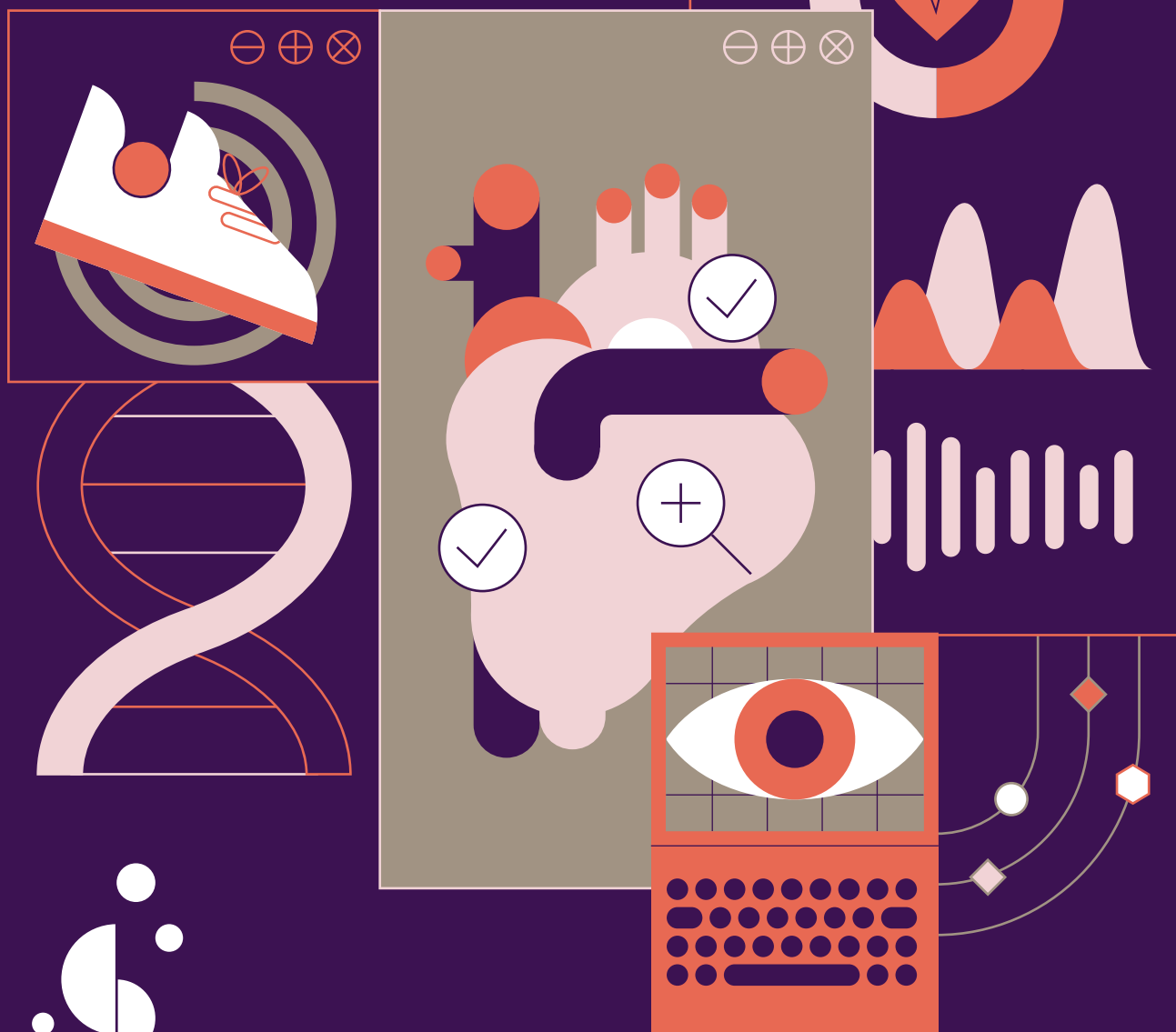


Dialogues about Data:

Building trust and unlocking
the value of citizens' health
and care data

Sinead Mac Manus



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Any errors or omissions remain, of course, my own.

About Nesta

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Contents

Foreword	2
About the Data Dialogues programme	3
1.0 Introduction	5
1.1 Purpose of the report	5
1.2 What do we mean by health and care data?	6
1.3 Why data is one of the most important resources in modern health and care	7
1.4 Trends and factors influencing trust and value	9
2.0 Data challenges and opportunities	11
2.1 Introduction	11
2.2 Trust and transparency in data sharing	12
2.3 Unlocking the value in health and care data	24
3.0 A culture of participation	31
3.1 Introduction	31
3.2 A role for participatory futures?	32
3.3 What Nesta is doing in this space	33
3.4 Conclusion	35
Appendix A: Select literature review	36



Foreword

The last decade has seen an exponential growth in the amount of data generated, collected and analysed to provide insights across all aspects of industry. Healthcare is no exception. We are increasingly seeing the value of using health and care data to prevent ill health, improve health outcomes for people and provide new insights into disease and treatments.

We are at a critical juncture in the development of this data-driven system, with a number of technological, social and economic factors at play. Across the UK health and care records are being digitised at pace and new digital technologies from apps to biometrics are enabling more and more data to be collected about us every day. Despite this, pre-COVID-19, the public's trust in the use of their data was low in the wake of high-profile scandals such as Cambridge Analytica.

At the same time there is increasing demand from an ageing population which is putting strain on health systems.

Bringing together common themes across the existing research, this report sets out two interlinked challenges to building a data-driven health and care system. This is interspersed with best practice examples of the potential of data to improve health and care, as well as cautionary tales of what can happen when this is done badly.

The first challenge we explore is **how to increase citizens' trust and transparency in data sharing**. As health and care professionals and citizens use more data-driven technologies, it's becoming ever more important that people understand and trust when and how their data is shared and how their privacy is protected. The public also needs to trust the systems and procedures that third parties, from universities to commercial companies, have in place to access this data. The public needs to feel confident that their personal data will be kept safe.

The second challenge is **how to unlock the value of health and care data**. It is clear there is huge value to be gained from health and care data for individuals, for the health and care system, and for wider society. However, there needs to be stringent safeguards in place to make sure that the benefits are felt by citizens, populations, and health and care systems, and not just private corporations. The benefits to citizens of sharing their data, and associated trade-offs, need to be clear if we are going to encourage people to participate in data sharing, not only to help their own health, but to benefit the health of people like them and the health and care system.

The COVID-19 pandemic is bringing the opportunities and challenges of sharing health and care data to the front of public debate. Increasing transparency and understanding of how data is collected, shared and used, will be key to building on the momentum we have seen during the pandemic, when citizens have been more open than ever to sharing their data if there is a clear and urgent public benefit.

We are excited about the role for participatory futures – a set of techniques that systematically engage people to imagine and create more sustainable, inclusive futures – in helping governments and other organisations work with citizens to engage them in debate about their health and care data to build a data-driven health and care system for the benefit of all.

Sinead Mac Manus,
Senior Programme Manager, Nesta



About the Data Dialogues programme

In 2019, Nesta and the Scottish Government embarked on a year-long dialogue with Scottish citizens to understand their opinions and ideas for the use and sharing of health and care data and to explore possible futures that improve outcomes for everyone. This builds on Nesta's previous work on new methods of public engagement, which seeks to better engage citizens to collectively imagine and create more sustainable, inclusive futures.¹

Scotland's Digital Health and Care Strategy,² published in April 2018, sets out a vision where the citizens of Scotland have access to their health and social care data and information to help maintain and improve their health and wellbeing, and where frontline staff and carers can access the information they need to deliver high quality care and support. In this Strategy, the Scottish Government has committed to:

- ⊕ **Involve citizens in developing a consistent national approach to the use of health and care data.**
- ⊕ **Provide clear and appropriate choices about how the information collected will be used and shared.**
- ⊕ **Build and maintain trust with greater transparency over how and why such information is used for wider public or societal benefit.**

The technical delivery of this ambition is being taken forward through the development of a national digital health and care platform. This will allow citizens to access and update information about their health and wellbeing, including their medical records and personal monitoring data, and to interact with services in a different way. Potential users of the platform will be involved in the development of the platform through the Scottish Approach to Service Design.³

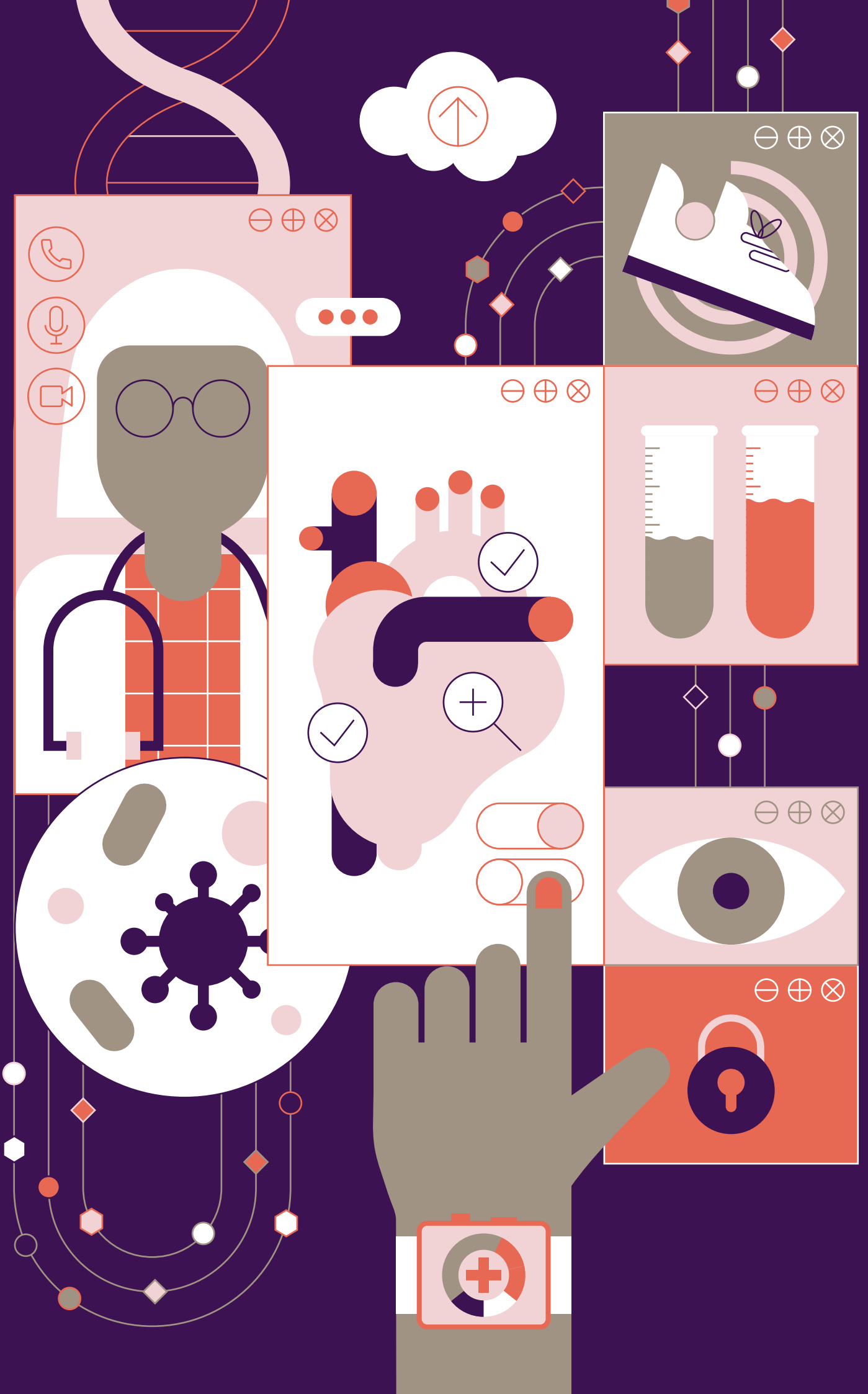
The Data Dialogues programme⁴ is part of the Scottish Government's Open Government Commitment 3: Improvements to the way information/data is used.

