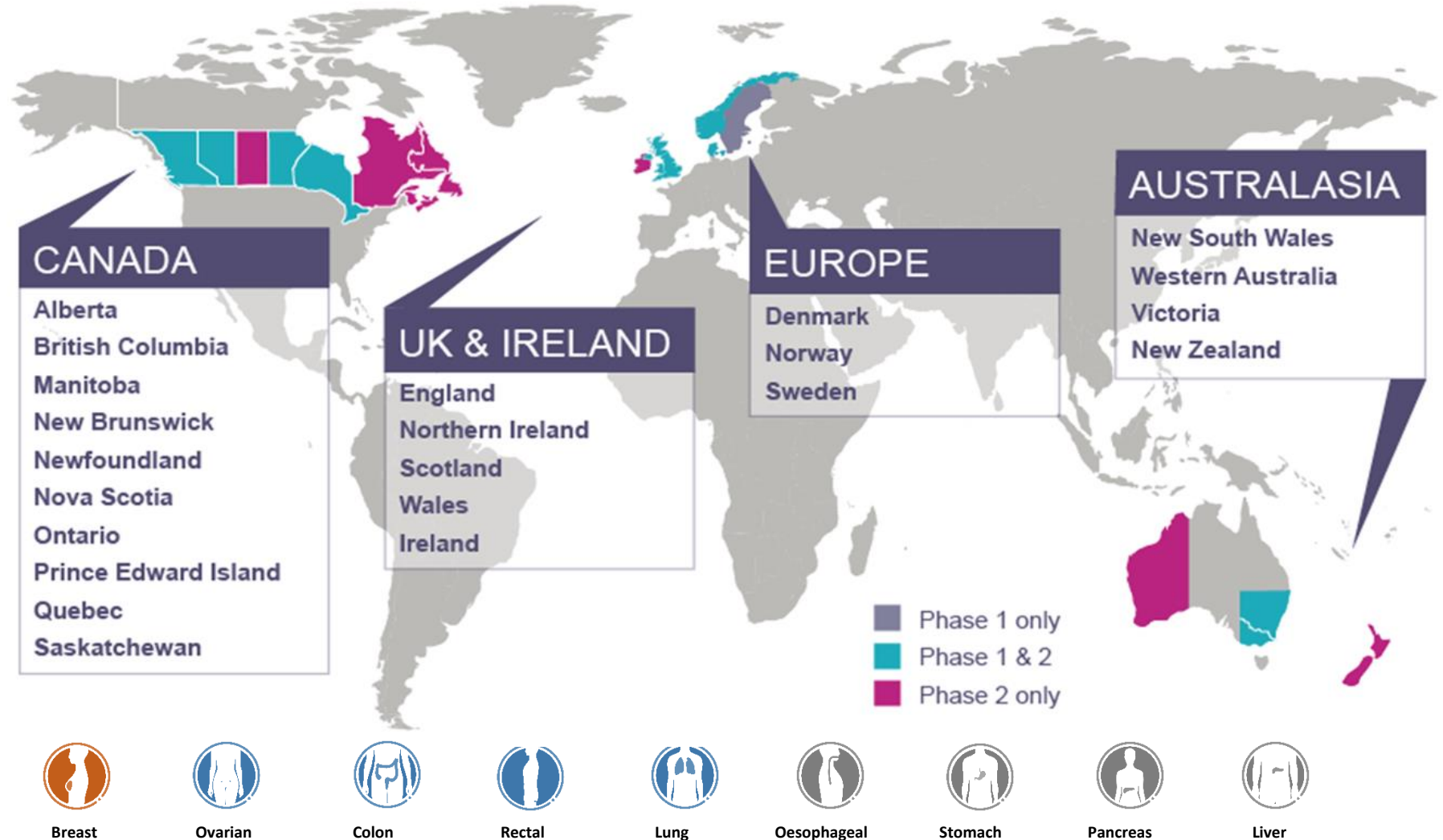
Authors: Ethna McFerran, Sanjay Gautama, Emma Pace, Sally Wiltshire, Jocelyn Palmer, Phil Koczan, Luke Readman, Mark Lawler

Data to Policy : The International Cancer Benchmarking Partnership - Capturing and exploring differences in cancer survival and outcomes

Explores differences in cancer survival and outcomes & factors that may be contributing.

Provide evidence for policy & practice change –to improve patient outcomes.

Partnership of clinicians, researchers, policy makers and data experts.



All our partners have:

- Population based cancer registries
- Similar spend on healthcare
- Universal access to health care

The cancer sites chosen:

- Include relatively common cancers and cancers that are hard to treat in high-income countries
- Experience significant variation in cancer survival
- Contribute to overall burden of disease in high-income countries

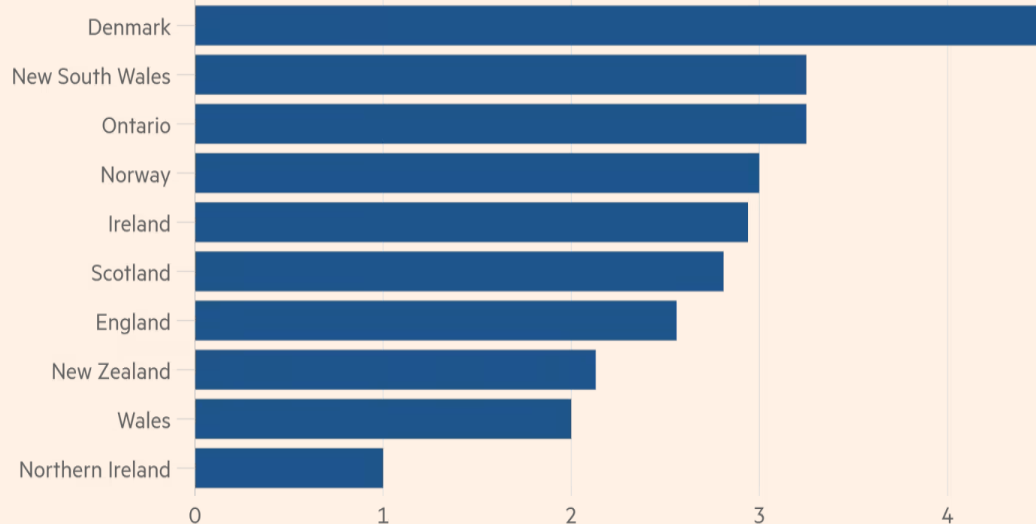
The need for consistent cancer policy AND FOLLOW THE DATA

