



Public deliberation in the use of health and care data

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Foreword

This timely and significant report follows the remarkable journey of the 100 people who took part in the OneLondon Citizens' Summit held over two weekends in February and March 2020. These 100 Londoners - reflective of our diverse population - came together from across all 32 boroughs, from different backgrounds and walks of life, and with contrasting attitudes, to discuss, debate and deliberate some of the complex issues as to how we - as a London health and care system - should be joining-up and using people's data to support individual care, to plan public services, and to enable research.

There is huge potential to harness health and care data in a safe and secure way to improve the health and wellbeing of Londoners. From helping NHS staff to provide safe, quality care, to improving services, to enabling the discovery of new treatments: all contribute towards our shared ambition to make London the healthiest global city. Understandably, how we use health and care data raises questions and concerns, particularly around access and privacy. To create and sustain public confidence we must understand and respond to Londoners' expectations about data sharing for multiple purposes, and ensure we operate in line with these expectations.

OneLondon has taken the first steps to achieving this, having brokered a meaningful and deliberative conversation with Londoners - including those from seldom heard and vulnerable communities. Importantly, this demonstrates two things:

1. The effectiveness of deliberation in engaging the public in a genuine and informed conversation to explore people's expectations and to involve them in decision-making in a way that builds confidence
2. The ability of the public to grapple with complex issues and form practical, meaningful recommendations which can be used to shape policy

Central to both is building public trust, and for this it is vital to ensure:

- Inclusion of a diversity of views, including seldom heard and vulnerable communities
- A transparency of process and a balance in the information presented
- That information is shared in simple terms that is easy to understand
- That enough time is available for people to ask questions, test their understanding and listen to others

These insights should guide how the public are involved in decision-making more generally, so that in future we have more of this type of participative input to shape how services work for Londoners.

We will use this report to develop a single set of policies for joining up people's health and care data in a way that is legitimate and continues to build trust and confidence. The recommendations are central to this, but it is the reasoning of how the recommendations were reached enables us to understand what is most important to people when considering the real-world expectations, issues and trade-offs with joining up health and care information. For example, while participants saw privacy as important, it was ultimately given less weight relative to the importance of patient safety and high-quality care. Using de-personalised data for planning health services was considered a must-do by this group of Londoners, but with clear expectations about the conditions needed to ensure accuracy, security, and choice. Similarly, some cautiousness about commercial organisations working with NHS analysts to make use of de-personalised data for research was counter-balanced by the recognition of potential benefits - including improved outcomes for patients and potential efficiency savings for the NHS. And whilst participants felt there was value in transparency around how organisations are using health and care data, they were clear that this should be proportionate and should not create significant costly burdens that might redirect NHS funding away from frontline services.

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Understanding how these features shape public acceptability, and what assurances and conditions the public expect to ensure trustworthiness, is invaluable. It ultimately enabled participants to reach a position where an overwhelming majority are in favour of health and care organisations in London joining-up data to support

individual care; and for using de-personalised data to support planning, research and development. This not only provides a clear instruction from the public to us as leaders in the system, but it also offers clarity and direction to frontline health and care staff and data controllers.



A handwritten signature in black ink that reads 'Theo Blackwell'.

Theo Blackwell MBE
London's Chief Digital Officer



A handwritten signature in black ink that reads 'Diwakar'.

Dr Vin Diwakar
Chief Clinical Information Officer
and Regional Medical Director for
NHS England (London), Senior
Responsible Officer for Onelondon



A handwritten signature in black ink that reads 'Luke Readman'.

Luke Readman
Director of Digital Transformation
for London, Chief Officer for
OneLondon

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Acknowledgements

The authors, the Ipsos MORI team, would like to thank The King's Fund, who were commissioned as a delivery partner to provide advice on public engagement and research methods and health and social care data policy. The King's Fund also provided facilitators and speakers at the Citizens' Summit and reviewed early report drafts. The project team members from the Fund were Dan Wellings, Matthew Honeyman, Helen Gilbert and Alex Baylis. We would also like to thank Anna Beckett, who was contracted to work part-time with the Ipsos MORI team, for her involvement and the expertise she brought to the exercise.

