

A close-up, low-angle shot of a person's face in profile, looking through the eyepiece of a microscope. The person is wearing a white lab coat and blue nitrile gloves. The background is a soft, out-of-focus blue and white. The overall tone is professional and scientific.

Towards a Healthier, Wealthier UK: Unlocking the Value of Healthcare Data

July 2023

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“Collaboration
can achieve
breakthrough
change.

Opportunities
for disruption
can energise the
UK economy.”

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Growth

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Executive summary

The UK faces several challenges over the coming years as we exit a period of almost unprecedented uncertainty. But there are two that stand out - the poor outlook for the economy and the huge pressure weighing on our healthcare system.

The country's low productivity, falling real wages, and lagging business investment are hitting the economic growth outlook while inflation and interest rates are rising sharply – precipitating a cost-of-living crisis. At the same time, both NHS waiting lists and the number of people out of the workforce due to long-term illness are at record highs of 7.42 million¹ and 2.5 million² respectively.

Neither of these challenges are insurmountable. But solving them needs creative thinking and urgent action.

With its vast amount of healthcare data and leading position in life sciences and artificial intelligence (AI), the UK has a unique opportunity to unlock the value of this resource and work towards becoming a healthier and wealthier country. Capturing the full benefits of healthcare data – an opportunity that has been long mooted but never grasped – can lead to better patient outcomes, more efficient healthcare delivery and will help drive R&D, innovation and investment across the life sciences and tech industries. Where healthcare data has been used in this way, both regionally in the UK and in other countries, there have been significant benefits realised. In this paper we discuss the current challenges in utilising healthcare data and outline 18 key recommendations for policymakers to unlock the value of healthcare data in the UK. The full recommendation list can be found in Chapter 4.

Healthcare data can have multiple benefits when used in the right way

60%

reduction in hospitalisations¹

- Sutter Health integrated real-time patient progress data into their clinical decision-making processes
- Delivered reductions of 60% in hospitalisation, 13% in emergency department visits and 70% in days spent in ICU



10pp+

improvement in suicide attempt prevention²

- New models combined electronic health records and answers to questionnaires
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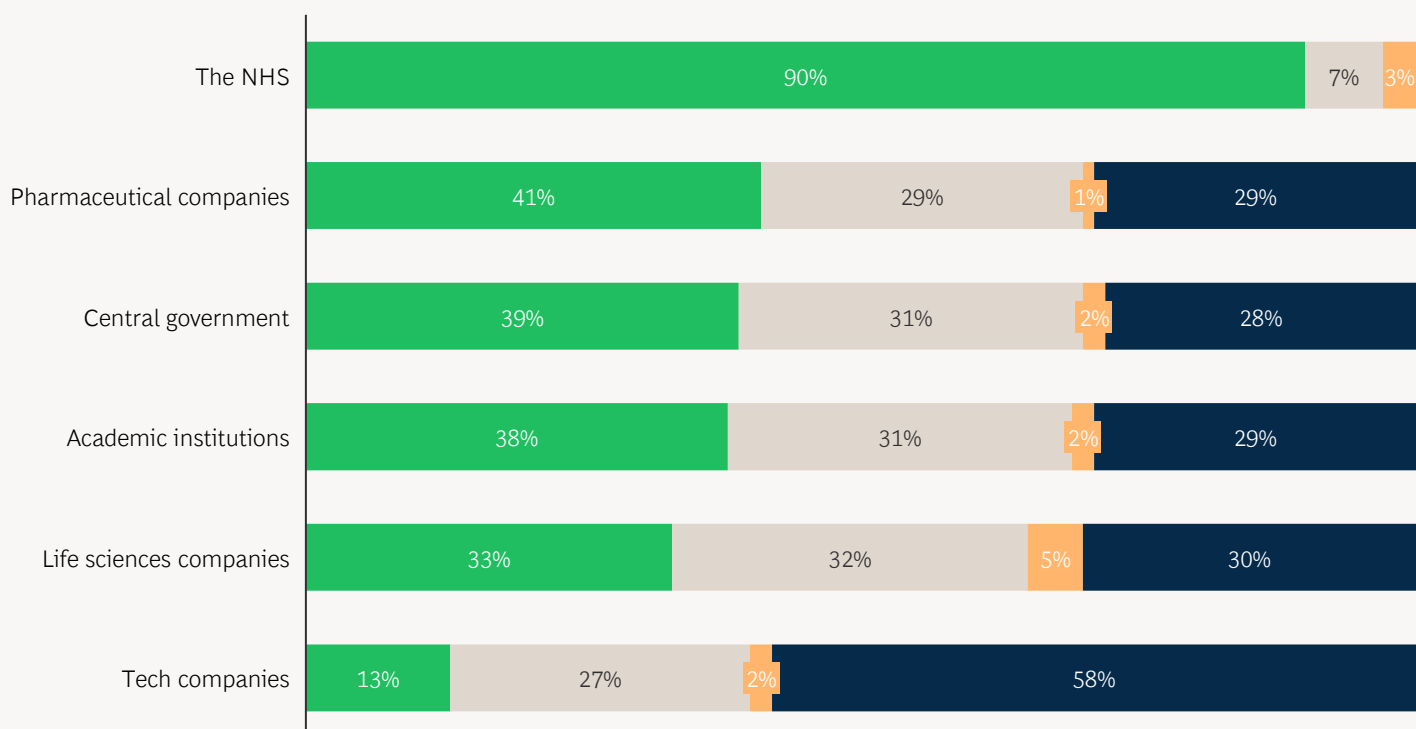
To understand public perceptions around access and use of healthcare data, BCG conducted a representative survey of the public in England (references to the NHS in this report refer to NHS England, but much of our analysis is relevant across all nations in the UK). Our survey found that, contrary to popular belief, people are generally open to allowing access to their healthcare data. However, the public's support for data sharing is dependent on targeting the most impactful use cases, articulating outcomes, and ensuring that security and privacy concerns are addressed.

Recommendation: Detail the outcomes from specific use cases of making healthcare data more accessible to generate public support and understanding.

Support for sharing data with the NHS is very high, with 90% of people willing to share data with the NHS for any purpose. While support is lower for other organisations, there is still much more support than opposition – with the exception of tech companies. Here, building public trust will be vital if they are to be involved in this space.

There is huge support for sharing personal health data with the NHS and more support than opposition for all other organisations, apart from tech companies

Do you **support** or **oppose** sharing your personal health data with the following for any purpose?



Source: BCG Healthcare Data Survey 2023

Support Neither support nor oppose Don't know Oppose

Our report and survey demonstrate that when the potential benefits are clearly communicated, and the right processes are put in place to manage trust, the public are supportive of allowing access to their data. However, previous missteps mean trust is fragile and cannot be taken for granted or squandered. Much work is already under way, building on the [Goldacre Review](#) and the NHS's "[Data Saves Lives](#)" strategy. But it is important the UK does not miss the opportunity to progress efforts in a way that maximises the potential value, both in terms of patient outcomes and wider economic benefits. We have identified and tested public support for a series of actions that can help achieve this dual value proposition.

The move from data sharing, where data is transferred to external parties, to data access, where data is hosted on platforms known as Secure Data Environments (SDEs) and access is controlled, has been under-discussed with the public. Our survey shows that when people are engaged on this point, a substantial majority (86%) said they felt more comfortable with data access over data sharing. The UK is therefore already starting from a stronger position than ever before.

To build on this we believe it is crucial to move towards targeting specific outcome-based use cases. These will help build and maintain public support and, by properly targeting the use cases and designing the SDEs with them in mind, the potential value of data can be maximised. Leveraging AI and machine learning is a common theme which will be crucial across the piece if these outcome-based use cases are to be achieved. For example, modelling of early AI R&D technologies has already indicated a potential reduction in time and cost of drug discovery by a minimum of 25-50%³.

Recommendation: Focus on outcome-based use cases in the following four areas:

I. Prevention

Recommendation: Allow for integration of a wider variety of non-healthcare data into

the SDEs including socioeconomic and demographic data from tax records, welfare claims and census records, behavioural information from consumer data, and lifestyle data from wearables and mobile phones.

This will support better identification of at risk groups within the population, helping to prevent disease before it develops or worsens. It will also help to improve communication, ensuring better targeting so people are more informed about their risks and healthier life choices.

II. Disease pathways

Recommendation: Fully integrate the widest range of healthcare data into SDEs, including biomarkers and multimodal health data.

This will help maximise understanding of diseases including better mapping of how diseases spread and develop, and the biomarkers used to identify them. It will also allow for more personalised interventions, as it increases the knowledge of how different groups respond to different treatments.

III. Clinical trials

Recommendation: Improve the process of setting up and recruiting for clinical trials in the UK, by developing an accessible 'concierge service' to quickly determine whether a particular trial is feasible, as well as tools to explore the sensitivity of inclusion/exclusion criteria for clinical trial participants.

Along with other steps, such as those set out in the recent [Lord O'Shaughnessy review](#), this can help restore the UK's position as a leading place to conduct clinical trials. In turn, this should help drive investment and innovation into the UK across related sectors, and ensure the UK is at the forefront of healthcare discovery.

IV. Clinical care

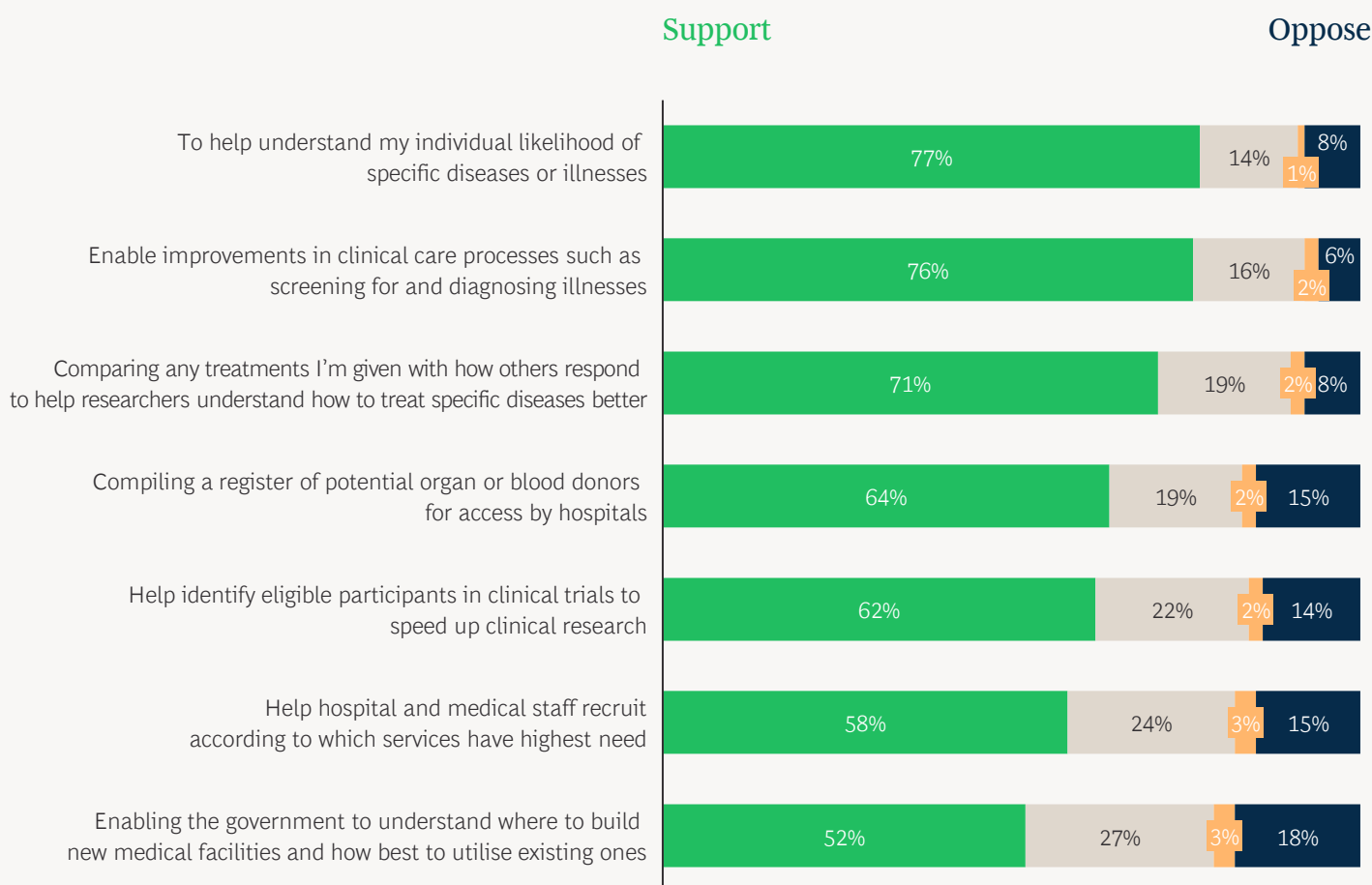
Recommendation: Leverage new technologies including machine learning, generative AI, and AI-driven algorithms to optimise clinical care decision-making and resource management in the NHS.

This can help improve diagnosis in hospitals, potentially reducing waiting times and improving treatment by giving a richer view of the impact of past treatments on different patients.

We tested these use cases with the public in our survey and found broad support for all of them. This illustrates that when the potential benefits and outcomes of accessing personal health data are properly explained, people are supportive.

There is majority support for data being used in all use cases

Imagine your personal health data was made accessible on a secure platform. For each of the following, would you support or oppose your data being used?



Source: BCG Healthcare Data Survey 2023

Support Neither support nor oppose Don't know Oppose

As well as targeting these outcome-based use cases there are several success factors that are crucial for realising the full potential of data and the creation of the SDEs:

Data transparency and public engagement

Trust and transparency are prerequisites when it comes to healthcare data. It is vital to proactively build public trust and ensure transparency at every stage of data access. This includes a genuine willingness to understand and communicate lessons that have been learnt from past mistakes.

Recommendation: Put in place the right frameworks and mechanisms to deliver the level of transparency and information needed, including a clear effort to be open about what lessons have been learnt and how processes have been adapted. This will ensure that public trust is maintained over time.

In the short term, a key part of this will be establishing better public communications around healthcare data usage and its potential benefits. This should form part of a wider long-term public engagement strategy that is coherent across NHS data projects. A common misconception has been that individuals oppose access to their personal health data by default, which has led to a general unwillingness to engage the public on the topic. However, our results show that nearly three-quarters of people (73%) either wanted to be proactively told about the use of their data (37%) or be able to request the information (36%) when they wanted. It is therefore important that stakeholders do not shy away from conversations about how, where, and why data is accessed. Section 3.1 details the key areas this campaign must address based on our survey findings.

Recommendation: Establish a joined-up public engagement strategy that is consistently adopted across all NHS data projects, with a specific comms campaign around healthcare data usage and the potential benefits.

In the longer term, the NHS should establish public decision panels, such as the public participation panel already used by Genomics England, and more accessible data usage registers for engaging the public in decisions around how their data will be accessed and used. Our survey showed 42% said the use of public decision panels made them more comfortable with data being collected and accessed, while 47% were reassured by data usage registers. These steps are key to ensuring the public are empowered with the right information and proactively involved in the decision-making process.

Recommendation: Use public decision panels and data usage registers to engage the public in decisions around how their data will be accessed and used. This will help ensure they have a say in decision-making processes and can review and refresh these processes over time (e.g. assess what level of engagement is needed from participants with relevant characteristics).

Use of COPI notices

During the pandemic, Control of Patient Information (COPI) notices were used to expedite the gathering of and access to data across the healthcare system, even if individuals had opted out of data sharing. COPI notices were used to support understanding of disease and were critical to the UK's rapid identification and delivery of treatments, including vaccines.

We found there is broad support (53%) for deploying a similar approach in the future. This rises significantly if used to address some of the most acute challenges facing the NHS. Nearly three-quarters of respondents support the use of notices (or similar) for researching chronic and/or serious diseases (73%) and treating and preventing long-term serious disease (72%). Two-thirds (65%) also supported the use of these regulations to improve efficiencies in the NHS that would reduce patient backlog.

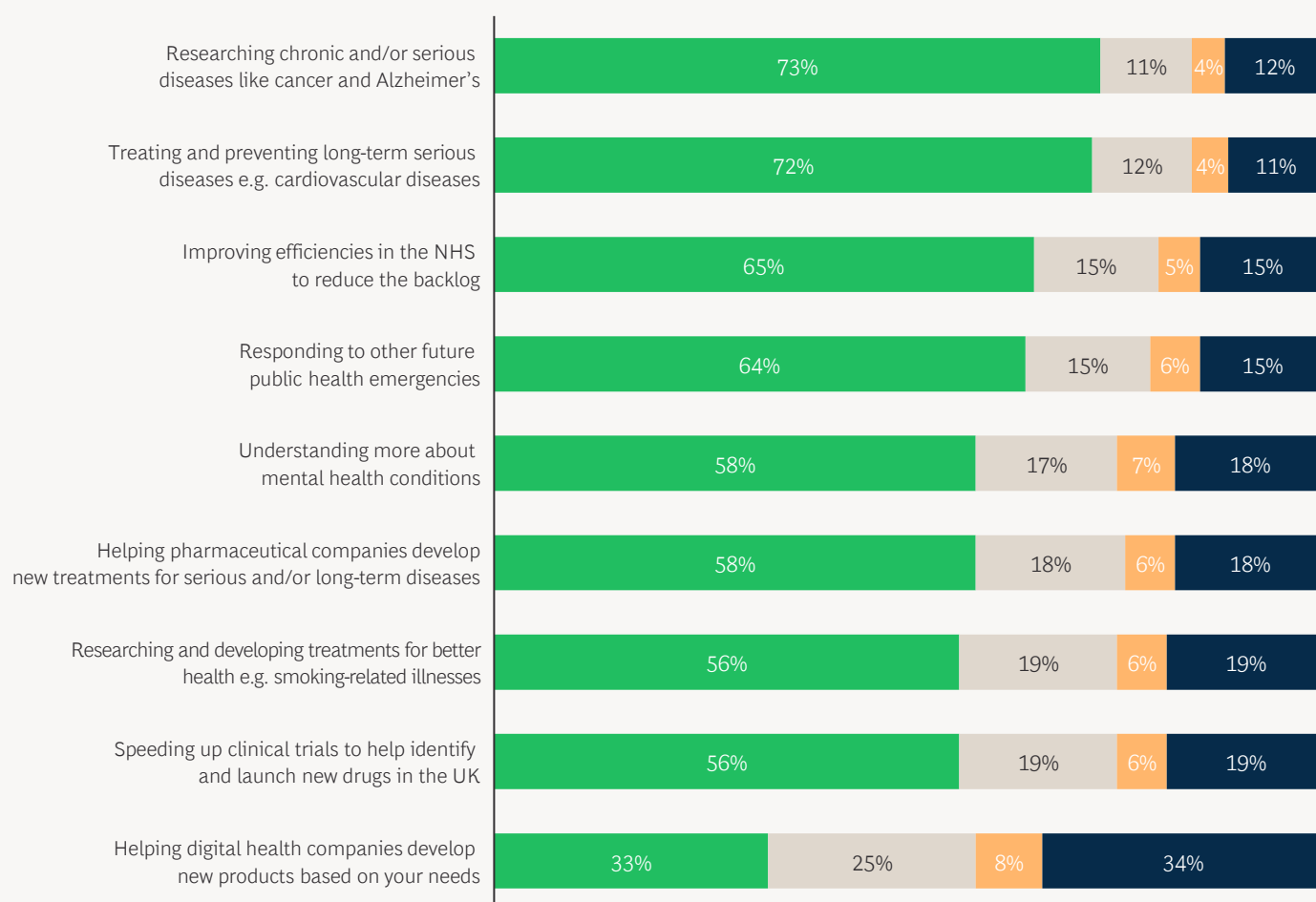


Consideration should be given to using this approach for the most difficult challenges facing the NHS in the future. However, it must be done in such a way that engages the public early, involves them over time, and clearly explains the benefits and end goal.