The programme will support the Scottish Government's ambitions by engaging Scottish citizens in a broad dialogue around data use and sharing. There are three key components of the programme:

- 01. Better understand the views, opinions and ideas of Scottish citizens around the use and sharing of health and social care data – now and in the future.**
- 02. Explore and co-design possible futures for the use of health and social care data that could benefit everyone.**
- 03. Test and evaluate innovative methods of engaging and involving the public in conversations about their data.**

The programme started in October 2019 and will end in summer 2021.

If you would like more information about the Data Dialogues programme please visit nesta.org.uk/project/data-dialogues/





1.0

Introduction

1.1 Purpose of the report

Health and care systems across the world are moving at pace towards digitised and linked health and care records. Citizens are increasingly expecting that information about their care is shared between appropriate professionals, and that they can share information easily themselves and on their terms. Outside the system, the amount of 'health' data collected about us is growing exponentially across all domains of our lives, from our smartphones, wearables and online searches and platforms.

We are increasingly seeing the value of using data to prevent ill health, improve outcomes for people and provide new insights into disease. However, big challenges and questions remain.

Pre-COVID-19, public trust in the use of personal data was at an all-time low in the wake of scandals such as Cambridge Analytica. As more complex and personal data is held about us digitally, including genomic and biometric data, it's becoming ever more important to build public trust around how data is used, both at an individual and population health level, now and in the future.

Increasing transparency and understanding of how data is collected, shared and used will be key to building trust. As we move into a post-pandemic world, we also need to have a more nuanced debate with citizens about the value of sharing data if we are to unlock its benefits, not only for an individual's care, but for others with similar health interests or conditions, as well as the wider clinical and research community.

The COVID-19 pandemic brought the opportunities and challenges of sharing health data to the front of public debate. Data sharing allowed millions of vulnerable people in the UK to be put on shielding lists and targeted for support within weeks of the first lockdown. Contact-tracing apps raised concerns about data sharing and citizen surveillance but can play a key role in

slowing down the transmission of the virus. New public-private-academic-charity partnerships have been set up at speed to aid research into this fast-moving disease but they bring challenges around data sharing and the nature of these partnerships when the pandemic is over.

Citizens have been remarkably open to sharing their data during the pandemic in a way few would have predicted at the start of 2020. As frontline NHS services moved from face-to-face to remote delivery overnight, citizens (and staff) embraced WhatsApp, Zoom and a host of digital technologies, sometimes relaxing strict data sharing rules to deliver care. The success of citizen data crowdsourcing studies such as the COVID Symptom Study⁵ developed by researchers at King's College London, show the willingness of the public to share data where there is a clear public benefit, with, to date, more than 4.3 million members of the public contributing their data to the project.

This report aims to:

- ⊕ **Bring together the existing research on how citizens feel about the use and sharing of health and care data.**
- ⊕ **Unpack the key challenges that need to be addressed in order to reap the benefits of data-driven health and care.**
- ⊕ **Start to explore innovative ways of overcoming these challenges including new ways of engaging the public.**

1.2 What do we mean by health and care data?

In this report, we are using the term 'health and care data' to refer to the wide variety of information generated by, and collected about, us that impacts on our health and wellbeing. This includes the information in our health record and collected by all parts of the health and care system.

However, data about our health and wellbeing sits in many domains of our lives, not just in the health and care system. Online search data can point to someone being in mental distress long before they ask for help.⁶ Smartphone apps track everything from diabetes to our bowel movements, and many of us record our physical activity with FitBits or Apple Watches. A company like Amazon probably knows more about your health and lifestyle than you would imagine from data about the books and food you buy and the TV shows you watch.⁷

For this reason, our definition includes, but is not limited to, online search data, social media data, environmental data, housing data, employment data, self-generated data from apps and wearables, and so on. For clarity, the box below outlines some definitions of common terms used in this report.

4.3m+

members of the public contributed their data to the COVID Symptom Study developed by researchers at King's College London.

Definitions:



Patient data

Data that relates to a patient. It falls into three broad categories: demographic, administrative, and medical.

Confidential patient data

Data that both identifies the patient, and that the patient does not want to share. This includes some information about their medical condition or treatment.

Personal data or personally identifiable data

Data relating to a person who can be identified a) from those data, or b) from those data and other information which is in the possession of, or is likely to come into the possession of, the organisation in receipt of the data.

Anonymisation

The processing of personal data in such a manner that personal data cannot be attributed to a specific person.

Pseudonymisation

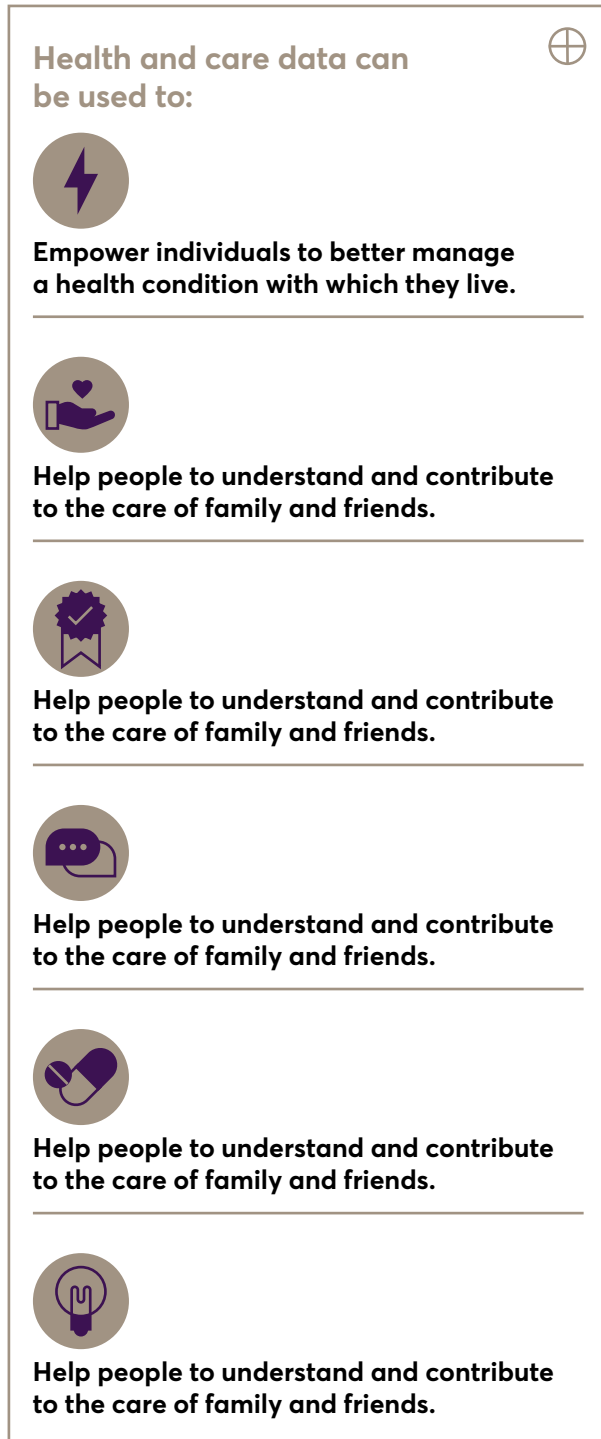
The processing of personal data so that the personal data can no longer be attributed to a specific person without the use of additional information. A pseudonym is a unique identifier which does not reveal the patient's 'real world' identity.

1.3 Why data is one of the most important resources in modern health and care

The last decade has seen an exponential growth in the amount of data generated, collected and analysed to provide insights across all aspects of industry. Healthcare is no exception.

The collection, sharing and analysing of data can:

- ⊕ **Improve clinical care by helping identify disease earlier⁸ and improving clinical pathways, from cancer⁹ to asthma and diabetes.¹⁰**
- ⊕ **Help people to maintain better health and self manage their conditions more effectively.**
- ⊕ **Support better conversation and shared decision-making between citizens and their care team.**
- ⊕ **It also has many uses outside of individual care, as illustrated by the diagram below.**



Source: Future Care Capital¹¹

Data from different sources collected for different purposes can reveal new insights when linked or pooled and is a valuable tool for the study and improvement of health. Data can reveal new scientific, clinical or behavioural insights that can generate new treatments, pathways and better outcomes, as illustrated by the example below.

Pooled data can be used to plan and evaluate health and care services as well as ensure that services that are being delivered are safe, effective and equitable. Data can reveal variations in practices, processes and outcomes, and identify areas for improvement, as illustrated by the example below.

