Healthcare data beyond the pandemic

Building a world leading cancer data infrastructure in England

December 2021

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About the report

> *The pandemic has shown us the importance to public health of having access to accurate real time data. The NHS has a strong track record in collecting cancer data to support research through cancer registries and clinical audits. Now though there is an opportunity to apply the learnings from the pandemic to significantly upgrade our cancer data infrastructure. Improving the timeliness, reliability, integration and accessibility of our data can help tackle the cancer backlog, deliver earlier diagnosis and improve patient outcomes. This report and its recommendations provide a helpful policy framework for action on this important issue.*
>
> ***Professor Sir Mike Richards, former National Cancer Director and author of the Independent Review of Adult Screening Programmes***

> *This is a very timely, lucid and well-balanced report. It highlights the strengths, opportunities and challenges for cancer data collection and analytics in this period as we begin to emerge from the pandemic. Drawing on insightful observations on previous data initiatives and reviews of the NHS and combining these with the current plans and lesson from selected national and international case studies, the report makes a range of pragmatic recommendations that if adopted would be of significant benefit to patients, NHS and wider UK economy.*
>
> ***Dr Jem Rashbass, former National Director for Disease Registration and Cancer Analysis at Public Health England***

About the author

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Richard Sloggett is the Founder and Programme Director of Future Health. He was Special Advisor to the Secretary of State for Health and Social Care from 2018-19 and previously led Policy Exchange's health and social care work. Richard is a regular commentator in the national media on health and social care including in The Times, Telegraph, Financial Times, Economist and on Times Radio, BBC and LBC. He has been named as one of the top 100 people in UK healthcare policy by the Health Service Journal.

During his time with the Secretary of State, Richard worked across Whitehall, the NHS and local government on major policy decisions including the NHS Long Term Plan and the Prevention Green Paper. He has fifteen years' experience in public policy and healthcare, starting his career in Parliament before a successful career in public affairs where he led a team of 20 to the prestigious Communique Public Affairs Team of the Year Award.

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About Future Health

Future Health is a future focused Research Centre with a mission to advance public policy thinking that improves the health and wealth of people, communities and nations. Healthcare systems around the world are facing significant challenges of demographic, societal and technological change.

The importance of prevention and the development of new technologies have long been seen as ways to transform health systems to improve patient outcomes and performance, but progress has often been slow.

COVID-19 is an inflection point, demonstrating the need and opportunity of investing in and delivering more effective and efficient healthcare services in the future.

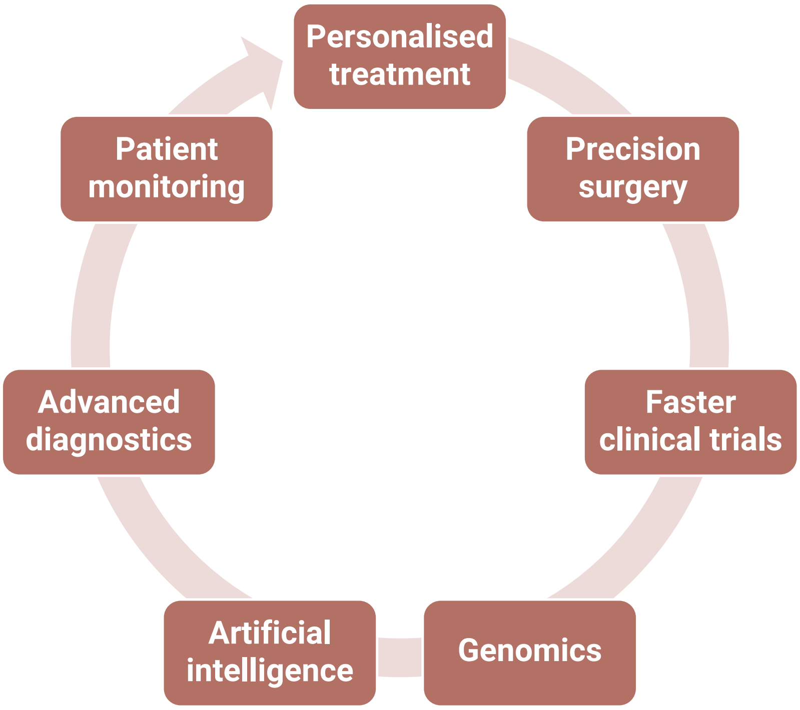
In undertaking cutting edge public policy research and generating new insights and solutions, Future Health seeks to shape the global healthcare policy debate and inform the decisions made by Governments and health systems to enable healthier, wealthier people, communities and nations.

Executive Summary: The future of cancer care and the importance of data

We know that 1 in 2 people will get cancer at some point in their lifetimes. Cancer Research UK's future of cancer project starkly sets out what could happen if action on treating cancer in the UK is not adequately prioritised. On CRUK's modelling, the impact of an ageing population, underlying poor health and health inequalities would see over 500,000 people per year needing cancer treatment in 2035.[1]

Fortunately advances in medical diagnostics and treatment – underpinned by innovation – mean the outlook for health systems in tackling the disease has never been more promising. New more personalised treatments, cutting-edge technologies such as genomics and AI, rapid clinical trials, precision surgery, advanced diagnostics and patient sensors and monitoring all provide a new toolbox for the NHS and clinicians to deliver significant improvements in cancer care.

Figure 1: The emerging cancer innovation toolbox



Despite recent improvements, cancer outcomes in the UK continue to lag behind other countries. A study by the International Cancer Benchmarking Partnership (ICBP) found that "cancer survival across 2010-2014 was generally higher in Australia, Canada, and Norway than in New Zealand, Denmark, Ireland, and the UK."[2]

The NHS Long Term Plan commits the NHS to tackling this by increasing the levels of diagnosis of stage 1 and 2 cancers to 75% by 2028.[3] The pandemic has clearly impacted on these ambitions, though NHS leaders remain committed to the target.

To close the outcome gap and properly take advantage of the new technologies available to improve cancer care will require a commitment to improvements in NHS data and new capital investment. Action is urgently needed in both areas. A recent study by Channel 4 News found a set of NHS organisations continuing to use scanning equipment that was over 10 years old.[4]

The challenges associated with NHS data are well known. NHSX's recent draft data strategy heavily reflects the difficulties of inputting, connecting, securing and actioning data. The UK has a strong track record and heritage in collecting and analysing cancer data through its national cancer registration service and associated datasets for radiotherapy, diagnostics and chemotherapy. Cancer registries now get almost full records from patients.

However the structures and approaches for this now need new investment for the future to upgrade system insight and capability. There are three main weaknesses that need to be addressed: timeliness, accessibility and integration.

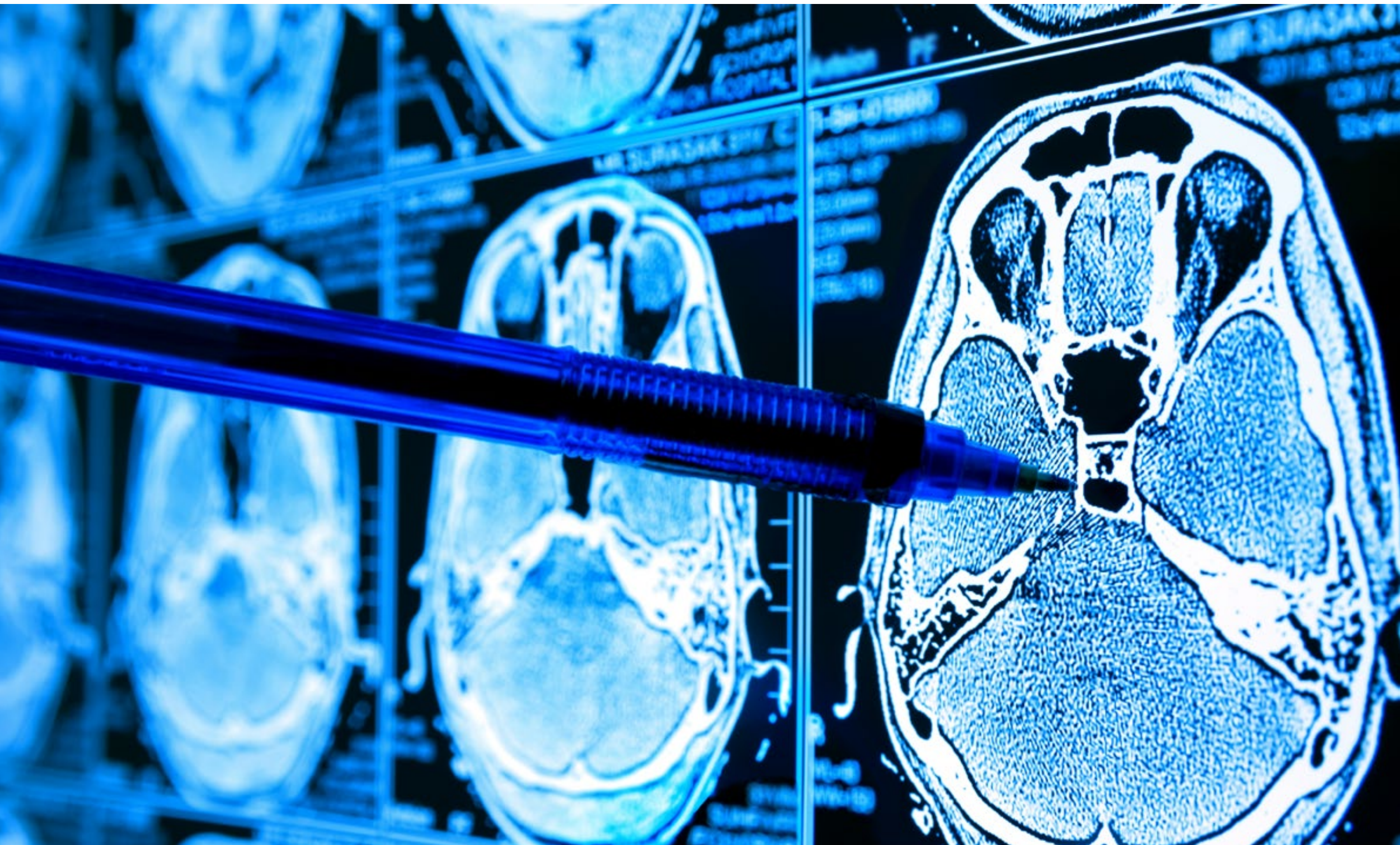
The healthcare data landscape is complex. But the pandemic has presented an opportunity for agile and dynamic movement on the agenda. The creation of the Covid 19 dashboard including vaccination data has greatly helped and improved the public health response. The level of disruption to cancer services during the pandemic has spawned real time cancer data projects such as the Covid cancer dashboard.

