



Utilising Data to Transform Cancer Pathways

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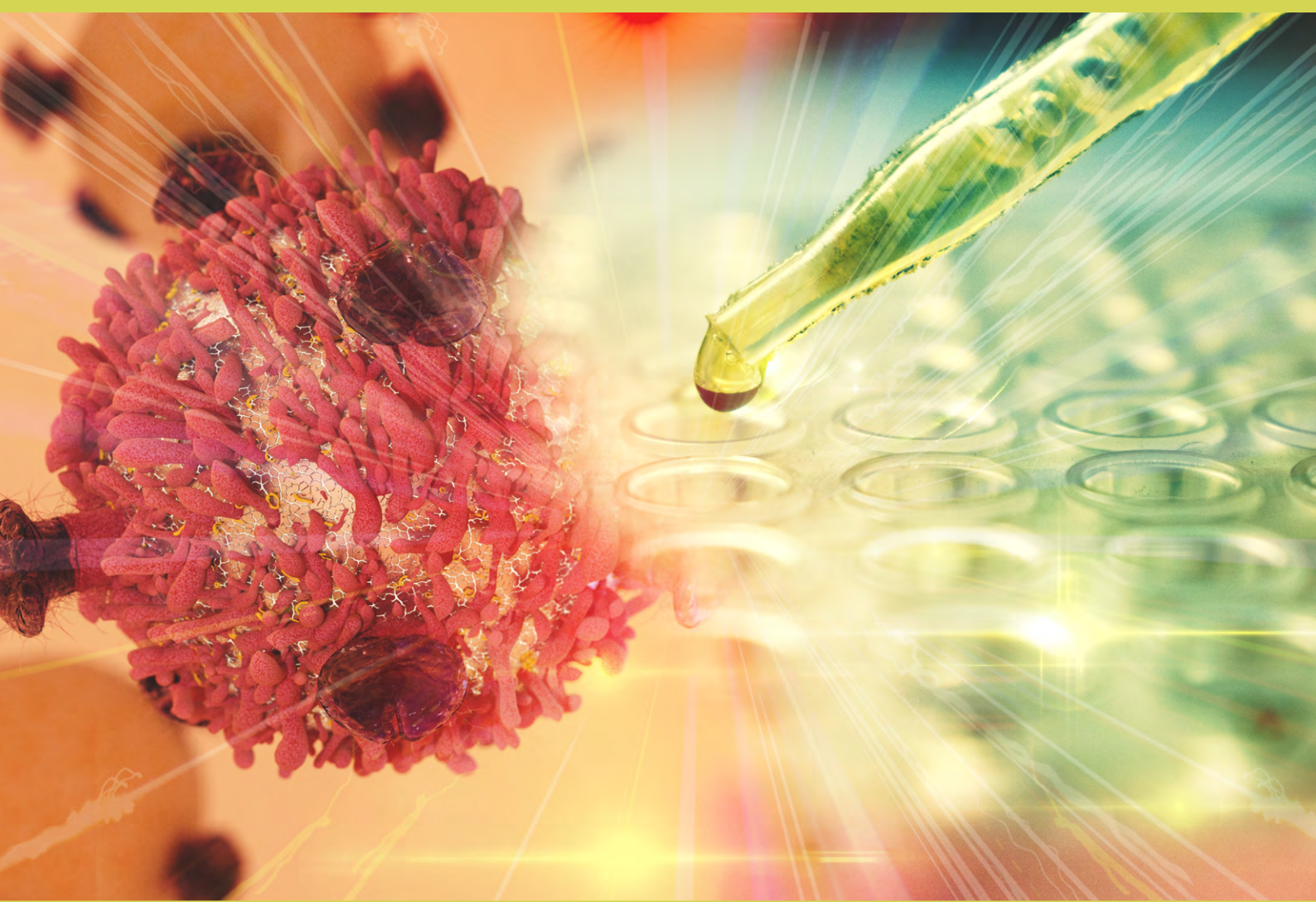
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Introduction

Nearly one in two people will be diagnosed with cancer at some point in their lives, with predictions stating that cancer incidence rates will continue to rise. Currently, over three million people in the UK are living with cancer, and there are more than 390,000 new cases each year.¹ Cancer referrals have increased to three million, with incidence rates climbing by three per cent annually.² Every day, around 1,000 new cancer cases are diagnosed and there are 460 cancer-related deaths.³

