

Unlocking the Potential of Data to Transform Cancer Outcomes

Cancer Research UK's Vision for NHS Health Data in England

Data, and data-driven technologies, have the potential to transform outcomes for cancer patients in the NHS, and empower UK research and innovation to stay at the cutting edge of the global research community. Used to its full potential information routinely collected by the NHS, in national datasets and medical records, is an invaluable resource driving research into the causes of disease, improving the effectiveness of diagnosis and treatments and facilitating service optimisation across the NHS.

However, there is much more we can do to ensure the optimal use of health data for improving outcomes for patients and supporting world-leading research. Developed with clinicians, patients, and a range of users of NHS data, here we set out Cancer Research UK's vision for health data in England and the steps we must take to realise this potential. Though this vision enumerates principles that Cancer Research UK holds across the UK, this document focuses on England specifically due to the differences in regulatory environment and health service structures across the UK. This paper will also focus on data collected by NHS organisations, primarily in the delivery of routine care, rather than data generated through research. Though closely linked, the two areas have different challenges and opportunities, making it important not to conflate them. Cancer Research UK welcomes further conversations on this vision, and our broader data policy work across the UK.

Cancer Research UK's vision is that:

Health data will be a leading driver of improvements in outcomes for patients.

Used optimally, it will support reducing inequalities across the cancer pathway and for all cancer sites, optimise cancer services and be an invaluable resource for researchers and the NHS.

This can be achieved through data holders at all levels of the NHS ensuring that high quality and relevant health data is digitised, findable, accessible, interoperable, re-useable and secure. This will unlock the full potential for service optimisation, introducing data-driven technologies into the NHS, and innovation by researchers in academia, charities, government and industry.

Strong foundations

There are huge opportunities for the NHS through seizing the benefits of health data to support service optimisation, research and innovation, and the adoption of new technologies. This is due to the unique structure of the NHS, which as the Life Science Industrial Strategy highlights, has the benefit of being a single national provider with population-level datasets and a large, diverse population.¹

The development and adoption of new digital technologies is a major priority in the NHS Long Term Plan (LTP)², which outlines ambitions for a radically different, 'digital-first' model of care. The LTP also seeks to deploy digital technologies to support patient care through upgrading IT infrastructure, digitising services to support integration, clinical decision-making and population-level service planning technologies, as well as improving data linkage and quality for research and innovation.

Indeed, many of the most impactful recent developments in the NHS have relied on high-quality, accessible health data. Complex genomic data is unlocking new possibilities for personalised cancer

treatment, whilst artificial intelligence (AI) has much potential to support clinicians in diagnostic services, freeing up time to spend with patients.³ Cancer data in particular holds huge potential with the English Cancer Registry containing data on over 14 million current and historical tumours and patient-level information collated from 19 distinct NHS datasets.

The depth and breadth of data held by the NHS could also allow England, and the UK, to lead the way in innovative research models, with England-wide longitudinal data facilitating large-scale, long-term projects as well as research into rare and paediatric cancers, where there is only a small number of people nationally with a condition. There are also best practice examples of how NHS data could be best used to facilitate clinical trials using real world data from routine care, as seen in the Salford Lung Study, which assessed a COPD treatment across 2800 consented patients in Greater Manchester.⁴

Realising the potential of data

However, much more needs to be done before the NHS can realise the full potential of the data it collects. The core challenges in cancer data and informatics identified in the 2015 *Cancer Strategy for England* are yet to be fully addressed – namely data collection and analysis, timely access for research, and capacity to deliver this.⁵

The NHS must focus on the following to unlock the potential of data to transform cancer outcomes:

Optimising health and care datasets and systems

Health data must be accurately recorded in routine clinical care and be capable of being accessed across the NHS as standard. At the point of care, where patient data is collected, often the NHS workforce is not trained with the right data skills. In clinical settings, laborious data collection processes that expect healthcare professionals to record information that lacks direct utility to their work often hinders the development of a culture that recognises the value of collecting accurate, high-quality data.

- **Health Education England (HEE) and NHS England (NHSE) must support the NHS workforce with training to upskill.**

Investment in Hubs through Health Data Research UK (HDR UK) to collect, analyse, access and utilise high-quality data across the health sector, is highly welcome. However, data analytics is under-resourced across the NHS, there is a shortage of people with analytical skills who are often poorly deployed on low value tasks,⁶ and a lack of investment in IT infrastructure is holding back developing a joined-up system. This means NHS commissioners and service planners often lack the timely and accurate intelligence to lead change in the NHS in an informed way.