We would like to thank the many stakeholders who gave up their time to inform the design of the deliberative materials for the Citizens' Summit, ensuring that the information participants received was correct, fair and balanced.

We would also like to thank the members of the Oversight Group (OG), which was supported by OneLondon, for their invaluable contributions throughout the project.

We would like to thank the expert commentators who provided presentations over the four days, and the many expert observers who came along to listen into discussions.

We would like to thank the panel of regional and national system leaders, policymakers and politicians who were present on Day 4 to receive the recommendations from participants. Dr Vin Diwakar, Lord James O'Shaughnessy, Sarah Wilkinson, Luke Readman, Dr Natalie Banner, Theo Blackwell and Dr Simon Eccles. Thanks also to Ben Page, CEO of Ipsos MORI for chairing this panel.

Most importantly, we would like to thank the participants, who gave up two weekends to contribute to a set of complex and challenging discussions, and for their tremendous commitment to making policy recommendations on behalf of Londoners.

Finally, we would like to thank members of the OneLondon team and the executive team for their time and effort and working so closely with us to ensure that the process was well-informed and ran smoothly and effectively.

Executive summary

Background

The sharing of health and care information is an important and complex area of policy. New technologies increasingly allow health and care information to be brought together to support care for an individual, to enable health and care planning for populations, and to inform research and development. As with many technological advances, new capabilities create new issues; and policy should respond to these new opportunities and challenges in ways that the public feel are acceptable and trustworthy. As Integrated Care Systems emerge across the country, and establish new ways of joining up information, it is vital that these local partnerships engage with the public to develop policies that build public trust and which are seen to be legitimate.

The OneLondon Local Health and Care Record Exemplar (LHCRE)¹ is one of five ‘first-wave’ national programmes that has been established to join up personal information across health and care organisations, within and between the five emerging ICSs in the Greater London region. The programme aims to improve outcomes for people and to support safe, timely and effective care. In recognition of the important policy questions raised by the ground-breaking nature of the programme, the OneLondon partnership (representing local authorities, the Greater London Authority and the NHS in London) has established a multi-stage process of public engagement. This process is structured to understand the public’s expectations of health and care services, to explore the issues presented by joining up health and care information, and to invite members of the public to deliberate how to best balance these issues to inform how health and care information will be used in the Capital.

The engagement process has synthesised previous public engagement within London (and beyond) to understand what is already known about Londoners’ attitudes towards joining up personal health and care information, and to highlight where there were significant gaps in the evidence, for example: noting that too little was known about the views of seldom-heard groups; and that some topics were less well explored, such as public expectations relating to the use of health and care information for proactive care and system planning. In light of those initial findings, the programme commissioned further engagement exercises with the aim of mobilising a different type of conversation with the public. This included a large-scale deliberative event to capture empirically – for the first time – the expectations that Londoners had when given the information, time and space to explore and weigh-up the real-world benefits, concerns, risks and constraints associated

with joining up health and care information. This type of deliberative method is well-suited to inviting the public to inform policy-making, and it is used increasingly to build acceptable policy responses to questions where the issues at stake are more nuanced than a simple ‘agree’ / ‘disagree’ dichotomy.

This report is a culmination of this deliberative engagement, which brought together 100 participants – one of the largest of its kind – in a four-day Citizens’ Summit held over two weekends in February and March 2020. Participants were recruited to be reflective of London’s diverse population, and to involve people with a range of attitudes towards data sharing (positive, neutral and cautious).

The deliberation was designed and delivered by Ipsos MORI and The King’s Fund, with support from an academic advisor, Professor Graham Smith. The design of the deliberation, including format and content, was informed by OneLondon’s previous evidence synthesis insights work and the further social research completed by Ipsos MORI. This social research comprised spending time with marginalised and vulnerable communities to understand their views, and holding workshops with health and care professionals to understand related policy challenges. To ensure appropriate rigour and to test the robust methodology, the design of the deliberation was supported by an independent Oversight Group.

Summary findings and recommendations

The deliberative format of the four-day Summit facilitated a genuine conversation that empowered participants to explore the levels of acceptability of using and accessing health and care data for different purposes: individual care, proactive care, planning and improvement, and research and development. A mix of plenary sessions with experts and in-depth table discussions supported participants to weigh-up benefits and concerns, and to consider the trade-offs that were agreeable to ensure their expectations could be met in a real-world context. Materials used in the sessions have been published on a public website².