Nolte E, Morris M, Landon S, McKee M, Seguin M, Butler J, Lawler M. [Exploring the link between cancer policies and cancer survival: a comparison of International Cancer Benchmarking Partnership countries](#). *Lancet Oncol*. 2022 Nov;23(11):e502-e514

- Our ICBP study [links consistent cancer policy](#) and better outcomes
- Our [Policy scorecard](#) indicates that **the UK is at the bottom of this league table**
- Why? And Why has England **abandoned** its cancer plan?
- NI **has only fully implemented** ONE cancer strategy **in 20 years**

Denmark leads the way on the consistency of its cancer policies

Consistency of cancer policies in 10 jurisdictions, 1995-2014*



*Data are weighted scores

Source: International Cancer Benchmarking Partnership

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UK lags behind comparable countries in cancer survival rates, study finds

Research draws link between strategies to combat disease and the time people live after diagnosis

Chemotherapy being administered. Researchers' findings suggest jurisdictions that score higher on cancer policy consistency also largely show improvements in five-year survival © Bella West/Alamy

**We Need to
Do a
Denmark!**



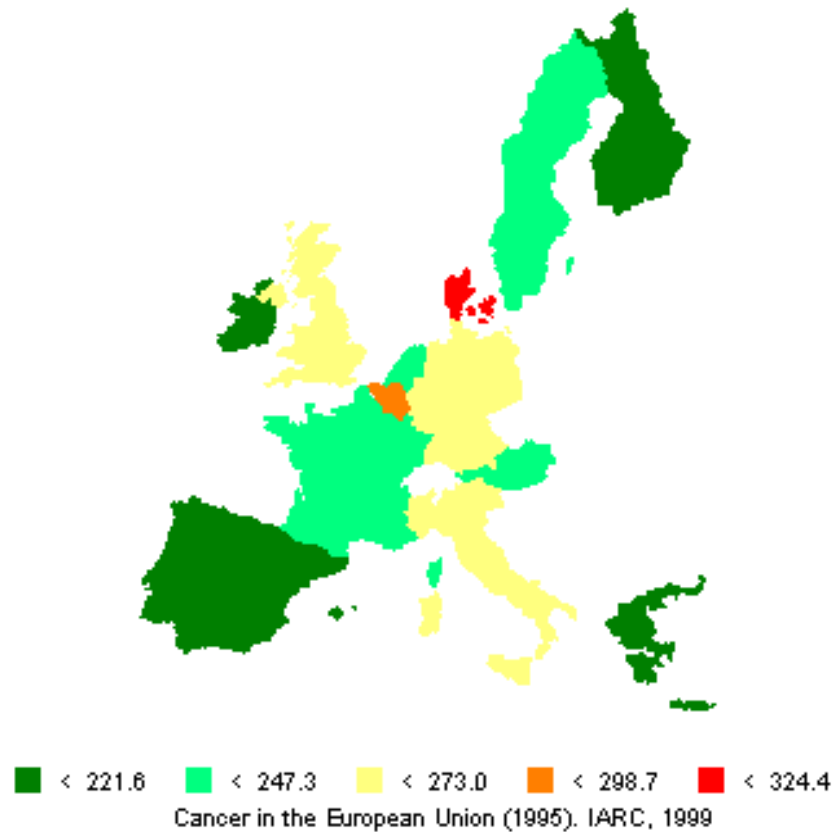
- **WHAT ABOUT THE UK?**
- **OUR POLICIES MUST MATCH OUR AMBITION!**
- **How not to do it:**
 - Announce a War on Cancer to much fanfare on World Cancer Day 2022
 - Subsume cancer plan into Major Conditions Strategy in 2023
- **Opinion is the lowest form of evidence**
- Presented the Evidence Base to the **House of Commons Health and Social Care Select Committee Inquiry on The Future of Cancer**
- **Key recommendation: Restore a National Cancer Plan as a matter of urgency**
- **LET'S BE LEADERS NOT LAGGERS!**



¹Lawler M, Aggarwal A, Gralow J, Sullivan R, Price P. [The UK needs to be a leader, not a lagger, in the global cancer effort.](#) *Lancet Oncology*, October 2024

At turn of the century, Denmark had highest cancer incidence and mortality in Europe

Mortality from All sites but skin: Crude rate-Both sexes (All ages)



BUT: A Decision made at highest level to do something about it



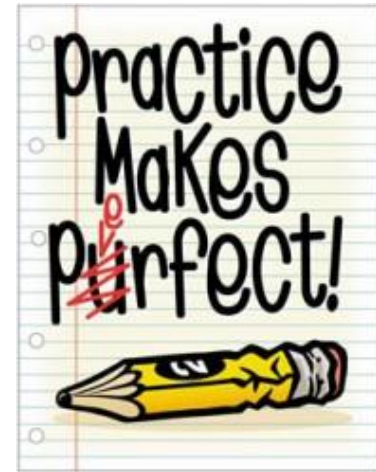
- Investment in **radiotherapy capacity**
- **Centralization** of treatment (esp. surgery)
- **Screening** programmes
- **Multidisciplinary** Groups
- **Organisation** of diagnostics and treatment (cancer pathways)
- **Disease-specific** follow-up
- Pathways for **rehabilitation & palliation**
- **Patient-responsible** doctor
- **Patient Reported Outcomes** in cancer care
- Danish **Comprehensive Cancer Centre**