- **Further investment is needed by the Department of Health and Social Care (DHSC), NHSE, NHSx, and NHS Digital (NHSD) to develop the capacity, skills and infrastructure to ensure the best technologies and practice is shared across the NHS.**

NHSE should consider financial incentives for NHS organisations to encourage investment in digital technologies to support the better delivery of care.

Data-driven research, innovation and service improvement

Real world data collected by the NHS is an invaluable resource for the public good. It can enable innovative research methods, support innovation and service improvement. The 2013 Caldicott Review set out the principle that the duty to share information can be as important as the duty to

protect patient confidentiality. Data stewards in the NHS must ensure that where lawful, and with adequate and proportional safeguards, data is accessible for patient benefit.

For researchers, the current data access system can be costly, resource intensive and often has inconsistent and opaque application processes across data holders.

- **NHSx, NHSD and PHE should develop a system-wide harmonised data access request and assessment process for researchers, with straightforward, transparent application processes and clear timelines for the application process.**

NHS data holders must also ensure there is tangible and equitable benefit for the NHS, public and patients where NHS health data is made available with researchers across the life sciences sector. Innovative anonymisation approaches, such as artificial or synthetic datasets, should be further explored to ensure valuable data is readily accessible to research whilst protecting patient anonymity.

Maintaining and Improving Trust and Confidence

Data is collected from patients for the benefit of patients now and in the future, and they must therefore remain at the centre of any decisions around how data is used and accessed. Similarly, healthcare professionals collect data at the point of care, and deploy new technologies, and must be consulted to ensure systems are clinically valuable.

- **Government and the NHS must lead the way in supporting all who work with patient data to make proactive and positive efforts to promote the safe and responsible use of patient data for service planning, research and innovation to patients, clinicians and the public.**

Optimising Health and Care Datasets and Systems

Data must be accurately recorded, clean and be capable of being accessed across different NHS organisations if we are to gain the most benefit for patients and the health system from NHS data.⁷ This will unlock efficiencies and enable the development of many new technologies that will support prevention, early diagnosis and optimal treatment.⁸

NHS Clinical Workforce

Efforts towards this ambition should begin at the point of care. However, digital literacy in the health and care sector is low and variable across settings and professions. Many health professionals do not currently have a strong understanding of how data is recorded or used. In the case of cancer data, our 2016 survey found that just 55% of healthcare professionals interviewed had some awareness of cancer registration, whilst most never discussed cancer registration with their patients (83%).⁹

The quality of data collected can also be variable. This is a pressing issue for cancer. The English Cancer Registry is complex and contains data from multiple sources, but this data is not always complete and requires significant quality assurance. For example, the Systemic Anti-Cancer Therapy (SACT) dataset is a world-leading dataset which has already driven improvements in clinical practice.¹⁰ However, there are issues with clinical data input, such as treatment intent not being recorded or clinicians only recording the first cycle of treatment, which damages completeness of the dataset.¹¹ These challenges create delays between data being collected and being useable, as seen in the long gaps between publication of cancer staging data.

As the Topol Review outlined, to realise the benefits of new technologies there needs to be **immediate plans for national programmes aimed at upskilling trainees and existing staff.**¹² The Review set out a positive way forward, and DHSC, NHSE and HEE should support its implementation with funded training programmes. This upskilling should also meaningfully engage and inform healthcare professionals on the uses of patient data. This is vital to build and maintain knowledge and confidence in the way this data is used. Patients also consider healthcare professionals a trusted source of information, and thus upskilling NHS staff to more assuredly communicate to their patients how their data is being used is important for patient confidence.¹³

Staff should also be supported through more extensive access to new digital technologies. This could not only simplify and integrate data collection into routine care, removing a burden from clinicians, but also provide valuable insight into care that could drive improvements. This value is already being seen through the adoption of e-prescribing systems in secondary care which is enabling data-driven analyses of prescribing. Improvements in data collection may also benefit clinical trials by minimising the significant resource cost often required to 'clean' electronic patient records (EPRs) before patients become trial participants.

It is welcome that the NHS Standard Contract for 2020/21 will include provisions to ensure compliance with the new MedTech Funding Mandate, which rightly recognises that new technologies can both improve patient care and drive cost efficiencies. However, upfront investment will still be required to introduce new interventions, which can often be neglected where NHS organisations have a range of competing demands for resource. **NHSE should consider financial incentives for NHS organisations to encourage investment in new digital and innovative medical technologies to support the better delivery of care.**

Collecting the right data

Ensuring that we are collecting the right data is also vital. As identified, where information is not recorded by omission, supporting the NHS workforce to collect the right data is important. There is also data that is not routinely collected which could more accurately inform our understanding of cancer services and outcomes.