A feature of deliberations, this one included, is that the interactions between participants change over the course of the two weekends, as they become more familiar with the topic area and more familiar and trusting of one another. At the beginning, participants were generally comfortable stating opinions; but by listening to others over the course of iterative group discussions and plenary, they increasingly began to share opinions and their reasoning. This allows participants to respectfully

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challenge and self-moderate as groups, and enabled people to more explicitly recognise and respect that other people have different experiences and perspectives, and that they legitimately form different points of view. In this case, as participants became increasingly informed about current and potential use of data for health and care they became increasingly supportive of using health and care data for purposes beyond individual care. That said, there was also a consistent support for the general idea that policies should take into account the wishes of people who do not want their information to be used in this way.

On the final day of the Summit, participants formed a set of recommendations, underpinned by supporting principles, or conditions, as to how Londoners' health and care data should be joined-up and used. These covered participants expectations about: the consistency of the policy approach across all ICSs in London; data access and control arrangements; the use of de-personalised data for proactive care; the use of de-personalised data for system planning; the use of de-personalised data for research; and governance and oversight arrangements.

These recommendations were received by a panel of regional and national system leaders, policymakers and

politicians, with a commitment to use them to inform policy and practice. The recommendations were tested with representatives from marginalised and vulnerable communities during a one-day workshop convened shortly after the Citizens' Summit. Feedback and additional considerations noted in this session are also included in the report.

The full recommendations and conditions established through the OneLondon deliberation are set out here:

Consistency across London

- The vast majority of participants (nine in ten) expressed an expectation for a single set of policies across all health and care organisations in London
- Almost all participants agreed that all health and care organisations in London should join-up identifiable information to support individual care
- Almost all participants expressed an expectation that all health and care organisations in London join-up de-personalised information, as part of a population dataset, to support proactive care, planning and research

Access and control in health and care data

Recommendation:

We expect health and care data to be accessed and used by those who need information to perform their role, with the following conditions:

Conditions:

- A senior person or group should authorise the level of data a staff member can access, for a small number of categories (three to five)
- Data should only be accessed on a need to know basis, which needs to take into account the level of urgency/threat posed and vulnerability of the patient
- Safeguards should be applied, including:
 - Background checks for any staff being given access
 - Mandatory training on induction, repeated regularly, and checked
 - Additional safeguards, e.g. passwords, contracts, confidentiality agreements, appraisals
- There should be accountability, including:
 - Serious consequences for misuse (deterrents, penalties, sanctions), for the individual and the organisation
 - Checks and an audit trail should be built in to find out who is looking at which data, and this should be reviewed regularly
 - There should be mechanisms for raising concerns, e.g. whistle-blowing policy
- Vital information should be flagged and available to all, e.g. allergies to medication, End of Life care decisions

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Use of de-personalised data for proactive care

Once the concept was explained, the use of de-personalised data to support proactive care was considered low-risk and its preventative aspect was positively received. This issue proved uncontentious and therefore did not require further deliberation on Day 4 of the Summit.

Recommendation and conditions:

There was overall acceptance for de-personalised data to be used for proactive care, and this came with specific conditions. These conditions aligned with those specified for other uses of de-personalised data, i.e. planning and research.

- Data must not be shared with, or sold to, insurance companies or for marketing purposes
- Data should not be used by policymakers for reasons which are not in the public's interest, and there need to be severe punishments for misuse
- There should be reassurance and information about the process for de-personalising data; who is involved and how is this done

Use of de-personalised data for health and care planning and improvement

Recommendation:

De-personalised health and care data must be shared and used by relevant bodies to plan and improve services and demonstrably benefit health in London.