Recommendation: Consider using COPI notices more frequently beyond COVID-19. This includes utilising them for researching chronic and/or serious diseases, treating and preventing long-term serious diseases, and improving efficiencies in the NHS to reduce the backlog, as supported by the public.

Continuing the same approach to data access used in COVID-19 garnered majority support in a number of high impact areas

Do you think it is appropriate or inappropriate for data to be collected, used and shared in a similar way to during COVID-19 for each of the following scenarios?



Source: BCG Healthcare Data Survey 2023

■ Appropriate
 ■ Don't know
 ■ Neither appropriate nor inappropriate
 ■ Inappropriate

Design and operation of SDEs

As part of the shift from data sharing to data access, the government is building a series of SDEs at both a national and sub-national level to bring together data for research. Section 3.2 includes more detail on our series of recommendations to ensure they are set up in a way that maximises patient and economic benefits. The common theme is that the SDEs need to be fully resourced over the medium and long-term – a potentially costly exercise. It is therefore vital that their value is fully captured and partially reinvested to cover their running costs and development over time. It will also be essential to have sufficient support from the Integrated Care Boards to ensure that the SDEs are sufficiently funded and resourced.

Recommendations:

- Review the Data Access Request Service (DARS) process once the SDEs are fully up and running to ensure it is as streamlined as possible, whilst maintaining the vital security and ethical checks on those seeking to access the data.
- Ensure the DARS process is sufficiently resourced.
- Review and revise (where appropriate) the necessary purpose and benefits of data access to also capture wider potential benefits to the UK economy from innovation.
- Create a service wrapper that provides all NHS SDEs (national and sub-national) with the same basic governance and administrative processes such as applications for permissions, requirements for approval, and management of the users accessing the data.
- Maintain an element of competition between SDEs – such as on services and analytical tools, including marketplaces for them – to help foster innovation and drive improvements.
- Integrate data across the national SDE and sub-national SDEs, as well as the Federated Data Platform which is also being built.

- Bring skills into the NHS to ensure the quality of data on the SDEs is of the necessary level and the workforce is equipped to analyse the data and use the analytical tools provided.
- Ensure sufficient funding is put in place to target outcome-based use cases.
- Introduce targets to hold Integrated Care Boards (ICBs) directly accountable for creating research opportunities to ensure sufficient resourcing of SDEs.

Capturing value from data

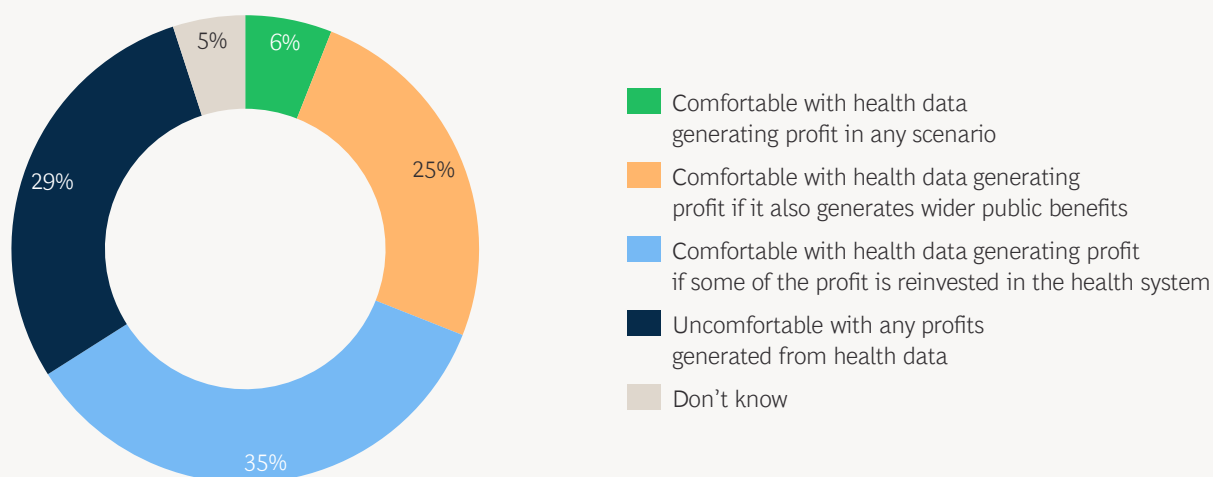
The NHS must capture and reinvest the value created from data access. This is vital for ensuring the effectiveness and longevity of SDEs and realising the wide-reaching benefits of better healthcare data access.

A simple way to do this would be to charge certain organisations for access to the SDEs, though this may risk missing some of the value created down the line. Furthermore, the current approach taken by the NHS is to make access to the SDEs free. If data access is to be free, it is vital the NHS uses alternative value-sharing mechanisms to adequately capture the potential value. This may require a flexible approach that draws upon a range of short and long-term value-capturing mechanisms, depending on the situation. Clear guidance should be provided so all parts of the NHS are consistently able to understand the potential value in data use and negotiate appropriate terms that deliver maximum value. Some of this must then be reinvested back into local NHS services.

This final point is crucial. We found that 66% of the public do not mind value or profits being generated from their healthcare data providing some of that value is reinvested into the health system and/or there are wider public benefits. When this happens, the level of support for profit-making from health data was more than double that of those uncomfortable with any profit-making. We believe the best way to reinvest into the healthcare system would be to create a central fund where revenue from healthcare data is collected and used to reinvest in local NHS services, as well as to help resource the SDEs over time.

Respondents were significantly more comfortable with profit being generated, if some of those profits were reinvested in the health system

Health data can be used to provide insights on drug developments and technical innovations. This can also result in future profits for those companies, as well as wider public benefits through improved healthcare (e.g. more effective treatments for disease). Which of the following is closest to your view?



Source: BCG Healthcare Data Survey 2023

Recommendations:

- Establish a range of value-sharing mechanisms to ensure the NHS captures maximum direct (e.g. financial) and indirect (e.g. health benefits) value from providing access to the healthcare data.
- Provide guidance for negotiating with commercial partners on how best to leverage the full range of value-sharing mechanisms. This will ensure maximum value according to the characteristics of each situation, including long-term value via intellectual property (where appropriate).
- Ensure value acquired through data is reinvested into local health systems and the SDEs.

There are few policies that could address pressure on the NHS and boost our economy – making better use of healthcare data is one. Furthermore, it does not need major additional investment or spending. It is an opportunity we cannot afford to miss.

Chapter 01

Introduction

This paper sets out what we believe is needed to ensure the full benefits of healthcare data are captured for all and public trust is maintained over time. To support our research, we spoke to stakeholders across the healthcare space, spanning the public, private and NGO sectors. We also conducted a representative survey of 2,000 members of the public to test views around healthcare data and support for our recommendations.

1.1. WHAT IS HEALTHCARE DATA?

Healthcare data is any information about personal and population-level health. It includes personal health records (otherwise known as NHS records), information about healthcare and social care delivery, treatment history, health appointment records, and details of illnesses or conditions. It can include data from clinical research and diagnostic tests conducted by the NHS or private organisations. Health data can also include wider information about individuals such as ethnicity, date of birth, and location; and lifestyle factors like alcohol consumption, diet, exercise, smoking, and socioeconomic background. The volume of healthcare data is expanding rapidly and will continue to do so in scale and modalities, particularly with the era of remote monitoring.

When used for research or to inform healthcare processes, health data is de-identified to ensure patients remain anonymous.

Healthcare data can be legally used to research diseases, identify treatments, inform provision of health or social care services, or guide local and national health policies. At the moment, personal health and care data is mostly held by local NHS trusts. However, it has sometimes been brought together at a national level when required, for example during the COVID-19 pandemic.

In the UK, it is important to note that while parts of the legal and R&D landscape are shared nationally, responsibility for health services is devolved.

1.2. BENEFITS OF HEALTHCARE DATA

Healthcare data in abstract does not have much value but when used in the right way and to the right ends, it can have multiple benefits:

1. **Better outcomes for patients.** Leveraging data can help us better understand the causes of disease and disease pathways. This allows for better and potentially quicker treatments for patients, with less trial and error, and applies to both physical and mental health. Better patient outcomes not only improve health and happiness, but also mean fewer people off work through sickness, more labour availability, and a reduction in lost economic output.

Sutter Health, a California-based network of healthcare providers, successfully integrated real-time patient progress data into their clinical decision-making processes. This integration resulted in significant reductions, including 60% fewer hospitalisations, 13% fewer emergency department visits, and a 70% decrease in intensive care days for severely ill patients⁴.



2. **Better understanding of illness.** Healthcare data can help doctors and patients better understand the causes of illness, particularly when it is combined with wider lifestyle and economic data. As a result, healthcare professionals can more easily identify and implement the steps necessary to prevent serious illness. This will result in a healthier population that is less likely to be economically inactive. It will also help ease the burden on the NHS's stretched resources by reducing the number of people requiring treatment.
3. **Improved efficiency.** Data can show which parts of the healthcare system drive best impact. This can help underpin a more efficient allocation of financial, staffing or infrastructure resources. Ultimately, better value for money in the NHS benefits everyone. In the Royal Free London NHS Foundation Trust, an app that alerts clinicians to patients at risk of Acute Kidney Injury (AKI) has resulted in a £2000 reduction in the cost of a hospital admission for a patient with AKI⁵. Clinicians were able to respond to urgent AKI cases in 14 minutes or less - a process which would have taken several hours previously. The app brings together data from blood tests with a patient's medical history as well as decision tree tools used in clinical care to identify at-risk patients.
4. **A foundation for innovation and investment.** Leveraging healthcare data in the right way can also support innovation and investment in key UK sectors such as life sciences, medical technology, biotech, and pharmaceuticals. The unique breadth and depth of UK data means that firms in these sectors will be able to innovate in ways that might not be possible elsewhere. This, in turn, will help drive investment in these sectors across the UK.

When healthcare data is used more effectively, it can create a 'virtuous circle' of value, leading to richer and deeper datasets that provide further insight and learning.

Fig 1. Examples of impact from healthcare data use

Healthcare data can have multiple benefits when used in the right way

60%

reduction in hospitalisations¹



- Sutter Health integrated real-time patient progress data into their clinical decision-making processes
- Delivered reductions of 60% in hospitalisation, 13% in emergency department visits and 70% in days spent in ICU

10pp+

improvement in suicide attempt prevention²



- New models combined electronic health records and answers to questionnaires
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- App alerts clinicians to patients at risk of Acute Kidney Injury (AKI)
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Nearly

30%

reduction in reoperations after complications⁴



- Data sharing for key value-based metrics across network
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1.3. UK COMPETITIVE ADVANTAGES

The UK has several overlapping strengths and advantages which put the country in a strong and possibly unique position to fully capture the benefits of healthcare data.

Data

The nature of its healthcare system gives the UK a unique breadth and depth of healthcare data. For example, NHS GP records are an ethnically diverse dataset that provide nearly 75 years of detailed data across a population of tens of millions. The diversity of UK data gives researchers rich insights into how individuals and communities respond differently to disease, and enables them to unearth relationships between populations and health.

During the first wave of the COVID-19 pandemic, despite the US having a huge number of COVID-19 patients and research institutions, most vital research on risk factors for COVID-19 mortality and features of long COVID came from the UK. This was because public health researchers had access to anonymised data from 56 million NHS patients' medical records, whereas the US had almost no centralised medical data at the time.

Healthcare innovations also require rapid access to a large pool of diverse patients. The NHS is the largest integrated healthcare provider in the world, with 300 million yearly GP consultations alone⁶. Coupled with huge biomedical datasets from [Genomics England](#), [UK Biobank](#) and [Our Future Health](#), this makes the UK a gateway for innovators to develop proofs of concept on a diverse population, prove that treatments are clinically effective and scale up reliably within a single system. It also highlights that the data goes beyond the NHS, reinforcing the UK's unique breadth and depth of healthcare data. However, much of this data is currently disconnected and hard to access, limiting the value and insights it can provide.

Research

The UK's science and research offerings are amongst the world's best. UK universities spearhead the global ranking for life sciences teaching and research, with two in the top five, and ranking first and second for research⁷. UK researchers produce the third highest number of life sciences papers worldwide⁸, ranking first for the number of publications that are in the top 1% of most-cited medical sciences publications⁹. On clinical research, the UK is one of the top three destinations for delivery of commercial early-phase trials and delivered 12% of all global trials for innovative cell and gene therapies in 2019¹⁰.

Industry

The UK's life sciences sector is world-leading. Over 5,600 life sciences businesses operate in the country - including all of the top 30 global medical technology companies, and the top 25 global pharmaceutical companies¹¹. Life sciences businesses in the UK generate nearly £90 billion in turnover¹² and directly employ more than 250,000 people¹³. In 2021, the UK ranked second globally against comparator countries for life sciences inward foreign direct investment capital expenditure¹⁴. The UK also leads Europe in terms of biotech products in development, which are estimated to be worth £80 billion in turnover, and to generate exports of £30 billion¹⁵.

The UK's artificial intelligence (AI) sector is also thriving. The country is home to more than 3,000 AI companies, with total revenues of over £10.6 billion¹⁶. It currently ranks third in the world in terms of investment, innovation, and implementation of AI¹⁷, and is home to twice as many companies providing AI products and services than any other European country¹⁸. A new £21 million fund has recently been announced to accelerate the use of AI across the NHS¹⁹.

Global comparative advantages in these two sectors mean the UK has the tools, skills and environment to capitalise on the value of healthcare data.



Funding

As well as having one of the world's leading financial centres, the UK benefits from a supportive start-up and early-stage funding ecosystem. The UK ranks third globally in number of start-ups and venture capital (VC) investments²⁰. In 2021, the value of inward life sciences foreign direct investment was £1.9 billion, the world's second highest²¹. UK biotech and medtech start-ups received a record £4.5 billion in venture capital and public financing in 2021; over half of that was through venture capital, meaning UK biotechs landed half of Europe's VC pot for the sector— an 81% increase over UK's 2020 figures, despite Europe's biotech investment falling 12% as a whole²².

Of course, there are factors weighing on the UK's competitiveness in this space. Brexit has had an impact on the attractiveness of the UK as a place to license medicines, develop medical devices, and perform clinical trials, as separate approvals and processes will be needed for the EU. Furthermore, the size of the UK market is not always sufficient to attract the global firms which operate in these arenas. That said, this drives home the need to leverage the opportunities and areas of competitive advantage which the UK does have.

1.4. WHY NOW?

There has long been discussion about capturing the full benefits of healthcare data, but the project has never been fully realised. However, we believe this time is different, for several reasons.

It must be now. The current combination of healthcare and economic challenges means the UK cannot afford to squander an opportunity to tackle both at once. In the year between May 2022 and May 2023, the average time for Medicines and Healthcare products Regulatory Agency (MHRA) first reviews in the UK of Phase I-IV patient trials increased almost four-fold at 125 vs. 32 days²³. The ONS reported a record high of 185.6 million working days lost to sickness or injury in 2022, with the sickness

absence rate having increased 0.4 percentage points from 2021 alone²⁴.

The impact of longer-term sickness has also negatively affected labour productivity, which at the end of January 2023 was the most common reason for economic inactivity. Declining clinical trial activity will also mean that UK patients do not get access to innovation as early as other markets.

We now know the potential power of data.

The use of data and digital processes during COVID-19 has shown the meaningful difference that proper use of healthcare data can make. Our survey found that 61% of the UK public support the use of emergency regulations that allowed the NHS to share confidential patient information with organisations for COVID-19 purposes; even if they had previously opted out of data sharing.

When asked if the same regulations should continue to be applied to improve processes, support health research, and to improve patient outcomes, 53% were in support.

We are now seeing the strongest-ever confluence of expertise and competitiveness in the UK. The combination of a world-class life sciences sector, a leading tech sector, deep capital markets, and data collected over many decades by the healthcare system make the UK uniquely placed to fully capture the benefits of healthcare data for all.

There is already much work underway in this space. However, to fully capture the benefits across both improved healthcare outcomes and economic prosperity, it is vital that it is done right.

The UK has an opportunity to compete with the EU. While Brexit has impacted the UK healthcare sector, the EU is also facing several challenges that give the UK an opportunity not only to halt any decline but also to attract new investment. The numbers of drugs developed in the EU flatlined between 2017 and 2022,



compared with the US, where it grew 23% from a higher starting point²⁵. The recent European Commission proposals on reforming EU pharmaceutical legislation have provoked concern in the industry. Specifically, the plans to reduce the period of exclusivity for drugs developed in the EU have raised concerns around IP protection and the ability to generate long-term returns on investment in the EU. This presents an opportunity for the UK to take a different approach and present itself as a more attractive place for R&D investments.

1.5. STATE OF PLAY

A series of government strategies touch on various aspects of the data issue. The [Life Sciences Vision](#) identified data as a key component to the prosperity of the sector; the [NHS Long Term Plan](#) established the importance of data to deliver improved healthcare and medical breakthroughs for the NHS; and the Department for Health and Social Care's vision for [The Future of UK Clinical Research Delivery](#) highlights the importance of improved data availability and quality.

This all sits around the [NHS's 'Data Saves Lives' strategy](#). Published in June 2022, it builds on the work of the [Goldacre Review](#) in setting out the overarching approach to the UK's healthcare data. It includes a commitment to transition from 'data sharing' to 'data access' through the creation of Secure Data Environments (SDEs) – £260 million has been earmarked for these across the UK. (See Fig. 2 for a definition of data sharing and data access).

This shift from data sharing to data access is crucial, and could be transformative for people's level of trust around their healthcare data. As part of our survey, we described these approaches and asked respondents which they felt more comfortable with. Data access was the preference for 86% of respondents.