Advances in technology present new opportunities to build an enhanced data system for cancer that can support more real time data flows and analysis that in turn can support improvements in patient care and treatment. With more technology rapidly coming through across the cancer pathway, it is increasingly important for the underlying data infrastructure to be interoperable, to meet minimum standards and to include high quality data and information.

To do this will require new investment that can:

- Reduce friction and difficulty in the data collection and entry process
- Quickly and safely secure the data
- Improve the flow and connectivity of data between trusted parties
- Support rapid analysis and interpretation of the data

An improved cancer data infrastructure along these lines can be both a powerful enabler for the recovery of cancer services from the pandemic and the improvements in diagnosis and outcomes that are needed.



Summary of recommendations

This report includes a set of recommendations for action that build from the learnings of the pandemic. These include greater national co-ordination of ambition and policy on healthcare data including cancer data, unlocking the power of real time data and investing in new technologies and infrastructure that can overcome the hurdles to data entry and difficulties of variable data quality.

The NHS has a chance to build new international collaborations for improvements in data standards and governance in cancer which domestically will also require strong public and patient engagement on the importance of and secure access to patient data through the expansion of work such as Trusted Research Environments (TREs).

Critically a more integrated and interoperable infrastructure for cancer can support more value based healthcare approaches paying for outcomes rather than activity that supports the adoption of new innovations in a more sustainable manner.

Conversely if such opportunities are not taken forward a poor, mis-aligned and insecure data infrastructure will present a major barrier to Government ambitions for levelling up the nation’s health and making the UK a leading global science superpower.

The following provides a summary of the recommendations within the report. A full assessment and further detail for each area with examples is included later.

Recommendation 1: National leadership and co-ordination: Government should create a National Health Data Council bringing together the various bodies involved in healthcare data to support a more co-ordinated and joined up approach to building a world leading health data infrastructure. As an NHS long term priority cancer should be an early focus for the Council

Recommendation 2: Real time and enhanced data reporting: The real time cancer dashboard introduced during Covid 19 should continue to be resourced fully beyond the pandemic to support cancer service recovery and improvement. Investment in cancer data infrastructure should prioritise critical assets such as the Systemic Anti-Cancer Therapy (SACT) dataset to enable improvements and enhancements in what is captured and reported

Recommendation 3: Health data infrastructure accelerator: To support implementation of the Life Sciences Vision the Department of Health and Social Care and the Office for Life Sciences should develop a health data infrastructure accelerator. The accelerator would see innovative partnerships between clinicians, industry and patients enabling the uptake and implementation of infrastructure that can deliver improvements in health service data entry, quality and analysis

Recommendation 4: Integration and interoperability: The Department of Health and Social Care and NHSX should align the health data strategy and forthcoming integration white paper to ensure it delivers a more integrated and interoperable cancer data system. There should be greater transparency and accountability of organisational compliance with data return requirements

Recommendation 5: Value based healthcare and outcome based innovation payments: New, integrated real time data infrastructure for cancer should be used to unlock and expand commercial deals for the NHS for new cancer innovations such as outcomes based payments delivering improved value and patient outcomes

Recommendation 6: International cancer data collaboration: The UK should prioritise cancer data in its post G7 commitments on improving health data standards and utilise the opportunities of the US-UK cancer summit to share learnings and future opportunities on the cancer data agenda

Recommendation 7: Trusted Research Environments (TREs): The expansion of TREs present an opportunity to provide secure and safe access to linked cancer datasets by accredited researchers to support cancer service improvement

Recommendation 8: Patient and public engagement: The Government and NHS should ensure there is a strong focus on patient and public engagement on healthcare data use that builds from the work and advances seen during the pandemic, such as the COVID 19 dashboard and Chest Imaging Database

Introduction: Data at the heart of Government ambitions for public service reform and UK global leadership

Government ambitions for public service improvements and economic growth

The UK Government has long held ambitions to unlock the power of data to improve public services. Under Lord Maude, then a Cabinet Office Minister, the coalition Government created the Government Digital Service (GDS) which: "builds platforms, products and services that help deliver a simple, joined-up and personalised experience of government to everyone." Maude's view was that a more joined-up digital approach would increase the operational effectiveness and efficiency of public services and make them more responsive to public needs. Former Prime Minister David Cameron called GDS "one of the great unsung heroes" of the early 2010s.[5]

Fast forward to today and the desire to improve the country's data and digital capability remains at the forefront of Government thinking. In 2020 DCMS published the National Data Strategy which seeks to "leverage existing UK strengths to boost the better use of data across businesses, government, civil society and individuals." The strategy was explicit in its desire to reduce barriers to data sharing and accessibility to improve public service performance:

"Data is a non-depletable resource in theory, but its use is limited by barriers to its access – such as when data is hoarded, when access rights are unclear or when organisations do not make good use of the data they already have. These barriers undermine the performance of public services and our economy, risking poorer outcomes for citizens. We will ensure that data can be leveraged to deliver new and innovative services, promote stronger competition, and better prices and choice for consumers and small businesses. We will drive an approach to data that holds that all can benefit when data is used responsibly, and that withholding data can negatively impact society."[6]

The strategy has four pillars to underpin success: data foundations and quality, data skills, data availability and responsible data. The strategy also includes a mission to promote improvements in international collaboration around data use.[7]

Delivering a global life sciences hub

The 2019 Conservative manifesto included a commitment to make the UK a 'global leading hub' for life sciences as part of post Brexit ambitions. The collaboration between Government and industry during the pandemic has resulted in a new Life Sciences Vision published in July 2021. Data is seen as critical to delivering the Vision:

"To be sustainable, the NHS needs to focus on the right interventions early in the course of disease, with a reinvigorated approach to deliver innovations for the major diseases that drive most morbidity and mortality, with predictive and monitoring technologies, genomics and data used to prevent, detect, diagnose, and treat disease early, rather than concentrating on late-stage disease – in line with the commitments in the NHS Long Term Plan."[8]

The Vision adds: "to drive value creation for the Sector, with the Government, Medical Research Charities and NHS taking the same mission-orientated approach to innovation seen in the pandemic across a range of diseases with patients benefiting from new ways of working, the NHS operating as a data-driven test bed for new technologies, and Government making the UK a hospitable commercial and operating environment for companies to innovate, grow and invest."[9]

The Vision also notes the importance of innovative data partnerships "whether this is through clinical research, validating AI using the UK's uniquely diverse population, or continuously surveying the uptake, safety and efficacy of diagnostics, treatments, and care pathways."[10] It also highlights opportunities to work closely with industry through Trusted Research Environments to "allow more accurate assessment and evaluation of new innovations and technologies."[11]

Better healthcare data to improve health outcomes

Frustrations at the quality and timeliness of healthcare data are longstanding. In his 2002 Treasury review looking ahead at the future of the healthcare system, Sir Derek Wanless noted that improvements in information technology would deliver significant benefits to the effectiveness and efficiency of healthcare. Setting out how success should be seen in 2022, 20 years after his Review, Wanless noted:

“Modern and integrated information and communication technology (ICT) is being used to full effect, joining up all levels of health and social care and in doing so delivering significant gains in efficiency.”[12]

Despite such ambition progress has been mixed. The Life Sciences Vision commits the Government and NHS to a radical simplification of access to NHS data backed by the highest standards in data protection. It notes the challenges that Covid 19 has highlighted with regards to health data:

“COVID-19 has highlighted long-standing problems in the landscape. As is the case in other countries, UK health data is mainly focused on managing patient records in the support of clinical processes and is not structured to facilitate population-wide research and analysis. It is fragmented across a complex institutional landscape, is of variable quality, and is often difficult and slow to access.”[13]

The creation of a Covid 19 data dashboard has significantly helped over recent months and supported more effective policy interventions. NHSX has launched its own healthcare data strategy for consultation in June 2021. The strategy has sought to take the learnings from the digital response to Covid and ‘bottle’ them to tackle other long term health challenges.[14] The strategy aims to make the healthcare system more “efficient, responsive, personalised and ultimately safer.”[15]

The strategy covers seven areas for improving NHS data as set out below.