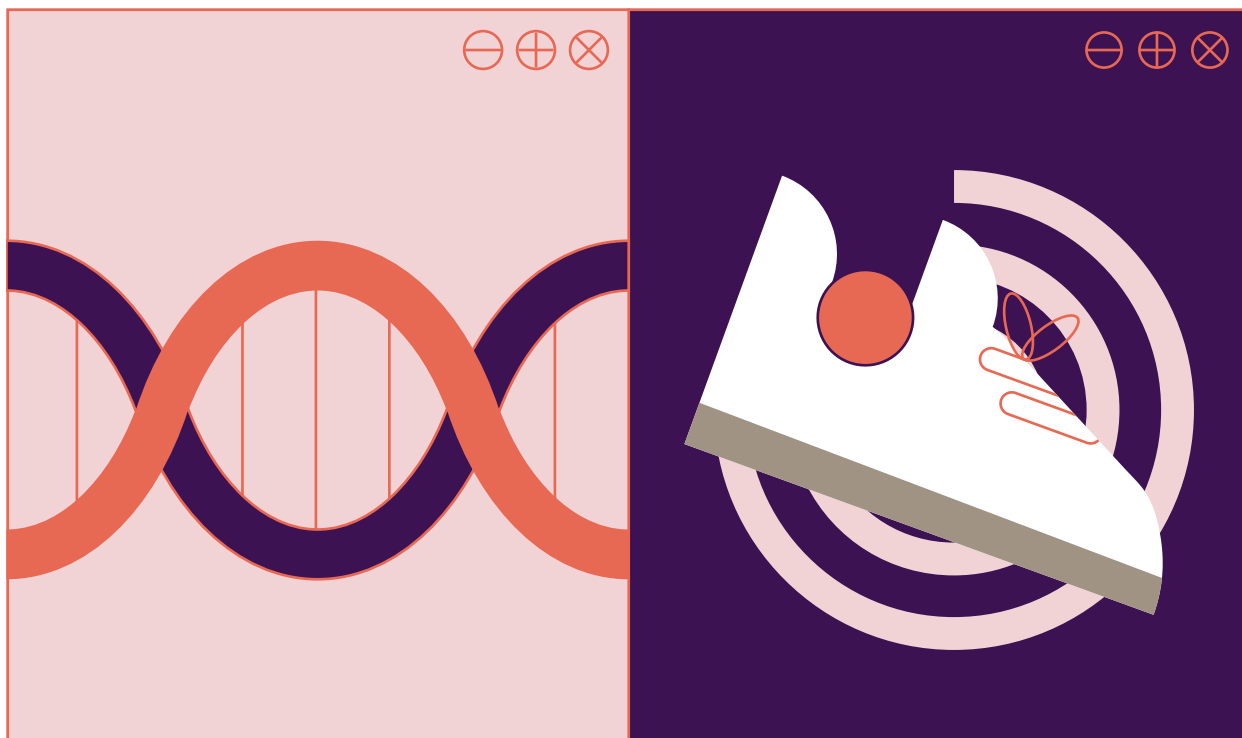
Improving diagnosis in cancer with data

Diagnosing cancer earlier can increase survival rates and quality of life. However, many cancers are diagnosed too late as their symptoms are similar to more common conditions. For example, blood in urine is likely to indicate a bladder infection, but it may also be an early sign of bladder cancer.

The Clinical Practice Research Datalink (CPRD)¹² has been collecting de-identified patient data from a network of GP practices across the UK for the past 30 years. The data is linked to a range of other health-related data to provide a longitudinal, representative UK population health dataset encompassing more than 35 million patient lives. The CPRD helps researchers calculate how many patients with a particular symptom go on to be diagnosed with cancer, allowing them to attach a level of risk to all the symptoms commonly seen in patients visiting their GP. The National Institute for Health and Care Excellence (NICE) uses this research to produce guidelines that help GPs know when further investigation is needed.

The Scottish Atlas of Variation

The Information Services Division (ISD) of NHS Scotland holds and analyses all the health (and increasingly social care) data in Scotland. Their Scottish Atlas of Variation¹³ uses data to highlight geographical variation in the provision of health services and health and wellbeing outcomes across Scotland. While it is recognised that there will always be some variation because health systems are complex and populations have differing needs, some variation cannot be explained by the characteristics of the people being treated or their geographical setting, which is called unwarranted variation. The Atlas is an important tool contributing to eliminating unwarranted variation and ensuring a more equitable Scottish health service for all.



1.4 Trends and factors influencing trust and value

Firstly, pre-COVID-19, the past couple of years have seen an erosion of the public's trust in the use of their data in the wake of high-profile scandals such as Cambridge Analytica's misuse of 87 million Facebook profiles to influence the 2016 US presidential election.¹⁴ More recently, NHSX, the government body tasked with driving forward the digital transformation of health and social care, was forced to do a U-turn on the development of their coronavirus contact tracking app, away from a centralised model storing lots of very sensitive information, after privacy campaigners and technology experts raised concerns.¹⁵

Secondly, the health and care system holds data about us across a variety of systems spanning GP records, pharmacies, hospitals and local authorities. Across the UK plans are moving at pace to digitise and link health and care records through national programmes such as NHS England's Local Health and Care Record Exemplars (part of the NHS Long Term Plan¹⁶) and the Scottish Government's ambitious plan to develop a National Digital Platform through which real-time data and information from health and care records will be linked and available to all.¹⁷

Thirdly, the NHS UK-wide is facing unprecedented increasing demand due to an ageing population living longer with multiple long-term conditions while dealing with a budget that has been cut in real terms. Cuts to local authority budgets by central government mean both public health and social care budgets have also been significantly reduced since 2010 – while demand is increasing. Understandably, the health and care system is looking towards data-driven technologies to find efficiencies, through preventing ill health, intervening earlier and personalising care.

Fourthly, new digital technologies are enabling more and more data to be collected about us every day. Near ubiquitous smartphone use has meant there are now health apps for everything from diabetes to diet. Internet of Things (IoT) devices such as wearables and sensors are becoming cheaper and more powerful. Over the counter genetic testing kits are becoming mainstream. Biometric technology is progressing rapidly, from using your fingerprint to unlock your phone to sophisticated gait and voice analysis. With this explosion of data, tools such as artificial intelligence (AI), machine learning and Natural Language Processing (NLP) are becoming much more powerful. We are on the verge of unlocking the potential of datasets that have previously been untapped.





2.0

Data challenges and opportunities

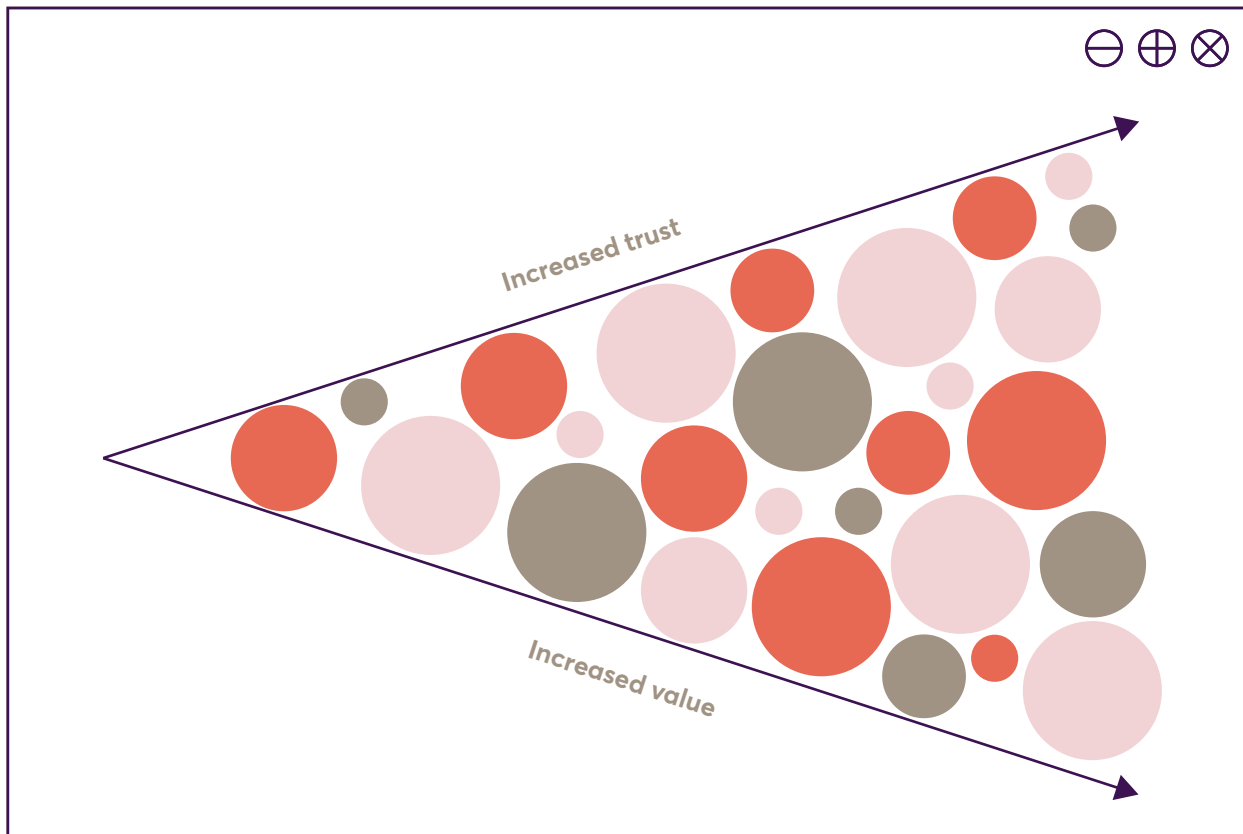
2.1 Introduction

There have been many studies asking the public about their opinions on the uses and sharing of health data.¹⁸ Appendix A outlines the major studies since 2017. These have taken many forms, from online and offline polls and surveys to more deliberative methods such as citizen assemblies and workshops.

In this section, we attempt to bring together common themes across the existing research and set out two interlinked challenges to building a data-driven health and care system.

The first challenge relates to the need to increase the real and perceived trustworthiness of the health and care data ecosystem, and have clear lines of accountability when something goes wrong. This is underpinned by the need for greater transparency and understanding of what health and care data is used for, or could be used for, not just in the health and care system but more widely across the data ecosystem.

The second challenge is around unlocking the value of data. Health and care data sits in many disparate silos meaning that opportunities to use data to improve outcomes or achieve cost savings are not being realised. Further, many citizens are reluctant to participate in data sharing because they do not see the potential benefit for themselves, for people like them or the public good.





2.2 Trust and transparency in data sharing

2.2.1 Introduction

Health and care services have always depended on trust. People must feel able to discuss sensitive matters with a doctor, nurse or care worker without fear that their information may be improperly disclosed. At the same time, people are also increasingly expecting that their information will be shared with other professionals in the care teams supporting them.

As health and care professionals and citizens use more data-driven technologies, it's becoming ever more important that people understand and trust when and how their data is shared and how their privacy is protected. The public also needs to trust third parties' systems and procedures for accessing this data and have confidence that their personal data will be kept safe. The ramifications of what can happen if this is not done well is illustrated by the example below.

Care.data



Care.data¹⁹ was an £8m national programme commissioned by NHS England in 2013 to join up patient data from GPs and hospitals at a national level. The aim was to collect anonymised patient data from GP surgeries in a central database to be used by NHS and non-NHS organisations. The programme came under criticism over the lack of clarity around options for opting out of the scheme, with confusion and concern over safeguards to protect privacy. It was abandoned in 2016.

The programme highlights the issues the NHS faces with data sharing, such as the importance of adequately explaining the benefits of data sharing, as well as winning the public's trust and doctors' support. Furthermore, the failure was compounded by frequent data breaches and the possibility of personal data being sold to commercial companies. The Caldicott enquiry that followed highlighted the importance of rigorous data governance policies in establishing trust, especially when dealing with highly sensitive data.

2.2.2 Data sharing within the health and care system

Until the COVID-19 pandemic, public trust in the NHS was falling. The most recent relevant British Social Attitudes survey showed that only 53 per cent of the public feel very or quite satisfied with the NHS against an all-time high of 70 per cent in 2010.²⁰ A consumer survey from the Open Data Institute (ODI) and YouGov published at the end of 2019 on the ethics of personal data found that only 59 per cent of respondents trusted the NHS and healthcare providers to use personal data ethically. This was still significantly higher than central government (30 per cent); local government (31 per cent); family and friends (34 per cent); and social media organisations (5 per cent).^{21,22}

How does the health and care system protect data?

There are good controls in the UK for ensuring the safety of confidential patient data.