While cancer survival rates have doubled in the past 50 years, with approximately 50 per cent of patients now surviving for over 10 years, the UK still sees over 160,000 cancer deaths annually, and survival rates lag those of comparable countries.⁴ The NHS has implemented a Long Term Plan to improve these metrics, aiming to diagnose 75 per cent of cases at stage one or two by 2028, and to meet 31- and 62-day treatment targets.⁵

Published under the last Government, the 2021 UK Life Sciences Vision⁶ committed to tackling five health missions, including cancer, ensuring that oncology policy will remain a high priority for this Government. This priority has been continued by the new Government as part of their Life Sciences Industrial Strategy, jointly launched by the Secretaries of State for Health and Care, and Science, Innovation and Technology.⁷

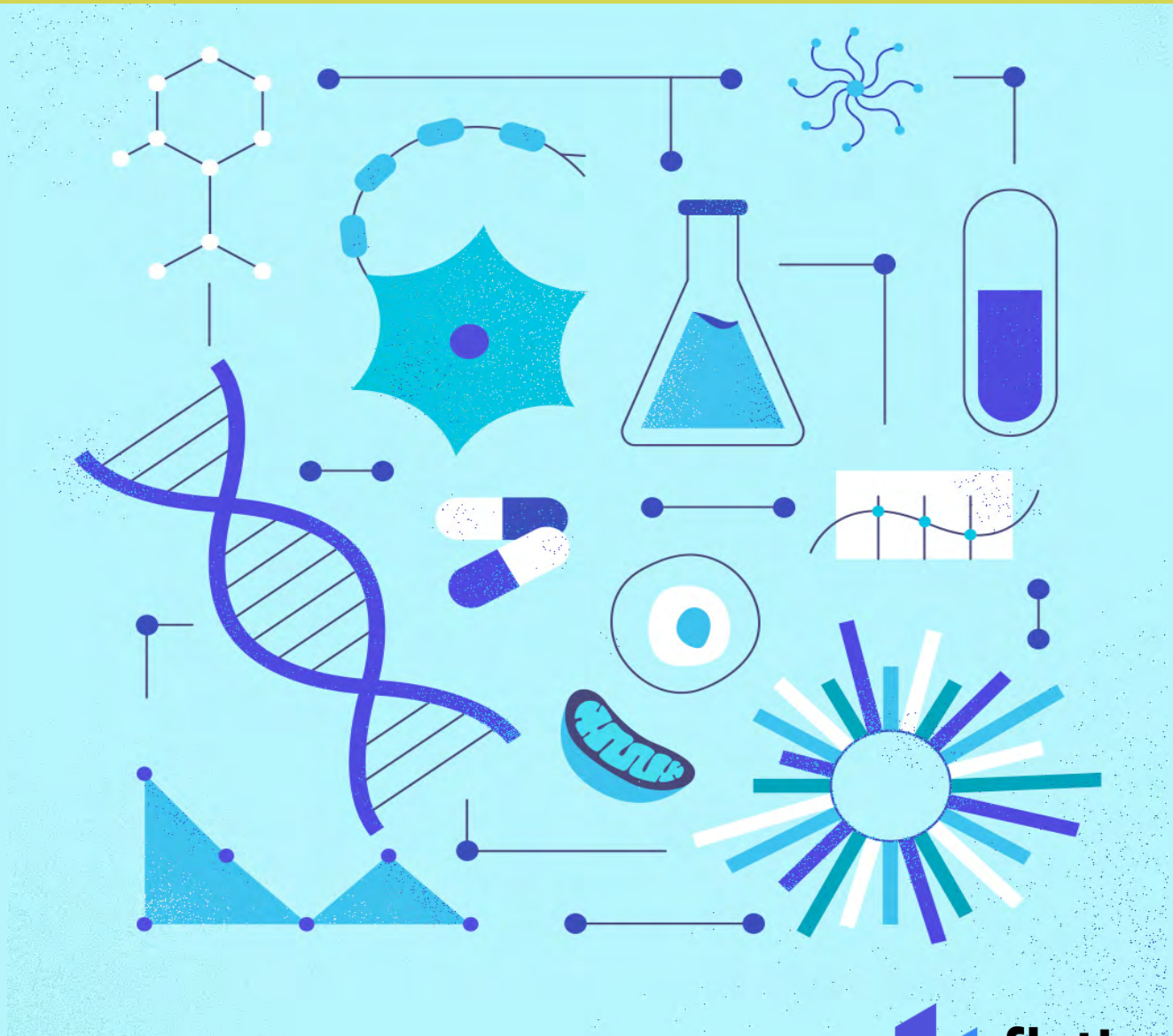
Given the significant impact of cancer, the potential to use data encompasses a wide range of areas, including identifying risk factors, cancer occurrence, recognising symptoms, tracking disease progression, optimising treatment responses, and enhancing care delivery. Utilising data not only helps to assess the current landscape but also pinpoints areas needing improvement and formulates strategies that could advance patient outcomes across all aspects of cancer care.