Figure 2: NHSX data strategy

Public	• Bringing people closer to their data and giving people confidence in how this data is being used
Health professionals	• Giving health and care professionals the data they need to provide the best possible care by simplifying information governance, creating a new duty to share, delivering shared records, reducing the data collection burden, harnessing safe and effective innovation
Interoperability	• Supporting local and national decision makers with data by integrating local care systems with a culture of interoperable by default, building analytical and data science capability, working transparently in the open, sharing data for wider purposes and collaborating with wider partners
Social care	• Improving data for adult social care by improving access to information for adult social care providers, integration of health and social care data and expanding the use of care technologies
Research	• Empowering researchers with the data they need to develop life-saving treatments, models of care and insightsby providing safe and secure data for analysis and research, sharing data for research, encouraging clinical research
Modernising data architecture	• Helping colleagues develop the right technical infrastructure by modernising our data architecture, promoting and developing data and technical standards, staying ahead of evolving cyber risk, separating the data layer
Supporting innovation	• Helping developers and innovators to improve health and care by driving interoperability for innovation, encouraging AI innovation, clear and understandableAIregulation, supporting innovators to work with health and care organisations, creating fair returns in data partnerships

Building off a review into NHS Bureaucracy, the Strategy also set out a commitment to have "in place a system-wide target for the rationalisation of data collections to reduce the time spent by health and care staff inputting and processing data for national use (by 2021 to 2022 and reviewed annually)."[16]

The NHSX Strategy built out from a Technology Vision published by the former Secretary of State for Health and Social Care, Matt Hancock, in October 2018. The Vision included commitments to invest in infrastructure, improve digital services, scale innovation and invest in digital skills and expertise.[17] The NHS Long Term Plan similarly included a commitment to:

"Link clinical, genomic and other data to support the development of new treatments to improve the NHS, making data captured for care available for clinical research, and publish, as open data, aggregate metrics about NHS performance and services."[18]

The opportunity of cancer data and NHS global leadership

The NHS has a strong track record in developing its cancer data and registries and stands in a position to capitalise on this platform, with the opportunities through the NHS Long Term Plan, Life Sciences Vision and data strategy.

The below looks to compare the position of the UK with the US and EU with regards to cancer data and data infrastructure.

Figure 3: UK/EU/US comparison on cancer data ambitions

Geography	Life science and health data agenda	Major cancer innovation and data commitments	Strengths/challenges
UK	New Life Sciences Vision seeks to build from successful previous Government strategies and sets an ambition for delivering unrivalled 'at scale' data infrastructure[19] NHSX draft data strategy is focused on improving the interoperability and integration of healthcare data[20]	NHS Long Term Plan includes commitment to increase the proportion of cancers diagnosed at stage 1 and 2 to 75% by 2028[21] Life Sciences Vision looks to unlock future innovations in cancer treatment in the NHS	Strong track record of leading advances in cancer data and building registries Positive advancement of improving cancer data during the pandemic (eg Covid cancer dashboard and Trusted Research Environments) National single payor system presents clear advantages for utilising health data for health outcomes Well established difficulties with the NHS data infrastructure, integration and usability of cancer data for improving patient outcomes and service delivery
EU	The EU has proposed a new pharmaceutical strategy to ensure the quality and safety of medicines, while boosting the sector's global competitiveness[22]. The European data strategy and the European Health Data Space (EHDS) seek to unlock the potential of health data to improve patient outcomes At individual country level, life sciences and healthcare data are a strategic priority. France has included life sciences as a priority within its France 2030 economic and growth programme.[23] The Benelux countries have been tipped as a leading hub with the move of the EMA to Amsterdam.[24] Other countries with notable advantages on the health data and digital agenda include Denmark and Estonia	The EU Beating Cancer Plan seeks to tackle cancer across the whole pathway[25] The EHDS will enable cancer patients to securely access and share their health data in an integrated format in the electronic health records The European Cancer Information System is set to be expanded and include new outcome indicators	Established processes at the national level for cancer data collection; though these are highly variable. The EHDS is looking to address this A recent report from the European Cancer Organisation set out some of the challenges for EU wide action on cancer data including differences in the interpretation and implementation of GDPR, problems with connecting different local and national registries, and the validity and completeness of data[26]

Geography	Life science and health data agenda	Major cancer innovation and data commitments	Strengths/challenges
US	President Joe Biden's 2022 budget pledges to create an Advanced Research Projects Agency for Health "tasked with developing a new generation of medical breakthroughs—marshalling our Nation's incredible scientific capacity to help prevent, detect, and treat diseases like cancer, diabetes, and Alzheimer's"[27]	The US Government's cancer moonshot programme has three goals: to accelerate scientific discovery in cancer, foster greater collaboration, and improve the sharing of data[28] The Federal Health IT Strategic Plan 2020-2025 includes a series of opportunities for delivering a more digital health system including: empowered patients, more value based healthcare, advanced interoperability, unlocking new technologies, improved regulation and system security[29] The Office of the National Co-ordinator for Health Information Technology launched a Interoperability 2030 initiative which will include a prioritised set of interoperability outcomes later this year[30]	Significant investment is being made in US healthcare innovation and cancer research As set out in the IT Strategic Plan, the US healthcare system is highly fragmented, posing challenges for connecting and realising the potential of health data for patients

Summary

- The NHS has a strong and established track record in developing and unlocking its cancer data for improved population health; though challenges exist particular in accessing more real time data
- Many countries and regions face similar challenges to the NHS in integrating and connecting health data; though some smaller countries have overcome challenges, often due to broader infrastructure capabilities and policies (eg Denmark and Estonia with national ID systems)
- Both the EU and the US are upgrading their healthcare infrastructure and capability, and have set new ambitions and policies to deliver this. Both have also pledged new action to improve cancer care and outcomes
- Progress during the pandemic in regards to the use of health data, and cancer data specifically, presents opportunities for UK global leadership through the development of 'at scale' health data infrastructure development within a single integrated system

CHAPTER 1

The NHS cancer data landscape in England

Tackling health inequalities and improving health outcomes are ambitions for the Government's healthcare and life science data improvements with cancer a priority focus.

NHSX's data strategy includes commitments to share "data with researchers to develop COVID-19 vaccinations, for improved cancer treatments to be developed, and help health and social care organisations to more effectively support their patients and service users."[31]

The Life Sciences Vision is based around a set of missions: dementia, cancer, vaccines, CVD, respiratory disease, ageing and mental health. For cancer, the Vision includes a set of focus points set out below:

Figure 4: Life Science Vision: cancer commitments

- **Supporting at scale cancer diagnostics**
- **Clinical trials for new therapies such as immuno-oncology and cancer vaccines**
- **Unlocking the potential of genomics and polygenic risk scores**
- **Commercialise cancer technologies in the UK**
- **Hold a US-UK cancer summit**

To deliver on these commitments will require improvements in the cancer data infrastructure and the quality of cancer data to be fully realised.

The main national responsibilities for cancer data have been primarily split between NHS Digital, Public Health England and NHS England/Improvement. The following seeks to summarise the main cancer datasets and responsibilities in England as at early November 2021. The decision to merge NHS Digital and NHSX into NHS England will create further changes with greater centralisation.

NHS Digital cancer data responsibilities[32]

In October 2021 the Government disbanded Public Health England (PHE) that housed the National Disease Registration Service (NDRS) and which led a number of national efforts to collect and improve cancer data. The NDRS collects data on patients with cancer, congenital anomalies and rare diseases and includes the National Cancer Registration Analysis Service (NCRAS) and the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS).

PHE has been split in two with the creation of a new UK Health Security Agency (UKHSA) focused on health security threats and an Office for Health Improvement and Disparities (OHID) to tackle health inequalities. The NDRS has subsequently moved to NHS Digital.

National Cancer Registration Analysis Service (NCRAS)

Part of the NDRS, NCRAS receives about 25 million records each year covering 300,000 malignant tumours.[33] NCRAS collects cancer data from:

- histopathology and haematology services
- secondary care medical records
- radiotherapy departments
- hospices
- independent hospitals
- screening services
- death certificates
- GPs
- other UK cancer registries[34]

NCRAS merges data from multiple datasets to create the National Cancer Registration Dataset (NCRD). This dataset contains three types of tables for patient information, tumour information and treatment information, which are linked by NHS number. The national cancer registration dataset includes a subset of Cancer Outcomes and Services Dataset, as well as the Route to Diagnosis for each tumour and information from the Index of Multiple Deprivation (IMD). In their article in the International Journal of Epidemiology, Henson et al note that NCRAS: “creates a monthly snapshot of data for analysis. A provisional quarterly snapshot is generated to facilitate timely data release, and then a designated annual snapshot when each calendar year of registrations is completed. The annual snapshot is used to produce national statistics.”[35]

The below summarises the main datasets NCRAS is responsible for.

Figure 5: Summary of key national cancer datasets[36,37,38,39,40]

Cancer Outcome and Services Dataset (COSD)	• The Cancer Outcome and Services Dataset (COSD) overseen until recently by Public Health England has been the national standard for reporting cancer in the NHS in England since January 2013.There have been frequent updates to the dataset, which is aimed supporting the delivery of the goals within the national cancer strategy. The dataset contains 489 items including operational data on patient waiting times, treatment data including surgery, chemotherapy and radiotherapy, and mortality data.
Systemic Anti-Cancer Therapy Dataset (SACT)	• The Systemic Anti-Cancer Therapy (SACT) dataset collects information reported routinely by NHS trusts on the treatment of malignant disease in secondary care in England. This database relates to all cancer patients, both adult and paediatric, in acute inpatient, day-case and outpatient settings and delivery in the community. It covers systemic anti-cancer treatment for all solid and haematological malignancies, including patients in clinical trials. The SACT dataset collection was launched in April 2012 across England in a phased process over two years. All NHS provider trusts have been mandated to send monthly data submissions from April 2014.
Rapid Cancer Registration Dataset (RCRD)	• The Rapid Cancer Registration Dataset contains proxy tumour registrations and some associated events on the cancer patient pathway. It takes data from a range of cancer registration sources, particularly (COSD) and is: "a quicker, indicative source of cancer data compared to the gold standard registration process, which relies on additional data sources, enhanced follow-up with trusts and expert processing by cancer registration officers."
National Radiotherapy Dataset (RTDS)	• NDRS is responsible for the ongoing maintenance, development and implementation of the National Radiotherapy Dataset which collects standardised data monthly against a nationally defined dataset. It covers every patient receiving: • External beam radiotherapy (teletherapy) • Brachytherapy • Proton therapy • Radioisotope therapy (including radioiodine) • Molecular radiotherapy

National Cancer Diagnosis Audit (NCDA) and Clinical Audits

The NCDA is a partnership between PHE, NHS England, Macmillan Cancer Support, CRUK, Public Health Scotland, the Royal College of GPs, Public Health Wales and the Wales Cancer Network.