Each organisation holding health or care data – for example, a hospital, a GP surgery or a local authority – has responsibility for the data it collects and stores and has a legal obligation to keep confidential information stored securely.

Only a health professional directly involved in the care of the patient has permission to access the relevant health data. Further, the confidentiality of personal information such as medical records is protected by data protection laws such as the General Data Protection Regulation (EU) 2016/679 (GDPR) and the Data Protection Act 2018, as well as the Freedom of Information Act 2000.

All NHS organisations²³ and local authorities in England which provide social services are required to have a Caldicott Guardian and in Scotland this is also advised. This is a senior person responsible for protecting the confidentiality of people's health and care information and making sure it is used properly and in accordance with a set of national guidelines known as the Caldicott Principles.²⁴

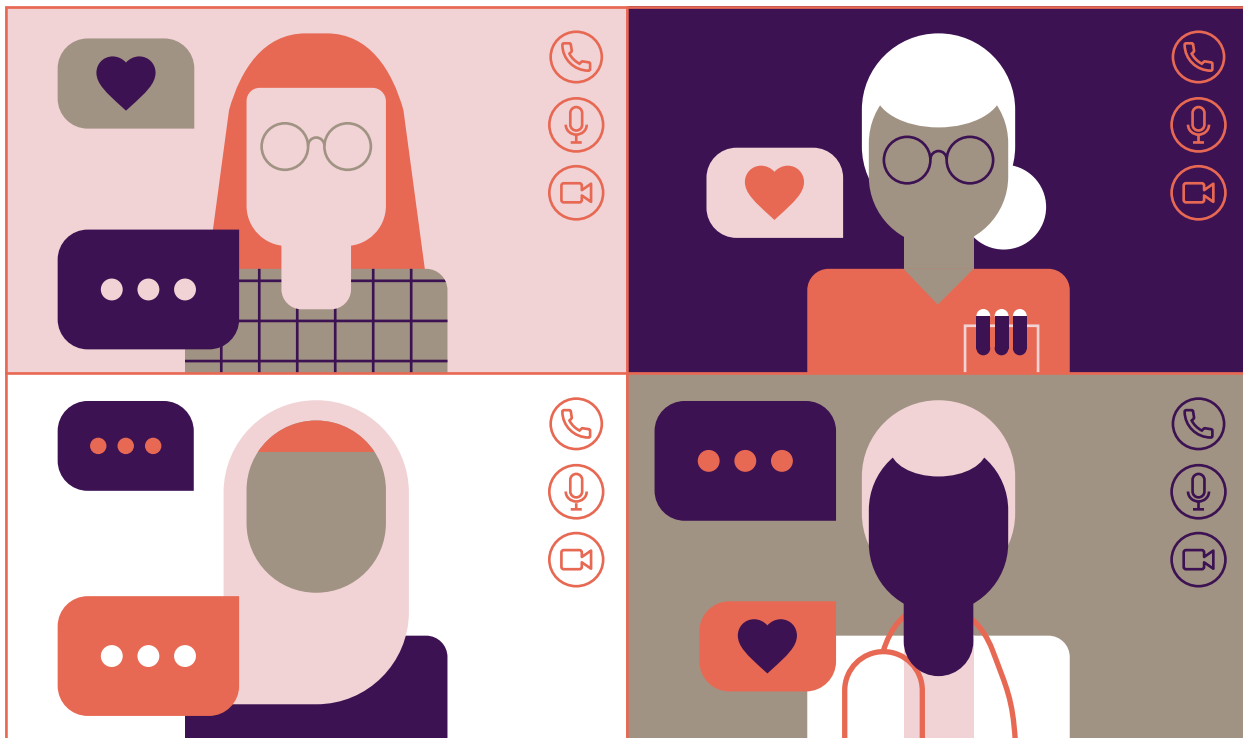
Do citizens have concerns about sharing data within the health and care system?

With moves toward more integrated health and care and the sharing of records across primary, secondary and social care settings, it is likely that select data will need to be shared outside the direct care team. In terms of acceptability to the public, although the vast majority of people expect their care records to be available to the staff involved in their direct individual care, including ambulance staff, they are more hesitant about access by certain professionals (see box below).

Who do citizens trust with their data?



Citizens who took part in research as part of the planning for the Yorkshire and Humber Care Record in 2018, were asked which professionals should be able to access their health and care record to provide care. The most trusted professionals were GPs (98 per cent) and hospital doctors and nurses (93 per cent). They were followed by practice nurses (76 per cent) and clinical staff (61 per cent). Pharmacists (37 per cent), care staff (36 per cent), social workers and researchers (both at 24 per cent) were rated quite low. Not surprisingly, housing officers (7 per cent), employers (4 per cent), and insurers (4 per cent) were the most problematic in terms of data sharing. Citizens have concerns about staff accessing or sharing sensitive personal data, such as that about sexual health, mental health or substance misuse.²⁵ There is also a risk that sharing data with other public bodies could result in people being penalised, as illustrated in the example below.



NHS Digital and the Home Office



In 2017, it came to light that the confidential patient records of more than 8,000 people had been handed over by NHS Digital to the Home Office in the preceding year as part of its drive to track down immigration offenders.²⁶ At the time NHS Digital was required by law to hand over non-clinical patient details including last known addresses, dates of births and GPs' details.

The plan provoked protests from health and civil liberties organisations, which said it was an invasion of patient confidentiality, discriminated against non-British patients and could deter people from seeking medical help for themselves or their children. After a legal challenge brought by the Migrants' Rights Network, a memorandum of understanding between the Department of Health, NHS Digital and the Home Office was scrapped and, in May 2018, the government agreed to suspend most of the data-sharing arrangement and limit its use to tracing those being considered for deportation because they had committed a serious crime.²⁷

2.2.3 Data sharing for research

As well as improving care directly, patient data also has many 'secondary uses' including improving diagnosis and treatment, planning services and evaluating the effectiveness of policy.

NHS organisations don't always have the expertise needed to do the work of linking and analysing large amounts of data on their own so they tend to work in collaboration with researchers in universities or private companies. Research from Understanding Patient Data²⁸ shows that many people struggle in the abstract to distinguish between direct and secondary uses of data. They have also found that concerns about secondary uses of data increase when the body accessing the data is outside the NHS e.g. other public bodies, local authorities, academic bodies and, particularly, private companies.

A poll of 2,220 people in England led by the National Data Guardian, Dame Fiona Caldicott, and published in July 2019 asked the public their views on the NHS working in partnership with private companies and universities to use patient data to develop new medicines and technologies to improve health. Only 58 per cent of respondents said they were aware that the NHS collaborated in this way,

How is data shared for research?

Patient identifiable data cannot be passed to any third parties, unless explicitly approved through a consent process at the point of data collection e.g. for a medical trial. Where the data is shared with a third party, legal contracts are required which set out strict rules about what the organisation can or cannot do with the data.

Organisations such as local and national public health services, charities, academic researchers and private companies may be given access to anonymised or pseudonymised data (where personal identifiable data is removed) and generally require approval before they can use the data, with a few exceptions.²⁹

Do citizens have concerns about sharing data for research?

As well as the lack of understanding in the public of secondary uses of data, the research shows that citizens have other concerns.

Anonymisation or pseudonymisation of personal data can help protect the privacy of individuals. However, de-identification of personal data may not be sufficient for protecting data subjects from privacy invasions. An individual may be re-identified if the de-identified dataset is linked with other datasets that contain identifiable data. For example, studies have shown re-identification to be possible when individuals' health records have been linked³⁰ with other databases, such as the electoral register.³¹

In May 2018, patient watchdog Healthwatch polled over 2,000 people to find out more about their views and concerns about sharing their data.³² The findings showed support from the public for data sharing as long as proper controls are in place. In the poll 73 per cent of adults said they were happy for their confidential patient information to be shared if it helped the treatment of others. However, two-thirds of people surveyed said they may later regret sharing their information if it was shared with private companies or universities at a later date.³³

A survey of 1,031 people the same year as part of the public engagement for the Yorkshire and Humber Care Record³⁴ found that 95 percent of people supported their data being used beyond their direct care. Interestingly, there was also support for using health and care records to intervene before people developed a health condition, for example contacting people at risk in order to offer screening or healthcare advice. Notwithstanding this, participants still had similar concerns about the security of their data and their data being sold to third parties.

Many NHS organisations are entering into partnerships with private technology companies to help make the most of the rich data they collect. This data has the potential to detect disease or deterioration early, speed up treatment and save money. However, these relationships can often be quite complex and there can be a lack of transparency about whether people have consented to their data being shared, who will have access to it or how it will be used, as illustrated by the example below.

73%



of adults said they were happy for their confidential patient information to be shared if it helped the treatment of others, according to a Healthwatch poll.

Google's DeepMind and Royal Free Hospital



In November 2016 the Royal Free NHS Foundation Trust entered into a five-year partnership with the technology company DeepMind (owned by Google) to transform care at the hospital through the use of a mobile app called Streams. The technology notifies nurses and doctors immediately when test results show a patient is at risk of becoming seriously ill and provides the information they need to take action. The Trust provided the personal data of around 1.6 million patients as part of a trial to test an alert, diagnosis and detection system for acute kidney injury – a life threatening condition.

In 2017, the Information Commissioner's Office (ICO) ruled that the Trust failed to comply with the Data Protection Act when it provided patient details to Google DeepMind. The investigation found several shortcomings in how the data was handled, including that patients were not adequately informed that their data would be used as part of the trial.³⁵

The lack of trust in our data being accessed by private companies is, perhaps, understandable, but it runs the risk of stifling much needed research and innovation. The NHS does not have the resources or skills to be at the cutting edge of developing data-driven digital health technologies. Increasingly it will need to partner with the private sector in order to innovate and provide better targeted interventions, treatments and care.

The challenge for health and care organisations is to be transparent about the uses of people's data beyond their care and work to increase understanding with their patient populations of these vital secondary uses of data.

A note on data opt-outs

By 2020 all health and care organisations in England are required to apply national data opt-outs where confidential patient information is used for research and planning purposes. The national data opt-out replaces the previous Type 2 objections and will simplify the process of registering an objection to data sharing for uses beyond an individual's care. The equivalent in Scotland is the Scottish Primary Care Information Resource (SPIRE) Opt-out.³⁶ These opt-outs will give patients direct control over setting their own preferences for the secondary use of their data.

However, lack of transparency, understanding or fear may bring a risk that some patient groups will opt out of the system with knock-on effects for the viability of the data and its insights, as illustrated by the example below.

Australia's My Health Record opt-out



The My Health Record³⁷ is a nationwide electronic health record for every citizen of Australia. It allows citizens to access their health information from any computer or device and they can choose to share their health information with the healthcare providers involved in their care. About six million Australians, or a quarter of the population, are already registered for My Health Record following an opt-in period launched in 2012 and currently every citizen has a record unless they opt out.