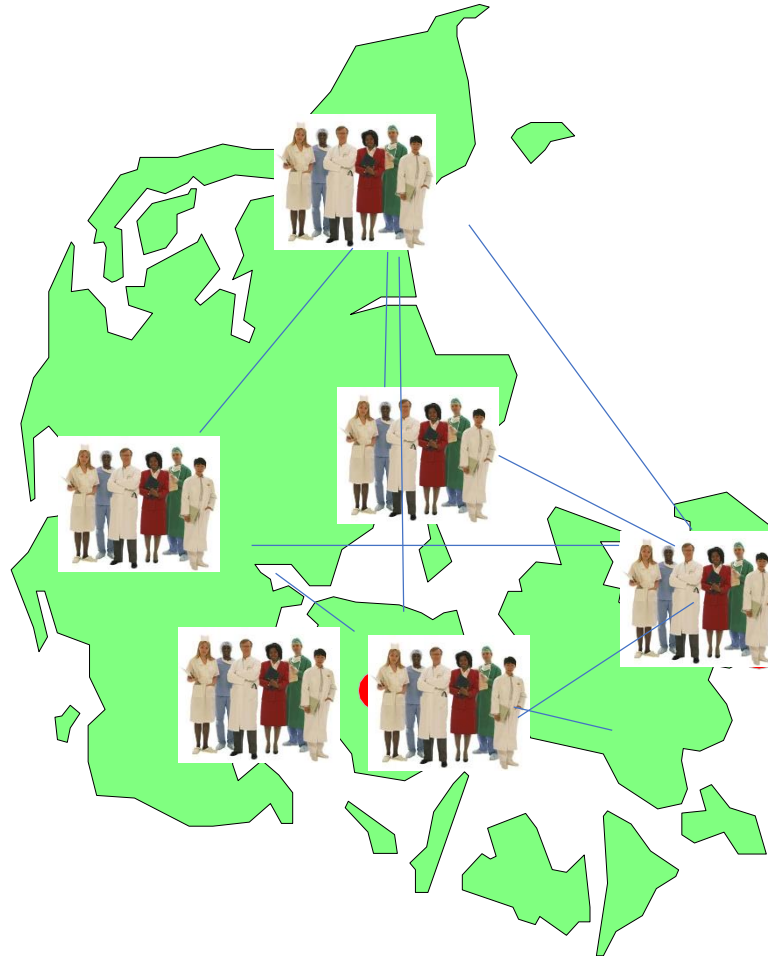
Large investments in radiotherapy and complete reorganization of cancer surgery



For example, **ovarian cancer surgery** – move from **58 departments** to **4 centers**



Creation of Danish Multidisciplinary Cancer Groups



- Clinical guidelines
- National databases
- Biobanks
- Early warnings
- Research protocols
- International collaboration
- Quality assurance



[AKUT LEUKÆMIGRUPPEN \(ALG\)](#)

[DANISH BREAST CANCER COOPERATIVE GROUP \(DBC\)](#)

[DANISH COLORECTAL CANCER GROUP \(DCCG\)](#)

[DANISH HEAD AND NECK CANCER GROUP \(DAHANCA\)](#)

[DANSK OKULÆR ONKOLOGI GRUPPE \(DOOG\)](#)

[DANSK ANAL CANCER GRUPPE](#)
Pt. ingen hjemmeside - nærmere følger

[DANSK GYNÆKOLOGISK CANCER GRUPPE OG DATABASE \(DGCG & DGCD\)](#)

[DANSK LUNGE CANCER GRUPPE \(DLCG\)](#)

[DANSK LYMFOM GRUPPE \(DLG\)](#)

[DANSK MELANOM GRUPPE \(DMG\)](#)

[DANSK MYELOMATOSE STUDIEGRUPPE](#)

[DANSK NEUROONKOLOGISK GRUPPE \(DNOG\)](#)

[DANSK PANCREAS CANCER GRUPPE \(DPCG\)](#)

[DANSK PÆDIATRISK HÆMATOLOGI OG ONKOLOGI \(DAPHO\)](#)

[DANSK SARKOM GRUPPE](#)

[DANSK STUDIEGRUPPE FOR KRONISKE MYELOIDE SYGDOMME](#)

[DANSK UROLOGISK CANCER GRUPPE \(DUCG\)](#)

[ØVRE GASTROINTESTINAL CANCER \(ØGC\)](#)

[DMCG-PAL](#)

Fast-track Cancer Pathways



Pre-booked **fast-track**
diagnostics, staging and treatment

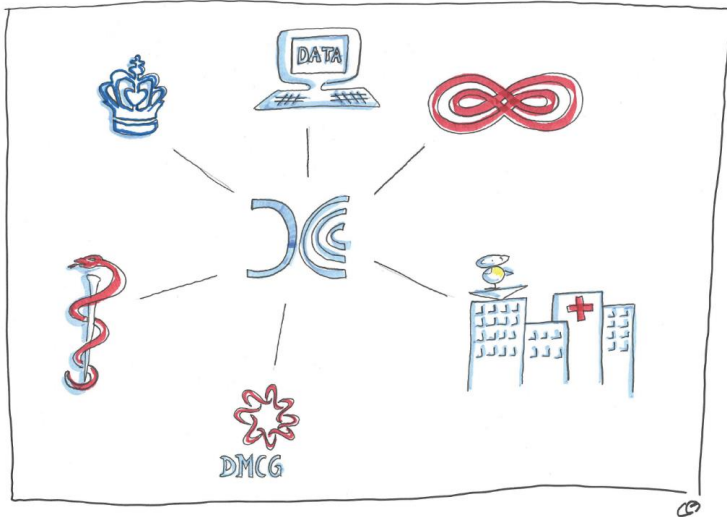
Monitoring and **reinforcing** targets in
trajectory



'Cancer packages'



Danish Comprehensive Cancer Center (DCCC)