For example, we know that BAME communities are less likely to take part in cancer screening programmes, and PHE is working to address this.¹⁴ However, in primary care ethnicity data is not routinely collected, which creates barriers to targeting and progressing work to address these inequalities. **NHSD and PHE should work with stakeholders from across the cancer landscape including clinicians, NHS informaticians and analysts, cancer charities, researchers and patients, to ensure the right data is routinely collected, alongside identifying where information currently mandated for collection offers little clinical value and could be phased out.**

Investment in data analytics

Data also needs meaningful analysis to convert it into intelligence that can guide timely and responsive service optimisation and system improvements. At present vital data can take so long to collate, clean and publish that it loses much of its value. For example, the significant gaps between publication of cancer staging data, due to the resource and talent needed to curate this data for publication, has meant it is challenging to assess the impact of interventions to improve early diagnosis.

Government must ensure adequate investment in capacity for information management and quality assurance, including an appropriately skilled informatics workforce at the national, Cancer Alliance and local levels. This would allow data holders to more rapidly provide the intelligence NHS organisations need to drive forwards more informed and responsive service optimisation. Ensuring that data holders have the capabilities to understand and process data access requests, and analysts to linking the requested data, would also facilitate timely responses to data access requests, which are particularly vital as new and more complex requests are made to develop emergent health technologies such as AI.

However PHE, which holds the English Cancer Registry, has seen repeated budget cuts since the 2015 Comprehensive Spending Review.¹⁵ The funding uplift for PHE in 2019/20 only brought spending back to 2017/18 levels,¹⁶ and will not benefit the National Cancer Registration and Analysis Service (NCRAS), the part of PHE that holds the Cancer Registry. Indeed, NCRAS expects to see further cuts despite the overall funding uplift for PHE. Despite welcome investment in digital through NHSx, it is not yet clear whether current funding levels will prevent further damage to the health service's capacity to collect, process and analyse data. **It is vital that these cuts are reversed, and sufficient funding is provided to ensure timely data collection, analysis and access.**

It is also important that the health system promotes the analytical skills needed to deliver insight and analysis from its data. Organisations such as HEE should look to supporting the education of analytical skills, drawing from best practice examples such as the ONS Data Science Campus.¹⁷

Data-Driven Research, Innovation and Service Improvement

The UK life sciences sector is world-leading and offers significant benefit to the NHS and patients through cutting-edge research into life-saving new treatments and health interventions. NHS health data has significant potential to drive forward this research, supporting innovative research models and use of real-world evidence in the development new treatments and technologies. It is important that the NHS works to support safe and responsible access to health data for all involved in life-saving research and innovation across the health service, academia, charities and the life sciences industry.

Making Data Accessible to Improve Care

Greater interoperability^A would facilitate better data accessibility across different clinical settings. At its core, interoperability is concerned with building systems that get the basics of data sharing right, ensuring that clinical information follows patients across their clinical pathway to improve their care. Cancer patients would not have to repeatedly explain their condition to different clinicians where currently important information such as age and comorbidities is often missed.¹⁸ This would improve patient experience and service efficiency, helping patients move more smoothly through diagnosis and treatment. It could also simplify information sharing between clinicians and patients, enabling more patients to access their health records, for example.

Greater interoperability and agreed clinical data standards could also facilitate greater use of digital technologies in clinical trials. For example, the Salford Lung Study drew on the integrated EPRs of 2800 consented COPD patients across 80 GP practices and 130 pharmacies in Salford and Greater Manchester. This model enabled a more inclusive and representative patient cohort compared to traditional clinical trials, provided timely results and proved much less burdensome for patients.¹⁹

However, use of this model has been limited to date, in part due to limited interoperability and a lack of standardisation in clinical data standards.²⁰ Agreed standards would also support research and innovation by making it easier for data holding organisations at both local and national levels to collate and make accessible this more complete aggregate data for further research.

Local Health and Care Records, the programme developing integrated regional EPR systems across England, offers a positive move towards simplifying data access and agreeing standards.²¹ **Current efforts to develop data sharing systems such as the LHCR programme should be supported by the DHSC, NHSE and NHSD, through capacity-building and sufficient funding to facilitate implementation.**

Supporting Innovation

Where innovation is being developed, there must be effective mechanisms for diffusion, so it benefits patients across the health system – for example advances in Global Digital Exemplars (GDEs), LHCRs, and in NHS Test Beds. The current East Midlands Radiology Consortium Wave 2 Test Bed programme is testing an AI tool in breast screening which has saved costs and helped limit patients' anxieties by reducing unnecessary recalls and biopsies.²² However, to roll this out more widely may require a significant investment in IT to facilitate digitisation of radiology images.