In April 2024, independent policy institute, Curia, convened a roundtable to explore the role of data in reforming cancer pathways. The goal was to develop a series of recommendations for health data policy to guide the next Government. This roundtable was partly supported by the sponsorship of Flatiron Health UK. By fostering collaboration across the public, private, and voluntary sectors, these recommendations aim to stimulate long-term industry investment and innovation in cancer care and research in the UK. The key discussion points, the recommendations from the roundtable session, and a prospective implementation plan for the new Government are detailed in this report.

Chair and Participants

The Chair and speakers included

- Lord James O'Shaughnessy, Co-Chair, Curia Health, Care, and Life Sciences Research Group (Chair)
- Dr Chris Russell, Head of Delivery, Data for R&D, NHS England
- Emily Jefferson, Chief Technology Officer, HDR UK and Chair of Health Data Science at University of Dundee
- Professor Geoff Hall, Professor of Digital Health and Cancer Medicine, University of Leeds
- Julia Millman, Research & Innovation Programme Director, Leeds Teaching Hospitals NHS Trust
- Sarah Stevens, Associate Director for Disease Registration, National Disease Registration Service
- Dr Crispin Hiley, Associate Professor, UCL
- Dr Emily Stanton, Darzi Fellow in Clinical Leadership, Imperial College NHS Trust
- James Hargrave, Government Affairs and Communications Lead, Daiichi-Sankyo
- Adam Manhi, Head of Network and Commercial Partnerships, Flatiron Health UK



Partnering to Transform Cancer Care and Research through Higher Quality Data

The UK cancer data challenge

In the current climate of rising cancer incidence, we need to do all we can to learn from the experiences of people living with cancer so that we can discover new ways of diagnosing, treating and managing the disease to improve patient outcomes.

Currently, information collected across a cancer patient's journey is siloed and fragmented. The entirety of a patient's journey from diagnosis is often not captured within a single system and much information is documented as free text and unstructured data (e.g., radiology / pathology reports), making it difficult to access, analyse and interpret at scale. NHS Trusts across the UK are currently unable to curate this data themselves at scale because of the significant investment, time commitment and specialised training required to consolidate fragmented patient data and curate it into research-ready datasets. As a result, opportunities to enhance cancer research and improve patient care are being missed.

Flatiron Health UK, a subsidiary of Flatiron Health in the US, has developed innovative processes and software to translate real patient experiences into research-ready datasets that can help improve the treatment, care and quality of life of people with cancer. In the US, our data and research has been used to transform cancer research and care, featuring in numerous high-impact journals and conferences, in regulatory decisions and health technology assessments. As examples, Flatiron Health RWD has been used to support label expansion (e.g. palbociclib for male metastatic breast cancer patients¹) and optimising dosing regimens and patient experience (e.g. reducing frequency of cetuximab IV infusion therapy, with no impact on patient outcomes²).

Flatiron Health UK is partnering with organisations across the UK cancer community to unlock and accelerate research and care improvement opportunities for cancer patients in the UK. Flatiron Health UK has recently announced an exciting partnership with Leeds Teaching Hospitals Trust (LTHT) as its first NHS Trust partner in the UK. See [here](#).

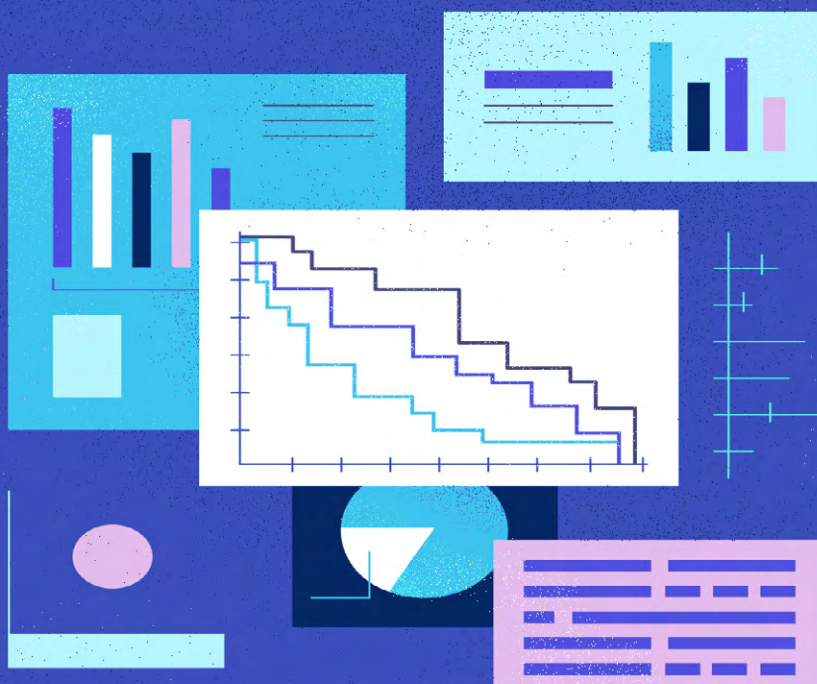
How this partnership addresses the challenge