According to CRUK the NCDA "helps us to better understand pathways to cancer diagnosis, what works well and where improvements could be made, to achieve better outcomes for patients." It collects a sample of data from primary care on:

- Presenting signs and symptoms
- Referral types used for patients later diagnosed with cancer
- Use of tests and investigations prior to referral
- Use of safety netting
- Interval length from patient presentation to referral and diagnosis
- Avoidable delay as judged with hindsight by the GP

Tailored data feedback is then provided to GP practices to support learning and quality improvement. The last NCDA audit was completed in 2021 having been launched in 2019. It is not an annual recurring audit and not all GPs participate.[41]

NCRAS also manages a series of national clinical audits for cancer. These include lung, prostate and breast cancer for older patients. NHS Digital will now have responsibility for these as well as the clinical audits for bowel cancer and oesophago-gastric cancer that it already led work on.

Cancer Alliance Data, Evaluation and Analysis Service (CADEAS)

NHS Digital also replaced Public Health England as a lead partner with NHS England and Improvement on CADEAS, which looks to support the regional cancer alliances in recovering services following Covid 19, and delivering on the NHS Long Term Plan cancer commitments. This includes reporting on cancer waiting times data and standards (2 week waits and the 31 and 62 day standards).[42]

NHS Outcomes Framework (NHS OF)

NHS Digital is also responsible for the NHS Outcomes Framework which includes a series of indicators to measure NHS cancer outcomes, including one and five year cancer survival.[43]

NHS England/Improvement

NHS England/Improvement is the other main national body with responsibility for cancer data and a focus on managing and improving operational performance. Responsibilities include:

- Cancer waiting times data – including key data such as 2 week waits, and 62 day referral data
- Diagnostic Imaging Dataset – a central collection of detailed information about diagnostic imaging tests
- National Cancer Patient Experience Survey (NCPES) - the NCPES is commissioned by NHS England and Improvement and has been designed to "monitor national progress on cancer care, to drive local quality improvements, to assist commissioners and providers of cancer care and to inform the work of the various charities and stakeholder groups supporting cancer patients."[44]

Outside of NHS Digital and NHS England a number of organisations also have a stake or role in the cancer data landscape in England:

NHSX	• Overseeing the new healthcare data strategy, focused on interoperability and improved data standards
HDRUK	• Leading research and efforts to create Trusted Research Environments for sharing and unlocking the potential of cancer data
OLS	• Lead national body for the delivery of the Life Sciences Vision, including associated commitments
DHSC	• Government department for health and social care with responsibility to Parliament for health data policy and health service performance
Genomics England	• Sequencing cancer patient DNA to support research and treatment discovery
National Data Guardian	• Advises and challenges the healthcare system to ensure citizen healthcare data is kept confidential

CHAPTER 2 Challenges for improving cancer data

The most recent national cancer strategy ‘Achieving World Class Outcomes: A Strategy for England 2015-20’ set out the importance of maximising opportunities for improvements in cancer data to deliver improved outcomes: “the commitments in this strategy will rely on high-quality, and in many instances near real-time, cancer intelligence capability.” The strategy included a series of recommendations for action on data including:

Recommendation 89: DH should urgently address the current information governance problems around access to NHS patient data experienced by bona fide clinical and research organisations which are compliant with appropriate standards of data security and confidentiality. It should ensure that a policy and legal framework is in place that facilitates the ongoing flow of data from and between HSCIC, MHRA, NIHR, and PHE.

Recommendation 90: Public Health England, working closely with partners in a newly constituted PHE Cancer Board, should improve the provision of cancer data and intelligence via the National Cancer Intelligence Network and the National Cancer Registration Service: • Greater focus should be achieved by ensuring adequate resources are applied to collect comprehensive cancer data, link it across the whole cancer pathway and analyse it through a centralised data system. • PHE should work with charities and researchers to clear the existing backlog of data requests from commissioners and researchers by the end of 2015. Thereafter, PHE, through NCIN and NCRS, should work to establish further linkages of datasets, including RTDS, CPRD, SACT, and DID to help drive further service improvement. • Public Health England and NHS England should establish robust surveillance systems and, if possible, mandate the collection of data on recurrent and secondary cancer occurrences for all cancers and make this available for analysis and research.[45]

In their 2020 assessment of the performance of NCRD and delivery of the strategy, Henson et al[46] set out a series of areas where the existing data system is strong and some of its limitations. These have been summarised in the below table:

Table 1: Strengths and limitations of the national cancer data system

Strength	Limitation
National coverage and strong levels of completeness	Some private sector cases not included (approx. 1%)
Records of cancer back to 1971	Some limitations in making comparisons due to data changes and requirements over time
Registrations coded to international standards, enabling international comparisons	
Strong quality assurance processes on data	Issues regarding timeliness of data analysis
Data can be linked to other data sets – eg HES, e-prescribing etc	Information on the intent of treatment and performance status is limited
Improvements in collections of certain data fields such as staging data and ethnicity	When new data items are added, data entry can be low, and providers need support to deliver increasing returns
Low opt out rates from dataset	Need for continued work between NCRAS and patient groups to build trust and the value of cancer data for improved outcomes
Primary care data can be linked at a population subset level, through CPRD	Primary care information is not available at the national level
Linkage to mortality data allows links to cause of death	Non -death outcomes, such as long-term treatment effects or quality of life assessments, are difficult to identify using registration data, particularly those that do not result in an inpatient hospital stay. Cancer recurrence and progression are currently poorly recorded in both hospital and registration data due to a number of challenges, including inconsistent definitions and the time lag between initial presentation and the cancer recurrence, which can be many years after the original diagnosis.
Body mass information can be ascertained for chemotherapy patients – though data is of variable quality	Lifestyle information is limited – such as smoking and obesity rates
Much work has been done to de-duplicate registrations in the system	Small number of duplicates (<1%) in the system pre 2012 – though these are excluded from analyses and data releases
Clear, robust and transparent processes in place for accessing the data	Can be costs involved with the data release

The summary above provides a good insight into the challenges and limitations to improving cancer data in the NHS. These challenges can be grouped under a set of areas and are regular themes and feedback that come back when looking at the difficulties of improving healthcare data in England.

Figure 6: Summary of challenges and limitations to improving cancer data in the NHS

Quality	• Incomplete data or poor quality, duplicated data • Unrepresentative data from the population • Data not being rapidly processed and as a result not actionable
Integration	• Difficulties in connecting and linking together different datasets • Some public health and primary care data is more limited and less well connected
Cost	• In administering and inputting the data (eg clinical/operational time) • To release the data effectively for further research
Governance	• Need to build patient trust in data use

These areas and themes do overlap and interconnect. For example, the cost of administering the data is a factor in incomplete datasets which in turn affects data timeliness and costs for checking and releasing the data when it is requested.

The challenges relating to data cannot also be detached from the wider structural pressures within the healthcare system. Specifically:

Backlogs of care – with substantial backlogs of care emerging from the pandemic and Government and NHS leaders looking to catch up with cancer diagnoses and cases, there may be challenges in managing the associated increases in activity data. The likely short term increased use of the private sector to support capacity may present difficulties in integrating cancer patient data

Workforce – with an estimated 100,000 staff vacancies across the NHS, staff pressures do create a limiting factor on the time available for data entry

Policy structures and governance – the 2012 Health and Social Care Act created an array of actors across health and social care with responsibility for data. This fragmentation has created challenges in connecting together different policy ambitions. Tasking various bodies with delivering specific improvements – such as NHSX, various actors on health innovation and interoperability, and HDRUK on health research data – has created more actors and the potential for overlapping responsibilities. Though moves to integrate NHSX and NHS Digital to NHS England should help with this.