^A Interoperability refers to the ability of different information systems, devices or applications to communicate across within and organisational boundaries. Optimally, interoperable systems ensure data can be securely and routinely shared, and is sent and received in a format that can be understood by all systems.

Academic Health Science Networks have proven effective at facilitating roll out of practice changes such as pathway redesign, but they lack sufficient resource and funding to drive change at scale, meaning further national support needs to be committed to technological transformation. HDR UK and its Hubs, which seek to support integrated health data for research and innovation, are a welcome step towards realising the potential of data collected by the NHS and allowing the UK to become a world-leading centre for innovative digital healthcare.

Access for Research and Innovation

Researchers requesting NHS data face a system that is costly, resource intensive and has often inconsistent and opaque application processes.^{23,24} We have heard consistently that research progress is limited by delays in accessing data through NHSD and PHE. For example, last year CRUK submitted data access applications to a national data holder for two research projects. The projects had almost identical designs, but faced markedly different approval trajectories, with different assessments made by the data holder resulting in one project being approved after 3 months, and the other after 8 months. The reason for different assessment processes is unclear. This case is indicative of the delays which increase the cost and length of research projects, and indeed there are examples of delays to data access for CRUK-funded research that have been longer than 2 years. These unreasonable delays limit the ability of researchers to produce timely, relevant research that will deliver improved outcomes for patients.

Though it is important to have proportionate processes and access conditionality to protect identifiable patient data, there must be a balance between security and timely access. The current inefficient system requires both considerable time on the part of the data applicant to develop the application, but also significant resource for the data holder in processing the applications. Overcautiousness, particularly since the introduction of GDPR in 2018, has proven a significant barrier to research and innovation. Making data so difficult to access that it may as well not be available hinders analysis, innovation and ultimately improvements to cancer services.

It is welcome that PHE has made significant efforts to improve timely access in the face of significant resource constraints. However, there remains the fundamental issue that there is no harmonised data access request and assessment process for NHS data for researchers. This would improve efficiency, and support data-driven transformation. Looking forward, national NHS bodies should develop a **safe, straightforward, transparent and harmonised access model to NHS data for research. This should include clear Service Level Agreements on how long the process will take to complete**, with formal monitoring of timelines to ensure timely access. It is positive that NHSx has been tasked with leading on this work for the wider health system, and it is important that appropriate accountability structures are in place to ensure that timely progress is made. At the national level, the transfer of responsibility for the Cancer Registry from PHE to NHSD as part of the McNeill Review offers an opportunity to align approaches, in particular building on much of the positive work around data access that PHE has done in recent years.

Health data held by the NHS is an invaluable resource for the public good, and therefore where it is access is agreed with industry there must be equal benefit for the NHS, public and patients. It is key to maintain this principle to maintain public confidence - the National Data Guardian (NDG) found that over 70% of respondents to a public survey thought the NHS should benefit from commercial agreements through access to new technologies or medicines at a reduced cost, with the main benefit of these agreements being improved care and treatment.²⁵

NHSx, in particular its commercial department and planned Centre of Expertise, must work with data-holders across the NHS to guarantee any data access agreements with the life sciences

sector are fair and guarantee equitable benefit for patients, the public and NHS. A broad conception of what constitutes a benefit should be deployed, reflecting the value of supporting cutting edge research and the more rapid introduction of innovative health interventions to the NHS. This should be informed by the report on value exchange currently being developed by the Office for Life Sciences as part of the Life Sciences Industrial Strategy Sector Deal 2. Equitability should recognise both the inherent value of NHS data and the contribution of the life sciences research community in contributing to research and innovation, and ensure that innovation is not hindered by an overly-stringent and costly access model.

Where there are ethical concerns around making personal health data accessible for research, alternatives that facilitate research and innovation whilst protecting patient confidentiality should be considered. One option that could support this is developing synthetic datasets for researchers. These are developed from real health data but manipulated so that they retain the level of insight of the original datasets but cannot be linked to any real individual patient. Valuable steps have already been taken by PHE in partnership with Health Data Insight, AstraZeneca and IQVIA, who have developed the Simulacrum – an artificial dataset developed from English Cancer Registry data. The Simulacrum allows researchers to work with patient level data whilst still maintaining patient confidentiality, which could significantly accelerate the progress of research projects that are reliant on detailed datasets.