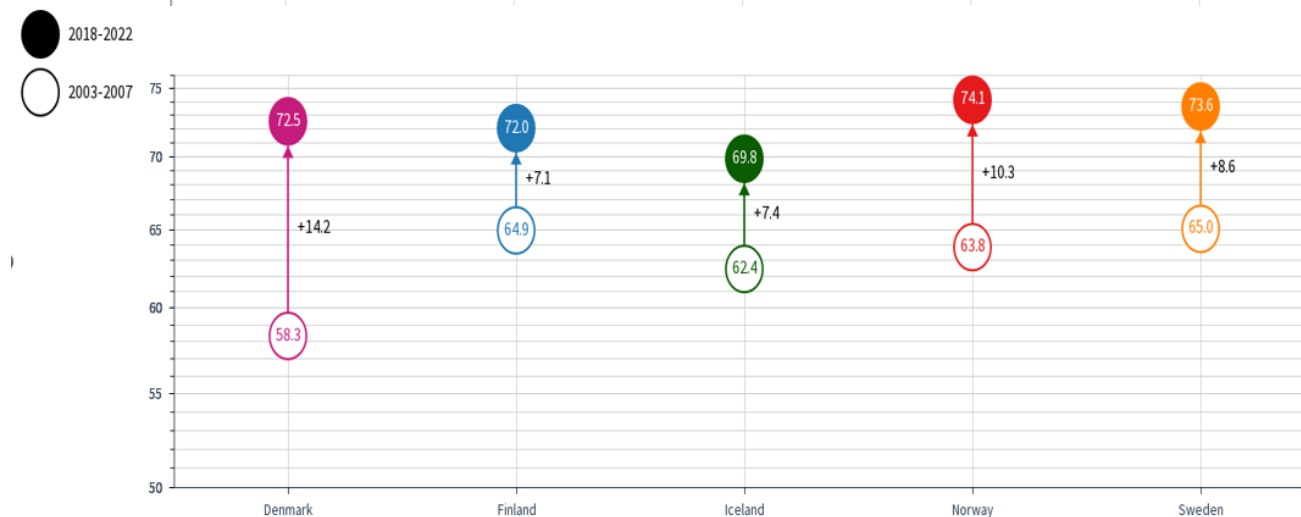
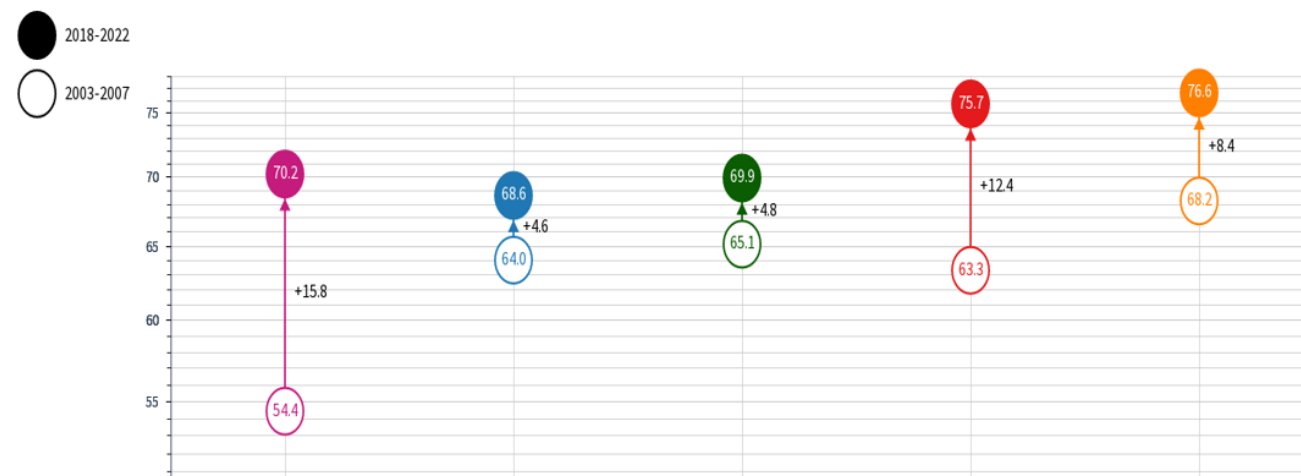


- **A national, binding collaboration**, initiated in 2017
Stakeholders: Ministry of Health, Danish Regions & hospitals, Danish Cancer Society (incl patients), Universities
- Aims to:
 1. **Strengthen** national **collaboration** in cancer
 2. Enable **rapid translation** of research into clinical practice
 3. **Attract** research funding and clinical expertise
- Utilizes **existing research infrastructure** at research institutions, universities and hospitals
- **Integrates** basic, translational, clinical research, epidemiology and the cancer clinic
- Initiated 12 national **cancer research centers**



Improvements in Relative Survival, 2003-7 to 2018-22

5-year age-standardised relative survival (%), from 2003-2007 to 2018-2022, Males
All sites but non-melanoma skin cancer



Concerted efforts: Danish cancer management on the right track

- Since 2000, the **Danish Cancer Plans I-IV** have resulted in **considerable investment** in **infrastructure, equipment** and **staff** for cancer management
- The Cancer Plans have promoted a **strong patient-centric multidisciplinary approach** to cancer treatment. Efforts are coordinated on a national scale (DMCG.dk, DCCC)
- **Patients** are now **much more involved** in **clinical decisions** and in research
- **Outcomes**, including survival and patient satisfaction, have **greatly improved**



The Unavoidable Truth: How the Mighty Have Fallen...

- **PROBLEMS:**
- **#28 out of 33** countries for 5 year lung & stomach cancer survival
- **Haven't achieved 62 Day Target** from diagnosis to first treatment since 2015
- **~40% of patients waiting >specified 31 days** for radical radiotherapy
- **0.6 nuclear medicine physicians per 1 million inhabitants**; average is **10.5**, an **8-fold difference** contributing to delays in diagnosis and treatment
- **92%** of UK cancer centres reported **delays for patients starting radiotherapy**
- **~50%** reported weekly **delays for chemotherapy** and other cancer drugs
- **84% heads of service concerned** that **workforce shortages** affect care quality

Ward Z, Atun R, Aggarwal A, Lawler M, Hricak H. Investing in cancer care in the UK: why aren't we acting on the evidence? Lancet Oncology 2024 (**Launched at London Global Cancer Week, November 2024**)

The Unavoidable Truth: How the Mighty Have Fallen...

But Data can show us the WAY FORWARD

- **SOLUTIONS:**

- Lack of investment in cancer care - **significant missed opportunity**; would also **yield large societal gains**.
- **Improving quality of care** and availability of treatment modalities **to mean level** of high-income countries could **prevent 30,700 deaths** from 11 common cancers **by 2030**, yielding **net economic benefits of £24.4 billion** – a return of **£17.30 per £1 invested**.
- **Scaled up imaging modalities** could prevent **68,400 deaths** from the 11 cancers, yielding even **larger net benefits of £52.9 billion** – a return on investment of **£31.05**
- **After 14 years of gross mismanagement of cancer by the previous administration... THE NEW GOVERNMENT IS LISTENING!**

theguardian

Streeter King considers reviving dedicated cancer strategy after Tories axed it

September 30 2024



WE DID IT!

We provided the data intelligence and they listened!

*We recognise the need for leadership by the **Government**, and my right hon. Friend the Secretary of State has been clear that **there needs to be a national cancer plan**.*

*I have **absolutely heard the message about the need for a cancer strategy loud and clear** from hon. Members, and I will convey it to my ministerial colleagues and to officials.”*

BUT TALK THAT A CANCER PLAN MAY TAKE A YEAR TO CONCEIVE...