However, the introduction of the system has been tainted by privacy and security concerns. The government extended the opt-out period and redrafted legislation to remove the ability for the body running the scheme to hand over sensitive information to authorities such as the police as well as removing the ability to hold a cancelled record for 30 years after that person's death.³⁸ Notwithstanding this, over half of the 23 million records created lie empty and 2.5 million people have opted out of the record.³⁹

2.2.4 Data sharing with and by health and care apps

Although it is hard to get accurate figures, it is estimated that there are currently more than 400,000 apps categorised as 'health' or 'wellbeing' apps. These apps allow people to generate, store and analyse their own health and wellbeing data and help users to gain insights and support in everything from fitness, nutrition and sleep, as well as disease and medication management.

There is real potential for citizens and the health and care sector to benefit from these technologies in terms of prevention, early intervention and self-management of conditions. However, as increasing amounts of data is held about us by these private companies, greater transparency is needed over the uses of that data, including clear lines of accountability if things go wrong.

What are the data sharing challenges of health apps?

Firstly, some of the data collected by these apps is personally identifiable and, potentially, sensitive health data, for example, an app that tracks someone's mental health over a period of time. This issue is compounded by the security of data and poor information privacy practices in many health apps. Despite the GDPR requirement for organisations to implement data protection by design principles,⁴⁰ health apps (and websites) continue to present people with dated models of license agreements, terms of service and privacy policies that are lengthy and prone to jargon. They also offer limited options or control with the use of data and can be opaque about which third parties they share the data with, as illustrated in the example below.

Problematic data sharing practices of medicine-related apps

Researchers⁴¹ used an 'app store crawling program' to identify the top 100 medicine-related apps available to Android mobile users in the UK, USA, Australia and Canada. The team tracked how new data was being transmitted from the app and used internet protocol lookup tools to identify the data recipients and analysed their company information, privacy terms, data sharing agreements, and business models. Nineteen of the 24 apps shared their users' data (which were received by 55 unique third parties including social media networks) without this being transparent to their users.

Another study by the University of Connecticut, examining the problem of people not reading the terms of service of websites, found that only a quarter of their 543 participants had looked at the fine print (agreeing to give away their future first-born children as part of the terms of service).⁴² This isn't that surprising given that, for example, Paypal's terms of service is 50,000 words long – greater in volume by 20,000 words than Hamlet, Shakespeare's longest play.⁴³

Even an independent six-month assessment of 79 apps⁴⁴ certified as clinically safe and trustworthy by the NHS Apps Library found systematic gaps in compliance with data protection principles leading to the question whether certification programs relying substantially on app developer disclosures can provide a trusted resource for patients and clinicians.

Secondly, there is also a lack of trust and transparency in the health claims of some of the apps, as illustrated by the example below.

Using 'science' to sell mental health apps



A 2019 study in Nature Digital Medicine⁴⁵ sought to examine whether mental health apps had any credible scientific evidence to support their claims. The researchers identified 1,435 mental health apps from the Apple iTunes and Google Play app stores, and closely examined 73 of the most highly ranked apps to evaluate their claims. Nearly 65 per cent of the apps claim to effectively diagnose conditions (such as depression, anxiety and substance abuse), improve symptoms or mood, or foster self-management. The study found that 'scientific language' was used by 44 per cent of the apps to support their claims, although these claims included techniques not validated by literature searches. In fact, only one of the 73 apps included a citation to published scientific literature.

Further, there are no official guidelines to help healthcare professionals and patients in app selection, leaving the question of how both groups can trust and evaluate the effectiveness and suitability of one app over the other. With wellbeing apps, this might not be hugely problematic. However, when we get into clinical areas such as diabetes, where tracking things like insulin doses, carbohydrate intake and blood pressure can be lifesaving, using the right app might be crucial.

There have been some attempts to solve this problem. ORCHA⁴⁶ attempts to provide an independent service by reviewing and rating health apps and recommending them in digital health portals. The NHS Apps Library⁴⁷ has a growing family of NHS assessed health and wellbeing apps that have been through an assessment process (although very few of these apps come with the 'NHS Approved' badge).

Not surprisingly, many people still turn to the internet for suggestions on what app to use for their condition. This creates the danger that apps from those developers that can optimise search results will be discovered, and they may not necessarily be the most effective and trustworthy ones.

65%



of the apps in claimed to effectively diagnose conditions (such as depression, anxiety and substance abuse), improve symptoms or mood, or foster self-management according to a study by Nature Digital Medicine.

Lastly, the regulatory framework for health and care apps, and who is accountable, is also confusing. The Medicine and Healthcare products Regulatory Agency (MHRA) is the body responsible for regulating medicines and medical devices, while the Care Quality Commission (CQC) monitors, inspects and regulates health and social care services, including technology-enabled care. However, many health or care apps do not fall under the medical device category or come under the jurisdiction of the CQC. Users of these apps would need to rely on the GDPR for protection.

The problem with a patchwork quilt of regulators is that it does not provide the public with a single trusted point of contact to raise their concerns or provide feedback, as illustrated by the example below.

Babylon Health's symptom checker



Chatbots have epitomised the difficulty in regulating new data-driven technologies. Following complaints to the CQC in 2018 about Babylon Health's symptom checker,⁴⁸ it came to light that five public bodies were responsible for assessing the impact and safety of Babylon's products (CQC, MHRA, NHS Digital, NHS England, and Hammersmith and Fulham clinical commissioning group (CCG), which provided the GP services). This example demonstrates the lack of clarity that currently exists in the oversight of technology products such as chatbots. (Babylon's products have since been registered as medical devices with the MHRA.)

2.2.5 Data sharing and emerging technologies

The past few years have seen a growth in new data-driven technologies such as Internet of Things (IoT) and wearables, as well as data from genomics and biometrics. These technologies are mainly controlled by the private sector from the large technology giants such as Apple and Google to smaller health and care startups.

These data-driven technologies have huge potential to provide a step-change in the way we manage our health and wellbeing, and interact with health and care services. However, inevitably, they come with increasing trust and transparency challenges around the collection, use and sharing of data. We explore these challenges in this section.

Artificial intelligence

Artificial intelligence (AI) is the general study of making intelligent machines. Machine learning (ML), a subset of AI, focuses on the ability of machines to receive data and learn for themselves without being programmed with rules by humans.⁴⁹ AI has been around since the 1950s, but it's only recently, with improvements in technology and the high volume of health data being generated and captured, that we are seeing AI's true value in healthcare. Emerging areas of promise include managing chronic conditions such as diabetes,⁵⁰ more efficient delivery of services through data analytics,⁵¹ and improving diagnosis especially through better diagnostic imaging,⁵² as illustrated by the example below.

AI and breast cancer screening



An area that AI has shown promise to date is in medical imaging, particularly in breast cancer. In the UK, all women between 50 and 70 are offered a mammogram by the NHS to screen for breast cancer every three years. A recent study,⁵³ including researchers from Google Health and Imperial College London, designed and trained a computer model on images from nearly 29,000 women.

The AI system outperformed both the historical decisions made by the radiologists who initially assessed the mammograms, and the decisions of six expert radiologists who interpreted 500 randomly selected cases in a controlled study. The AI was also as good as two doctors working together to make an assessment.

AI trained on large datasets has the potential to revolutionise our health and care system, but it also has the potential to make the system less transparent in terms of decisions. Many media stories have highlighted the problems when AI goes wrong. LinkedIn's recruitment programme showed a preference for men,⁵⁴ decision-making on parole cases has been shown to be biased against black prisoners,⁵⁵ and Microsoft's Tay went from innocent chatbot to a crazed racist in just a day, corrupted by Twitter trolls.⁵⁶

The tight regulations for data security and privacy for NHS data means that it's incredibly hard for AI companies to gain access to the large volume of data needed to train the models. The 2017 Google DeepMind fine outlined above is an example of what can go wrong if the NHS and private companies are not completely transparent about the use of people's patient data.

A second issue is the quality of data from training sets used to create predictive models and the 'explainability' of the AI so that a human can understand it. In Nesta's 2018 report, *Confronting Dr Robot*,⁵⁷ we argued that it must be possible for AI to be understood, questioned and held to account, otherwise AI could fundamentally disempower users – both citizens and health professionals. However, many AI companies and academics are struggling with the challenge of explainability.

Lastly, with the majority of AI development being driven by private companies, there is a risk that a small number of technology companies monopolise access to the data to build the AI, and then sell applications back into a health service which does not fully understand the technology they are buying and using.



Internet of Things (IoT)

Internet of Things (IoT) are connected 'smart devices' equipped with microprocessors and sensors. These technologies have been deployed mainly in smart home devices such as temperature and light controls, as well as voice assistants such as Amazon's Alexa. Their popularity is on the rise in the health and care sector with many platforms using IoT sensors to track the health and wellbeing of people in their homes or care settings.

Wearable technologies, an IoT subset, are networked devices that can collect data and track users' activities. Commercial examples of these include the Apple Watch, the Samsung Gear and fitness bands such as FitBit. Wearables can also be medical devices such as heart rate monitors and blood pressure cuffs.

Many consumer IoT and wearable technologies have failed to live up to their original hype and have not been widely adopted by the public.⁵⁸ This is likely to change as the devices become cheaper, processing power increases and companies can demonstrate the benefit to consumers and the health and care system. With one trillion new Internet of Things (IoT) devices predicted to be produced by 2035, and next generation microchips able to process data on devices rather than transmit to the cloud, the amount of health and care data we collect, store and analyse will be transformational.⁵⁹ But this is likely to only increase concerns around the transparency of the uses of the data.⁶⁰

Amazon's Alexa keeps voice recordings 'indefinitely'



In 2019 Amazon confirmed what many people have suspected for a long time, that it keeps the transcripts and voice recordings from the device indefinitely, only removing them if they're manually deleted by users.⁶¹ But even then the company retains the right to keep other records of customers' Alexa interactions, including records of actions Alexa took in response to the customer's request. The company is using machine learning to learn from this personal data to, in its words, 'get smarter every day'.

Genomic data

In May 2007, the 454 Life Sciences founder, Jonathan Rothberg, presented James D Watson with a digital copy of his personal genome sequence on a portable hard drive. Rothberg estimated the cost of the sequence – the first personal genome produced using a next-generation sequencing platform – at \$1 million. Today that same genome could be sequenced for well under \$1,000 with commercial companies now racing to produce the first \$100 sequence.⁶²

In the UK, the 100,000 Genome Project recently completed sequencing 100,000 genomes of people with rare diseases and cancers. The UK government has committed to sequence 1 million more genomes followed by 5 million more within the timeframe of the NHS Long Term Plan. With the cost of sequencing dropping and the benefits of genomic medicine starting to be realised, it's not a stretch to imagine a near-term future where everyone's genome is sequenced and accessed by the NHS.

100k



Genome Project recently completed sequencing 100,000 genomes of people with rare diseases and cancers.

Ipsos MORI Public Dialogue on genomic medicine: a 'new social contract'?



Genomics England, the Scottish Genomes Partnership and UK Research and Innovation's Sciencewise programme undertook a public dialogue in 2019 to explore public aspirations, concerns and expectations about the development of genomic medicine in the UK⁶³ to inform healthcare policymaking in Scotland and the future of genomics more broadly.