CHAPTER 3

COVID 19: an acceleration of real time and improved healthcare data

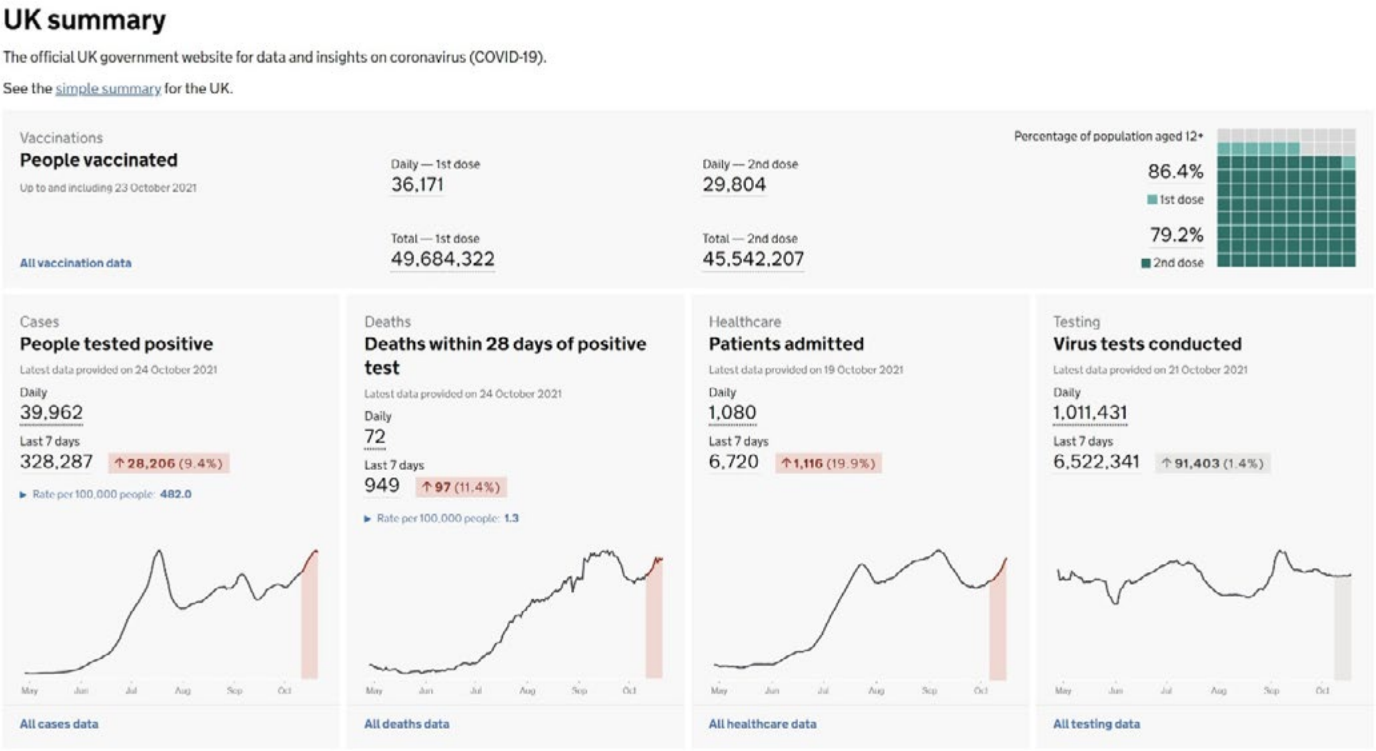
With the arrival of COVID 19, there was an urgent need to gather, analyse and interpret healthcare data in real time.

The Government and the NHS created the COVID 19 Datastore. The Datastore brings a wide range of information from across the healthcare system relating to the pandemic into one place. The system is held on the cloud by Microsoft Azure with NHS England and Improvement having access to the information. The NHS contracted with Palantir to clean up the data so that it can support the development of effective tools for service management, such as the COVID 19 dashboard (a picture of which is below).

NHSX has argued that the datastore has helped it:

- understand how the virus is spreading and identify risks to particularly vulnerable populations
- proactively increase health and care resources in emerging hot spots
- ensure critical equipment is supplied to the facilities with the greatest need
- divert patients and service users to the facilities that are best able to care for them based on demand, resources, and staffing capacity
- support clinical research to understand more about the virus and the impact it is having[47]

Figure 7: Snapshot of NHS Covid 19 dashboard



UK summary

The official UK government website for data and insights on coronavirus (COVID-19).

See the simple summary for the UK.

Vaccinations

People vaccinated

Up to and including 23 October 2021

Daily — 1st dose
36,171

Daily — 2nd dose
29,804

Total — 1st dose
49,684,322

Total — 2nd dose
45,542,207

Percentage of population aged 12+

86.4%
1st dose

79.2%
2nd dose

All vaccination data

Cases

People tested positive

Latest data provided on 24 October 2021

Daily
39,962

Last 7 days
328,287 ↑28,206 (9.4%)

▶ Rate per 100,000 people: 482.0

All cases data

Deaths

Deaths within 28 days of positive test

Latest data provided on 24 October 2021

Daily
72

Last 7 days
949 ↑97 (11.4%)

▶ Rate per 100,000 people: 1.3

All deaths data

Healthcare

Patients admitted

Latest data provided on 19 October 2021

Daily
1,080

Last 7 days
6,720 ↑1,116 (19.9%)

All healthcare data

Testing

Virus tests conducted

Latest data provided on 21 October 2021

Daily
1,011,431

Last 7 days
6,522,341 ↑91,403 (1.4%)

All testing data

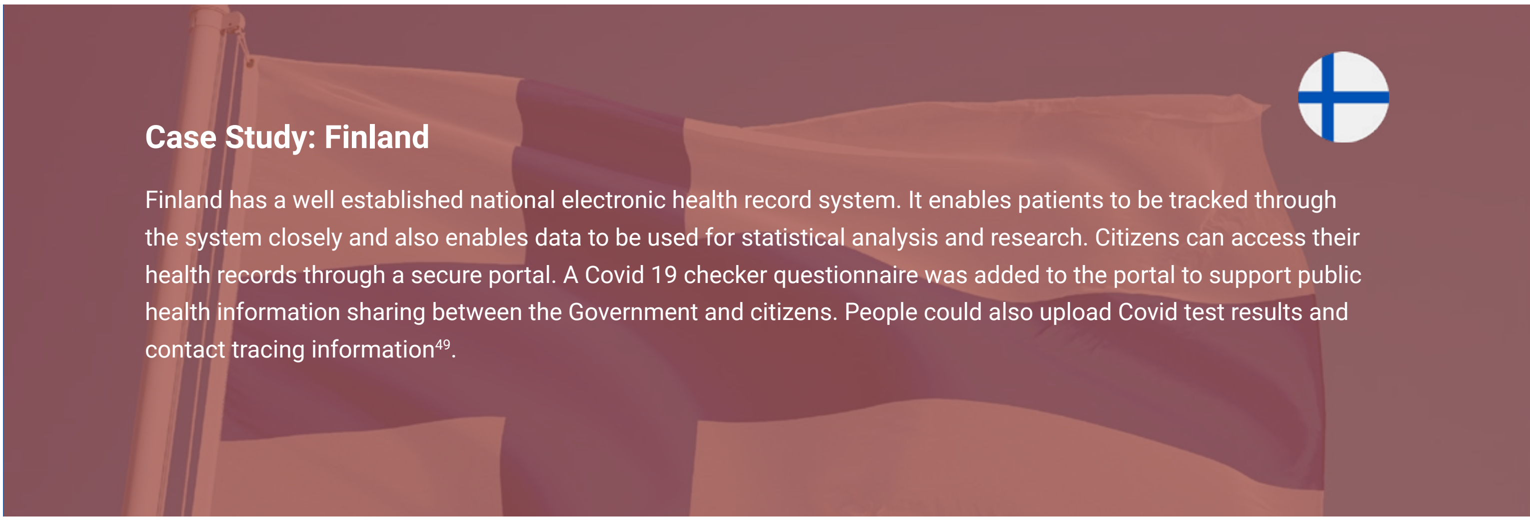
The project lead for the dashboard Dr Ming Tang has identified a number of opportunities for building practical learnings from the pandemic, including:

- Building a consistent version of the truth
- Making understanding variation in performance simpler
- Making it easier to get started on improvement
- Supporting consistent frameworks for insight, diagnosis, improvement and evaluation based on a continuous improvement cycle;
- Building improvements in skills and system data science[48]

Many other countries also moved quickly to unlock the potential of real time data to support their health system response.

Case study: South Korea

South Korea already possessed a strong underlying health data infrastructure before the pandemic. This enabled the country to quickly collect and analyse relevant information to the pandemic and distribute resources appropriately. South Korea also developed a real time monitoring system for travellers after the MERS pandemic which was put to use during Covid 19. Data from the health system was inter-operable with data outside of the health system to support disease monitoring and spread.



Case Study: Finland

Finland has a well established national electronic health record system. It enables patients to be tracked through the system closely and also enables data to be used for statistical analysis and research. Citizens can access their health records through a secure portal. A Covid 19 checker questionnaire was added to the portal to support public health information sharing between the Government and citizens. People could also upload Covid test results and contact tracing information[49].

The pandemic has also spurred new action on cancer data. Rapid cancer registration and associated clinical activity has been made available during the pandemic to support the NHS and public health agencies.

According to NDRS: “The data is based on a rapid processing of cancer registration data sources, in particular on Cancer Outcomes and Services Dataset (COSD) information. Full, gold standard cancer registration data is not yet available for much of this time period as it relies on additional data sources, enhanced follow-up with trusts and expert processing by cancer registration officers. This rapid dataset provides a quicker, indicative source of cancer data.”[50]

A comparison of rapid cancer registrations data to full cancer registration data for April-September 2018 has shown the differences between the apparent level of difference in accuracy between the rapid registration and the full registration:

- 16.6% of gold standard cancer registrations were not identified using the rapid cancer registration process (missed registrations)
- 5.1% of cases identified in the rapid cancer registration dataset could not be linked to a gold standard cancer registration (incorrect rapid registrations, false positive error)[51]

NDRS has also developed dashboards for radiotherapy and chemotherapy to support clinical decision making in cancer.

From a clinical research perspective, NHS Digital and HDRUK have been building a series of Trusted Research Environments (TREs).

During the pandemic Data-CAN, the UK’s Health Data Research Hub for cancer, has worked to speed up processes to ensure rapid, safe and trustworthy access to cancer data in a transparent way that accelerates the pace of high quality research. The TRE is aimed at marrying these policy goals, which can often push systems in opposite directions.[52]

Case study: Pandemic learnings: National Covid 19 Chest Imaging Database

There are a number of learnings that have been taken from the pandemic in relation to improving healthcare data and the data capability of the system.