***Cancer won't wait, patients can't wait
The waiting is over – its time for action!
Time to hold our hands to the fire***



The future of cancer care in the UK – time for a radical and sustainable National Cancer Plan

Cancer care in the UK is in crisis and in need of an ambitious reset to deliver the world-class service patients deserve.

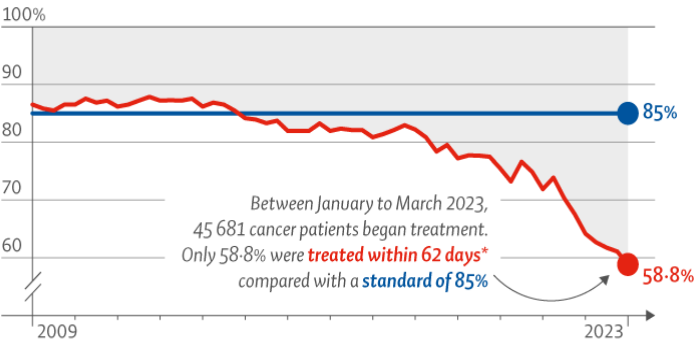
Waiting times

Cancer affects 1 in 2 people in the UK and its burden is set to increase. In the next decade the UK will see:



Waiting times for cancer treatment have been steadily deteriorating since 2013, and this deterioration has been exacerbated by the COVID-19 pandemic. In May, 2023 NHS England reported the worst ever waiting times for cancer treatment:

Proportion of patients with cancer in the UK treated within 62 days of a referral*



The recommended maximum wait time from a suspected cancer referral to start of treatment is 62 days. However, in September, 2022, and again in May, 2023, more than 1 in 10 referred patients (13%) waited more than 104 days.

* Within the 62-day target between an urgent GP referral and treatment; † In curative or palliative settings; ‡ Age-standardised rates per 100 000 population.

Treatment

Surgery will be needed in more than 80% of cancer cases†:



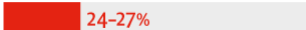
Radiotherapy is needed by at least 53% of UK patients with cancer...



... and is involved in 40% of cancer cures:

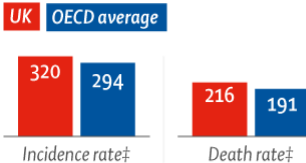


However, in 2019 — even before the COVID-19 pandemic — radiotherapy was accessed by just 24–27% of patients with cancer:



Incidence and deaths

UK cancer incidence rates and death rates are both higher than the international average:



A blueprint for a radical and sustainable UK cancer plan

To achieve this, we propose a ten-point plan:



1 Create and properly resource dedicated UK-wide National Cancer Control Plan through a more integrated devolved government consultation, which are patient centred; empower clinical frontline staff; and deliver equitable, affordable, data-informed, and research-active cancer control



2 Re-establish a strengthened and more comprehensive National Cancer Research Institute and broaden cancer research strategic agenda and funding



3 Deliver on NHS Long Term Cancer Workforce Plan with fair pay and better working environments coupled to a rethink on future cancer workforce skill sets



4 Significantly strengthen primary care and deliver on the target of 75% of cases diagnosed at stage 1 or 2 by 2028 through enhanced screening



5 Properly fund a UK wide evidence-driven prevention programme particularly for tobacco control, alcohol, and obesity



6 Integrate hospice care within the NHS and increase support for psychosocial and survivorship, keeping patients and those living with cancer out of hospitals



7 Address domain-specific and vulnerable population solutions in national planning such as in radiotherapy, surgery, pathology, imaging, and systemic therapies and in children and young adults



8 Develop an integrated pan-UK data and digital infrastructure that delivers intelligence-driven service design, performance assessment and quality improvement. This should be coupled to cancer targets that focus on delivery of the main 62-day treatment target and reflect the totality of the system; time to diagnosis, time to treatment, and quality metrics



9 Deliver a sustainable plan for equipment and infrastructure across the UK to assist the work force and help increase its productivity and ensure patients with cancer get access to appropriate technologies and that proven innovations are equitably implemented through a value-based approach



10 Rethink governance, structure, and relationship of advice to Government and NHS England for cancer. Reinstate the role of an independent National Cancer Director and office of support with authority to drive through changes and liaise between government and the NHS to provide robust independent oversight

Read the Policy Review in full at www.thelancet.com

Image credits: MartinPrescott, Solskin, shapecharge, Anthony Miller, SimpleImages, Monty Rakusen, murtbas, Science Photo Library, sturti, and Getty Images.

Unlocking the Power of
Health Relevant Data to shift
the dial, drive sustainable
innovation and improve
health and wellbeing FOR
ALL



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**OPINION**

Pepper...and Salt

**WORLD NEWS**Science-Fiction
Writer Ursula K. Le Guin
Dies at 88**WORLD NEWS**The Internet Is Filling
Up Because Indians Are
Sending Millions of ...Leadership can be learned.
See you in class.MUHTAR KENT
CHAIRMAN OF THE BOARD,
THE COCA-COLA COMPANY

LESSONS IN LEADERSHIP

[LEARN MORE](#)

LIFE

The New Einsteins Will Be Scientists Who Share

From cancer to cosmology, researchers could race ahead by working together—online and in the open

By Michael Nielsen

October 29, 2011

**Global Alliance**
for Genomics & Health**QUEEN'S
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Driving a “Big Data for Better Health” Agenda

Key issues for cancer care, research & innovation but **most importantly patients:**

- **BREAK DOWN THE SILOS:** Get researchers, clinicians, industry, regulators and patients to **collaborate** and **share** data/code etc
- **LEARN FROM THE DATA:** Use data from **diverse sources** (‘omic, clinical, epi-demiological, socio-economic etc) to increase our understanding and **empower innovation**
- **BIG DATA FOR BETTER HEALTH AGENDA** - Use this **intelligence** to:
 - **Improve health** and **wellbeing** of the citizen
 - **Contribute** to **economic/societal benefit**
 - **Provide** an **evidence base** for **influencing policy**

¹Lawler *et al.* All The World’s A Stage: Facilitating Discovery Science through the Global Alliance for Genomics and Health *Cancer Discov.* 2015;