Ninety-seven members of the public and thirty experts took part. Participants had a limited understanding of genomics: almost nobody had heard of a 'genome' or 'genomics'. However, when introduced to the idea, almost all responded positively and many developed high expectations of genomics, envisaging a near-term future with new treatments and personalisation of care, and significant cost savings for the NHS. Almost all were relaxed about their health and genomic data being used in health research, provided that this was managed carefully.

However, participants had some clear limits for how far they thought genomic data, and information derived from genomic analysis, should be used. These included genetic engineering, surveillance, administrative / political uses, predictive insurance tests and targeted marketing.

Data wise, a pressing concern is the rise of direct-to-consumer genetic testing companies. Companies such as 23andme and AncestryDNA are seeing exponential growth as people rush to find out more about their heritage and their genetic predisposition of getting a condition. There are now over the counter genetic testing kits that can reveal whether someone is at risk of specific diseases and conditions, such as Alzheimer's disease, heart disease and cancer. Questions remain about how transparent these companies are about how they hold this data and who they can share it with, as illustrated by the example below.

23andMe and GlaxoSmithKline⁶⁴



23andMe is a private US-based company that offers direct-to-consumer (DTC) genetic testing kits. These allow customers to find out more about their ancestry and their health e.g. by identifying the breast cancer gene BRCA. Backed by Google Ventures and with more than 5 million customers, the company has curated the biggest biological dataset in the world.

In 2018 the company announced a \$300m (£233m) / four-year deal with pharmaceutical company GlaxoSmithKline to develop drugs based on this data. 23andMe has always been explicit about using the data in this way and gave all its customers the option of opting out of sharing their data with commercial companies. One million customers took up the offer. As a 23andMe board member stated in 2013, 'The long game here is not to make money selling kits ... Once you have the data, [the company] does actually become the Google of personalised health care.'

When genetic testing and sequencing becomes widespread, it will give rise to a whole new area of privacy concerns such as accidental exposure of medical conditions and family relationships. And as the data is your DNA, it could potentially have knock-on effects for people in your family as well.

Biometric data

The collection and use of biometric data, which is physical or behavioural human characteristics unique to a person, is on the rise. Examples include fingerprints, facial patterns and voice or gait analysis. Biometric data has mainly been used in the digital authentication space, for example, using your fingerprint to open your smartphone, but its use is increasing, with implications for health and care. Emerging research is showing that biometrics, such as the way someone walks, talks or their finger moves on a touch screen, can point to early signs of heart disease or post-traumatic stress disorder⁶⁵ or can predict challenging behaviour in those with autism.⁶⁶

But it's not all positive. Physiological recognition, such as facial recognition or iris or retinal scanning, is also being used by companies such as Facebook to tag images, by countries around the world to keep track of refugees, and by China to monitor segments of the population, as illustrated by the example below.

China using biometrics to monitor Xinjiang's population



Xinjiang is the only Chinese territory (apart from Tibet) where ethnic Han Chinese are not in the majority. The region's residents, which include 11 million Muslims, are subject to a new law allowing the collection of images, fingerprints, iris scans, blood types and DNA biometrics of those between the ages of 12 and 65. This biodata profile is then linked to a resident's hukou, or household registration card. The controversial registration system limits where people can access education, medical and housing benefits, essentially limiting many to the region where they were born. The scheme has been called a gross violation of human rights.⁶⁷

2.2.6 Conclusion

Decreasing levels of trust in use of our data is an understandable reaction to the many data misuses that we have witnessed over recent years. However, we run the risk of moving too slowly to reap the benefits of a data-driven health and care system if the public does not trust that their data will be securely and transparently handled.

We need to work with citizens to design new ways to build an ecosystem of trust⁶⁸ with transparent uses of data that put the citizen in control. If we get these fundamentals right, we can start to unlock the untapped value in health and care data. We will explore this in the next section.

2.3 Unlocking the value in health and care data

2.3.1 Introduction

The next challenge, and opportunity, is how to unlock the value of health and care data for individuals, the health and care system and society – while also respecting people's privacy and preferences. Data is often referred to as 'the new oil'⁶⁹ and while this analogy may be unhelpful and certainly incomplete,⁷⁰ It reminds us that health and care data has public and commercial value, as we will explore in this section.

2.3.2 Unlocking the value of data for individuals

Treatment and care for people with long-term conditions is estimated to take up around 70 per cent of the health budget in the UK. Prevention, early intervention and supported self-management are a core component of both NHS England's Long Term Plan and Scotland's Digital Health and Care Strategy.

Data has a crucial role to play in this fundamental shift. As health and care becomes more integrated, data needs to be able to flow between community, primary, secondary and care settings and be accessible to appropriate professionals, with citizens' consent. Citizens should be able to access their own data in formats that make it easy to access and use it to monitor and manage their own health. They should have the opportunity to share useful data from their apps and devices, such as wearables and sensors, with their clinical team to support better shared decision making, as illustrated in the example below.

Digital Health & Care Institute, Asthma Action Plan



The Digital Health & Care Institute (DHI) in Scotland has a mission to help NHS Scotland and the private sector redesign operational health and care design models using data and technology. One project that illustrates the potential of data integration and linkage for individuals is its Asthma Action Plan. Asthma is a long-term condition that affects the airways carrying air in and out of the lungs. It affects 5.4 million people in the UK, some of the highest rates in Europe. An asthma action plan could help someone monitor their asthma daily (categorised as green / amber / red) – and suggest what to do if it's getting worse. The DHI worked in a co-designed way with asthma patients to use more personalised data sources, for example, sleep, pollen count, could they sing a particular song etc.) Combined with co-managed 'rules' with their clinician, these data sources would, if triggered, alert the health system and, in this hypothetical scenario, book a same day appointment precisely when they need it – not when they are next due for a check-up.

Further, there is a huge amount of potential value in combining data from multiple sources such as private, statutory, charitable and community organisations outside the health and care system, but this useful, and potentially life-saving, data sits in silos and is rarely linked or accessible so insights are lost, as illustrated in the example below.

Ella Kissi-Debrah – the UK's first 'air pollution' death?



An estimated 40 million people in the UK are living in areas with illegal levels of air pollution and the rate of asthma deaths in the UK has increased by more than 20 per cent in five years. In 2019, a London child, Ella Kissi-Debrah, may have been the first person in London to be killed by air pollution since the Great Smog of 1952.⁷¹ The court found it likely that unlawful levels of pollution, detected one mile from Ella's home, contributed to her fatal asthma attack. There is a clear opportunity here for data about air pollution to be accessible in real-time to allow parents and people with lung conditions such as asthma or chronic obstructive pulmonary disease (COPD) to make better-informed choices about daily activities.

2.3.3 Unlocking the value in the health and care system

The NHS holds one of the most valuable databases in the world. In 2019, consulting firm EY estimated that the 55 million patient records held by the NHS today may have an indicative market value of several billion pounds to a commercial company.⁷² They predicted that the NHS could use the patient-level data it holds to unlock significant value in operational savings, and generate benefits of around £4.6 billion per annum in enhanced patient outcomes, and up to £5 billion in wider economic benefits to the UK.

There is increasing recognition of the potential value that can be derived through research based on these large-scale health datasets, such as those held by the NHS and bodies such as Public Health England. Initiatives such as HDRUK's Digital Innovation Hubs⁷³ and SHARE in Scotland (see box below) will provide the infrastructure and mechanisms for the public, voluntary and private sectors to access large scale datasets for health research and innovation.

SHARE, Scotland

SHARE⁷⁴ is a Scottish initiative created to establish a register of people who are willing to be invited to take part in medical research projects and have consented to allow researchers to use any leftover blood following routine clinical testing for approved research. There are a number of clear benefits to signing up. Firstly, there is the altruistic benefit of the pooled data being used for medical research to benefit the public. Secondly, participants might be invited to take part in a research study in the future (with no obligation) which could benefit their treatment or condition. Lastly, if any clinically useful information comes to light, this may be added to their health records (via strict NHS approved protocols) to guide their treatment. SHARE is a good example of how value sharing can work by providing an easy way for people to get involved, clear benefits for research that donors might benefit from, and importantly, the data being held securely with clear opt-out mechanisms. More than 280,000 people (5 per cent of the population) have signed up, demonstrating willingness of the Scottish public to share their health information for research purposes.

As the largest single payer healthcare system in the world, the NHS is sitting on vast amounts of data that could be hugely valuable to private companies who have the skills to create new data-driven products. These products could ultimately benefit the health system and improve patient outcomes, as illustrated by the example below.

Google Health research partnership with Moorfields Eye Hospital

Google Health is one of the world's leading AI companies. Its research partnership with Moorfields Eye Hospital NHS Foundation Trust, one of the world's leading eye hospitals, is demonstrating how the NHS can work successfully with technology companies to use NHS data to innovate and create new clinical pathways, products and services that improve outcomes and quality of life and, eventually, save money for the system.

Using data from patient retinal scans at Moorfields, Google Health trained an AI system to quickly and accurately interpret eye scans from routine clinical practice. The results of the first study, published in *Nature Medicine*, found that the AI can correctly diagnose more than 50 sight-threatening eye diseases, and prioritise and recommend treatment, as accurately as world-leading doctors.⁷⁵

If this technology is validated for general use by clinical trials, Moorfields' clinicians will be able to use it for free across all 30 of its UK hospitals and community clinics for an initial period of five years.

However, the public have strong views on the kinds of organisations they trust to conduct research using their data. A YouGov survey of more than 2,000 people shows that only 13 per cent of the public trust multinational tech companies to handle sensitive health data in a confidential manner.⁷⁶ Similarly, just 1 in 10 of respondents said they are happy for NHS data to be analysed by businesses that do not pay tax in the UK, while 69 per cent raised concerns about this information being analysed in other countries with different laws governing data security and confidentiality.

2.3.4 Benefit sharing and trade-offs

Much of the previous research and engagement with the public has tended to focus on perceived benefits and risks of data access and use. There has not been enough exploration of how different groups of people might balance these concerns with the potential benefits and value of data sharing, not just to themselves but to people like them and the system.

Many people are prepared to make trade-offs: to share data if it benefits themselves and others. A 2018 Nesta poll found, for example, that 73 per cent of people said they would share their personal data in an effort to improve public services if there was a simple and secure way of doing it.⁷⁷ Exploration of such trade-offs would be a hugely useful next step in deepening our understanding of how public institutions build trust and confidence with their local populations.

In 2013 the Scottish Government commissioned research into how the public felt about data sharing between public, private and the voluntary sector for research and statistical analysis.⁷⁸ The majority of respondents supported public bodies, such as the Scottish Government and NHS Scotland, having access to anonymised personal data for research purposes. Voluntary sector access to data was seen as more acceptable than private sector access but somewhat less so than public sector access, as respondents felt that they would be promoting the public good. Not surprisingly, private sector access to data sharing was most contentious with strong views on the private sector not accessing data for the sole purpose of profit maximisation.

However, a further exploration of the concept of benefit-sharing led to more nuanced views emerging. It was acknowledged that private companies are incentivised by profit to conduct research and produce innovative products. Nevertheless, the respondents felt it important that benefit-sharing models incorporated clear provisions to curb the level of profits from research. Specific suggestions included provisions to ensure that private companies pay to use data, share profits from data use, provide affordable products and services built on data, or reinvest profits in local communities.