The National COVID-19 Chest Imaging Database is a joint initiative established by NHSX, the British Society of Thoracic Imaging (BSTI), Royal Surrey NHS Foundation Trust and Faculty. It is a centralised UK database containing chest X-ray (CXR), magnetic resonance imaging (MRI) and computed tomography (CT) images from hospital patients across the country. The database was created to support a better understanding of Covid 19 and develop technology which will enable the best care for patients hospitalised with a severe infection.[53]

Those involved in the National Covid 19 Chest Imaging Database[54] have identified eight learnings in their work summarised in the table below.[55]

Table 2: Learnings from National Covid 19 Chest Imaging Database

Strength	Limitation
Information Governance	There is a need to clarify and standardise data governance processes to reduce barriers to NHS Trust participation in national data collection exercises
Database linkages	Linking datasets is critical to improving the quality and coverage of data collected
Automation	Automation is critical to enable mass data collection
Trusted Research Environments (TREs)	National infrastructure supports data being accessed and analysed in a safe and secure way
Availability of validation dataset	Large-scale high quality validation datasets help accelerate routes to market for innovatio
Funding	Local NHS Trust data collection requires funding mechanisms to support engagement on data collection
Patient and public engagement	Is critical to ensure that concerns about how data is used and stored is done so in a safe, secure and ethical way
Benefit and share models	Sharing such models between national and local NHS organisations, helps support and incentivise local NHS participation in national data collection exercise

CHAPTER 4

Beyond the pandemic: opportunities for improving NHS cancer data and patient outcomes

Covid and cancer are very different. Covid is essentially a single disease, diagnosed through a single test, with two main data points (hospitalisation and death). Cancer by contrast is hundreds of conditions diagnosed in a number of different ways with multiple data sources.

The learnings from the pandemic do present opportunities for policy action to improve cancer data. Seizing these opportunities could advance efforts to build a world class cancer data infrastructure that delivers improvements in cancer outcomes. The opportunities include:

National leadership and co-ordination

Real time cancer data

Infrastructure investment

Integration and interoperability

Value based cancer care

International collaboration

Trusted Research Environments

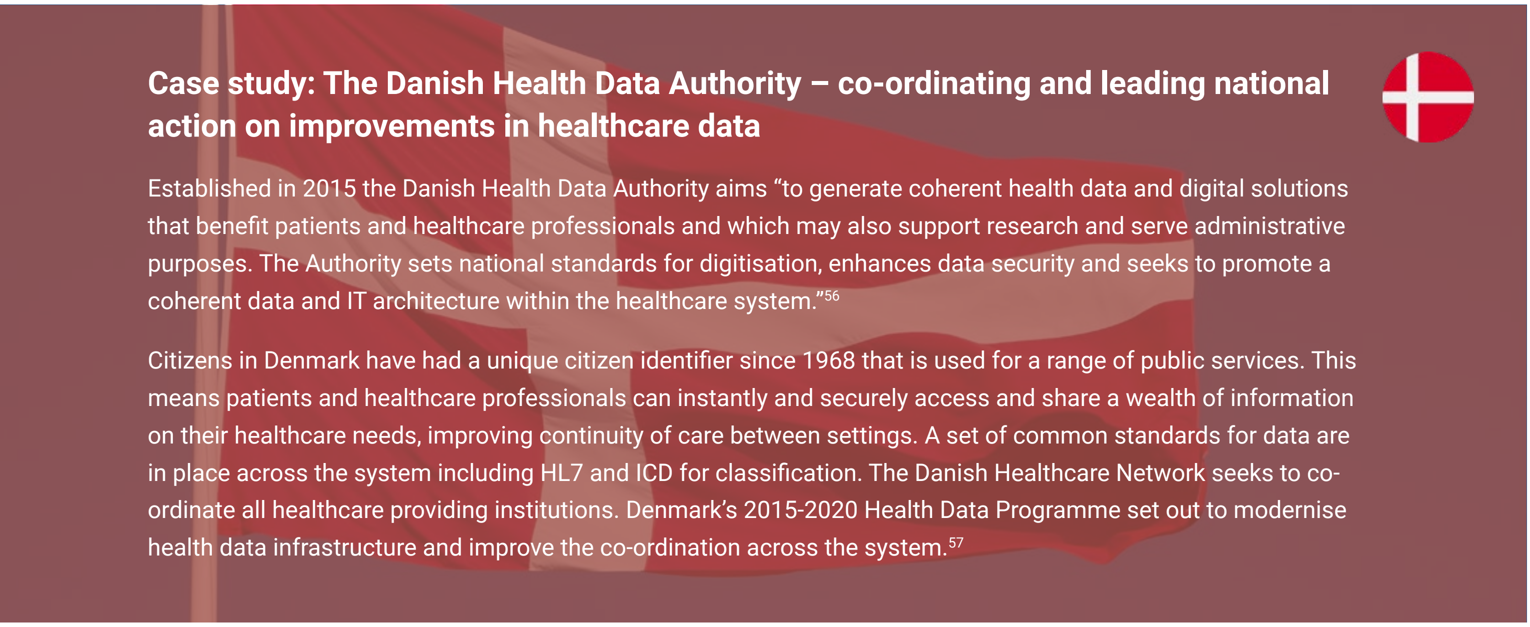
Public and patient engagement

There are already examples of innovative practice and approaches taking place within the NHS. And with many other countries grappling with similar challenges, it is also possible to look globally at ideas and suggestions for improving cancer data infrastructure and the delivery of improvements in patient care.

Recommendation 1: National leadership and co-ordination: a National Health Data Council

The publication of NHSX's data strategy provides a positive and welcome national policy framework for delivering improvements in healthcare data. However, at a national level the accountability and responsibility for different elements of the health data agenda are split amongst a range of bodies including NHSX, NHSD, NHS E/I, DHSC, the National Data Guardian, HDRUK and other research bodies such as Genomics England. This presents difficulties in realising the opportunities and improvements of NHS data.

Moves to integrate NHSX and NHSD into NHSE should help. But the Government should go further and create a National Healthcare Data Council chaired by Ministers to co-ordinate action across the various bodies. As a priority in the NHS Long Term Plan cancer would be a natural early focus for the Council's work.



Case study: The Danish Health Data Authority – co-ordinating and leading national action on improvements in healthcare data

Established in 2015 the Danish Health Data Authority aims "to generate coherent health data and digital solutions that benefit patients and healthcare professionals and which may also support research and serve administrative purposes. The Authority sets national standards for digitisation, enhances data security and seeks to promote a coherent data and IT architecture within the healthcare system."[56]

Citizens in Denmark have had a unique citizen identifier since 1968 that is used for a range of public services. This means patients and healthcare professionals can instantly and securely access and share a wealth of information on their healthcare needs, improving continuity of care between settings. A set of common standards for data are in place across the system including HL7 and ICD for classification. The Danish Healthcare Network seeks to co-ordinate all healthcare providing institutions. Denmark's 2015-2020 Health Data Programme set out to modernise health data infrastructure and improve the co-ordination across the system.[57]

Recommendation 2: Real time and enhanced data reporting: investing in the cancer data dashboard and other cancer data assets

Investment in cancer data infrastructure should prioritise existing data assets. As set out above, Covid has transformed elements of data use and sharing across the NHS to deliver improvements in public health with a particular focus on unlocking real time data. The development by NCRAS of a COVID 19 rapid cancer registration and treatment dashboard providing real time data for systems should be funded and extended beyond the pandemic to support managers and clinicians in the planning and delivery of their cancer services.

Further investment should be made to upgrade existing cancer data assets so they can support more effective real time reporting, monitoring and decision making.

Case study: Upgrading the SACT dataset

The SACT dataset is an integral part of the NHS disease registry system. As set out above the SACT system collects data on patients receiving chemotherapy within the NHS. However, returns to the system are not complete and some Trusts are still not using the mandated e-prescribing platform.

Investing in upgrading the SACT system should focus on two elements: improving the quality and timeliness of the data returns from Trusts; and supporting moves to more enhanced system reporting regarding patient outcomes. The European CanCer Organisation (ECCO) and the Collaboration for Oncology Data in Europe (CODE) have produced a three stage approach to building a comprehensive set of cancer outcome measures:

Stage 1: Harness cancer outcome measures available today that are low complexity

Stage 2: Focus resources on capturing medium complexity data: eg patient recorded data

Stage 3: Work towards large scale use of clinical, highly complex value measures eg disease progression, survival

Investment in infrastructure to capture this can help support improvements in access to innovation, through tracking the outcomes of cancer patients, and in turn the wider efforts of Government and the NHS to close the gap on cancer outcomes with other countries.

Recommendation 3: Infrastructure investment: creating a health data infrastructure accelerator

To support implementation of the Life Sciences Vision the Department of Health and Social Care and the Office for Life Sciences should develop a health data infrastructure accelerator. The accelerator would see innovative partnerships between clinicians, industry and patients supporting the uptake and implementation of infrastructure that can deliver improvements in health service data entry, quality and analysis.

The importance of improving cancer diagnosis and outcomes and the prominence of cancer in the Life Sciences Vision would make cancer a natural priority for the health data infrastructure accelerator. The national accelerator would be accessible to Integrated Care Systems and Cancer Alliances and would support the adoption of technologies that:

- Are easy to adopt
- Save clinical time
- Increase patient safety
- Enable greater information flow and connectivity

The accelerator model would also support the existing work of the NHSX AI Lab and the NHS England Accelerated Access Collaborative (AAC) providing new funding and resource to upgrade the underlying health system infrastructure that can enable the more rapid uptake of new innovations in digital, diagnostics and therapeutics. The accelerator would be able to unlock capital investment from the recent Spending Review and also private investment with appropriate governance mechanisms in place.