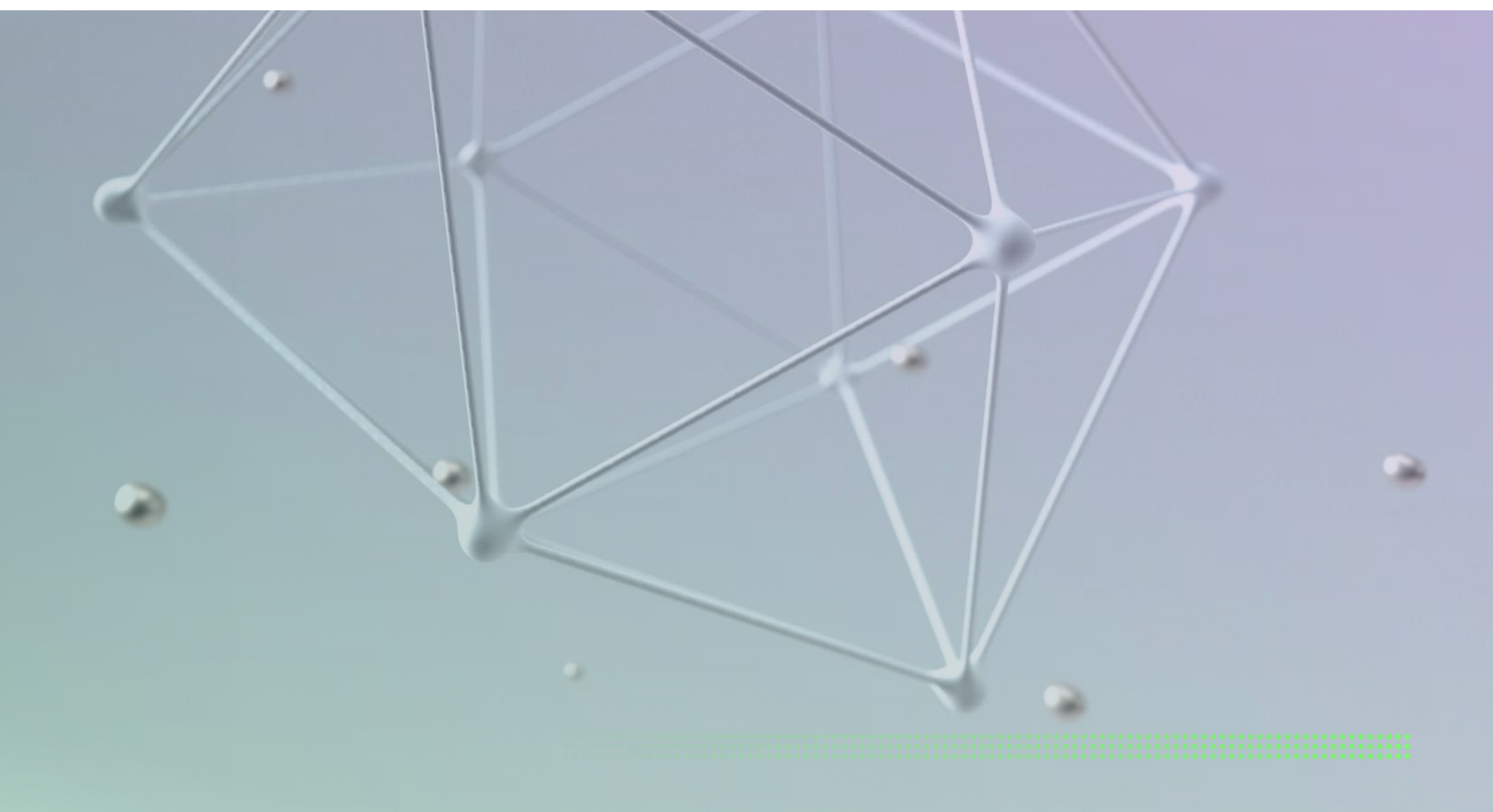


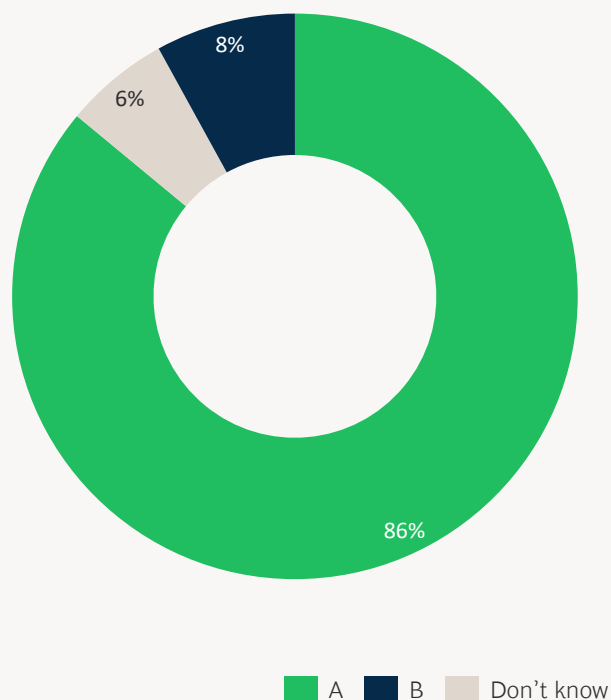
Fig 2. Data sharing and data access: definitions and survey results

There is an overwhelming preference for use of a more secure data access model over a data sharing model

Which of the following ways of accessing personal health data would you feel more comfortable with?

A: Data is stored on 'platforms' that have the highest privacy and security protocols. The organisation that runs the data platform must approve anyone who wants to access the data. They can control what data users see and what they can do with it. Data cannot be removed from the platform to be stored or used elsewhere.

B: Organisations can transfer data to third parties through data sharing agreements. These agreements outline how data can be used, and what privacy and security standards are needed. Requirements can differ each time. Once transferred, the data is the responsibility of the third party and it can be accessed freely by this third party. Although the third party is under a legal obligation to use the data only as agreed, you may not be able to verify how the data is used once it's been transferred.



Source: BCG Healthcare Data Survey 2023

The work on data access has already begun, with the creation of an interoperable NHS Research Secure Data Environment Network. As well as the national NHS England SDE, the NHS England Data for R&D Programme is funding development of regional-scale sub-national SDEs. These sub-national SDEs are NHS-led and bring together Integrated Care Boards with local universities and industry

partners to build on existing partnerships. NHS funding will mean sub-national SDE coverage across England. Funding has currently been awarded to the East of England; East Midlands; Great Western; Kent and Medway and Sussex; London; North East and North Cumbria; North West; Thames Valley and Surrey; Wessex; West Midlands; Yorkshire and Humber.

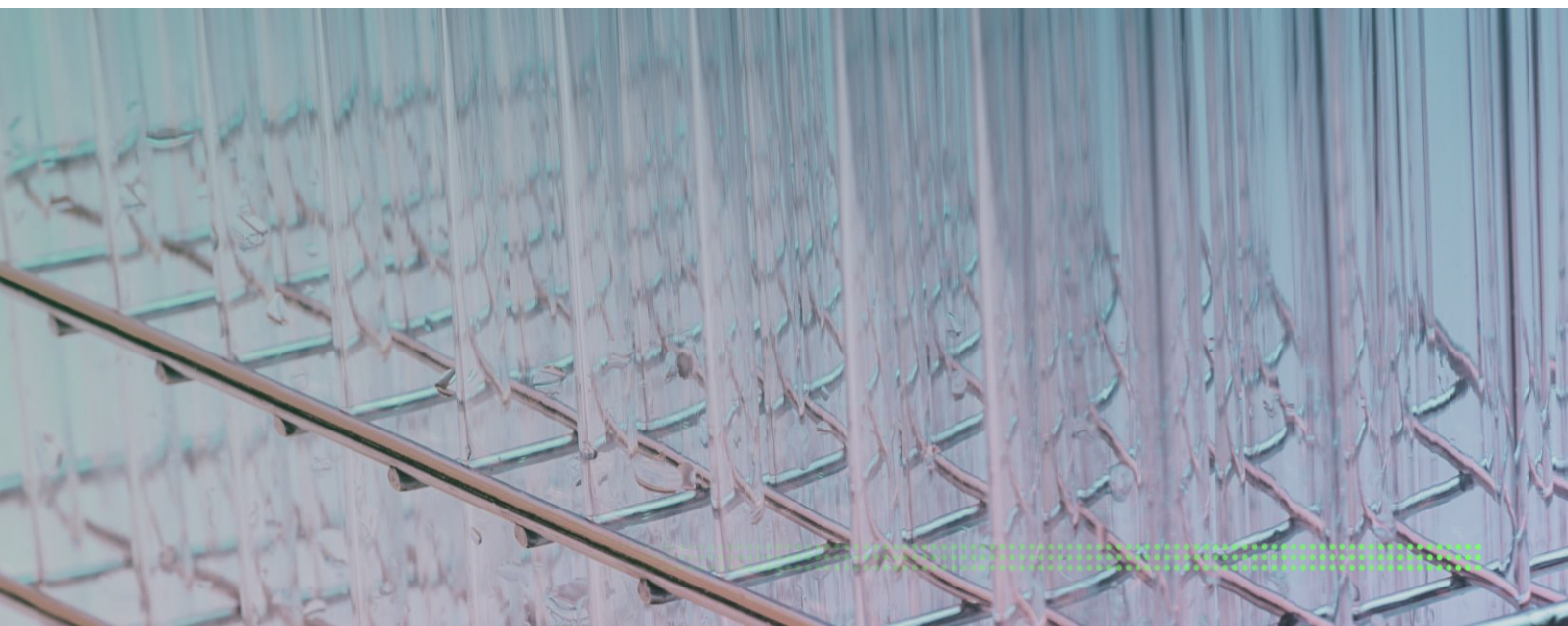
In addition, the NHS is progressing a £480 million programme to build a Federated Data Platform (FDP), which would enable every hospital trust and integrated care system (ICS) to connect and share information between their individual data platforms²⁶. Initially, the FDP will be used to support five national NHS priorities around improving its operational efficiency:

1. **Elective recovery** – reducing the backlog for appointment and treatments.
2. **Vaccination and immunisation** – vaccinating and immunising vulnerable people, ensuring equality of access across different communities.
3. **Population health management** – to help local NHS systems understand and proactively plan services to meet the evolving needs of their population.
4. **Care coordination** – reducing long stays in hospitals by improving coordination between different health and care services.
5. **Supply chain management** – improve value for money by optimising NHS supply chains and enabling better purchasing decisions.

These investments come alongside £2.1 billion for NHS IT upgrades and improvements²⁷.

The UK's commitment to furthering its data capabilities has been additionally supported by its sustained funding in AI technology and innovation. In early 2023, to accelerate research, the government announced that £16 million would be allocated to the nine most promising AI healthcare technologies²⁸. This investment contributes to a total investment of £123 million across three government funding rounds in 86 AI technologies to date. This has supported over 300,000 patients through improvements to care, and treatment for health conditions such as cancer, heart disease, diabetes, mental health, and neurological disorders.

These steps are welcome. But it is crucial that the various data environments and related platforms are set up in the right way to fully leverage the benefits of the data for all. So far, the focus on the construction of the SDEs and FDP has understandably been on leveraging data to help improve healthcare research and operational efficiency. However, to fully capture the benefits of this data for the wider economy and broader patient outcomes, further steps need to be taken both in terms of the use cases, and the structures put in place around the SDEs.



Chapter 02

Use cases

So far, the NHS has laid out six high-level use cases on which to target current and future R&D investments:

1. **AI/algorithm development** – testing, training, and validation.
2. **Clinical trial activities** – feasibility, recruitment, efficacy through short- and long-term trial follow-up.
3. **Real-world studies** – safety, effectiveness, and cost effectiveness.
4. **Translational research** – academic discovery and implementation of discovery into practice.
5. **Epidemiological studies** – large cohorts for population health research.
6. **Health systems research** – evaluation of systems or processes, including operational and applied research.
7. These use cases are a good starting point for building the necessary data architecture. However, they remain focused on process. We believe that to fully understand and capture the patient and economic benefits of healthcare data, it is important to also focus closely on the outcomes of specific use cases. Detailing these outcomes is vital for generating public support and understanding. Our survey showed that where specific use cases and explanations for data are provided, the public are much more willing to support allowing access to their data.

Fundamentally, people need to see the link between their data and the good it can do, rather than just being asked to allow access to their data.

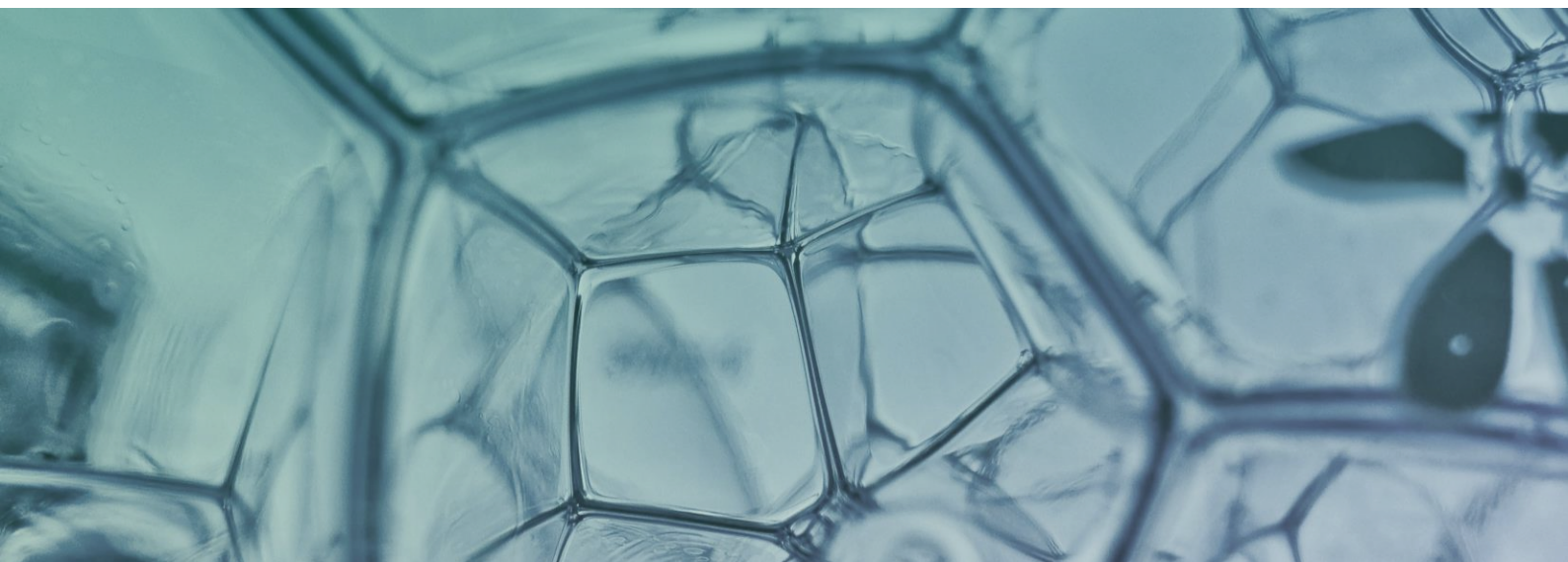
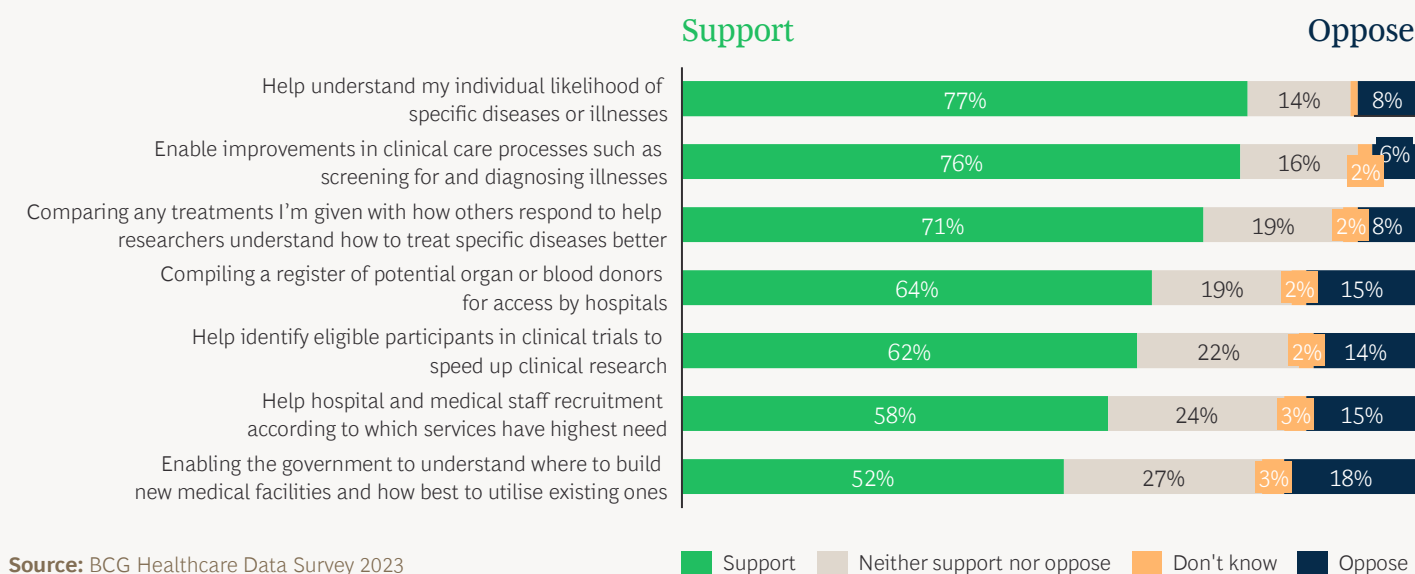


Fig 3. Public attitudes to healthcare data access for use cases

There is majority support for data being used in all use cases

Imagine your personal health data was made accessible on a secure platform. For each of the following, would you support or oppose your data being used?



Source: BCG Healthcare Data Survey 2023

To define a set of outcome-driven use cases, we sought input from across the healthcare sector with the aim of identifying use cases that could drive specific outcomes related to major problems faced across the industry. These also had to meet criteria of improving patient outcomes and/or driving wider economic benefits. Finally, they had to have broad public support or the ability to generate public support together with a wider campaign. As part of our survey, we tested public opinions on these outlined use cases alongside a variety of other potential applications; there was majority support amongst respondents for the four targeted use cases detailed below.

In this section, we explore four outcome-driven use cases and set out recommendations for both public and private organisations looking to capture value in the healthcare data space.

2.1. PREVENTION

Problem statement: Sickness rates in the UK have risen to an all-time high yet investment in preventive healthcare remains low in comparison to the potential gain

The NHS's Long Term Plan cited prevention as a priority commitment over the coming decade. Yet despite sickness absence being at its highest since 2004, spending on preventive care accounted for only 7% of government healthcare expenditure in 2020, and was driven mainly by COVID-specific disease detection and epidemiological surveillance²⁹. With the NHS facing immediate challenges, it is always going to be difficult to pivot any substantial funding towards prevention. If done right, the data brought together under the new SDEs can be used to help improve preventive healthcare without requiring significant additional funding or redirection of NHS spending.

Use case: To fully capture the potential benefits for preventive healthcare, the SDEs should allow for integration of wider deidentified datasets with core healthcare data.

This should include:

- Socioeconomic and demographic data from tax records and welfare claims
- Demographic data from census records
- Behavioural information from consumer behaviour data
- Lifestyle data from wearables and mobile phones

There are several specific uses that flow from the integration of health data with wider data, but two that we think are worth highlighting:

I. Identifying at-risk groups and communities. By using a combination of historical records on disease prevalence in various demographic and socioeconomic groups, medical staff could better target groups and communities at risk of certain diseases and illnesses. This data could potentially be used to inform patient lifestyle choices and improve GP monitoring of vulnerable patients. The NHS's Population Health Management (PHM) programme is an example of how integrating public authority information into patient health records has improved how GPs coordinate care for at-risk patients. By partnering across the NHS and other public services, the PHM programme has been able to use historical and current data to understand what factors are driving poor outcomes in different population groups. Taking this concept a step further, for example by integrating data relating to lifestyle, has the potential to build richer patient profiles and move towards achieving personalisation in patient care.

II. Improved communication targeting.

Data on the response rates of various demographic groups to health-related communications can help medical professionals and policy makers tailor communication to achieve more effective public engagement. The COVID-19 pandemic showed how varying levels of health literacy among the population impacted responses to health guidelines such as social distancing. Understanding people's responses could prove powerful if done over time. It would allow different approaches to be iterated and adjusted as more data is gathered and the effectiveness of various forms of communication becomes clearer.