Further, with regard to the source of the data, respondents made a useful distinction between research that draws on routinely collected data by the health system and data donated on a proactive voluntary basis. With regard to the former, it was felt that individual data subjects should not benefit directly. Instead, society in general, or a specific population, for example with a long-term condition, should benefit by improving early detection of disease or better public health. With regard to the latter, the consensus was that data subjects should benefit directly, with suggestions ranging from financial incentives to advice and access to services.



Sensyne and the NHS: benefit sharing in practice⁷⁹



Sensyne Health is a private health technology company that uses artificial intelligence and anonymised patient data from electronic health records to improve patient care and treatment. The company has struck several partnerships with NHS trusts in England to develop smartphone apps that monitor heart conditions, lung disease and diabetes in pregnant women. Six NHS trusts have been given shares in Sensyne in return for providing anonymised patient data and will receive 4 per cent of future royalties from any products developed. The company collaborates with NHS trusts under Strategic Research Agreements. Under the Strategic Research Agreements, the NHS retains full control over patient data. No data is sold nor is any ownership or control of data transferred to Sensyne or any third party.

2.3.5 Value exploitation by the private sector

Many large corporations are making steady inroads into the healthcare sector because they recognise the rich potential for profit.

In 2018, Google's search engine processed over 200 billion healthcare queries and 51 per cent of searches on Youtube (owned by Alphabet – Google's parent company) also related to health. The Google search algorithm decides what information and advice a searcher will find and their monopoly on health search queries is giving the company unprecedented insights into health and lifestyle behaviours. They are also in the process of acquiring wearable device company FitBit, which has nearly 30 million active users globally.⁸⁰

In 2019 Google came under fire for its partnership with Ascension, a major hospital chain and health insurer in the US, that resulted in the transfer of the health records of 50 million insurance customers without their knowledge or consent.⁸¹ These commercial deals, as well as the data from its search engine, could give the tech giant access to billions of data points that it can use to train algorithmic models to predict disease and track interventions.

It is not just Google that is making forays into healthcare. In 2018, Amazon bought an online pharmacy Pillpack and is marketing it to Prime subscribers.⁸² It also entered into a joint venture, Haven,⁸³ with JPMorgan and Berkshire Hathaway, to create a new health insurance company for its 1 million employees. Amazon's voice assistant Alexa also has a controversial partnership with the NHS (see box below).

200bn+



healthcare queries processed by Google in 2018.

51%



of searches on Youtube (owned by Alphabet – Google's parent company) also related to health.



NHS gives Amazon access to health data collected by Alexa devices



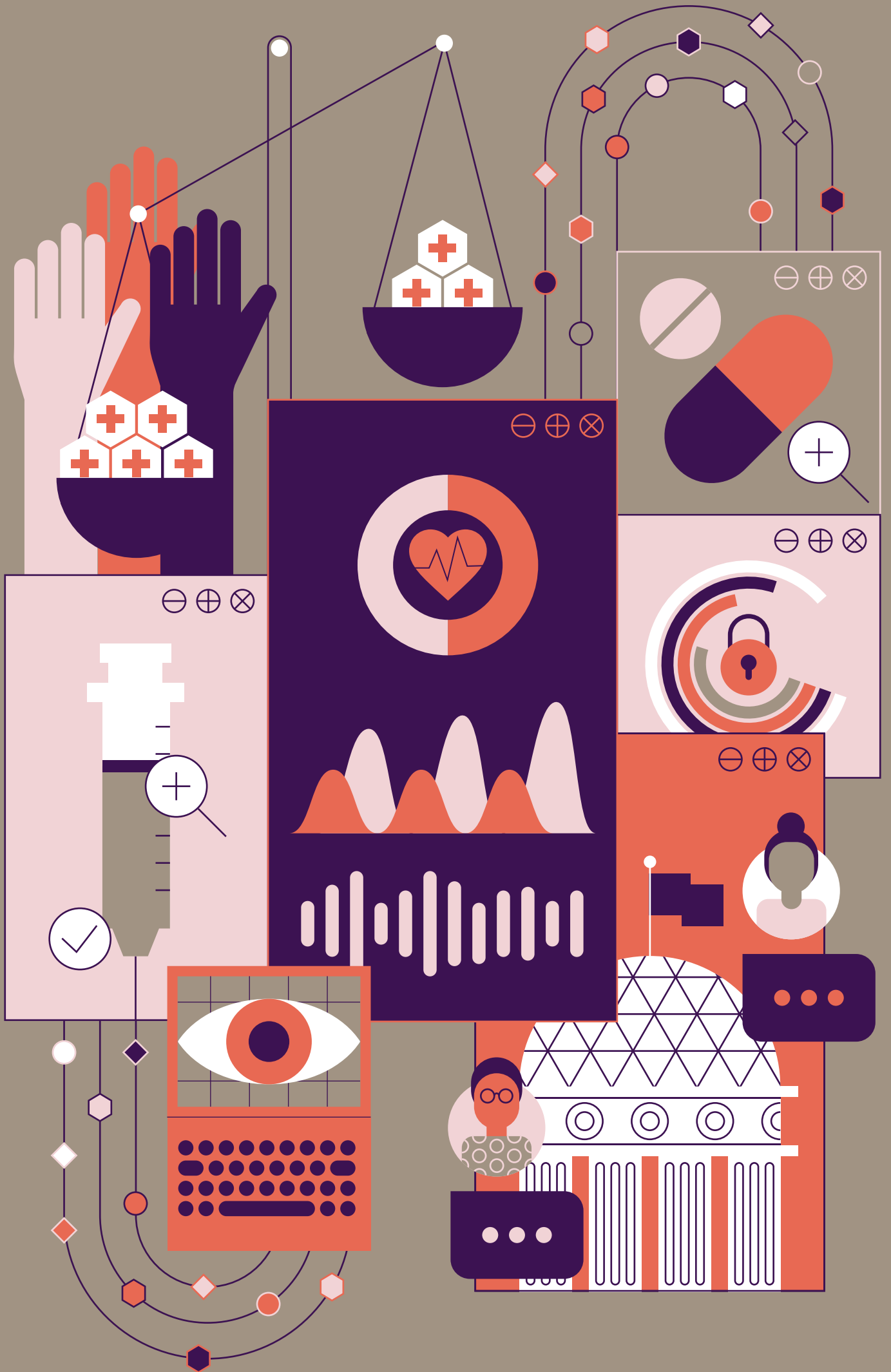
In July 2019, the health secretary, Matt Hancock, announced a partnership between the NHS and Amazon to offer expert health advice to users through its AI-powered voice assistant Alexa devices with the hope of reducing pressure on NHS staff. It was revealed in December 2019, after Freedom of Information requests, that the contract will also allow the company access to information on symptoms, causes and definitions of conditions. The contract also allows Amazon to create 'new products, applications, cloud-based services and/or distributed software', which the NHS would not benefit from financially. It can also share the information with third parties.⁸⁴

Facebook announced in 2019 that it was partnering with US health organisations to offer a new Preventive Health tool that connects people to health resources and check-up reminders, focusing on the top two killers in the US: heart disease and cancer, as well as flu.⁸⁵

Partnerships between a healthcare provider with data and a company like Google that has the technical capabilities in data, AI and sensors, could provide a step-change in our knowledge of health. However, these partnerships come with risks: what data these companies are accessing, how consent is, or isn't, being sought, and who ultimately benefits from the value of the data.

2.3.6 Conclusion

It is clear there is huge value to be gained from health and care data for individuals, for the health and care system and for wider society – but there needs to be stringent safeguards in place to make sure that the benefits are felt by citizens, populations, and health and care systems, and not only private corporations.





3.0

A culture of participation

3.1 Introduction

Accessing, sharing and analysing the increasing amounts of data collected by and about us could fundamentally change the way we approach our health and wellbeing, unlocking predictive prevention, discovering new treatments and enabling independent living.

However, as we have seen, there are significant challenges to be overcome in terms of public trust in the data ecosystem, transparency in uses of data, and understanding of the value of data sharing. To overcome these challenges, there is a need to support and encourage citizens to participate in safe data sharing at all levels of the ecosystem.

The Scottish Government's ambition for digitised health and care records is that citizens will be in control of who they can share their data with. For example, a person living with a heart condition may want to ensure their data is easily shared between the health professionals in their care and might also want to share data from a cardiac rehabilitation smartphone app⁸⁶ and their wearable device.

The challenge here is not simply a technical one. Digitised health and care records are on the horizon and the infrastructure needed will soon be in place. The problem is a cultural one: how can we ensure a trusted and transparent data system, while also supporting diverse groups of citizens to have a better understanding about the benefits of participating. This participation may be anonymously for research (by not opting out) or by actively donating their personal data to be used for analysis, for example by a health charity.

This is important for a number of reasons. At a national level, if citizens opt out of allowing their data to be used for research aimed at finding new ways of preventing illness and improving treatments, we run the risk of incomplete datasets. This is especially problematic if certain populations are more likely to not want to participate, for example, people from different ethnic backgrounds or with different health conditions or disabilities. The result is in inherited biases in the data or the AI models running on the data.

At an individual level, we run the risk of creating a data divide between different members of society and increasing health inequity. Currently, much data-driven digital health technology such as smartphone apps, wearables and home testing kits, are consumer focused, expensive and are targeted at engaged citizens who want to improve their health. Thus, technologically savvy and engaged people, who use technology and new data-driven insights to lead healthier lives, may have more personalised information about their risk of developing disease and can manage their conditions more effectively. Excessive data collection and the use of AI by engaged and data-rich individuals could also put a burden on the health and care system by over-monitoring healthy people.⁸⁷

Conversely, we could have individuals, who for reasons of lack of trust, interest or understanding, do not use technology and opt out of sharing their data and may have poorer health outcomes as a result of this. It's likely that those worst affected by these changes will be those with hard to diagnose conditions, complex social and health needs, and who already face disadvantage.

Governments, the NHS, local authorities and other public bodies have an urgent need to engage a wide range of citizens in conversations about this data-driven near future. They need to be willing to work with citizens to co-diagnose the issues and opportunities, build common ground and collectively imagine preferred futures. Policy and practical action should then be aligned to help deliver these common visions.

3.2 A role for participatory futures?

Promoting public dialogue is a key component of the policymaking process. Benefits include generating an understanding of public attitudes, stimulating greater public participation in civic life and engendering trust. Public engagement can also directly shape the future of health and care data.

There have been a range of public engagement activities across the UK in recent years engaging citizens in how they feel about the use of patient data,⁸⁸ ranging from surveys to public dialogues and citizen juries. These activities have generated useful insights, as summarised in this report, but they have seldom moved beyond engaging with the 'usual suspects' (i.e. engaged, expert patients) to involving diverse and seldom heard groups. The Scottish Government and Nesta believe it is time to embed public engagement more deeply in how we design, implement and govern data-driven technologies; and to explore methods that can support citizens to engage with questions about the future, while still being rooted in the present.