Conditions:

- Ensure the data being shared is accurate
- All parties must sign up to the 'five safes'³ in order to access/use data
- Data is shared for an agreed purpose (not for general analysis)
- Only data relevant to the specific analysis are shared
- Shared data must be held securely by all agreed recipients
- Maintain the national 'opt out' option, but also provide an option to opt 'back in'
- There should be legal penalties for misuse of the data (e.g. selling on to 'third parties')
- The organisations that are sharing/using the data should be stated and published somewhere for the public to see
- There should be a defined process for sharing the data that is published somewhere for the public to see

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Use of de-personalised data for research and development

Recommendation:

We expect a fair and productive partnership to meet the following conditions:

Conditions:

Benefits

- To be shared with the NHS including: shared Intellectual Property, royalties, stake (in companies), profits and outputs (i.e. discount on new drugs)
- To be shared across the NHS - to avoid inequalities (starting with London first), maintain British values and the principle of the NHS

Charges

- NHS to recover maintenance/usage costs as a minimum
- NHS to charge for access to data (not selling data) - for a time-limited period and/or license access to data
- Differential charging (reviewed every year) - tiered charges based on turnover and profit-making (e.g. start-ups, charities, universities, pharmaceutical companies may be charged relative to their turnover and potential to make profit)

Transparency

- NHS to produce a publicly available annual report (in plain English) detailing who has accessed and uses the data (and why), the impact of the research undertaken, and distribution of any financial benefits to the NHS
- NHS to publish criteria for vetting potential partners – i.e. the process they need to go through to obtain access (e.g. for charities, commercial companies, universities)

Other

- The 'five safes' model must be reviewed regularly – i.e. reviewing the legal and regulatory frameworks that underpin the five safes
- No access to data will be granted to insurance companies
- All accepted research proposals should demonstrate that they are in the public interest

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Governance and oversight

Recommendation: ongoing roles in policy development

We expect that there are several ways that the public are involved in ongoing policy development.

Conditions

- There should be a diverse citizens' advisory group where people are recruited to be reflective of London (i.e. similar to the OneLondon Citizens' Summit), with a lower age limit (17 years), supported with the right information to understand the issues
- Two or three citizen representatives should also sit on decision-making boards with people who work in health and care as well as experts. They need to be recruited (i.e. similar to how school governors are recruited) with the skills to take part
- These roles should be time-limited (and replaced every three years)

Recommendation: ongoing roles in governance and oversight

We expect there to be trustworthy oversight of the system of joining-up and using health information, which would include:

Conditions

- Experts playing a lead role in making detailed decisions
- With additional roles for experts from the health and care professions, scientists, and cyber security experts, as well as people with a range of other background who might bring creative ideas
- A specific role for a powerful elected representative at the London level, supported by the right expert advice to hold the system to account, and a role for the London Assembly
- Make sure the accountability process is transparent for all Londoners (should they wish to see)

This report

The structure of this report follows participants' journey over the course of the four-day deliberation. It sets out the recommendations formed and, importantly, captures the detailed reasoning and nuance behind these recommendations: the discussion and debate between participants, and the trade-offs which supported a civic-minded view to be reached on behalf of Londoners.



1

Introduction

Introduction

Policy context

The commitment in the NHS Long Term Plan⁴ to fully digitise health and care organisations by 2024 paints a new vision of data use within the health and social care setting. Data will be captured, stored and transmitted electronically, integrating health and care records across GPs, hospitals, community services and social care. To support this vision, NHS England announced in 2018 that it would be investing in Local Health and Care Record Exemplars⁵ (LHCREs) to enable efficient and secure access to patient health and care records across different parts of the NHS and social care services.

OneLondon is the name of the LHCRE covering the whole of London. Launched in May 2018, the programme brings together the leadership of all five Strategic and Transformation Partnerships (STPs), and the Greater London Authority (GLA), with support from The Mayor and London's three Academic Health Science Networks. The programme aims to:

- Create consistent access to data across health and care organisations
- Enhance abilities to use data to facilitate activities relating to proactive care and population health management
- Utilise de-personalised data to support system planning and research activities
- Provide patient access to their own health records to support self-care

The work being undertaken by the LHCREs has the potential to result in a range of benefits, enabling health and care professionals to have immediate access to patients' comprehensive care records, when and where they need it. This will improve the coordination of care, with better pathways between health and social care, enhance the precision of health interventions, deliver more personalised medicine, and improve population health management.