For cancer the accelerator could be used to tackle particular challenges. For example bringing together effective data on haematological cancers poses high degrees of complexity. There are over 100 types of blood cancer now recognised, which includes leukemia, lymphoma and myeloma.[58] Public awareness of the condition is lower than other cancers, diagnoses take place in multiple settings and there are a range of different treatment options available. An accelerator could help join together the information and technologies involved to support improved patient care and outcomes for a cancer that kills 15,000 people each year.[59]

Case study: Royal Free London and breast cancer screening

A study at the Royal Free London (RFL) is looking at whether artificial intelligence (AI) could potentially be used to detect breast cancer. The RFL's innovation and intelligent automation team has teamed up with North London Breast Screening to run a clinical evaluation of Kheiron Medical Technologies AI tool, Mia, to see if AI could provide a solution.

As part of the evaluation, mammograms previously carried out at North London Breast Screening run by the RFL at Edgware Hospital, will be reviewed by the AI programme Mia, which will continually improve its ability to detect cancerous or pre-cancerous cells the more mammograms it analyses. The images being used in the study will have already been reviewed by at least two radiologists, which is normal current practice, so that the diagnoses made by Mia and the radiologists can be compared at the end of the study. Any woman whose mammograms look abnormal or cancerous to the radiologists will have already been referred for further investigations or treatment as usual.[60]

Case study: Israel: Algorithms, data and earlier cancer diagnosis

The Morris Kahn and Maccabi Research & Innovation Institute has been working with Israeli startup Medial EarlySign to identify patients at risk of or with colon cancer earlier. By using algorithms that scan patients' data, over 300 cases have been found.

Maccabi is Israel's second largest health care provider and has been digitising its information for 30 years. The provider has 2.5 million patient records and has also got the permission of some 70,000 patients to add their blood and urine samples to the database. This approach enables the delivery of more personalised cancer care.[61]

Recommendation 4: Integrated and interoperable cancer data: the opportunity of the integration white paper and building minimum cancer data standards

The Government's plans for a forthcoming integration white paper will only be successful if supported by the implementation of the NHSX data strategy supporting closer working and flows of data between health and social care.

With increasing numbers of people surviving and living longer with and beyond cancer, cancer should be a priority for the white paper and efforts should be made to improve the interoperability of cancer data sets at national and local level. This should be supported by implementing a minimum set of standards for cancer data. New technologies and tools can help reduce the burdens on local systems to fulfil their obligations on this.

Timely cancer data is vital to improved diagnosis and patient outcomes. Amid a Government drive to invest in technology, there should be new commitments and transparency on cancer data entry. Organisational compliance levels with the national cancer reporting standard should be collected and published by the NHS. Areas where compliance levels are below the standard should be identified, supported and improved.

Case study: Yorkshire and Humber care record

The Yorkshire and Humber Care Record (YHCR) brings together 74 organisations, including 22 acute trusts and 700+ GP practices. These organisations all share patient information so that everyone involved in a person's care can access the data they need to make the right decisions at the right time. The YHCR stores all patient data across the region in a cloud-based platform which protects sensitive data from access or misuse. Social care organisations are now starting to feed data through. It allows healthcare analysts to understand their population's needs and plan services accordingly. Analytics modelling has estimated that there could be between 7,000 and 18,000 excess deaths from cancer in the first year of COVID-19. Recovering cancer care and services is a priority for the YHCR team, using the data and intelligence to identify those who may not have come forward for treatment and ensuring they get the healthcare they need.[62]

Case study: The OSIRIS French Program

The OSIRIS French program is composed of cancer research sites and university hospitals. The initiative aims to improve and accelerate retrospective and prospective clinical and genomic data sharing in oncology.[63] Dr Pierre Saintigny has set out how the participating institutes have migrated their data into an agreed model.[64] This has helped develop a terminology designed to be scalable and modular. According to the Instiut du Cancer: in the future other specific terminology aspects will be added according to localisation (breast, lung, digestive tract etc.), treatment (chemotherapy, radiotherapy, immunotherapy), and analysis (e.g. other genomics fields).”[65]

Case study: United States – mCODE – setting minimum standards in cancer data

The American Society of Clinical Oncology (ASCO), CancerLinQ LLC (its nonprofit subsidiary), and MITRE have developed and launched mCODE.

mCODE seeks to develop: “minimal cancer data elements that are essential for analyzing treatments across patients (via their EHRs) and cancer practices to improve treatment and care coordination and are making mCODE specifications available to stakeholders across the oncology community.”

mCODE is initially focused on solid tumours but hopes to be applicable to all cancers. mCODE consists of data across six areas: patient group, disease characterisation group, laboratory results, treatments, genomics and outcomes.[66] The organisations have also established CodeX (Common Oncology Data Elements eXtensions) as a member driven HL7 FHIR accelerator to build a community to accelerate interoperable data modelling and applications using mCODE.

Recommendation 5: Value based healthcare: Unlocking opportunities for new commercial flexibilities and access to cancer innovation

Investment in new healthcare data and infrastructure can support the NHS in using more flexible commercial agreements to adopt new innovative products, including in cancer. This includes schemes such as outcomes-based payment models.

The NHS has made progress on this agenda in recent years. Under the Value Pricing and Access Scheme (VPAS), a voluntary agreement between the pharmaceutical industry, the Government and the NHS, the NHS has developed a commercial framework to support the introduction of new reimbursement for high cost medicines. The NHS has struck deals for two CAR-T medicines, Kymriah and Yescarta, which have been agreed on the condition of further data collection through the Cancer Drugs Fund. The agreements also include the collection of Real World Evidence through the Systemic Anti-Cancer Therapy dataset, Blueteq and public health databases. Such agreements are encouraging and can be expanded more widely with new investment in an enhanced, integrated and underlying data architecture.

Case study: Italy and outcomes based payment schemes for CAR-T

Italy has been delivering aspects of value-based healthcare using data for over 15 years. It established its health data collection infrastructure, the AIFA registry, in 2005. The AIFA registry supports the development of outcome-based payment schemes by tracking patients in the treatment pathway. The launch of new CAR-T medicines for cancer has seen AIFA introduce a staged payment scheme. Two schemes that have been made public see the manufacturer paid in three instalments based on the outcomes delivered for the patient.[67]

Recommendation 6: International collaboration: the G7 health data agenda and the US-UK cancer summit

As noted above many advanced healthcare systems around the world face similar challenges regarding the adoption of more advanced cancer innovation and connecting data. The recent G7 Health Ministers Communique stressed the importance of building upon existing open health data standards and work towards a standardised minimum health dataset for patient information.[68]

The upcoming UK-US cancer summit presents an opportunity for both countries to work together and share learnings on how to improve their cancer data systems. Data should be a prominent agenda item at the summit.

Case study: International collaboration through the international cancer benchmarking partnership (ICBP)

The ICBP is a unique and innovative collaboration that brings together clinicians, policymakers, researchers and data experts across the world. It measures international variation in cancer survival, incidence, mortality and stage at diagnosis and identifies factors that might be driving these differences. It is an international partnership that includes 22 jurisdictions across eight countries – Australia, Canada, Denmark, Ireland, New Zealand, Norway and the United Kingdom (Sweden was also part of the first phase) – with the programme management team based at Cancer Research UK.

The ICBP advocates for consistent and high-quality data to enable further insights to be generated. One of the challenges the partnership faces is trying to bring together different data from different systems, recorded in different ways. An example includes the recording of emergency admissions data, of which the definition varies across jurisdictions. The partnership is embarking on a piece of work across geographies to explore opportunities to improve real time cancer data monitoring, linkage and data coding and entry.

Recommendation 7: Building Trusted Research Environments (TREs)

TREs seek to provide researchers with access to a secure analytics environment where researchers can undertake analysis. TREs have a number of practical and cost saving benefits, including unlocking the power of high performance computing and ensuring that liabilities for researchers through having to download and protect datasets are reduced.[69] The UK Health Data Research Alliance has identified six requirements for a TRE:

- Safe people – appropriate researchers with correct credentials
- Safe projects – projects that are appropriate and have public benefit
- Safe setting – holding data securely whilst enabling secure remote access
- Safe data – data is proportionate to the research requirements and aligned with relevant regulations
- Safe outputs – ensuring an 'air lock' when looking to export data from the TRE
- Safe returns – returning data insights to individuals and clinicians requires robust data pathways and patient consent

Case study: NHS Digital and DATA-CAN; a cancer TRE

DATA-CAN
The Health Data Research Hub for Cancer

The NHS Digital Trusted Research Environment is providing researchers from trusted organisations with timely and secure access to de-identified cancer data. DATA-CAN is a UK wide partnership that is unlocking the power of health data to improve cancer care.

Two of DATA-CAN's founding partners, the University of Leeds and Leeds NHS Teaching Hospitals Trust, are leading on this work which will enable important research on rates of cancer referrals, diagnoses and treatment. The Trusted Research Environment is making data on Hospital Episode statistics (HES) and COVID 19 testing available through the Health Data Research Innovation Gateway and this has been extended to national cancer datasets (Cancer Outcome and Services Data set, Chemotherapy and Radiotherapy datasets).

Recommendation 8: Patient and public engagement: Communicating the value and power of health data

The pandemic has led to a rapid transformation in the use of connected and real time healthcare data to support public health and service management. Communicating the value of these moves to the public will be critical to maintain public trust and build momentum on the improvements in health data use and sharing as the healthcare system looks to recover from the pandemic.