The synthetic data approach would be particularly valuable for the development of machine learning algorithms, which require vast amounts of data to train the algorithm, so that it is reliable. **NHSD and PHE should continue to lead efforts to improve availability of synthetic datasets.**

Maintaining and Improving Trust and Confidence

Ensuring public and professional trust in the use of patient data must be a priority for the Government and the NHS. Most people are supportive of patient data being shared for their own individual care, and a high proportion of people are also happy for patient data being accessible where there is public benefit^{26,27}. However, support varies depending on who has access to patient data, the type of data, and how it is used. Therefore, there needs to be **proactive, ongoing and positive efforts to explain and promote the use of patient data for service planning and research**. This should include retrospective sharing of the positive impact of insights gained through data analysis, to demonstrate the value of secondary uses of data.

All organisations that use patient data have a role to play in facilitating this – including charities, industry and the NDG – and **it is important that Government and the NHS leads the way in these efforts**. This should inform and engage all relevant groups, including healthcare professionals, patients and the public, and should be proactive, ongoing, and designed to be audience-appropriate.

Patient and public understanding of uses of health and care data is not currently high. As part of the 2016 Review of Informed Choice for Cancer Registration, a survey of people with cancer and the general public commissioned by Cancer Research UK and Macmillan Cancer Support found just 6% of people with cancer knew a great deal or a fair amount about the English Cancer Registry; three quarters had never heard of the registry.²⁸ However, people affected by cancer want to know about the English Cancer Registry: 83% of patients surveyed said it was important patients were informed.

In an increasingly digital health service, and with new data-driven technologies entering the NHS, it is vitally important that the way the NHS uses data is **trustworthy, transparent and well communicated**. To avoid damaging public confidence, uses of patient data must reflect public expectations and understanding, and respect patient's wishes.

It is similarly important to ensure that clinicians and healthcare professionals are informed on the ways that data is used and consulted on what data is collected and the functionality of any systems. This is vital to ensure that they have confidence in both the clinical systems they deploy, and the secondary uses of information they collect from their patients.

Whilst working to unlock the benefits of new technologies in the health system, it is essential that patients have **easy and equitable access to health services** and that a move to more digital interactions with health and care systems does not exacerbate inequalities in accessing healthcare. BAME groups are underrepresented in clinical trials²⁹, and the consequence can be that data-driven technologies and research developed from these datasets is not reflective of all ethnic groups.

In the case of genomics for example, many models are based primarily on data from people with European ancestry, meaning that genetic markers used to indicate a person's risk profile may not offer an accurate assessment for ethnic minorities. In developing new data-driven technologies, it is important to **redress the balance so that everyone can benefit equitably from new treatments and interventions**, for example through making efforts to ensure datasets used in developing new technologies are as representative as possible of the population as a whole.

Consideration must also be given to ensuring no disadvantaged or vulnerable communities are excluded from the benefits of new technologies. For example, the NHS move towards a digital-first primary care offer will significantly change the way the public access NHS services. However, only 10% of the public have used an online service to book a GP appointment³⁰ despite this service is now widely available, and 22% of adults in the UK still do not use a smartphone.³¹ Also, patients with low technological literacy or cognitive issues which impair understanding – such as the 810,000 people over 65 affected by dementia³² – may struggle to adopt new technologies. New digital and data-

driven technologies must be designed to be accessible, and patients should be supported to access them. Recognising that a one size fits all approach will not be appropriate for all patients is also vital. It is important both to capitalise on opportunities to improve patient experience – for example, making good on the commitment to give cancer patients digital access to their test results – whilst guaranteeing nobody is left behind in the process.

About Cancer Research UK

Cancer Research UK (CRUK) is the world's largest independent cancer charity dedicated to saving lives through research. We support research into all aspects of cancer which is achieved through the work of over 4,000 scientists, doctors and nurses. In 2018/19, we committed £546 million to fund and facilitate research in institutes, hospitals and universities across the UK. CRUK wants to accelerate progress so that 3 in 4 people survive their cancer for 10 years or more by 2034.

CRUK works extensively with NHS cancer data through our research, policy and information work, developing new insights that will benefit people with cancer and prevent future disease. We are the only organisation producing UK level cancer statistics, and our research adds considerable value to NHS data. We work in close partnership with Public Health England (PHE) to produce analyses that support policy makers, commissioners, health professionals and people affected by cancer.

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