DATA-CAN
The National Health Data Research Hub for Cancer

BIA Conference
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Our vision

DATA-CAN – The Health Data Research Hub for Cancer – aims to unlock the power of data to improve cancer care
Why cancer?

- One in two people will get cancer during their lifetime

- Every year, almost 400,000 new cases are diagnosed in the UK, and cancer costs the NHS £7bn annually

- Using cancer data more effectively could improve cancer survival rates, potentially contributing to saving the lives of 30,000 cancer patients a year and many more around the world
What we will do

We will make high-quality health data easily available for cancer researchers and clinicians.

By connecting data from across the UK and making it easier to use, we will facilitate research into new treatments and improvements in care for people affected by cancer.

Working with patients, the public and practitioners, we will ensure that data is used safely and ethically, and that the benefits are returned to the NHS and the wider UK community.
How we will work

➢ We will **collaborate** across organisations, sectors and boundaries

➢ We will be **enablers**, making it easier for others to improve cancer care

➢ We will ensure **fair value** from data, and return benefits to the NHS

➢ We will **signpost** to others when possible, so we do not duplicate others’ work

➢ We will **listen** and respond, aware that cancer data and research moves rapidly

➢ We will be **open** to working widely with others; we are not exclusive to any company, data or organisation

➢ We will **empower patients**, who will have more influence than any other partner
A unique partnership
Support from across the United Kingdom
Patients at our heart

DATA-CAN has been designed with the patient, around the patient and for the patient.

Patients will be involved at all levels of the Hub, all data will be held securely, and patients will be able to decide how their data might be used.
Working together
DATA-CAN video
What does this mean for industry?

- 80% of clinical trials are delayed by at least 2-3 months.
- -3% decrease in the UK’s share in global pharma R&D (10% > 7%).
- 45% of protocol delays could be avoided through better use of data.
- Increase to UK cancer research returning to the UK’s 2011 % of total R&D spend.

Global R&D Spend

- 2011: Non-UK not cancer: 70%, Non-UK cancer: 20%, UK not cancer: 5%, UK cancer: 5%
- 2016: Non-UK not cancer: 70%, Non-UK cancer: 20%, UK not cancer: 5%, UK cancer: 5%
Challenges we have heard from industry

**The problem**

- Inefficient & unpredictable access process
- Slow
- Complex; multiple counterparties for national data access
- Disparate and unlinked data sources

- Currently too slow to enable the UK to compete for global trials
- Decreasing position of UK as a R&D centre for oncology treatments

- 75% of UK SME's data access requests are unsuccessful; SME’s done have specialist data access and analytics teams
- Supporting the AAC and innovation ecosystem
DATA-CAN will help evolve how research questions can be answered using UK data

Can you get me full clinical phenotype, digital pathology and imaging on patients on 1st-line immune-checkpoint inhibitors in non-small cell lung cancer?

Today

- NCRAS + SACT to 2017
- Patchy coverage for
  - Digital imaging
  - Primary care

By 2022

- 27M DATA-CAN population
- Digital imaging & pathology from National Digital Imaging hubs
- LHCRE-linked primary care data
- Detailed molecular and genetic phenotype
Academic researchers get better data access and funding in return for data sharing

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<tr>
<th>DATA-CAN LEVERAGES</th>
<th>RESEARCHERS RECEIVE</th>
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<td>Patient-centred data sharing</td>
<td>Resource, platforms and methods for improving the access process</td>
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<td>HDR UK Data Alliance</td>
<td>Pump-priming high-value dataset curation to user standards</td>
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<td>Efficient access process (in-house or delegated)</td>
<td>Improved UK data access on affordable terms</td>
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<td>Discoverability via the HDR UK Gateway</td>
<td>Global funding for data, curation &amp; services</td>
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<td>Data curation and expert services</td>
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Genomics England will work with the partnership to provide a Trusted Research Environment for DATA-CAN (IG level 3)

Genomics England will seek links as appropriate to the International Genomics Consortium and other international partnerships
IQVIA are proud to support DATA-CAN through technology to support priorities

- European Real World Oncology data
- Data sharing network
- Automated extracts from clinical systems
- 120+ centres across 7 countries

*Non-identified data is processed and stored in secure data centres which are certified by government agencies as required in each country, or otherwise comply with industry security standards.
DATA-CAN aims to unlock the power of health data to improve the lives of patients affected by cancer

- Over half of UK citizens will get cancer\(^1,2\)
- We can improve outcomes if we use data-driven approaches to learn from every case
- The UK has lower 5 year survival than the best in Europe\(^3-5\)
- DATA-CAN can help save 30,000 lives a year by informing better deployment of current approaches and providing cancer intelligence to drive innovation\(^6\)

**DATA-CAN**

The UK’s National Health Data Research Hub for Cancer

- Enable and expand UK-wide cancer dataset access for research
- Provide high-quality real-world data to support health and care delivery
- Use real-world data to support patient enrolment in clinical trials, improve clinical trial design and reduce delays in clinical trial start-up times

“ Patients want their data to be used to improve care. In fact, they’re often surprised it’s not used already. ”

Jackie Gath, Cancer survivor and patient advocate (ICPV/YHCRP)

Source: \(^1\)ONS (age-standardised mortality, 2017); \(^2\)CRUK; \(^3\)Eurocare 5, \(^4\)International Cancer Benchmarking Partnership; \(^5\)Lawler et al Lancet Oncology 2014; \(^6\)Selby Lawler et al Journal of Cancer Policy 2019
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Unlocking the power of health data to improve the lives of patients affected by cancer

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