At a regional level Integrated Care Systems working with Cancer Alliances should ensure that they have patient and public forums where they are working closely with their populations on how cancer data is being used, analysed and stored.[70]

Case study: COVID 19 National Chest Imaging Database

The National COVID 19 Chest Imaging Database included a Data Access Committee with ethical and patient advisors to participate in and review all applications to the database. The NCCID also published regular updates on the project on its website. The model for engagement through the NCCID is looking to be applied more widely through work between NHSX, DHSC and the National Data Guardian. Further public consultations are also planned.[71]

Summary: recommendations that deliver on the life sciences vision ambitions for cancer and data

Implementing the above set of recommendations would deliver the cancer ambitions within the Life Sciences Vision:

- Better connected and integrated data infrastructure can support new diagnostic and genomic innovation that can deliver the earlier diagnosis of cancer and the NHS Long Term Plan commitment to diagnose 75% of cancers at stage 1 or 2 by 2028
- New partnership working to upgrade the current cancer data infrastructure – through a health infrastructure accelerator – can improve the collection of real world evidence and the trialling and introduction of new cancer innovations for patients
- Upgrading existing cancer data assets such as SACT to better measure and monitor patient outcomes will enable the NHS to strike innovative and value based commercial deals for new medicines
- Realising the UK's ambition on cancer data can support the nation's G7 ambitions on healthcare data and underpin a successful US-UK cancer summit

CHAPTER 5

Conclusion

The NHS has a strong track record in its development and utilisation of cancer data. Opportunities are now opening up to take this to a new level. A level that can improve the speed and quality of data, minimise barriers to data entry and linkage and support more value based healthcare approaches that deliver for patients.

The pandemic has shown the importance of having access to real time, quality healthcare information. It has also helped transform the way data has connected and flowed to support improvements in population health. The creation of a national cancer dashboard to support health service leaders in managing services and delivering care under immense pressure has been a real success. The challenge now is how to lock in this progress for the future.

This paper argues that this will require national leadership and greater co-ordination of efforts across bodies with responsibility for healthcare data including cancer data. New resources and investment in healthcare infrastructure that can break down barriers to data sharing and data entry will also be critical. Maintaining the real time cancer dashboard and continuing a public and patient dialogue on uses of and access to patient data must also remain central.

There will also be opportunities for the UK Government and the NHS to build international alliances that can further unlock progress. This can include commitments at the recent G7, the upcoming US-UK cancer summit and work already established through the International Cancer Benchmarking Partnership.

Unlocking the cancer data opportunity through improvements in the underlying infrastructure has the potential to transform cancer services. It presents an opportunity for global leadership and health improvement that the Government and healthcare leaders should grasp.

Endnotes

1 https://www.cancerresearchuk.org/sites/default/files/future_of_cancer_care_-_setting_the_context_-_final_1.pdf

2 https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(19)30456-5/fulltext

3 https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

4 https://www.theguardian.com/society/2021/oct/18/nhs-england-hospitals-having-to-rely-on-obsolete-imaging-equipment

5 https://gds.blog.gov.uk/about/

6 https://www.gov.uk/government/publications/uk-national-data-strategy/national-data-strategy

7 https://www.gov.uk/government/publications/uk-national-data-strategy/national-data-strategy

8 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1000030/life-sciences-vision.pdf

9 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1000030/life-sciences-vision.pdf

10 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1000030/life-sciences-vision.pdf

11 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1000030/life-sciences-vision.pdf

12 Wanless Review, 2002

13 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1000030/life-sciences-vision.pdf

14 https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data-draft/data-saves-lives-reshaping-health-and-social-care-with-data-draft

15 https://www.nhsx.nhs.uk/blogs/a-single-data-strategy-to-unite-the-system-and-save-more-lives/

16 https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data-draft/data-saves-lives-reshaping-health-and-social-care-with-data-draft#giving-health-and-care-professionals-the-data-they-need-to-provide-the-best-possible-care

17 https://www.gov.uk/government/publications/the-future-of-healthcare-our-vision-for-digital-data-and-technology-in-health-and-care/the-future-of-healthcare-our-vision-for-digital-data-and-technology-in-health-and-care

18 https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

19 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1013597/life-sciences-vision-2021.pdf

20 https://www.nhsx.nhs.uk/blogs/a-single-data-strategy-to-unite-the-system-and-save-more-lives/

21 https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf

22 https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52020DC0761

23 https://sciencebusiness.net/news/macron-unveils-eu30b-innovation-plan-make-french-industry-great-again

24 https://www.mckinsey.com/~/media/mckinsey/industries/pharmaceuticals%20and%20medical%20products/our%20insights/biotech%20in%20europe%20a%20strong%20foundation%20for%20growth%20and%20innovation/scaling-innovation-how-benelux-could-become-europes-leading-biotech-hub-march%202020.pdf

25 https://ec.europa.eu/health/sites/default/files/non_communicable_diseases/docs/eu_cancer-plan_en.pdf

26 https://www.europeancancer.org/resources/222:unlocking-the-potential-of-digitalisation-in-cancer-care-no-stopping-us-now.html

27 https://www.whitehouse.gov/wp-content/uploads/2021/05/budget_fy22.pdf

28 https://www.cancer.gov/research/key-initiatives/moonshot-cancer-initiative

29 https://www.healthit.gov/sites/default/files/page/2020-10/Federal%20Health%20IT%20Strategic%20Plan_2020_2025.pdf

30 https://www.healthit.gov/buzz-blog/interoperability/health-interoperability-outcomes-2030

31 https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data-draft/data-saves-lives-reshaping-health-and-social-care-with-data-draft

32 https://www.ndrs.nhs.uk/wp-content/uploads/2020/07/National_Cancer_Registration_Guide-1.pdf

33 https://academic.oup.com/ije/article/49/1/16/5476570

34 https://www.ndrs.nhs.uk/national-disease-registration-service/clinicians/what-data-is-collected/

35 https://academic.oup.com/ije/article/49/1/16/5476570

36 https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dcb1521-cancer-outcomes-and-services-data-set

37 https://www.ndrs.nhs.uk/wp-content/uploads/2020/07/National_Cancer_Registration_Guide-1.pdf

38 http://www.ncin.org.uk/collecting_and_using_data/data_collection/chemotherapy

39 http://www.ncin.org.uk/collecting_and_using_data/rcrd

40 https://digital.nhs.uk/data-and-information/information-standards/information-standards-and-data-collections-including-extractions/publications-and-notifications/standards-and-collections/dapb0111-radiotherapy-data-set

41 https://www.cancerresearchuk.org/health-professional/diagnosis/national-cancer-diagnosis-audit/audit-to-improve-care#NCDA_Overview2

42 http://www.ncin.org.uk/local_cancer_intelligence/cadeas

43 https://digital.nhs.uk/data-and-information/publications/statistical/nhs-outcomes-framework/august-2021

44 https://www.ncpes.co.uk/

45 https://www.cancerresearchuk.org/sites/default/files/achieving_world-class_cancer_outcomes_-_a_strategy_for_england_2015-2020.pdf

46 https://academic.oup.com/ije/article/49/1/16/5476570#201520691

47 https://www.nhsx.nhs.uk/key-tools-and-info/data-saves-lives/improving-health-and-care-services-for-everyone/the-nhs-covid-19-data-store-putting-data-at-the-centre-of-decision-making/

48 https://www.dataiq.co.uk/dataiq100-2021/profile/1-ming-tang-managing-director-of-data-and-analytics-nhs-england

49 https://www.oecd.org/officialdocuments/publicdisplaydocumentpdf/?cote=DELSA/HEA/WD/HWP(2021)4&docLanguage=En

50 https://www.cancerdata.nhs.uk/covid-19/rcrd

51 https://www.cancerdata.nhs.uk/covid-19/rcrd

52 https://www.data-can.org.uk/impact-stories/covid-19/

53 https://www.nhsx.nhs.uk/covid-19-response/data-and-covid-19/national-covid-19-chest-imaging-database-nccid/

54 https://www.nhsx.nhs.uk/covid-19-response/data-and-covid-19/national-covid-19-chest-imaging-database-nccid/

55 Adapted from Cushnan et al, Towards nationally curated data archives for clinical radiology images at scale,: learnings from data collection in response to a pandemic

56 https://www.healthcaredenmark.dk/media/ykedbhsl/healthcare-dk.pdf

57 https://www.megabank.tohoku.ac.jp/wp/wp-content/uploads/2020/02/ID37398_3.pdf

58 https://www.yalemedicine.org/conditions/blood-cancers

59 https://bloodcancer.org.uk/news/blood-cancer-facts/

60 https://www.royalfree.nhs.uk/news-media/news/ai-study-for-breast-screening-trialled-by-royal-free-london/

61 https://www.timesofisrael.com/mining-data-israeli-healthcare-provider-flags-colon-cancer-risk-patients/

62 https://www.nhsx.nhs.uk/key-tools-and-info/data-saves-lives/improving-health-and-care-services-for-everyone/data-to-support-the-recovery-of-cancer-services/

63 https://ascopubs.org/doi/full/10.1200/CCI.20.00094

64 https://ecancer.org/en/video/8095-data-sharing-and-system-interoperability-the-osiris-french-program

65 https://en.e-cancer.fr/OSIRIS-a-national-data-sharing-project

66 http://hl7.org/fhir/us/mcode/

67 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7006635/

68 https://www.g7uk.org/g7-health-ministers-meeting-communique-oxford-4-june-2021/

69 https://zenodo.org/record/4594704#.YYAGZ57P1di

70 https://www.data-can.org.uk/health-data/trusted-research-environment/

71 Adapted from Cushnan et al, 2021. Towards nationally curated data archives for clinical radiology images at scale,: learnings from data collection in response to a pandemic

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