Scotland's Our Voice Citizens' Panel on the use of health data



Since 2016, the Our Voice Citizens' Panel⁸⁹ has brought together people across Scotland to inform and influence key decisions about health and social care policy and services. This is the first time a national Citizens' Panel focusing on health and social care issues has been established in Scotland. The Citizens' Panel was developed at a size that will allow statistically robust analysis of the views of its members at a Scotland-wide level, roughly 1,300 people from across all 32 local authority areas. Panel members were selected at random from the electoral register or recruited to be broadly representative of the Scottish population by gender, age, employment status, housing tenure, ethnic origin and geographic location. Panel members share their opinions using self-complete electronic or postal surveys or through telephone interviews.

Participatory futures⁹⁰ are a set of techniques that systematically engage people to imagine and create more sustainable, inclusive futures. These techniques are wide ranging and cover everything from massive online games to interactive theatre and installations.



SBC Theatre – The Nest

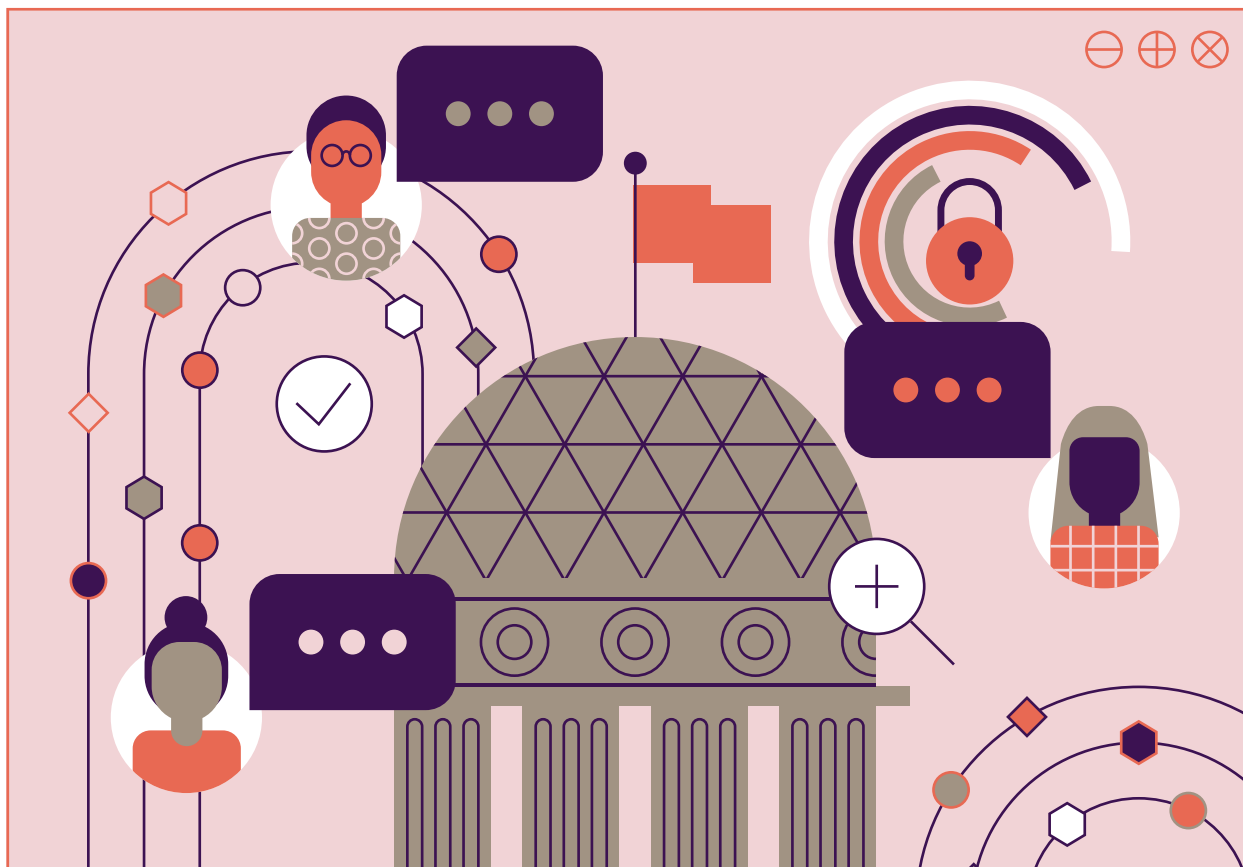


The Nest⁹¹ is an interactive theatre production exploring how and why people's attitudes towards the sharing of data, health data and patient records can differ and at times conflict. It was commissioned by the NIHR Greater Manchester Patient Safety Translational Research Centre, written and produced by Stand and Be Counted Theatre and supported by the Public Programmes Team at Central Manchester University Hospitals NHS Foundation Trust. Based on the theme of sharing personal data and health information, the Nest was used as a way of introducing the topic to a diverse audience and to find out about people's perceptions and opinions on sharing data.

3.3 What Nesta is doing in this space

Nesta's Data Dialogues programme⁹² with Scottish Government is using a range of participatory futures techniques – including online social games, speculative designs and pop up installations – to engage diverse groups in Scotland from different places, ages, socioeconomic and cultural backgrounds, as well as people with different experiences of health and using care services.

Much of the research in this area to date has been done in England. We want to explore the similarities and any differences in the views and behaviours of Scottish citizens and their responses to similar questions. The findings from the dialogues will be synthesised and presented in an interactive creative work, as well as a report and online event in 2021.



Through the programme we are attempting to explore questions like those in the box below.

Topic	Questions
Trust and transparency	<ul style="list-style-type: none">⊕ What creates trust (and engenders mistrust) when different types of organisations use our data e.g. NHS, local government, wider public sector, voluntary sector, private sector?⊕ How does this impact people's choices and behaviours?⊕ How does this vary for people from different backgrounds?⊕ What are the main barriers and enablers, and how could trust be earned with different groups?⊕ In our research we have found very few insights on social care data and its uses. What do people understand by 'care' data, particularly in relation to social care, and how it interacts with 'health' data?
Multiple perspectives	<ul style="list-style-type: none">⊕ How do we gain an understanding of what different 'publics' think about the use of their health and care data?⊕ Are there differences between people from different geographies (rural / urban) areas and between people with different ethnic, cultural, educational or socioeconomic backgrounds?⊕ Evidence suggests that people generally find it easier to engage with questions around their health data at a point of connection, for example, a cancer diagnosis. How could we encourage healthy citizens to engage with their data?
Control of data	<ul style="list-style-type: none">⊕ The research shows that people increasingly demand, and expect, more control over their health and care record. How much control do they want?⊕ How would such control be offered? In what circumstances are they willing to concede control?⊕ What types of data are people more willing to share? And what types of data are problematic, for example, data about someone's mental or sexual health?⊕ What are citizens' views on new data stewardship models such as personal data stores, data commons and data trusts?
Benefit sharing and trade-offs	<ul style="list-style-type: none">⊕ How could we encourage greater citizen-led data sharing not just for individual benefit but also for the greater good?⊕ What are some of the trade-offs people are willing to make balancing access and use of their data with value creation e.g. better individual care, a more sustainable health system, or a more equitable health system?⊕ What benefit-sharing models could be considered acceptable to the public? Does this vary for people from different backgrounds, health status or geographies?

We hope that participatory futures methods, such as pop-up installations and speculative design, can help to make an intangible idea like data more real and allow citizens to 'step' into their future and have a different conversation about the use of their health and care data. We are also excited to test whether these techniques can be effective at engaging with harder-to-reach groups and not just 'expert patients'.

3.4 Conclusion

We need to have a public debate about the value of responsible sharing of data if we are going to unlock its benefits, not just for an individual's care, but for others like them, as well as the clinical and research community and the private sector.

We need to experiment with new models of extracting, linking and analysing data from the public, private and third sector and engender a culture of data philanthropy underpinned by strong data ethics and regulation.⁹³ This should also extend beyond the boundaries of the health and care system, if we are going to truly maximise the potential of data to improve health outcomes for everyone in society.



Appendix A:

Select literature review

Name of research	Year	Completed by	Methods and who engaged
A public dialogue on genomic medicine: time for a new social contract? ⁹⁴	2019	Ipsos MORI Public Dialogue Centre and Genomics England, UKRI	Ninety-seven members of the public and 30 experts came to evening and day-long Saturday events in Coventry, Edinburgh, Leeds, and London.
Attitudes towards data ethics ⁹⁵	2019	Open Data Institute (ODI) and YouGov	Online consumer survey with 2,007 adults.
Joined Up Yorkshire & Humber ⁹⁶	2019	Brainbox Research (commissioned by Yorkshire and Humber Care Record)	Mixed method approach. Twelve community events ran. Pop-up case study events with 415 case study cards were completed. Survey with 1,031 people.
Data about us ⁹⁷	2019	RSA (Royal Society for the encouragement of Arts, Manufactures and Commerce), the Open Data Institute (ODI) and Luminare	Two focus groups and one workshop.
Is being informed about patient data enough? ⁹⁸	2019	Understanding Patient Data and Spotless	Nine interviews with health and care professionals, 30 one-to-one interviews with members of the public across Leeds, London and Bristol, and two public workshops in London and Bristol.
Understanding public expectations of the use of health and care data ⁹⁹	2019	Understanding Patient Data and Curved Thinking (commissioned by OneLondon Local Health and Care Record Exemplar)	Rapid literature review and 27 interviews conducted with a cross section of key stakeholders across the five London Sustainability and Transformation Partnership (STP) area.
Joined Up Leeds ¹⁰⁰	2018	Brainbox Research (commissioned by Leeds North CCG)	Seventeen city-wide events (1,100 people completed a survey, 189 completed event cards and 157 took part in conversations).



Name of research	Year	Completed by	Methods and who engaged
Attitudes towards data sharing ¹⁰¹	2018	Open Data Institute (ODI) and YouGov	Online consumer survey with 2,023 adults.
How do people feel about their data being shared by the NHS? ¹⁰²	2018	Healthwatch and ComRes	Survey of more than 2,000 adults.
Future data-driven technologies and the implications for use of patient data ¹⁰³	2018	Academy of Medical Sciences and Ipsos Mori	Fifty-three participants came to day-long Saturday events in Sheffield, London and Cardiff. Followed by an evening event with a smaller group of participants and 15 healthcare professionals.
Great North Care public engagement report ¹⁰⁴	2018	Connected Health Cities, Teesside University and local Healthwatch groups in the North East and North Cumbria	Twenty-three engagement sessions with a total of 314 citizens taking part.
Data sharing and technology: Exploring the attitudes of people with asthma ¹⁰⁵	2018	Asthma UK	Survey of 3,054 people with asthma across the UK.
Connected Health Cities Citizens' Juries Report ¹⁰⁶	2017	Northern Health Science Alliance	Two citizens' juries with a total of 36 people were held in York for four days.
Our Voice Citizens' Panel: third survey report ¹⁰⁷	2017	Healthcare Improvement Scotland	Citizens' Panel with a total of 496 responses.
Health Records research ¹⁰⁸	2017	PWC and Opinium	Survey of 2001 UK adults.



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