²Siu LL, Lawler M *et al.* Facilitating a culture of responsible and effective sharing of cancer genome data *Nature Med* 2016

Championing a citizen-focussed Data Sharing Culture

- Facilitating **access** to **rich** data resources to **enable research and innovation**
- Establishing a sustainable **Cancer Data Knowledge Network¹**
- Moving from a Closed **“Selfish Silo”** Mentality to a more Open Source **“Collaborative/Federated Culture”**
- **A Question of Trust – ensuring co-creation** with patients and citizens²

¹Lawler *et al.* *New Engl J Med* 2017

²Lawler *et al.* *Lancet Oncology* 2018 “A Roadmap for Restoring Trust in Big Data”

The NEW ENGLAND
JOURNAL of MEDICINE



25th May 2017

Sharing Clinical and Genomic Data on Cancer — The Need for Global Solutions

Mark Lawler, PhD; David Haussler, PhD; Lillian L. Siu, MD; Melissa A. Haendel, PhD., Julie A. McMurry, PhD; Bartha M. Knoppers, PhD; Stephen J. Chanock, MD; Fabien Calvo, MD., PhD; Bin T. The, MD; Guneet Walia, PhD; Ian Banks, MD; Peter P. Yu, MD; Louis M. Staudt, MD, PhD; and Charles L. Sawyers, MD. For the The Clinical Cancer Genome Task Team of the Global Alliance for Genomics and Health