These use cases (using a variety of data to improve prevention of illness and disease) had some of the highest support amongst those we tested in our survey. Indeed, the results suggest people may be willing to go even further to share identifiable data if the data were able to yield more granular, individual-level results. When people understand that data can help support improved healthcare outcomes, there are few objections.

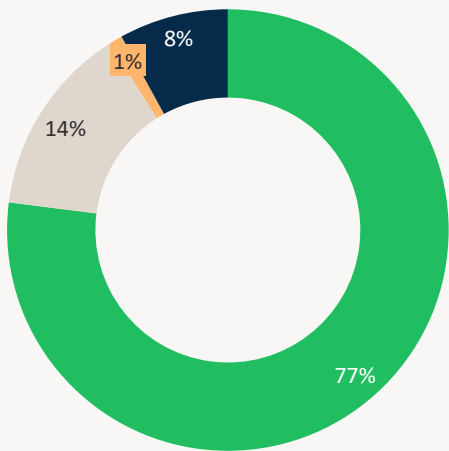
The success of this use case relies on the integration of a wide range of non-healthcare data into the SDEs. This initiative not only unlocks significant research into preventative interventions, but also enables a greater focus on addressing the health equity gap. This is particularly important because individuals who are underinformed or undiagnosed often come from poorer communities that are not as well integrated into society.



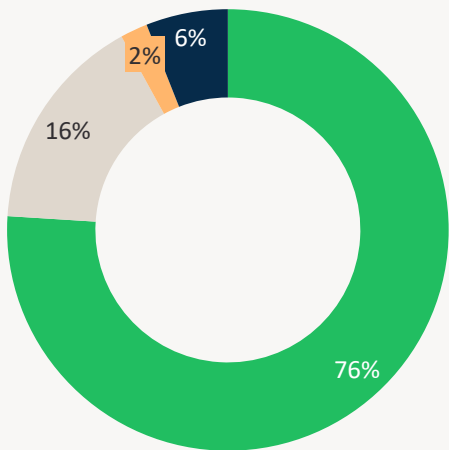
Fig 4. Public attitudes to healthcare data access for prevention use cases

Imagine your personal health data was made accessible on a secure platform. For each of the following, would you support or oppose your data being used?

Help understand my individual likelihood of specific diseases or illnesses



Enable improvements in clinical care processes such as screening for, and diagnosing illnesses



Support Don't know
Neither support nor oppose Oppose

Source: BCG Healthcare Data Survey 2023

Case Study: Local NHS ICS

A local NHS Integrated Care System (ICS) had been experiencing challenges surrounding the diagnosis of individuals living with hypertension. Public health data had shown that on average, 28% of adults in the region had high blood pressure. This is a lower figure than expected, suggesting that a large portion of the population might be undiagnosed.

Increasing awareness of the issue and encouraging action in at-risk populations – such as initiating more regular blood pressure testing – could make a significant difference. However, initial research showed that whilst individuals were typically open to having their blood pressure measured, resistance was higher in undiagnosed groups due to lack of clarity about the ‘why’ and ‘how’ of blood pressure monitoring. Due to the demographic diversity of the population, addressing this barrier would require more than just simple outreach.

To tackle the issue, the local ICS wanted to develop and apply a tailored machine learning model across its SDE to analyse a mix of health and demographic information, and identify people at high risk for hypertension. It took a five-step approach to building the model and embedding it into an ongoing process:

1. Combine data from the local ICS dashboards and censuses including information on

demographics, comorbidities status and care interactions.

2. Employ machine learning tools to detect underlying characteristics and patterns in hypertension patients, and assign risk scores based on these results.
3. Identify those areas/groups at highest risk for undiagnosed hypertension by creating a risk ranking system and using it to build a target population.
4. Create target demographic cohorts to most easily identify potential individuals not included in the original data.
5. Re-analyse the population on demand whenever new data is incorporated.

Through this approach, the local ICS was able to use its model to identify the exact communities it needed to design its hypertension outreach campaigns for, and consequently what elements of a successful campaign would be most applicable. Following on from this, the team can use the model to easily feed in new data as the population evolves. However, challenges around the lack of data integration and availability, particularly on comorbidities and wider socioeconomic data, drive home the importance of wide data integration.

2.2. DISEASE PATHWAYS

Problem statement: Chronic diseases represent the largest source of mortality and are a significant drain on NHS resources.

Chronic disease is one of the major socio-economic challenges facing the UK today. An estimated 26 million people live with at least one long-term condition (LTC) and 10 million with two or more³⁰. According to the NHS,

long-term conditions account for 50% of all GP appointments, 64% of all outpatient appointments, and 70% of inpatient bed days, with around 70% of total health and care spend in England attributed to caring for people with LTCs³¹. In 2021, this figure amounted to £60 billion, a growth of 4.4% since 2020³². Compared to its peers, the UK has higher avoidable mortality rates, including cancers which can be prevented and/or treated³³.



With this in mind, advancing research into disease has been identified as a key priority for the UK. In 2022, a £1 billion investment backed by the UK government was made in a bid to accelerate research into conditions such as cancer and heart disease, as well as to support the ambition of establishing the UK as a science superpower³⁴. The COVID-19 pandemic highlighted to policymakers, the private sector and the public why it is vital to understand the picture across the disease pathway – the fundamental causes of the disease, how it is transmitted, what the best treatments are, and how different patients respond to different treatments.

If done right, the data brought together under the new SDEs can be used to help improve understanding across disease pathways without requiring significant additional funding or redirection of NHS spending.

Use case: Fully integrate the widest range of healthcare data into SDEs to facilitate understanding of disease pathways.

To fully capture the potential benefits for better understanding of disease pathways, SDEs should bring together a wide range of health-related data, including:

- Social determinants of health (as discussed above) to inform prediction and primary prevention (i.e. preventing onset).
- Early biomarkers to inform secondary prevention (i.e. reducing impact of a disease) for 'silent' diseases (e.g. cardio-metabolic disease).

- Multimodal health data (genetics, health records, medical imaging, wearable sensors etc.) that could enable patient subtyping and personalised treatment options.

Alongside this, there should be a focus on prognosis analysis to enable more effective, focused, and higher-value care.

This integration of a wider variety of data can have several specific applications and benefits:

Understanding the biology behind disease intervention to offer more personalised treatments.

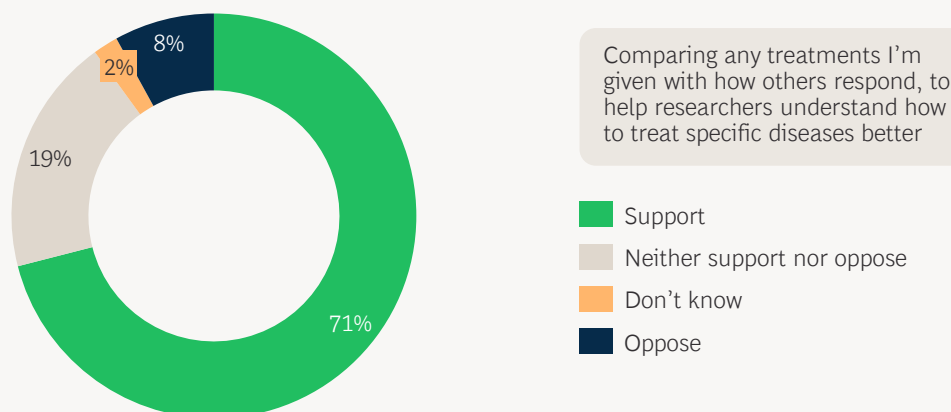
Capturing and analysing the full range of data relating to a specific disease treatment will make it easier for researchers and medical care professionals to understand unique response profiles. For example, whilst genomic profiling, liquid biopsy data, and polygenic risk scores are all examples of data that can now be used in clinical and research settings, the integration of these distinct types of data remains challenging. Combining data like this with electronic health records, imaging data and wearable sensor data could get us closer to a true understanding of each person's biological uniqueness, how it interacts with their vulnerability to disease, and how they respond to treatments. In turn, this enables the development of individualised preventative, diagnostic, and therapeutic strategies. AI is likely to be a critical part of the solution here and this is explored further below.

A majority of respondents supported their data being accessed via an SDE if it helps to further the understanding of disease and improve treatments.



Fig 5. Support for data access to help treat diseases

Imagine your personal health data was made accessible on a secure platform. For each of the following, would you support or oppose your data being used?



Source: BCG Healthcare Data Survey 2023

More accurate mapping of disease pathways.

Studying and linking disease data – from pre-diagnosis to early symptom detection to treatment within a care system – can help build a richer picture of how diseases develop. The Newborn Genomes Programme run by Genomics England is an example of how this could work. With a goal to map the genomes of 100,000 newborns, it aims to understand how diseases start in children, and evolve over time. Extending this concept to a wider population could see previously unidentified disease trends arising from different stages of the human lifecycle, or as a result of life events. This could further feed into developing greater knowledge of when and how best to prevent disease development and progression amongst at-risk populations.

This type of disease pathway mapping is currently the exception and limited to certain diseases. With the development of the national and subnational SDEs, it is important that it now becomes the norm. It should aim to build up detailed understanding across a wide variety of diseases, without the need for individual or bespoke SDEs. Getting it right the first time will avoid extra costs and complications down the line.

2.3. CLINICAL TRIALS

Problem statement: Clinical trials are the building blocks of health innovation, but the UK is rapidly falling behind peers, and risks missing out on the wide-reaching benefits.

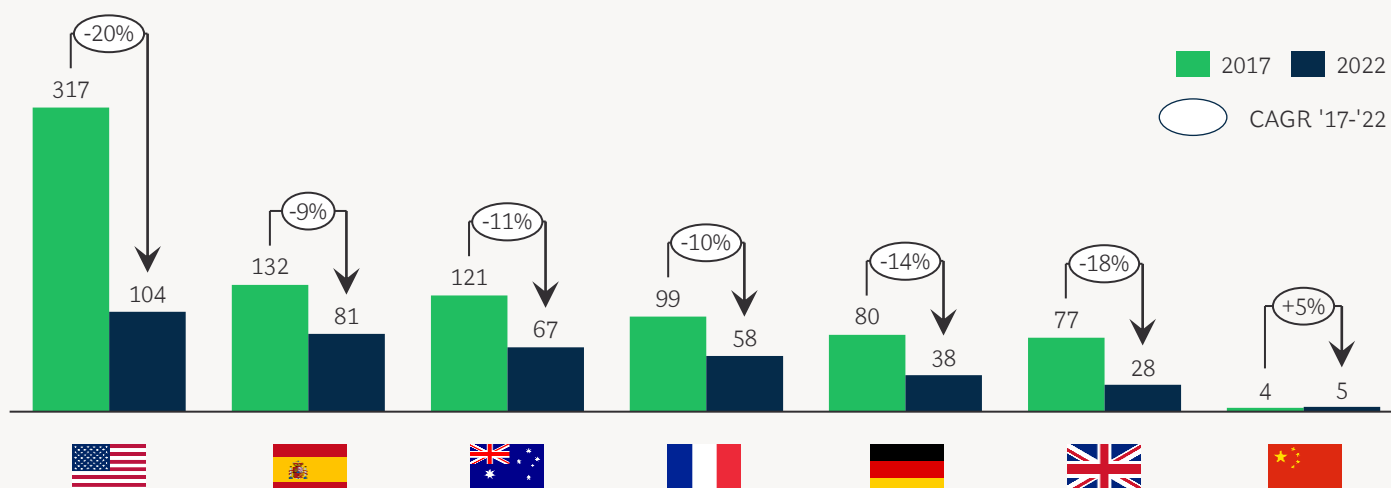
Clinical trials provide an opportunity to get early access to new interventions and are integral to improving patient care and addressing health inequalities. They benefit the NHS more widely; greater clinical trial activity is correlated with reduced mortality and better clinical Care Quality Commission (CQC) ratings in NHS ICSs. Clinical trials also provide a much-needed source of revenue for the NHS. In 2018/19, commercial clinical research generated income of £355 million and cost savings of close to £30 million for the NHS in England³⁵.

While the case for a healthy clinical trial ecosystem should always centre around the opportunity to improve patient outcomes, the benefits go beyond health. In 2020, the life sciences industry accounted for over £5 billion of pharmaceutical R&D³⁶ and generated 270,000 jobs³⁷.

Fig 6. The UK's declining performance in clinical trials

The UK's trial decline was reflected in the number of trial sites per capita with 18% YoY decrease

of clinical trial sites per m population for phase II/III trials (2017-2022, CAGR in %)¹



1. Compound Annual Growth Rate starting data from 2017 until 2022. **Source:** Evaluate Pharma; BCG analysis

Investment in clinical research represents the highest return on investment for any public service: every £1 the government spends on clinical research generates £19 of total economic returns³⁸.

However, as addressed in the recent clinical trials review led by Lord O'Shaughnessy, the UK is becoming a less and less attractive place to conduct clinical trials. Since 2017, difficulties recruiting patients have driven a nearly 50% decline in phase III trials per year³⁹. From 2017-2021, the UK dropped from second to sixth for phase II trials and fourth to tenth in phase III trials in the global rankings. Good performance in trials – especially late-stage research where treatments are closest to market – is vital to fully reap the benefits of clinical research. Whilst most countries have bounced back from the decline in non-COVID-19 clinical trials over the pandemic, the UK appears to be falling further behind. Research from the Association of the British Pharmaceutical Industry (ABPI) has shown that declining clinical trial activity caused a deficit of £447 million for the NHS in 2020/2021⁴⁰.

Regulators are at capacity and red tape is slowing down companies in long-winded processes. It now takes 60% longer in the UK than in the US to set up a clinical trial. The median time between first application to a regulatory authority and the first patient receiving a first dose in a clinical trial was 247 days in 2020⁴¹. Also, just half (54%) of open studies performed in the NHS are delivered on time and on target⁴².

Cumbersome and slow recruitment processes as well as lengthy approvals hurt the UK's reputation as an attractive place to conduct clinical trials. The average time for MHRA assessment of clinical trials was reported at 125 days for first review of phase 1-4 patient trials in May 2023⁴³, up from 32.2 days a year earlier⁴⁴. This has significant knock-on impacts for the UK's comparative advantages in life sciences.

Use case: Use data to improve the process of setting up and recruiting for clinical trials in the UK.

Setting up and running clinical trials can be laborious, complicated, and expensive. Evidence from early AI programmes has already suggested that AI-driven R&D could result in time and cost reductions of at least 25-50% for drug discovery⁴⁵. As technologies mature and implementation becomes more widespread, impacts will likely get more consistent and significant. Combining data from NHS health records with health information such as genomics data to create integrated datasets on SDEs would allow researchers and funding bodies to build a more detailed picture of the UK population. These datasets could then be combined to help accelerate clinical trial setup and improve cost-effectiveness in several ways:

- I. **Develop a clinical trial ‘concierge service’** to quickly determine whether a particular trial is feasible. Of publicly funded randomised controlled trials (RCTs) between 2004-2016, only 56% achieved their target sample size⁴⁶. For every clinical trial that fails to recruit sufficient participants, time and money is wasted and new treatments or insights are further away. A ‘concierge service’ that can rapidly analyse patient-level data to assess whether the required sample size exists and is achievable could help overcome this issue. This would require building a platform that sits across an SDE or several SDEs, and covers health records, ethnicity, location, relevant social and lifestyle factors, and imaging records. Researchers could use the platform to submit queries relating to their desired trial protocol to understand if and where such populations exist and get indicative costs and timings of recruitment. For maximum utilisation, the service should enable a drill down to evaluate potential participant pools at each proposed location within a clinical trial. Data/research experts would also be required to assess the reliability and validity of insights to provide additional context. The NHS DigiTrials service uses routinely collected NHS data to

provide an estimate of how many patients currently meet eligibility criteria for a trial, and where they are located. However, as this service is limited to selected secondary care data in England, an optimal approach is needed at scale. One option would be to expand the DigiTrials to a wider set of data to provide a concierge service. An alternative option is to leverage Clinical Practice Research Datalink (CPRD) data. In [one trial \(DaRe2THINK\)](#), CPRD primary care data was linked with secondary care data and death records. An algorithm was used to filter the GP records to identify how many matched eligibility criteria, without disclosing who they were.

- II. **Explore sensitivity of inclusion/exclusion criteria for clinical trial participants.** Having used a ‘concierge service’ to identify the size and location of potential participant pools, the next step would be to incorporate the ability to use historical clinical trial data to understand how adaptations to eligibility criteria could likely improve enrolment rates. Enrolling enough eligible participants is a significant challenge for clinical trials in the UK. Significant advantages could be gained from AI algorithms that analyse information on past clinical trials, regulatory filings and patient data including biomarkers, genomic, and imaging data to understand the impact of small changes in participant criteria. This analysis requires a register of UK clinical trials activity and their inclusion criteria (as called for in the O’Shaughnessy review) as well as data indicating their success, and whether sufficient participant numbers were reached. This would require building a platform on the SDEs that can determine where, how, and why other clinical trials did or did not succeed, so researchers could optimise the study protocols at the outset. These AI technologies could reduce trial costs, improve access (especially to historically underrepresented groups), and increase trial success rates.



III. Reaching eligible participants. The concepts above will make identifying pools of prospective participants easier, but they will only have the desired impact on speeding up clinical trials if it is also possible to reach them.

Currently, there are barriers to contacting potential trial participants, such as the challenge of seeking consent to contact. As called for in the O'Shaughnessy review, greater consideration of how it can be made easier for research organisations to reach potential participants is needed. In the DaRe2THINK trial, GPs were informed if a local patient was eligible for the trial and asked to reach out and gain consent for the researchers to make contact. Whilst this is a promising improvement, this process relies on GPs having the capacity to

make contact with eligible participants.

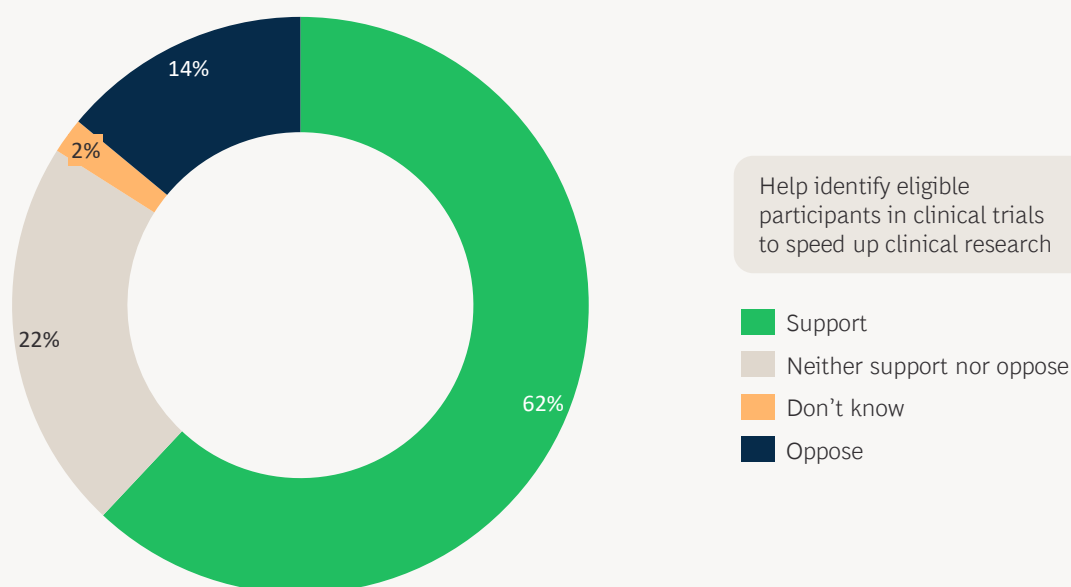
Moving forward, there is a significant opportunity to leverage the NHS app, such as giving the public the option to opt-in for clinical trial notifications to allow for improved communication.