Flatiron Health UK and LTHT have entered into a long term partnership to transform the availability and quality of real-world cancer data in the UK. The partnership has been approved by the Health Research Authority's (HRA) Confidentiality and Ethics Committees. Flatiron Health UK and LTHT have conducted an extensive PPIE program, independently and in partnership, and regularly consulted with key stakeholders across the UK (including DATA-CAN, NHS England, Cancer Research UK and use MY data) to inform the design of this partnership.

“Members [of the HRA Confidentiality Advisory Group panel] commended the applicants [Flatiron Health UK] for their patient and public involvement work to date.”

**CONFIDENTIALITY ADVISORY GROUP,
NHS HEALTH RESEARCH AUTHORITY, FEBRUARY 2023**

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- 1 Using real-world evidence for label expansion: Use of palbociclib in male breast cancer patients (see full article [here](#))
 - 2 Flatiron Health Real-World Data Support FDA Approval of New Dosing Regimen for ERBITUX® (cetuximab) (see full article [here](#))



Summary of Roundtable Discussion

Introduction

The roundtable on Leveraging Data to Transform Cancer Pathways was convened under the Chatham House Rule to explore how data can be effectively utilised to enhance cancer research and improve patient outcomes. Organised by Curia in association with Daiichi Sankyo and Flatiron Health UK, this event brought together a diverse group of experts from academia, the NHS, and the private sector, highlighting a collaborative approach to addressing the complexities of cancer care.

Chaired by former Life Sciences Minister and Co-Chair of the Health, Care, and Life Sciences Research Group, Lord James O'Shaughnessy, the primary objectives were to examine current strategies, identify and address existing challenges and brainstorm future improvements in the utilisation of cancer data. The participants were encouraged to share insights and experiences from their respective fields, fostering an environment of shared learning and innovation.

The session was opened by emphasising the critical role of data in transforming cancer pathways, noting the importance of collaboration across different sectors to unlock the full potential of health data. He outlined the structure of the discussion, which included presentations from key speakers, panel discussions, and interactive Q&A sessions. The agenda covered a wide range of topics, from the integration of data across various platforms to the ethical considerations and public trust issues surrounding data usage. It should be noted that the order in which these subjects were covered have been amended to help the flow of the write-up.

The event underscored the urgency and potential of leveraging data in cancer care, aiming to produce actionable insights and recommendations that could drive meaningful change in both research and clinical practices.

Discussion Summary

The roundtable on Leveraging Data to Transform Cancer Pathways was convened under the Chatham House Rule to explore how data can be effectively utilised to enhance cancer research and improve patient outcomes. Organised collaboratively by multiple stakeholders, the event brought together a diverse group of experts from academia, the NHS, and the private sector. The session was chaired by the moderator, who set the agenda for a comprehensive discussion, emphasising the goal of exploring the potential for data to transform cancer pathways.

Strategic Approaches to Data Utilisation

Two key speakers provided an overview of the current strategies and improvements in cancer data utilisation. One speaker, representing a national health data research organisation, highlighted their mission to accelerate trustworthy data use and improve public health through large-scale data applications. They explained the challenges of data silos and the importance of trusted research environments (TREs) for accessing sensitive data securely. TREs and SDEs essentially refer to the same concept, providing secure, controlled access to sensitive data for research purposes.

The other speaker, from the NHS, elaborated on their Secure Data Environment Research Network, emphasising the need for better data access and interoperability. They discussed the role of TREs in enabling quicker and more efficient clinical trials, real-world studies, and translational research, stressing the importance of patient and public involvement (PPI) in gaining public trust and support for data-driven initiatives.