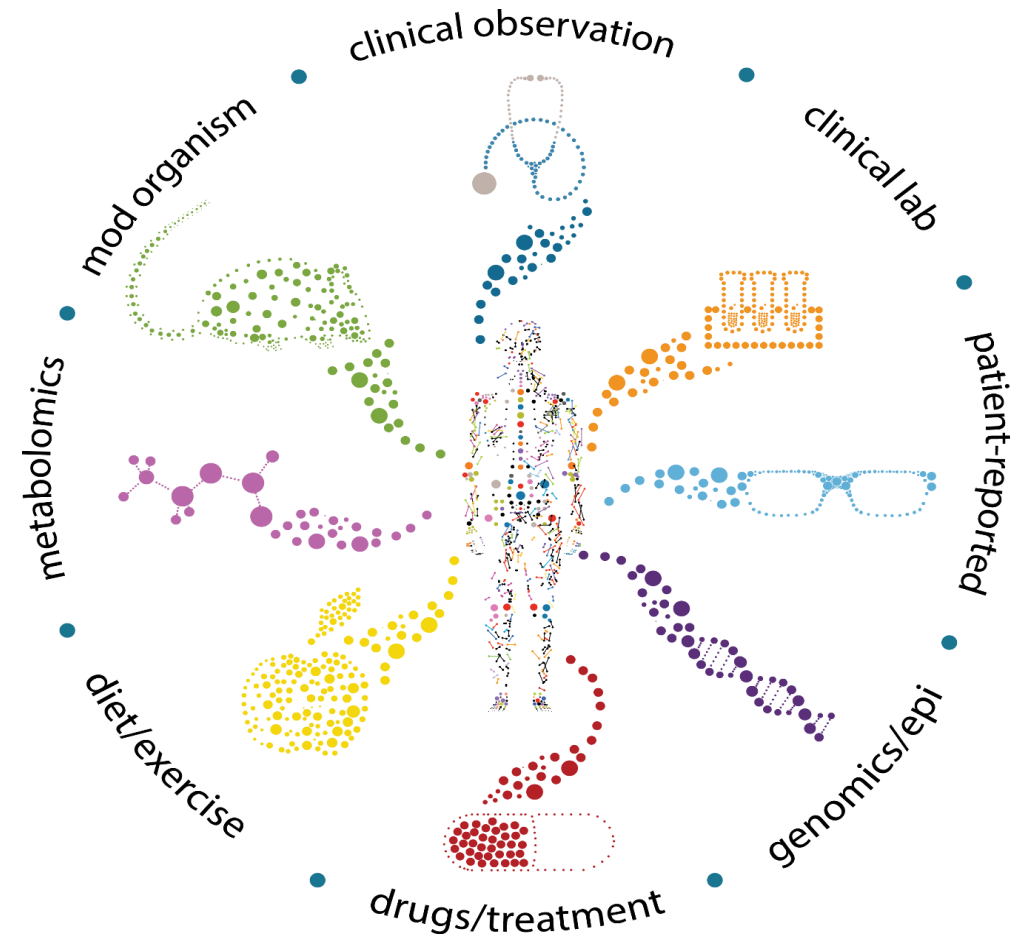


Global Alliance
for Genomics & Health

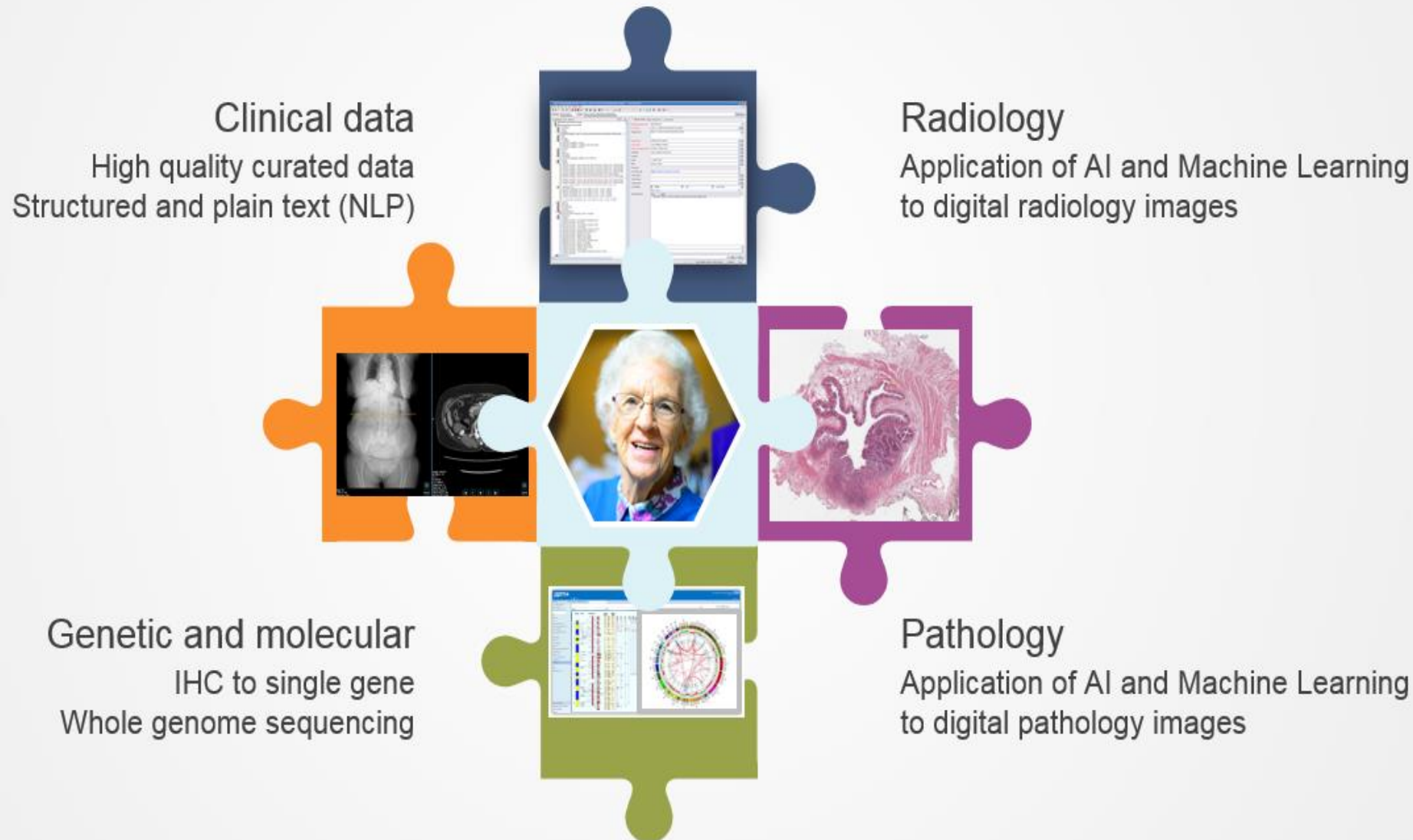


Empowering a citizen-centred data-driven ecosystem in the UK

- **DATA-CAN – A £5M Digital Hub Programme** to realise a **cancer data ecosystem to drive research and innovation**
- Enabling **more effective** prevention and early diagnosis approaches
- Facilitating **application of data-enhanced discovery** to deliver innovative therapies
- **Nurturing and empowering** patient recovery and rehabilitation
- Underpinning **enhanced industry partnerships and innovation.**



Harnessing Data to improve cancer control and enhance innovation in the UK



Improve access

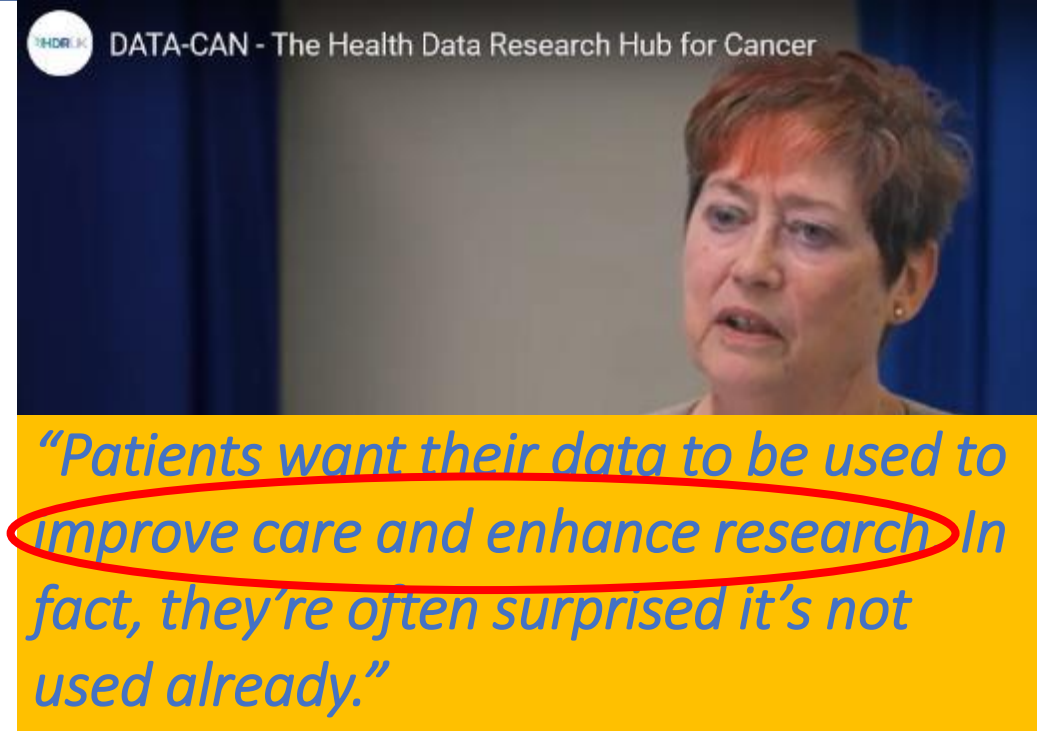
Enhance quality

FAIR principles

Ensure Fair Value

Placing patients at the heart of what we do: No Tickboxing here

- Patients are involved **from the earliest stage** and **at all levels of decision- making**
- **Enables/empowers genuine co-creation**
- We involve patients in discussions **with all partners, including commercial partners**
- **Patients** are key **gatekeepers** and have power of **veto**
- Seek to involve **underserved/minority communities** whose voice is often unheard