In our survey, we found that 62% of respondents supported using healthcare data via SDEs to improve clinical trials recruitment and clinical research.

A further 24% neither opposed nor supported the idea, so could yet be convinced. However, the survey pointed to no obvious approach that would meaningfully shift their view at this stage.

Fig 7. Support for data access to help treat diseases

Imagine your personal health data was made accessible on a secure platform. For each of the following, would you support or oppose your data being used?



Source: BCG Healthcare Data Survey 2023

2.4. CLINICAL CARE

Problem statement: The NHS is facing significant pressures, with backlogs reaching an all-time high. This has resulted in significant knock-on effects on the health and wealth of the nation.

As of April 2023, one in eight people in England – 7.42 million – are waiting for treatment⁴⁷. Of this group, 3 million have been waiting more than 18 weeks. The target for 92% of patients to be seen within 18 weeks has not been met since 2016 in England and currently stands at 58.5%⁴⁸. Although long NHS waiting times pre-date the pandemic, COVID-19 significantly exacerbated the problem. The average waiting time for treatment in England today has almost doubled from pre-pandemic levels to 13.8 weeks⁴⁹. To add to this, the UK has fewer doctors and nurses per person than many of its peer countries⁵⁰. NHS services across the board are being stretched.

This has wider economic costs. NHS backlogs have contributed to a significant rise in economic inactivity since the pandemic. Of the over-50s who left the workforce since the pandemic, over a third are on an NHS waiting list. The same proportion say a health condition is the reason they haven't returned to work. It is estimated that there are £73 billion worth of combined benefits over the next five years if the NHS can get people off waiting lists by 2027⁵¹. This includes £18 billion through people returning to work or increasing their working hours.

The UK is well placed to address these issues by harnessing its comparative global advantage in AI and tech. Positive first steps in this area have been made through the establishment of AI centres such as the NHS AI Lab and the London Medical Imaging and AI Centre for Value Based Healthcare. However, these initiatives need to be scaled up, both to increase the work on imaging and pathology use cases and to exploit the wider potential for speeding up administration. Scaling high-impact AI innovation in the UK is hard to achieve with the current health infrastructure. Establishment of SDEs and an FDP will help with this but it is important to have a foundational system that new AI technologies can all plug into. The NHS does not currently

have the breadth and scale of data skills needed to build, deliver and maintain this. It is therefore paramount to develop these innovations in partnership with expert external organisations.

There is no single solution, but better use of health data could help services run more efficiently and improve patient outcomes. This means accelerating the delivery of data-driven technologies that can streamline clinical processes, facilitate better decision-making and reduce inefficiencies across the system. NHS trusts that are digitally mature have been shown to be 10% more efficient⁵².

Use case: Leverage new technologies, including machine learning, generative AI and AI-driven algorithms, to optimise clinical care decision-making and resource management in the NHS.

There are two key areas in which health data can be used here:

- I. **Diagnosis.** Targeted efforts to diagnose patients more quickly and accurately will have positive knock-on impacts on waiting times and NHS services. There have been huge developments in AI diagnostics over the past decade, but the NHS must accelerate deployment of these technologies to see widespread impacts. AI and machine learning can analyse patient health records to identify previously undetected patterns in diseases. The NHS should build on the work done with the COVID-19 Chest Imaging Database and establish a nationally-available platform that integrates diagnostic imaging data with wider health records. At first, this should be developed for the highest-priority areas such as cardiovascular, respiratory and neurological diseases, and cancers, to test proof of concept before being rolled out further. AI algorithms can then be used to interpret images and flag the presence of disease indicators immediately, without the need to wait for a radiologist to make an initial assessment. This would allow clinical teams to rapidly triage cases and focus resources on the highest priorities from the outset.



Case Study diagnosis: COVID-19 Chest Imaging Database

During the pandemic, NHSX, with the support of the British Society of Thoracic Imaging and Royal Surrey NHS Foundation, built a national centralised database of chest images and supporting medical information. The aim was to use this data to develop machine learning technologies that would support better research, diagnosis and treatment of COVID-19. The database was used to develop:

- AI image processing software that was able to support clinicians in diagnosing COVID-19 quickly.
- Mathematical modelling to help determine the severity of disease and what interventions may be necessary, e.g. likelihood of needing ventilation.
- Validation of AI products – verifying whether AI tools that have been developed on non-UK populations are fit for purpose in the UK.
- Teaching resource for radiologists: supporting radiologists to diagnose COVID-19 cases after examining chest images and to receive feedback on their conclusions from the AI software.

The database contained over 60,000 images from nearly 30 NHS Trusts across England and supported the work of 16 research groups.

The COVID-19 Chest Imaging Database provided researchers with large, high-quality data that was instrumental in supporting clinical responses to the pandemic. The database also provided a valuable proof of concept and acted as a testbed for clinically viable medical imaging models.

The data has already been incorporated into several tools, including:

- An open-source AI tool to facilitate rapid diagnosis and triage of patients with COVID-19, led by the Cambridge University NHS AIX-COVNET collaboration.
- A simple but accurate risk calculator (LUCAS) to predict survival of COVID-19, for which inclusion of Chest Imaging data increased the accuracy of the prediction.

II. Treatment. Data tools and AI can also be used to support better decisions around clinical treatments. By combining end-to-end patient data, including genomics and clinical research data, AI algorithms can suggest treatment options, flag potential side-effects and identify contraindications at the patient and population level. For example, by capturing and storing all data from biopsies in suspected cancer cases on SDEs, it is possible to train AI algorithms to suggest the most effective treatment pathway based on an individual's biomarkers and how previous patients have responded. This could support clinicians in making much quicker treatment decisions as well as improving the efficacy of interventions.

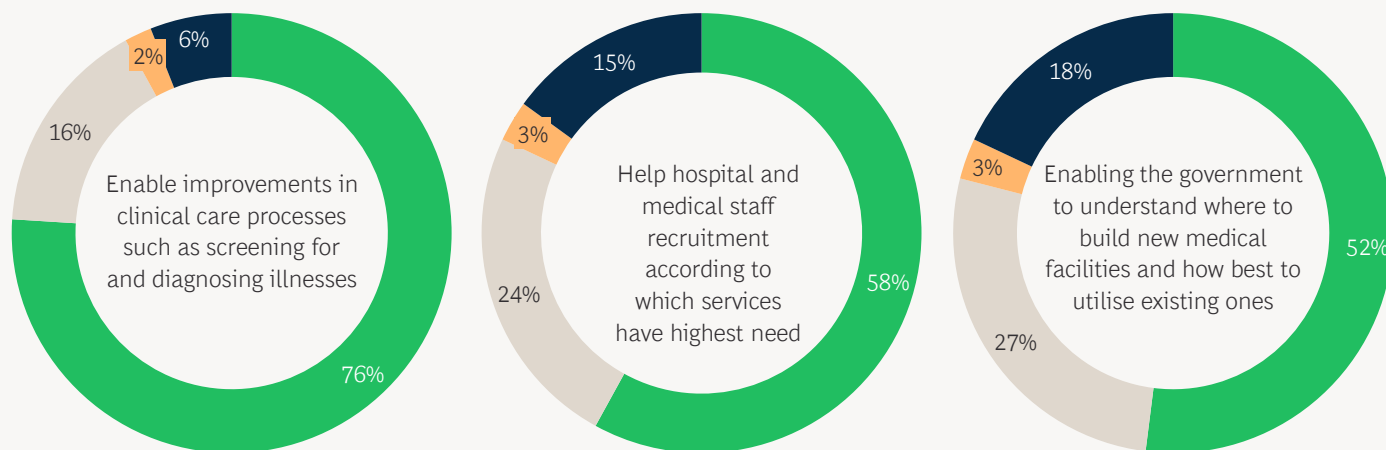
Beyond these examples, generative AI could be potentially transformative for wider service management, including administrative tasks and workforce planning. We look at these in more detail in Chapter 3.

In our survey, support for using data to improve clinical care was probably the most mixed, albeit still strongly positive. Using personal health data for direct improvements to clinical care processes such as diagnosis and screening at hospitals had strong support. Leveraging data to help improve and better target staffing/recruitment as well as the building of healthcare infrastructure had less support, with larger numbers of respondents neither opposed nor supportive.



Fig 8. Support for data access to improve clinical care

Imagine your personal health data was made accessible on a secure platform. For each of the following, would you support or oppose your data being used?



Source: BCG Healthcare Data Survey 2023

Support Neither support nor oppose Don't know Oppose

Case Study treatment:

An AI tool for cancer that identifies the best targeted treatments

A US technology company developed an AI tool that could analyse a wide range of tumour types to provide detailed genomic profiling. This facilitates the use of precision oncology interventions that target the molecular characteristics of an individual's tumour.

In a study, the tool analysed 500 individual cancer patients' clinical and molecular data, whole RNA sequencing and immunological biomarker measurements. This individual molecular profiling was then used to match patients with the best cancer therapies or clinical trials.

The tool was found to lead to substantial improvements in the identification and accuracy of mutations and reducing false positives.

The AI technology also resulted in:

- 92% of patients being matched to precision treatments.
- Over three quarters (77%) of patients were matched with at least one relevant clinical trial.

This technology supports clinicians in making much quicker treatment decisions that are tailored to individual patients to maximise efficacy and impact. This is particularly important in oncology, where speed of intervention is strongly linked with patient outcomes. This tool is also especially valuable for patients with advanced or rare subset cancers that are more complex to treat.

Chapter 03

Implementation factors

When it comes to implementing the SDEs and the wider data approach, several factors need to be considered if we are to have a chance of achieving these use cases and maximising the value from healthcare data.

3.1. DATA TRANSPARENCY AND PUBLIC ENGAGEMENT

Transparency and trust are prerequisites. The right frameworks and mechanisms must be in place to deliver the level of transparency and information that will maintain public trust over time. This is easier said than done, and there have been missteps in the past, such as the failed rollout of the GP Data for Planning and Research programme (see page 34). But given the opportunity and need, it is crucial to get it right this time by listening to what the public say, learning from past mistakes and drawing on what already works well.

Fortunately, we start from a relatively strong place, with 90% of people saying they are willing to have their data accessed by the NHS for any reason. This shows the high levels of trust the institution has with the public when it comes to handling and processing data.

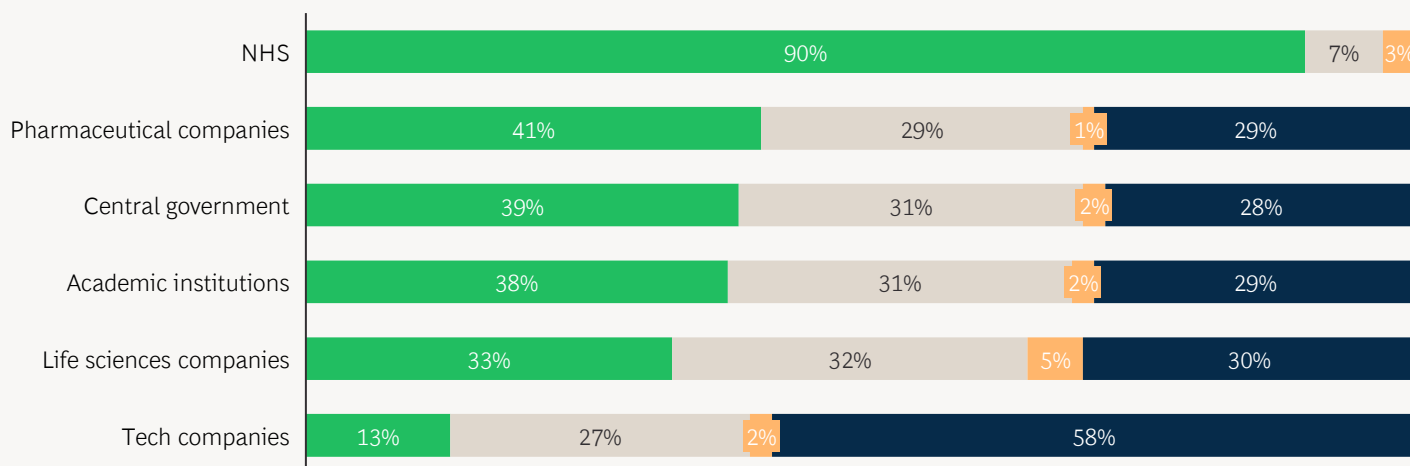
For some time, there has also been a misconception by stakeholders across the value chain, especially private organisations, that the public's default position is to oppose the sharing of their personal health data. This has meant many organisations have shied away from engaging with the public in conversations around personal data.



Fig 9. Support for sharing data with different organisations

There is huge support for sharing personal health data with the NHS; and more support than opposition for all other organisations, apart from tech companies

Do you **support** or **oppose** sharing your personal health data with the following for any purpose?



Source: BCG Healthcare Data Survey 2023

Support Neither support nor oppose Don't know Oppose

However, our results show that when you engage with people and set out the use cases and their potential benefits, they tend to be supportive of allowing their data to be accessed.

Those who responded 'neither support nor oppose' to the question "Do you support or oppose sharing your personal health data with the following for any purpose?" (Fig 9) were disproportionately more likely to answer other questions this way, which may indicate a group of people who would benefit from further information to help them form an opinion. This also suggests there is a group that is unlikely to have strong views and may either be able to be convinced or would not strongly oppose data use.

Linked to this is an assumption that, given the choice, people may prefer to opt-in rather than opt-out of data sharing. However, our survey suggested that there is no clear majority either way: 52% of respondents supported opt-in compared to 48% for opt-out. As might be

expected, people favouring opt-out tend to be more comfortable with sharing health data. For those on the opt-in side, there are steps that could make them more comfortable. For example, these respondents were more likely than the full sample to request being proactively told about their use of data (44% vs 37%). Detailed information on when and how their data is used could therefore help to convince this group.

Past mistakes should not be ignored either. When public engagement is an afterthought, perceptions of transparency plummet and public trust takes a direct hit – as in the recent attempt to launch GP Data for Planning and Research (GPDPR). There should be a clear effort to be open about what lessons have been learnt and how processes have been adapted. In fact, there should be a joined up public engagement strategy consistently adopted across all NHS data projects. This would help to maintain a coherent approach to building and maintaining public trust.

Case Study: GP Data for Planning and Research (GPDPR) stopped

In 2021, NHS Digital tried to launch the GPDPR – a programme that would give researchers and third parties access to pseudonymised GP data to analyse and improve healthcare planning and research. GP data is some of the richest and most complete in the NHS, but it is highly fragmented and difficult to extract under the current system. GPDPR aimed to improve data quality and access in a cost-effective way.

However, a significant lack of public engagement and communication led to serious concerns being raised from the public, patients, and professionals. As acknowledged in the government's 'Data Saves

Lives' strategy, the NHS failed to articulate the context and therefore the value of GPDPR, and did not sufficiently listen or engage with the public throughout. The result was widespread confusion and a perception that the NHS was intending to force the programme through without public support.

As a result, the rollout of GPDPR has been stopped indefinitely whilst the government looks into completely redesigning it. Public trust in data sharing has been badly damaged and more than a million patients opted out of data-sharing afterwards.

As part of this comprehensive public engagement strategy there should urgently be a public communications campaign around healthcare data usage and its potential benefits, particularly linked to the process of creating the FDP, national SDE, and sub-national SDEs. Our survey provides a few potential areas for focus in this campaign:

- Emphasis on the move to data access over sharing.
- Clear outcome-based use cases.
- Explanation of the wide range of benefits that better use of healthcare data can have.

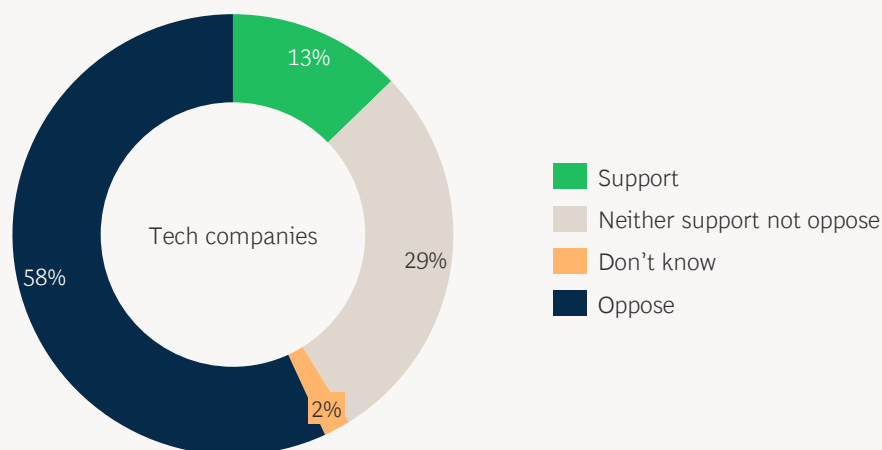
- Clear messaging on how value and benefits will be put back into the local healthcare system.
- Focus on building trust for certain institutions and partners (e.g. have pharma and tech companies sign up to a set of terms, including ethics principles).

This final point is worth expanding on briefly. There is a particular issue around allowing tech companies access to public healthcare data.



Fig 10. Support for sharing data with tech companies

Do you **support** or **oppose** sharing your personal health data with the following for any purpose?



Source: BCG Healthcare Data Survey 2023

We tested the above question at the beginning and end of our survey. We found that 45% of respondents were unchanged in their views on sharing health data with tech companies, while 29% of respondents were more opposed to sharing health data with tech companies at the end of the survey. Concerns are also consistently much higher amongst older people. Part of the concern may be driven by the fear that tech companies would simply sell the data on. When asked about what different organisations currently do with healthcare data, 23% said they believe tech companies sell it to third parties. The highest from other organisations was 11%. Making it clear that this isn't an option under a data access approach will be important.

There should be clear communications around who will be accessing and processing data from the SDEs. Given that tech companies are likely to be involved in the practical side of building these SDEs, it is important for the NHS to start communicating this now and in the wider context around healthcare data.

In order to maintain transparency and trust in the long term, it is essential to establish some clear frameworks for how the NHS should

engage the public in decisions regarding the access and use of their data. It is vital the public have a stake and a say in the decision-making process.

We have identified several options for how this could be done with the intention being that these are led centrally by the NHS. They are not mutually exclusive.

- **Citizen summits.** Temporary panels made up of members of the public are established to advise stakeholders from across the value chain on how the public should be engaged throughout a specific project. Advice is then used to form the public deliberation and governance structures needed throughout the work's lifecycle. Citizen summits can be used to develop public deliberation charters, and the terms of engagement to which stakeholders sign up. Typically, they are used in a multi-stakeholder setting, but could also look at public deliberation requirements for a single organisation. If used, citizen summits should be the first major public engagement step in the lifespan of a project.

- **Public decision panels.** Organisations that want to use personal health data must get the approval of a decision panel – also known as a participant panel – that is made up of members of the public. These panels should have a say in what data the organisation uses and how. Panels should be able to influence the organisation’s research and data use priorities and should be fully embedded in senior decision-making mechanisms. Panels should meet at least quarterly, and membership should be sufficiently long (e.g. years not months) to allow members to fully embed into the organisation’s activities and provide consistency.
- **National citizen jury.** A randomly selected public panel, which is independent from any organisations involved, offers advice on major national initiatives using personal health data, but does not provide explicit approvals. Jury members should have personal lived experience of the topic/disease areas. They should be nationally representative and from geographically diverse areas. Juries can be stood up relatively quickly and be used to advise on specific projects, typically in a ‘sprint’ style, where they assess a particular topic over a matter of days not months.
- **Other public engagement methods.** There are several other public deliberation tools that can sit within, alongside or separately to summits, panels and juries. For example, dedicated focus groups can be used to seek advice or make decisions on long-term strategic priorities as well as specific topics. Online forums can help broaden access and get perspectives from a diverse audience. These are also useful for understanding attitudes in response to current affairs, or for tracking sentiment over time.