Project commissioning

In August 2019, the OneLondon LHCRE commissioned Ipsos MORI to undertake a programme of deliberative engagement with Londoners. Ipsos MORI was supported by academic advisor, Professor Graham Smith, and commissioned The King's Fund as a delivery partner to provide advice on public engagement and research methods, and health and social care data policy. The overall aims and objectives of this work were to:

- Undertake a deeper dialogue and deliberation with Londoners to understand their reasonable expectations as to how health and care information should be used for the purposes of joined-up care
- Explore what trade-offs are agreeable to meet these expectations, within the constraints of technical systems and the realities of professional and organisational practice
- Enable the public to express a set of recommendations or principles as to how health and care information should be used, in order to inform policy and practice in a way that builds legitimacy and trust with Londoners and health and care professionals

The project builds on previous work commissioned by OneLondon and undertaken by CurvedThinking, synthesising the existing knowledge about public expectations and attitudes towards the use of patient data in health and social care⁶. It also builds on engagement undertaken in September and October 2019 with 169 Londoners. This work commissioned by OneLondon and delivered by Ipsos MORI was designed to include the voices of marginalised and vulnerable groups and to fill gaps in the evidence around different uses of data that have previously been insufficiently explored. This engagement also helped to inform the development of materials for the deliberative engagement, as well as the recruitment approach.

Deliberative engagement seeks to identify participants' views around complex technical, societal and ethical issues by guiding them through a process in which they learn about, and debate different perspectives and trade-offs related to a topic. A programme of deliberation was deemed to be appropriate given the complexities of joining up health and care data, and the trade-offs around its use. It proved to be an effective approach; allowing the public time and space to debate and discuss relevant issues and for key expectations to emerge. The deliberation culminated in a recommendation forming exercise whereby participants were asked to form recommendations around the key topics discussed, along with a list of principles/conditions to which these recommendations should adhere to.

In addition to the large-scale deliberative event held over two weekends, a smaller workshop with marginalised and vulnerable communities was convened, details of which are contained later in this report.