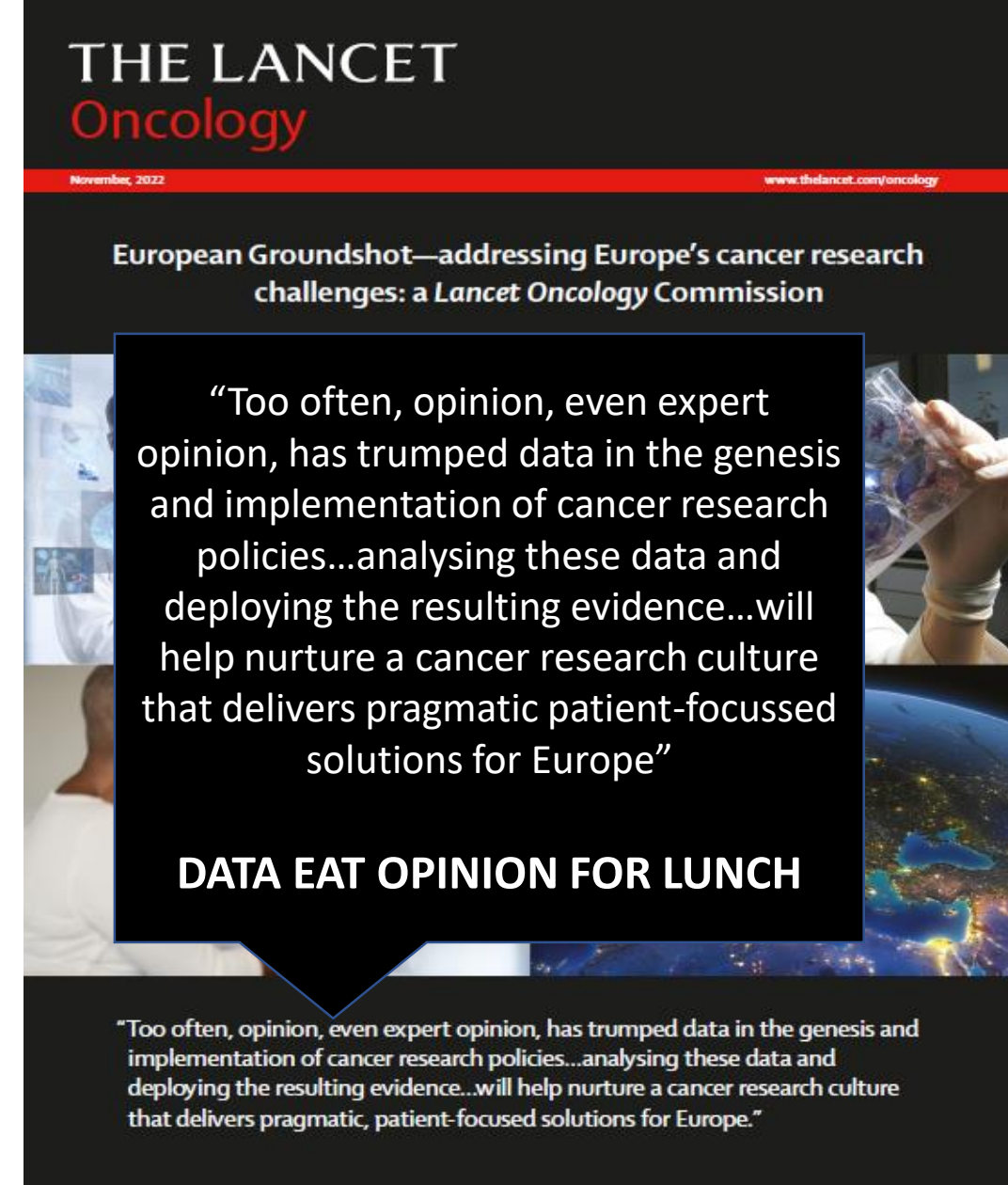
Jacqui Gath, Cancer survivor. patient advocate

“As patients, we not only are empowered but we feel empowered”

Wheatstone P, Gath J, Carrigan C, Hall G, Cook Y, DATA-CAN Sujenthiran A, Peach J, Davie C, Lawler M. *BMJ Partnerships in Practice* 2021
<https://blogs.bmj.com/bmj/2021/08/11/data-can-a-co-created-cancer-data-knowledge-network-to-deliver-better-outcomes-and-higher-societal-value/>

Beating Cancer: The Need for Research Informed Action

- We are facing a **cancer crisis**
 - **COVID-19 pandemic** and subsequent **national lockdowns**
 - the **Russian Invasion** of Ukraine
 - The global **economic downturn**
- We need to **Act Now**
- **The Lancet Oncology European Groundshot Commission**
- Critically **challenge today's efforts** and **how we might do better** in the future.
- **Data into intelligence** informing **12 Recommendations**.
- **Call for Action: Reimagine cancer research and its implementation across Europe**
- Addressing the realities **“on the ground”**



Our 70:35 Vision – 70% Long Term Cancer survival by 2035

- This is **not shooting for the moon**, it is firmly **grounded in reality** (hence the **Groundshot**)
- **Our data show that patients treated in research-active hospitals** have **better outcomes** than those who are not.
- Research is **not a luxury**, it is a **necessity** and an **essential and integral part** of modern cancer care.
- **Key driver** to **achieve our 70:35 Vision**; 70% long term survival by 2035 for the 20M people in Europe living with cancer (**Recommendation 1**)



Vignette II: Spend Less to Achieve More: How Data intelligence changed Cancer Policy

- Influential evidence-based study in patients receiving a **cancer drug** (cetuximab) as treatment for advanced **colorectal cancer** in England
- **No deviation** from protocol means that even if the doctor recommends his patient for a **treatment break because of toxicity**, patient cannot as they risk their **treatment being discontinued permanently**
- Partnered with **Bowel Cancer UK** to address this **unacceptable inequality**
- Collected **patient's testimonies** and **clinical evidence**
- **AND** performed comprehensive **health economic modelling and analysis**



Spend Less to Achieve More: How Data intelligence changed Cancer Policy

- Analysis indicated treatment break approach would not adversely affect patients' **quality-of-life or outcomes** but could **save £1.2 billion for NHS**
- **Crucial evidence** which **Bowel Cancer UK** presented to NHS England to **justify change** in bowel (colorectal) **cancer treatment policy**
- Led NHS England to **end their ban on 'treatment breaks'**, without the **risk of patients not being treated**, or having to **pay thousands of pounds to continue treatment out of their own pocket**
- Turning **data into evidence** to directly benefit our patients
- Won 2022 Health Data Research UK **Impact of the Year Award**

[Spend less to achieve more: Economic analysis of intermittent versus continuous cetuximab in KRAS wild-type patients with metastatic colorectal cancer.](#)

Henderson RH, French D, McFerran E, Adams R, Wasan H, Glynn-Jones R, Fisher D, Richman S, Dunne PD, Wilde L, Maughan TS, Sullivan R, Lawler M. *J Cancer Policy*. 2022