Members of public participation groups should always reflect the communities which they serve. As the context evolves, organisations need to continually assess whether they have the right representation and actively seek to recruit members in response. For example, if an organisation launches a new clinical trial in a specific disease area, they should recruit participants that have lived experience of that disease. The appropriate size of participant groups is dependent on the situation. Groups should be sufficient to reflect the population’s wide interests, but not so distorted they lose the ability to make decisions or converse effectively.

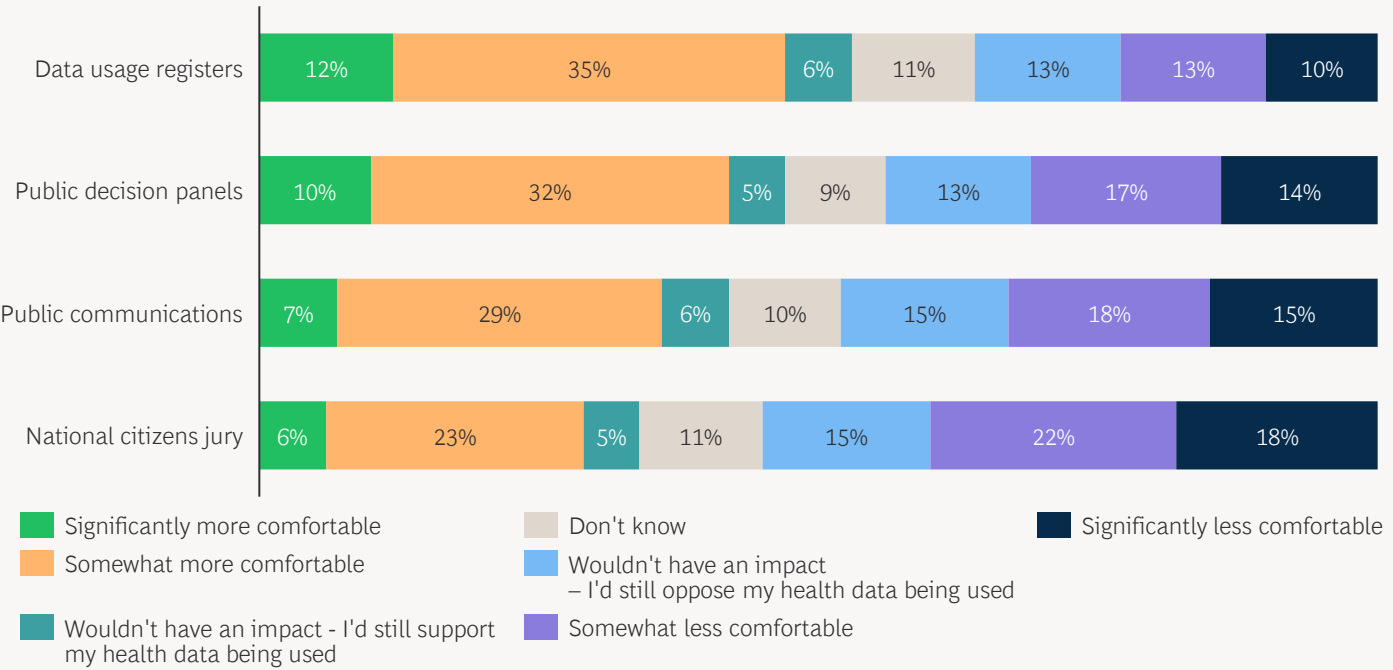
We tested some of these options in our survey and found that they can play a useful role in making people more comfortable with their data being accessed and used.



Fig 11. Views on public engagement tools

Data usage registers and public decision panels would make people more comfortable about their health data being collected and accessed

For each of the following, please say whether it would make you more or less comfortable about your health data being collected and accessed.



<p>Data usage registers – there is a publicly available record of every time the NHS grants external organisations access to personal health data.</p>	<p>Public communications – widely available public-facing materials that explain what data is being used for are shared. For example, leaflets in hospitals, schools, and GP surgeries, or adverts on TV.</p>
<p>Public decision panels – if any organisation wants to use personal health data, they must get the approval of a decision panel who report to the organisation but are made up of members of the public.</p>	<p>National citizens jury – a randomly selected public panel, which is independent to healthcare organisations and who provide advice on any major national initiative using personal health data, but don’t provide explicit approvals.</p>



Public decision panels and data usage registers (which allow the public to track and view how data is being used) provided the most comfort. Whilst data usage registers already exist, they are currently poorly signposted and hard for the public to navigate. Adopting a more proactive, potentially personalised, usage register model would have greater impact. As Genomics England has shown, involving public decision panels in decision-making and strategy can work at a practical level. We therefore believe it is important that over time, public decision panels are incorporated into the oversight of the SDEs and the NHS's wider data strategy.

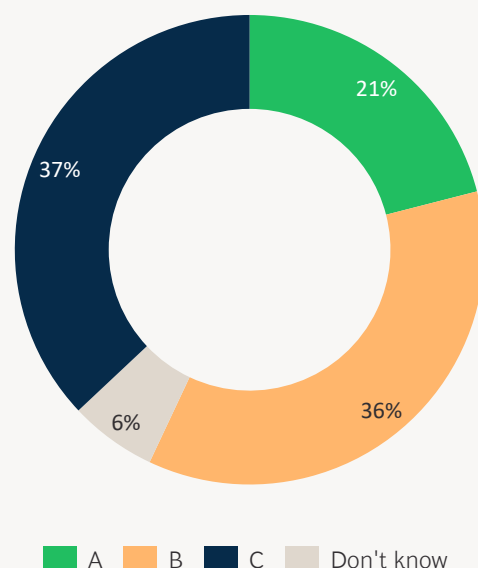
Engagement should not be static. Organisations should revisit conversations as the context evolves and update consent whenever necessary. Feedback loops should be built into the project's design to ensure people can share their views, advice, and experiences – not just at the beginning but after work has concluded, as this is where feedback is vital to capturing lessons learnt. Technology can be used to facilitate this, for example through the NHS app. Although its functionality is currently limited, broadening the app's use will encourage more engagement from existing users and downloads from future users.

For example, using machine learning analytics, the app could be used to push out notifications to individuals when they are eligible for clinical trials or screening(s) based on their health history. Automatic feedback requests after users have consented for their data to be used could help embed a virtuous cycle of participant engagement. This is also where data usage registers could be incorporated. Whilst they are already in use for the SDEs, these could be made more accessible via the NHS app and linked to individual data so a person can track how their own data is being used. When we asked people about the level of information they'd like to receive, views were mixed, but showed a broad desire to have some information. In the app, individuals could choose how often they wished to be updated on how their data was being used.

Fig 12. Views on receiving information about use of data

Nearly four in 10 people would like to be proactively told about the use of their data as soon as it is used

Imagine your personal health data was being collected for a legitimate purpose and was subject to strict privacy and security standards. How much information would you like to know about how your data was being used?



A: I wouldn't want any additional details - I'm content knowing data was collected for a legitimate and valuable purpose

B: I'd like to be able to request information about the use of my data, but I don't want to be told proactively

C: I'd like to be told proactively about the use of my data as soon as data is used

Source: BCG Healthcare Data Survey 2023

Case Study:

Genomics England participant panel

Genomics England established a participant panel comprising members of the public whose personal data or that of a family member is held by the company. The panel was set up so Genomics England could get regular guidance and advice from the public on how they should use personal data and how research needs to be designed to maximise patient benefits.

The panel is made of up a diverse group of 15 to 25 people. Each member is tenured to the panel for three years, with an opportunity to extend for a further three years with the permission of the panel chairs. Panel members meet quarterly and are expected to spend one extra day on panel business every quarter.

The panel represents the interests of all individuals whose data is used by Genomics England. Panel members bring their lived experiences and perspectives to decisions around how the company collects, accesses, and uses data. They influence decisions about which external parties can use their

data, and how they can use it. They also provide advice on what the company's research and strategic priorities should be. The panel directly advises the company's board and contributes to its ethics advisory committee and commercial team. When required, the panel stands up special groups whose remit is to investigate specific topics, for example COVID-19 and cancer. Participants also help inform the wider genomics value chain, including the NHS, about healthcare service delivery and other genomics projects.

The panel, which has now been successfully running for eight years, has been involved in countless projects and shaped the everyday thinking and decision-making of Genomics England. For example, when the company was struggling to secure initial genomics data, the participant panel wrote a letter on behalf of all participants to the data owners, articulating the value of this data. Within 24 hours, the company had secured a data agreement that granted the company access to over 3.8 billion data points from 90,000 people.

3.2. DESIGN AND OPERATION OF SDES

It is vital that SDEs, the wider data network, and the process of collecting data, are as effective and efficient as possible. The SDEs currently being established at the regional and national level are in their early stages. But there are a few important points to note to ensure the most value can be captured. An important balance to strike will be ensuring there is sufficient commonalities across SDEs to enable ease of use and data integration, whilst also ensuring there is space for healthy competition between SDEs for their tools, services and talent.

Accessibility

The Goldacre Review originally envisaged that the use of Trusted Research Environments (TREs), such as the SDEs, would allow for a significant streamlining of the data access process, stating:

"[TREs] use should also be incentivised by developing a two-track approvals process, with far quicker access to

data in a TRE, reflecting the reality that data privacy concerns are largely eradicated by this working practice."

As it stands, every request for access to an SDE must go through the NHS Data Access Request Service (DARS) and be examined individually before a bespoke Data Sharing Agreement can be created and access to the SDE granted. Parts of this process were clearly designed before the creation of the SDEs. For example, every application must set out security assurances with regards to data handling, storage and processing and explain the flow of information and data. These factors are largely irrelevant when working in an SDE given the security and operating parameters, by design, stop the data being stored or processed anywhere else. If researchers want to remove any code, data, or results from the SDE this must be done via the SDE 'Safe Output Service'. This is used to ensure any assets taken out of the research environment conform to mandatory data confidentiality and privacy rules.



Given the additional security that SDEs offer, the current accessibility system – particularly around accessing SDEs initially – looks somewhat outdated. Instead, the NHS should pursue a more streamlined approach. This would mean updating the SDE access process to reflect the safety and operating context of SDEs, reducing bureaucracy and administrative burden for DARS users and the NHS. The focus should instead be on verifying that anything removed from the SDEs is compliant to the highest security and privacy standards. Ensuring the Safe Output Service can be efficiently scaled with sufficient resource will be crucial for this.

There is also a case to review the necessary purpose and benefits of access. As it stands, these are set out in the Care Act 2014, which never really envisaged the type of data access via SDEs that is now being pursued. Applicants have to make the case for how their request will fit this purpose, and benefit the health and social care system. This could be made broader to capture wider potential benefits to the UK economy from innovation, with plans for ensuring benefits are captured by the health system also put in place.

User experience

As the various NHS SDEs develop, it will be important to encourage consistent practices to avoid duplicative effort and provide a standardised experience for users when it comes to the initial approvals and basic administrative processes. One crucial factor will be to create a service wrapper that provides all NHS SDEs (national and sub-national) with the same basic governance and administrative processes. For example, applications for permissions, requirements for approval, and management of the users accessing the data.

The government's current intention is that researchers will interact with a single Data Access Committee to apply for access to data for each sub-national or national SDE. However, there is an open option to delegate authority to individual SDEs in future. Whilst local knowledge of the data is undoubtedly valuable

in consideration of applications, approaching multiple committees to access different data sets will be laborious and deter researchers who are interested in using data from across the UK. Given the need to apply for a unique data agreement for each purpose, the inconvenience will quickly multiply if several committees for each purpose need to be engaged. Greater integration across SDEs should be accelerated to ensure use of the data is an attractive pursuit.

Interoperability is also a key part of providing a quality user experience. Whilst some collaboration is happening, the creation of the FDP, national SDE and sub-national SDEs risks it happening somewhat independently. However, the aim must be that over time it is possible to easily leverage and pool data across these platforms. As our use case section showed, many of the key insights and outcomes can only be generated when the data on the SDEs is integrated with other external data, as well as across all SDEs to create a broad and deep dataset. Without this kind of integration, the insights generated, and therefore the value created by the SDEs, will be more limited.

While a basic level of integration and interoperability will be vital, it is important to keep an element of competition between SDEs to help foster innovation and drive improvements. Ensuring commonalities across the approvals process and securing interoperability for data across the SDEs does not mean every SDE has to offer the same tools, research services or value propositions to prospective talent. Allowing for competition between the SDEs on these factors means there are incentives to strive for better insights, stronger AI tools, and greater health outcome improvements. This could be established in different ways. For example, SDEs could compete on how they use the data for their own hospital case innovation within trusts to improve efficiencies. Best practice would quickly become apparent and spread rapidly thanks to real world evidence. Alternatively, a separate body (e.g. a venture arm) could be established that can generate a profit for reinvestment and leverage it to attract top talent.



Talent

As always, getting the right people and the right skills in place will be crucial to the success of SDEs. Building, maintaining and improving the SDEs over time will be a complex and time-consuming process. One of the benefits of using healthcare data more effectively is that it creates a virtuous circle. It will generate more data, which can feed back into the system and further improve the outputs. However, this means the amount of data could grow significantly and quickly. Furthermore, as discussed in the Goldacre Review, data collection and curation remain a real challenge for the NHS. The quality of data can be variable across the system and the sharing of knowledge and best practice is not what it should be.

The creation of the SDEs should help to drive this process forward. However, it is still crucial for the NHS to possess the necessary skills to ensure the quality of data on the SDEs reaches the required standard. Additionally, the workforce needs to be equipped to analyse the data with the tools provided.

Ultimately, the common theme across these points is the need to put significant resource behind the SDEs. A large amount of money is being invested in the creation of the SDEs but the job does not finish there. It is just as important to ensure they run smoothly over time, that they are easy to use and access, and that data is integrated across the SDEs so that datasets can generate the most valuable insights. Ongoing maintenance and development of the SDEs should have a feedback loop and a continued process improvement mechanism with incentives built in.

The reality is that the NHS is constrained in terms of both funding and talent. That is why it is so important to capture the direct value created by the SDEs and put this back into the system. This will help to support them over the medium and long term.

Link funding and priorities

One concern that is often heard across the

healthcare system is that while the right priorities are often targeted, funding is not always directed towards them on a consistent basis. A key example of this is the fact that the Integrated Care Boards (ICBs) often aren't as interested or supportive of research as they should be, or need to be. Given that they are the legal owners of some of the SDEs it is crucial that they see the long-term value in research and support this by. For example, by helping to sign patients up for clinical trials.

The focus on outcome-based use cases should help since this clarifies the incentives for them to support research. However, often the constraints on funding mean that this may not be sufficient. This once again reinforces the need for there to be proper resourcing behind the SDEs. This, in turn, will make it easier for the ICBs to be supportive of research and see the broader value in it. However, we would go further still and suggest that ICBs be more directly held accountable for creating research opportunities. For example, by providing more detailed and specific statutory obligations for ICBs to collaborate and drive research with their local research institutions and network.

3.3. USE OF CONTROL OF PATIENT INFORMATION (COPI) NOTICES

The legislative and regulatory landscape around sharing, accessing, and using patient data in the UK is fragmented and complicated. However, during the pandemic, the need for organisations to have fast and wide-ranging access to health data forced the rapid development of new ways of working, and data-sharing agreements.

One of the most significant emergency interventions was the use of Control of Patient Information (COPI) notices. COPI notices are issued by the Secretary of State for Health and Social Care under Regulation 3 (4) of the Health Service (Control of Patient Information) Regulations 2002. In this case, it mandated that NHS Digital share confidential patient information with organisations for COVID-19 purposes without the need for individual consent and data-sharing agreements.



COPI notices are statutory exemptions to the common law duty of data confidentiality. They give researchers rapid access to large confidential datasets, providing they keep a record of all data processed and use it for the sole purpose defined in the notice.

The use of COPI notices during COVID-19 provided parties with the mandate and confidence to share data whenever a legitimate request was made. They enabled significantly faster access to health data, which resulted in an unprecedented increase in data and research activity. The level of cross-organisation data sharing as a result was extraordinary and made a meaningful difference to the pandemic response. For example, the COVID-19 RECOVERY trial, which led to the discovery of four COVID-19 treatments, was heavily reliant on data access through the notices and is thought to have saved millions of lives globally. The ability of NHS Blood and Transplant to reach COVID-19 patients

and research their plasma, the NHS Test and Trace system, and the development of the COVID-19 vaccines are other examples of activities made possible in part because of data accessed through the notices.

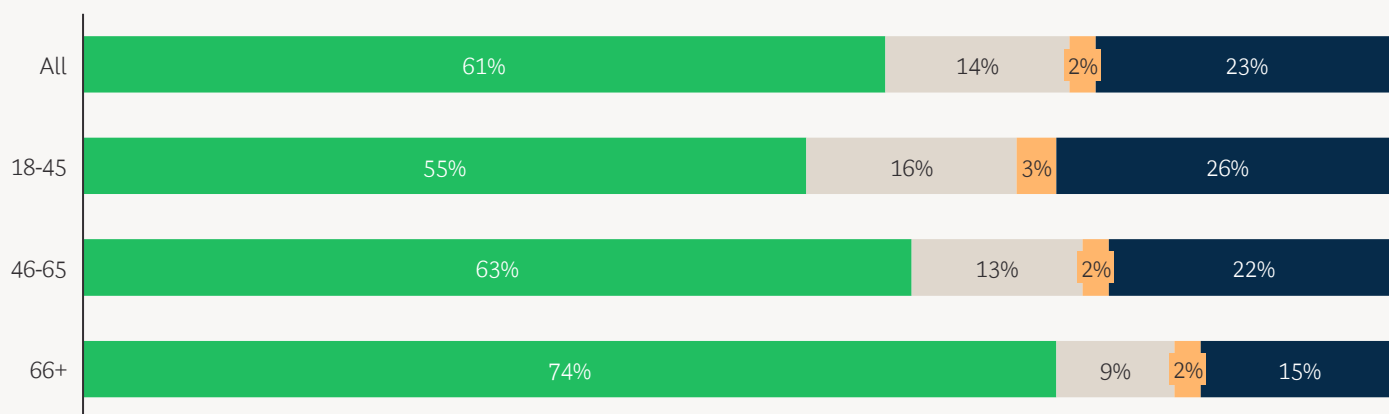
The use of COPI notices enables population-level data to be collated much more easily and quickly, giving researchers access to rich datasets that can be used to identify trends at pace. On the other hand, it grants organisations access to confidential patient information, even if individuals have opted out of data sharing. This poses potential concerns around public trust and confidentiality. Despite this, our research found that nearly two thirds (61%) supported the use of these emergency measures during COVID-19, whilst only 23% opposed it. Interestingly, support actually went up for those over 66 years to three quarters (74%), despite age being traditionally linked to lower levels of support for health data sharing.

Fig 13. Support for continued use of COVID-style data access

COVID-19 data sharing rules are supported by six in 10 people, with strong support across all age groups

During the pandemic the UK government used emergency regulations that allowed the NHS to share confidential patient information with organisations for COVID-19 purposes. Data was shared even if individuals had previously opted out of data-sharing and was used for things like understanding how COVID-19 spread and supporting vaccine development.

Do you **support** or **oppose** that these regulations were used in response to the COVID-19 pandemic?



Source: BCG Healthcare Data Survey 2023

Support Neither support nor oppose Don't know Oppose

Whilst the pandemic was an extraordinary period for public health and data use, there is an argument that COPI notices could be used more frequently to progress health research in other areas. Over half (53%) of our respondents supported the general continued use of these regulations to improve processes, support health research, and improve patient outcomes. Only a quarter (26%) opposed the idea.

While there were clear positive impacts from COPI notices during the pandemic, the use of this legislation – or evolutions of it – for all health research would be an error. The COPI mechanism was successful during COVID-19 largely because of the very tangible use case. As we have set out, if the reasons for data sharing and its value are not clear, public support can quickly decline. If COPI notices are to be used in the future, there must be a clear and urgent use case and tangible value to be gained by the public.

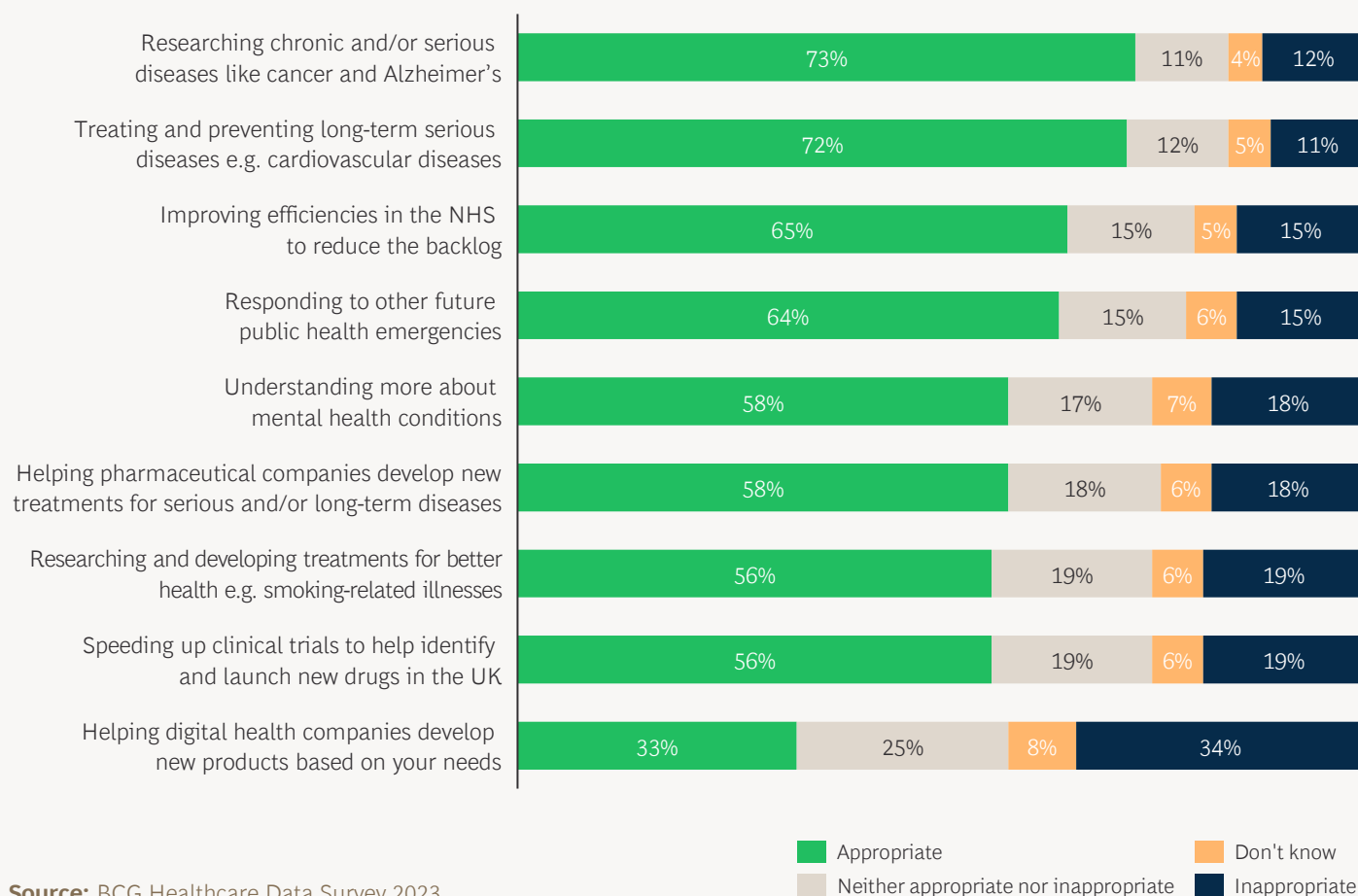
When we asked how people felt about specific scenarios where data could be collected, used, and shared in a similar way to COVID-19, we were surprised to find significant support for a number of outcome-based use cases. People were most supportive of similar practices being used for researching (73%) and treating (72%) serious illnesses like cancer and cardiovascular diseases. In fact, the only scenario for which there was not majority support was helping digital health companies to develop new products. Here, 42% of people said it was the least appropriate scenario in which to use similar approaches to COVID-19. This highlights the public's consistently lower trust in tech companies, and the inappropriateness of using COPI notices universally.



Fig 14. Support for continued use of COVID-style data access by use case

Continuing the same approach to data access used in COVID-19 garnered majority support in a number of high impact areas

Do you think it is appropriate or inappropriate for data to be collected, used and shared in a similar way to during COVID-19 for each of the following scenarios?



Source: BCG Healthcare Data Survey 2023

When asked in general about their support for COVID-style data access, older people were more supportive than younger people. This is somewhat surprising since it reverses the trend in the rest of the survey where younger people tend to be more supportive of data sharing.

However, this was not consistent across all scenarios we presented to the public. Those aged 66 years and older were more supportive of using COVID-style data access for speeding up clinical trials. By comparison, the younger group (18-45 years) were more supportive of using

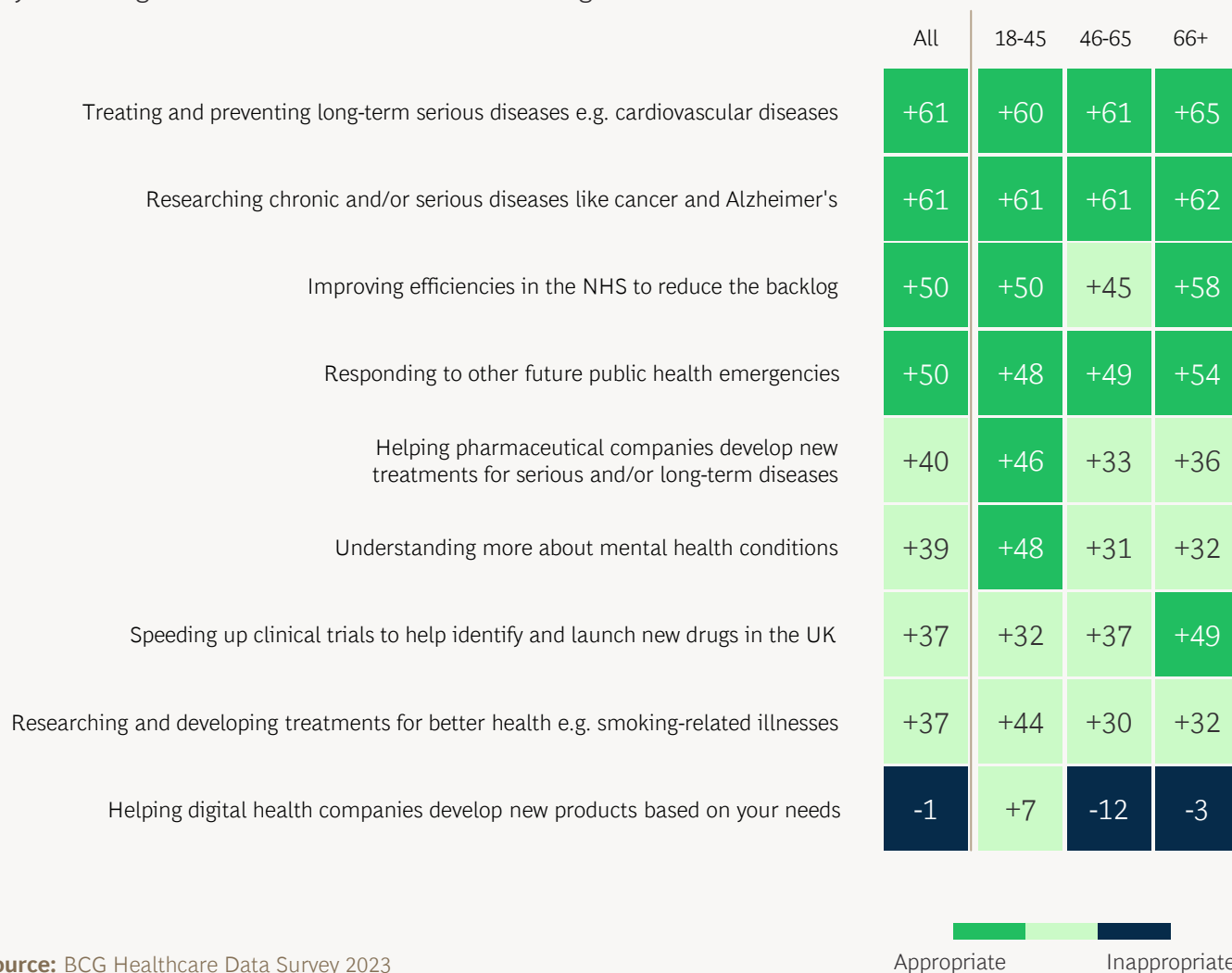
COVID-style data access for helping pharmaceutical companies develop new treatments for serious and/or long-term diseases and understanding more about mental health conditions.

These results suggest that, at least initially, if sharing confidential patient information with organisations for purposes beyond COVID-19 without the need for individual consent and data sharing agreements, the focus should be on those scenarios that garner widespread majority support.

Fig 15. Support for COVID-style data access by use case and age group

Strength of support for continued use of COVID-style data access varies for some use cases by age group

Do you think it is appropriate or inappropriate for data to be collected, used and shared in a similar way to during COVID-19 for each of the following scenarios?



Source: BCG Healthcare Data Survey 2023

COP1 notices can be used within the existing legislative framework, eliminating the need for new or amended legislation. However, it is important to note that legislation is often not the main barrier to better data access in England. Physical and digital data infrastructure and cultural factors, including public support, tend to pose far greater challenges. It is therefore important that legislation is not relied upon to resolve problems with data access that may stem from architectural, cultural or organisational issues.

Ultimately, the use of legislation should not challenge, or be seen to challenge privacy or security standards, or be used as a tool to avoid public engagement. Instead, it should facilitate wider secure access to data during emergencies and be used to tackle the overwhelming challenges facing the NHS. There is scope to potentially deploy COP1 notices or similar processes in other defined priority areas, but this must be approached in the right way.

Public support must be secured at the outset, there should always be sufficient anticipated value, and processes must be transparent. The pandemic showed that despite some initial challenges, legislation around data sharing and access is broadly fit for purpose in both emergency and non-emergency scenarios. It is important the government capitalises on the lessons learnt and value captured from use of COPI notices during COVID-19 to identify other areas to which they can be appropriately applied.

Whatever approach is taken, certainty is crucial for success. One issue with the deployment of COPI notices during the pandemic was their short-term nature, with notices being used for months at a time. The lack of certainty meant some organisations felt unable to commit investment and resources into fully using the data. This was due to concerns they would not be able to capture the value before the notices expired. While the use of confidential data exemptions should never be open-ended, they should span years instead of months to allow organisations the time to ramp up research efforts and encourage sufficient investment.

3.4. CAPTURING VALUE FROM DATA

The steps outlined so far aim to facilitate the creation of value through the utilisation of healthcare data in a sustainable manner that upholds public trust. But just as important will be capturing that value for the UK, both in terms of the NHS and the wider economy. It will be critical to design the system so it ensures value is effectively captured and reinvested. As highlighted in our introduction, the sharing of healthcare data can result in many types of value.

Indirect value:

- Benefits to patients and the public through improved care and services.
- Increase in R&D investment as firms have greater potential for breakthrough innovations in the UK.

- More effective provision of care focused on value.
- Job creation, potentially through investment.
- Economic growth, driven partly by innovation but also healthier populations.
- Access to innovative medicines and other medical products e.g. digital health innovation and medical devices – with the potential for preferential access terms.

Direct value:

- Revenue through income streams from data access.

The indirect value from improving research activity, drug discovery, and understanding of diseases in the UK is significant. Whilst indirect value will likely be larger, given its widespread impacts, a more direct financial value will also be crucial. The NHS will need to capture value directly to ensure the longevity and effectiveness of SDEs and continue the virtuous cycle of data and innovation.

Establishing and running SDEs is labour-intensive and costly. To operate effectively, they will need to be resourced appropriately. For example, substantial investment in computer infrastructure and improvements to data quality would increase the value of the data, both for driving health benefits as well as financial value. As acquisitions indicate (e.g. Roche's acquisition of Flatiron Health for \$1.9 billion), significant financial value can be found in high quality, clean, annotated, and curated data - something that remains a labour-intensive process requiring substantial funding. We therefore think it is important that mechanisms to capture value from healthcare data are actively embedded from the start.

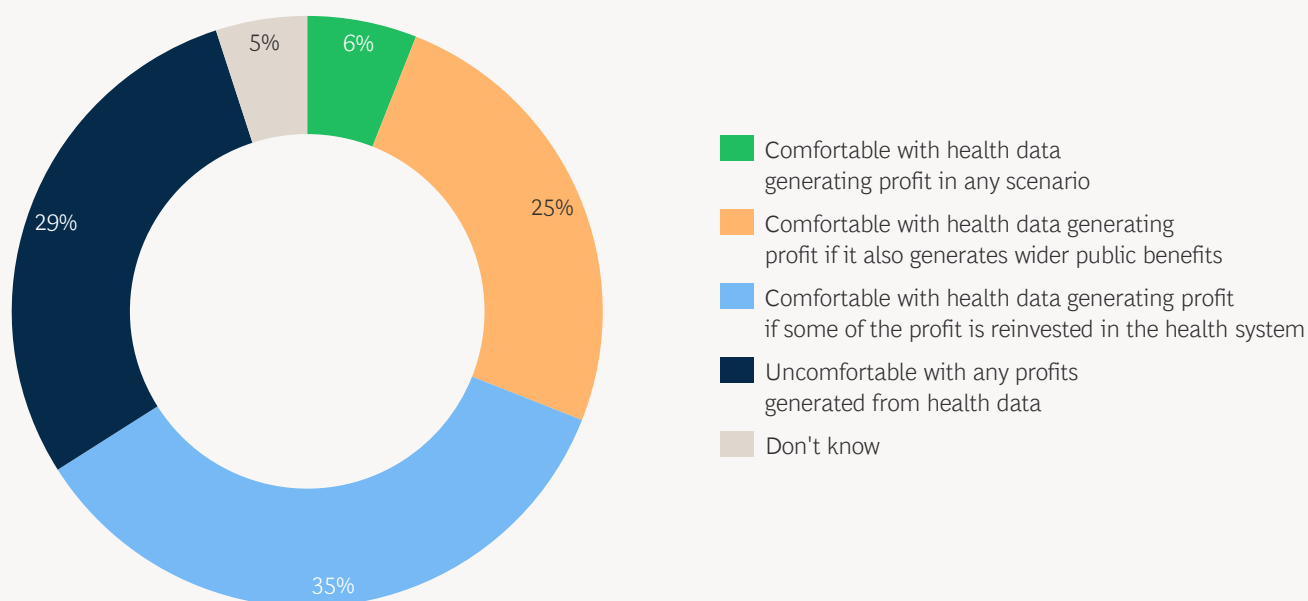
Contrary to previous concerns, our survey reveals 66% of people would be comfortable with profit being made from healthcare data if at least some of it is reinvested into the NHS to drive improved efficiency and outcomes, and/or it delivers wider health benefits. In fact, the public may disapprove if the NHS contribution towards innovations that stem from personal health data is not appropriately recognised.



Fig 16. Views on profit generation

Respondents were significantly more comfortable with profit being generated if some of those profits were reinvested in the health system

Health data can be used to provide insights on drug developments and technical innovations. This can also result in future profits for those companies, as well as wider public benefits through improved healthcare (e.g. more effective treatments for disease). Which of the following is the closest to your view?



Source: BCG Healthcare Data Survey 2023

“Have a frank public conversation about commercial use of NHS data for innovation, but only after privacy issues have been addressed through adoption of TREs; ensure the NHS gets appropriate financial return where marketable innovations are driven by NHS data, which has been collected at great cost over many decades; avoid exclusive commercial arrangements.”

Goldacre report

When considering value-sharing in relation to NHS healthcare data, there are a couple of high-level issues to consider: the mechanisms for value-sharing (including how to extract maximum value for the NHS); and how to ensure the value is effectively put back into the health system.

Value-sharing mechanisms

A simple option would be to charge certain organisations for access to SDEs. This would give the NHS a quick and less complicated income stream. But it would mean they could miss out on capturing fair value later down the line. It also has the potential to deter smaller players from gaining data access, which could have knock-on consequences, such as skewing the life sciences ecosystem and hampering a thriving AI and

life sciences start-up industry. Furthermore, as it stands, the NHS SDEs are to be run on a not-for-profit basis, only covering costs. If access to SDEs is to be free, it is vital the NHS uses a combination of alternative value-sharing mechanisms to adequately capture value.

A value-sharing framework is outlined in the recent [Imperial College London report](#) and details the relative benefits and challenges of each approach. Examples of mechanisms include both financial and non-financial returns such as preferential product access terms (even if for a limited time only), the return of curated data for others to benefit from, and royalty share. The most suitable mechanism(s) and the relevant terms will depend on a range of factors, including the type of resulting innovation, the extent to which the innovation relies on NHS data, and the availability of other similar data. An NHS value-sharing framework is expected to

be published later this year. This will be essential for ensuring all parts of the NHS are able to consistently identify potential value and therefore negotiate appropriate terms for data access and use. What is clear is that there is unlikely to be a single, one-size-fits-all answer.

One crucial but challenging component to unlocking maximum value capture will be the use of intellectual property (IP) rights. Wherever possible, the NHS should seek to leverage IP to secure potential long-term value capture. However, as IP rights are not usually given for raw data, the NHS will need to consider how it can best set up commercial arrangements to protect its interests. For instance, IP rights may be a more viable option when the NHS is looking to co-develop or co-create outputs. This will require clear guidance and relevant expertise in IP management and tech transfer processes.

Case Study: Our Future Health

Our Future Health is a collaboration between the public, charity, and private sectors to establish the largest health research programme in the UK. Its aim is to develop new ways to prevent, detect, and treat disease. Funding sources include UK Research and Innovation, a government-funded body, plus investment from private life sciences companies. The life science companies have each invested £10 million (£12.5 million in the latest round) to be an industry partner for the programme. In return, they can apply to use the Our Future Health resources for research. Once they have analysed the results, most will return a copy of their results to the

programme to benefit other researchers in the future. Industry partners may profit from their discoveries but have agreed to make reasonable efforts to ensure that innovations that have been developed as a result of access to the data are available in the UK to benefit NHS patients. This is a slightly different model to the one we see in the NHS SDEs as it requires an initial investment or payment to access the data. Since the SDEs are being set up without such a requirement, it is even more vital the appropriate mechanisms are put in place to capture value further down the data process.



As capabilities around the SDEs develop both within and outside the NHS, this could present an opportunity to establish a marketplace through which the NHS extracts both direct and indirect value. The NHS could establish a platform for themselves and/or third parties to provide access to software, applications or algorithms that can be used to generate insights from the SDEs. The potential of revenue would encourage those that use the SDE to invest in the creation of these tools and software which can help to drive innovation when it comes to the analysis of healthcare data.

For the NHS, revenue could be generated through charging listing fees for third parties to sell their products or preferential access to new technologies. Indirect value could also be captured through encouraging researchers to share open-access products which have the potential to help the entire ecosystem. For instance, researchers could provide open access 'starter packs' of basic code to clean, manage, or curate data (i.e. not code core to the algorithms or innovations themselves, but only to the preparation of data).

As highlighted in the Goldacre report, sharing of this code can support network effects by avoiding duplication in the data management exercise required to maximise utilisation of NHS data.

Reinvesting the value into the health system

As highlighted above, our survey revealed that 66% of people would be comfortable with profit being made from healthcare data if at least some of it is reinvested into the NHS to drive improved efficiency and outcomes. Only 6% would be comfortable with profits being made in any scenario. The key for people to feel comfortable is if profit generates wider public benefits (25% support) or is reinvested in the health system (35% support). Similar patterns hold across key demographics, with older people

more likely to want to see profits reinvested in the health system.

When asked which situations would make them more or less willing to share their healthcare data, the highest selected options were those evidencing a tangible benefit on the frontline of healthcare (e.g. reduced waiting times, faster detection of chronic disease). By contrast, respondents did not want it to be seen as another funding source for wider government public services. While the notion of a central fund was middling in their preferences – with 28% saying it would make them less willing and 22% more willing – we believe that some form of central fund will be needed to direct the revenue to the top outcomes they want to see.

There are a few key considerations for how a fund should be set up. First, we believe it needs to be an NHS-led fund, as opposed to held centrally in government. It should also sit outside the spending review timelines in order to be flexible to the timelines best suited for the inflow of the funds. The NHS should also consider whether this pot of funds should be managed in the style of a sovereign wealth fund to generate returns that can in turn be reinvested into the health system. Finally, a key consideration should be what level of the organisation the funds are targeted at. For example, is this an innovation fund that can be used for individual initiatives or will it flow into local NHS trusts and/or individual SDEs to be distributed according to their local priorities?

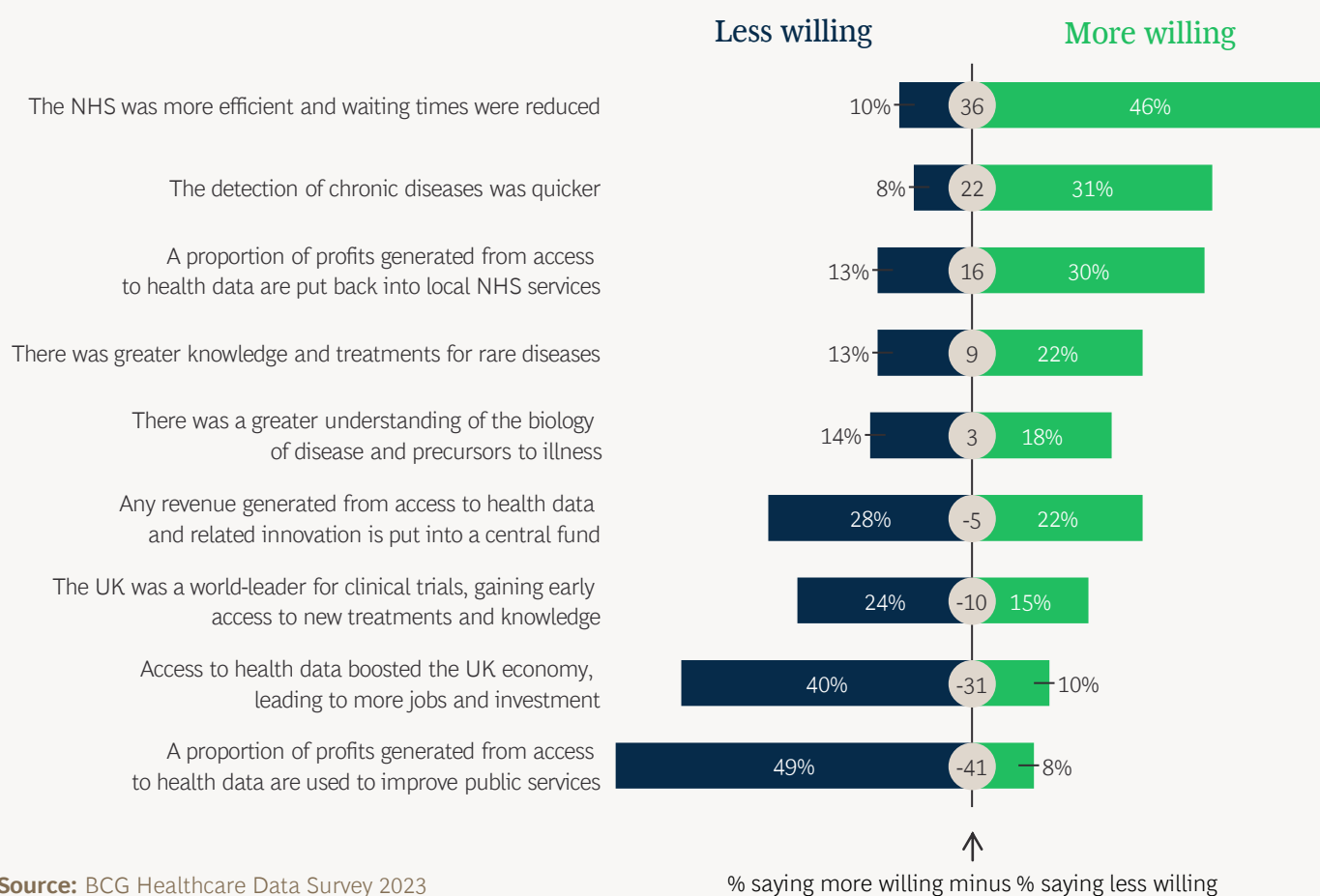
Given how key it is to public support that they see profits benefiting the health system, it will be important to set this fund up in the right way.



Fig 17. Arguments for sharing data

The strongest argument for sharing healthcare data is to make the NHS more efficient and reduce waiting times

Here are some scenarios to understand how profit and value from health data is best shared. Which two of the following would make you **most willing** to share your healthcare data? Which two of the following would make you **least willing** to share your healthcare data?



Source: BCG Healthcare Data Survey 2023

Chapter 04

Key recommendations

USE CASES

1. Detail the outcomes from specific use cases of making healthcare data more accessible to generate public support and understanding.
2. Focus on outcome-based use cases in the following four areas:

I. Prevention

Allow for integration of a wider variety of non-healthcare data into the SDEs including socioeconomic and demographic data from tax records, welfare claims and census records, behavioural information from consumer data, and lifestyle data from wearables and mobile phones.

II. Disease pathways

Fully integrate the widest range of healthcare data into SDEs, including biomarkers and multimodal health data.

III. Clinical trials

Improve the process of setting up and recruiting for clinical trials in the UK, by developing an accessible 'concierge service' to quickly determine whether a particular trial is feasible, as well as tools to explore the sensitivity of inclusion/exclusion criteria for clinical trial participants.

IV. Clinical care

Leverage new technologies including machine learning, generative AI, and AI-driven algorithms to optimise clinical care decision-making and resource management in the NHS.

DATA TRANSPARENCY AND PUBLIC ENGAGEMENT

3. Put in place the right frameworks and mechanisms to deliver the level of transparency and information needed, including a clear effort to be open about what lessons have been learnt and how processes have been adapted. This will ensure that public trust is maintained over time.
4. Establish a joined-up public engagement strategy that is consistently adopted across all NHS data projects, with a specific comms campaign around healthcare data usage and the potential benefits, including:
 - a. Emphasis on the move to data access over sharing.
 - b. Clear outcome-based use cases.
 - c. Explanation of the wide range of benefits that better use of healthcare data can have.
 - d. Clear messaging on how value and benefits will be put back into the local healthcare systems.
 - e. Focus on building trust with certain institutions and partners.
 - f. Establishing who will be accessing and processing data from the SDEs.
 - g. Early communication about the involvement of tech companies in the practical side of building SDEs, if they are to have a role.



5. Use public decision panels and data usage registers to engage the public in decisions around how their data will be accessed and used. This will help ensure they have a say in decision-making processes and can review and refresh these processes over time (e.g. assess what level of engagement is needed from participants with relevant characteristics).

DESIGN AND OPERATION OF SDES

Accessibility

6. Review the Data Access Request Service (DARS) process once the SDEs are fully up and running to ensure it is as streamlined as possible, whilst maintaining the vital security and ethical checks on those seeking to access the data.
7. Ensure the DARS process is sufficiently resourced.
8. Review and revise (where appropriate) the necessary purpose and benefits of data access to also capture wider potential benefits to the UK economy from innovation.

User experience

9. Create a service wrapper that provides all NHS SDEs (national and sub-national) with the same basic governance and administrative processes such as applications for permissions, requirements for approval, and management of the users accessing the data.
10. Maintain an element of competition between SDEs – such as on services and analytical tools, including marketplaces for them – to help foster innovation and drive improvements.
11. Integrate data across the national SDE and sub-national SDEs, as well as the Federated Data Platform which is also being built.

Talent

12. Bring skills into the NHS to ensure the quality of data on the SDEs is of the necessary level and the workforce is equipped to analyse the data and use the analytical tools provided.

Link funding and priorities

13. Ensure sufficient funding is put in place to target outcome-based use cases.
14. Introduce targets to hold Integrated Care Boards (ICBs) directly accountable for creating research opportunities to ensure sufficient resourcing of SDEs.

USE OF COPI NOTICES

15. Consider using COPI notices more frequently beyond COVID-19. This includes utilising them for researching chronic and/or serious diseases, treating and preventing long-term serious diseases, and improving efficiencies in the NHS to reduce the backlog, as supported by the public.

CAPTURING VALUE FROM DATA

16. Establish a range of value-sharing mechanisms to ensure the NHS captures maximum direct (e.g. financial) and indirect (e.g. health benefits) value from providing access to the healthcare data.
17. Provide guidance for negotiating with commercial partners on how best to leverage the full range of value-sharing mechanisms. This will ensure maximum value according to the characteristics of each situation, including long-term value via intellectual property (where appropriate).
18. Ensure value acquired through data is reinvested into local health systems and the SDEs.
 - a. Establish a fund that protects the use of this money for these purposes.



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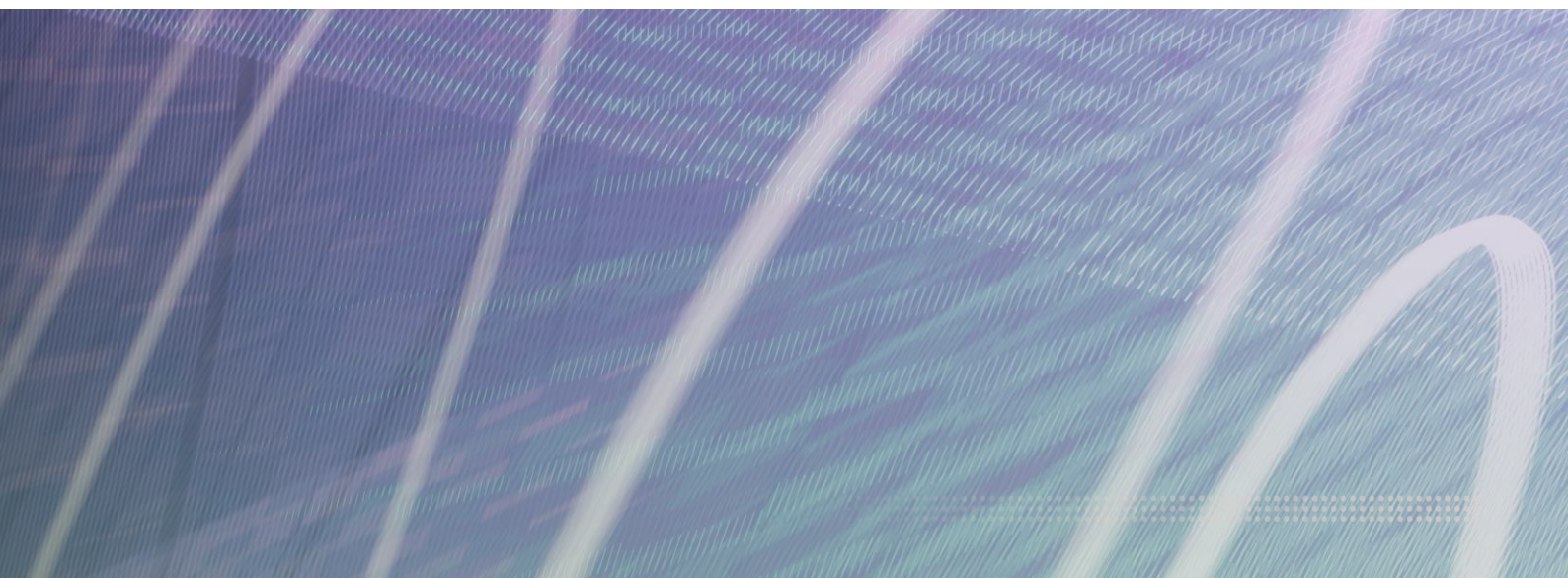


Appendix

Survey methodology

BCG commissioned J.L. Partners to poll a nationally representative sample of adults living in England.

- The data in this report is based on responses from 2,030 UK adults. Data was collected from 18th to 24th May 2023.
- The data was collected in accordance with MRS guidelines by J.L. Partners, a member of the British Polling Council and a Company Partner of the MRS.
- The sample of respondents for this survey was collected using an online panel with members of the panel emailed in batches throughout the collection window, inviting them to take part in the survey. The survey had a 10 minute duration.
- Quotas derived from census and ONS data were added to ensure representative data from the panel on:
 - Gender
 - Age
 - Region
 - Ethnicity
- The sample was weighted back to represent the entire population of England on the same variables: gender, age, region and ethnicity.
- The margin of error on headline figures from the survey is 2.2 percentage points above and below the point estimate given.



References

1. British Medical Association. [NHS backlog data analysis](#), June 2023
2. Office for National Statistics. [Labour market overview](#), June 2023
3. Wellcome & BCG. [Unlocking the potential of AI in drug discovery](#), June 2023
4. The Commonwealth Fund. [Supporting Patients Through Serious Illness and the End of Life: Sutter Health's AIM Model](#), January 2018
5. UCL. [Mobile app speeds up review and treatment of acute kidney injury](#), August 2019
6. NHS England. [Next steps on the NHS Five Year Forward View](#), 2017
7. QS. [QS World University Rankings by Subject 2022: Life Sciences & Medicine](#)
8. Nature Index. [Annual tables for health sciences](#), 2023
9. Office for Life Sciences. [Life science competitiveness indicators](#), 2022
10. Cell and Gene Therapy Catapult. [UK ATMP clinical trials database](#), 2022
11. Department for Business and Trade. [Healthcare and life sciences sector overview](#)
12. Office for Life Sciences. [Bioscience and health technology sector statistics](#), 2021
13. Department for Business and Trade. [Healthcare and life sciences sector overview](#)
14. Office for Life Sciences. [Life science competitiveness indicators](#), 2022
15. Visit Britain. [Healthcare and Life Sciences toolkit](#)
16. Office for Artificial Intelligence. [Artificial Intelligence sector study](#), 2022
17. The AI Index, Stanford University. [Global Vibrancy Ranking](#), 2021
18. Office for Artificial Intelligence. [A pro-innovation approach to AI regulation](#), March 2023
19. UK government. [£21 million to roll out artificial intelligence across the NHS](#), 23 June 2023
20. Dealroom. [UK Guide](#), July 2023
21. Office for Life Sciences. [Life Science competitiveness indicators](#), July 2022
22. BioIndustry Association. [Investment in UK biotech jumps 60% to £4.5bn in 2021](#), January 2022
23. Medicines & Healthcare products Regulatory Agency (MHRA). Performance Metrics: [Assessment of Clinical Trial Authorisation Applications and Substantial Amendments](#), May 2022-April 2023
24. Office for National Statistics. [Sickness absence in the UK labour market](#), 2022
25. Politico. [By the numbers: European drugmakers stuck between a dominant US and a rising China](#), April 2023
26. UK government. [NHS Federated Data Platform and Associated Services tender](#), January 2023
27. UK government. [Budget and Spending Review](#) October 2021
28. UK government. [Thousands of patients to benefit from quicker diagnosis and more accurate tests from ground-breaking AI research](#), 3 March 2023
29. Office for National Statistics. [Healthcare expenditure](#), 2020
30. NHS England. [Making the case for the personalised approach](#), 25 January 2018
31. NHS England. [Long-term conditions infographic](#)
32. Office for National Statistics. [Healthcare expenditure](#), 2021
33. The King's Fund. [How does the NHS compare to the health care systems of other countries?](#) June 2023
34. UK government. [Bold new life sciences vision sets path for UK to build on pandemic response and deliver life-changing innovations to patients](#), 6 July 2021

35. Office for Life Sciences. [Commercial clinical trials in the UK: the Lord O'Shaughnessy review](#), 26 May 2023
36. House of Lords library. [Research and development spending: Pharmaceuticals](#), September 2022
37. Office for Life Sciences. [Bioscience and health technology sector statistics](#), 2020
38. Department of Health and Social Care. [Saving and Improving Lives: The Future of UK Clinical Research Delivery](#), March 2021
39. The Association of British Pharmaceutical Industry. [NHS patients losing access to innovative treatments as UK industry clinical trials face collapse](#), October 2022
40. The Association of British Pharmaceutical Industry. [NHS patients losing access to innovative treatments as UK industry clinical trials face collapse](#), October 2022
41. Office for Life Sciences. [Life science competitiveness indicators](#), 2022
42. National Institute for Health and Care Research. [Data on performance in initiating and delivering clinical research.](#)
43. Medicines & Healthcare products Regulatory Agency (MHRA). Performance Metrics: [Assessment of Clinical Trial Authorisation Applications and Substantial Amendments](#), June 2022-May 2023
44. Medicines & Healthcare products Regulatory Agency (MHRA). Performance Metrics: [Assessment of Clinical Trial Authorisation Applications and Substantial Amendments](#), May 2022-April 2023
45. Wellcome & BCG. [Unlocking the potential of AI in drug discovery](#), June 2023
46. BMJ Open. Walters et al., 2017, doi.org/10.1136/bmjopen-2016-015276
47. British Medical Association. [NHS backlog data analysis](#), June 2023
48. The Health Foundation. [Returning NHS waiting times to 18 weeks for routine treatment](#), May 2020
49. British Medical Association. [NHS backlog data analysis](#), June 2023
50. The King's Fund. [How does the NHS compare to the health care systems of other countries?](#) June 2023
51. Institute for Public Policy Research. [Waiting for prosperity: Modelling the economic benefits of reducing elective waiting lists in the NHS](#), April 2023
52. NHS England. [Better insights, better decisions, better health](#), January 2023



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