2

Methodology

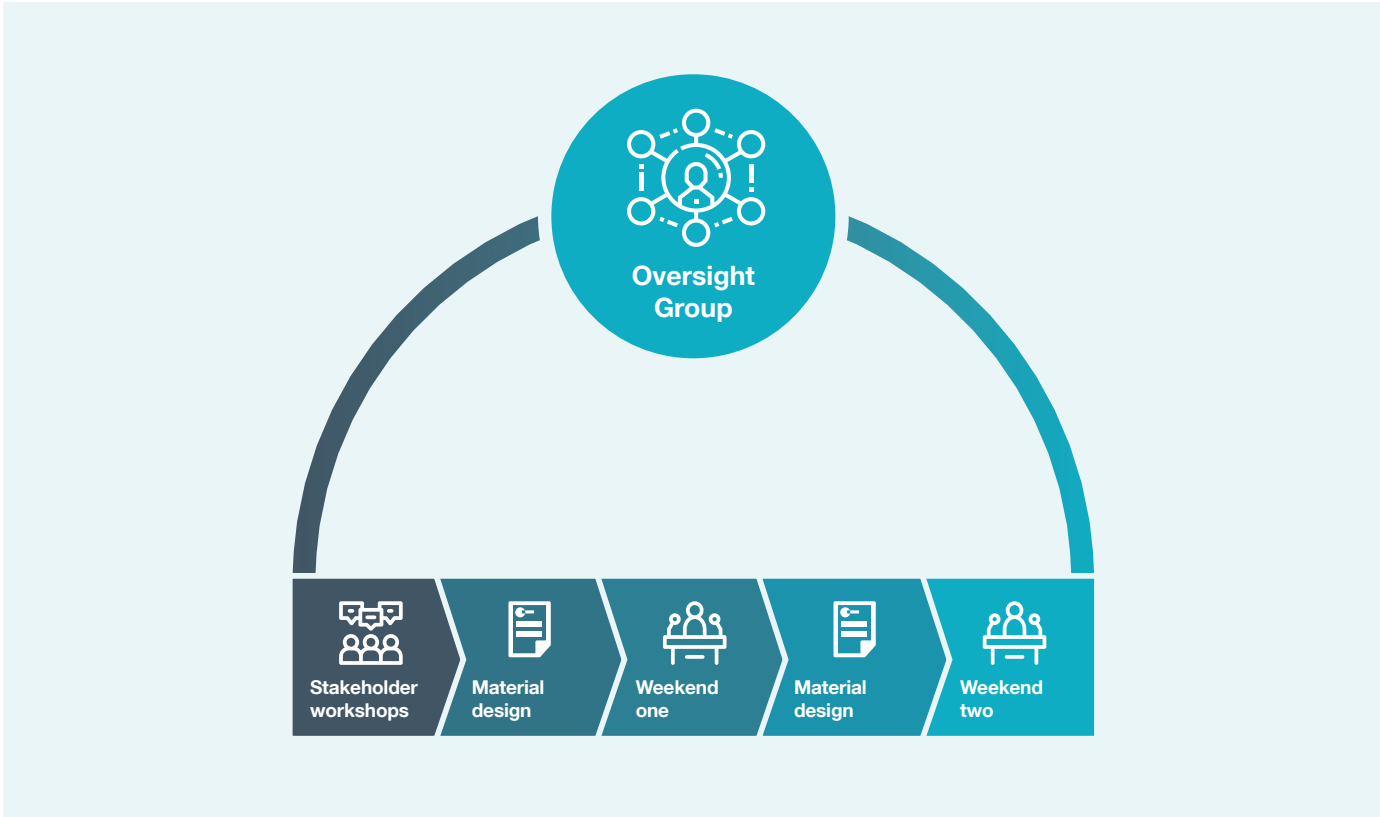
Methodology

A deliberative approach was considered the best way to explore public expectations in relation to the use of health and care data as it enabled a considered and informed discussion over a longer period of time than traditional methods of engagement. Importantly it provided an opportunity for participants to explore trade-offs between benefits and concerns in the context of how a health and care system operates and its associated constraints, e.g. patient safety, clinical quality, financial and legal considerations.

The deliberative approach helps participants to learn about a topic and allows them the freedom to express the issues that are salient to them and develop their views through discussion with other participants, expert presentations and discussions with specialists.

Figure 2.1 summarises the approach taken towards the design and implementation of the deliberation.

Figure 2.1: Design and implementation of the deliberation



Oversight Group

The design and delivery of this deliberative engagement was informed by an independent Oversight Group (OG). The purpose of the Oversight Group was to provide challenge to the design and development of the deliberation, including associated materials and stimulus; and to ensure that the engagement process was robust, rigorous, accessible and relevant. The group was made up of those with data expertise and engagement

expertise. The expertise and insight offered by the OG were crucial to the overall research process; as a result of the group's input, significant changes were made to the methodology and the content covered in the deliberation. Some OG members attended the deliberation where they answered participants' questions and helped present some of the key concepts. See Table 2.1 for a list of OG members.

Methodology

Table 2.1: Members of the Oversight Group

Name	Organisation
Natalie Banner	Understanding Patient Data
Phil Booth	medConfidential
Sarah Brooke	Member of Public Advisory Board, Health Data Research UK
Simon Burall	Involve
Professor Michael Burgess	The University of British Columbia
Vicky Chico	Health Research Authority
Amy Darlington	OneLondon
Mark Kewley	OneLondon
Rebekah Tailor	OneLondon
April Wareham	Working with Everyone
Amanda White	Health Data Research UK

Stakeholder workshops

During November 2019, three three-hour thematic stakeholder workshops were held to feed into the design of the workshop material to be used in the deliberative engagement. The first covered data flow between health and social care, and safeguarding data. The second covered secondary data uses such as population health management, service planning and quality improvement. The third covered data use for individual care and research. The three workshops were attended by a wide range of specialists⁷. For example, clinicians, strategy directors, analysts, public health officials, economists, industry representatives, information governance leads, social workers, legal representatives and patient representatives. Stakeholders were asked about participant information needs, how we should describe the different uses of data (and how this differs to what happens now), what trade-offs and dilemmas

they thought were important to explore with the public, and examples that could be used to help draw out the benefits and concerns – as well as some of the trade-offs – associated with data use for different purposes.

Participants of the stakeholder workshops were invited based on their key perspectives and/or expertise on the uses of health data and care data. Bringing together stakeholders from across a range of specialisms helped to ensure that the public participants in the deliberation engaged with, and were exposed to, the live issues and debates around the uses of data in health and care as identified by those working within the system. Bringing these key perspectives on the uses and joining-up of health and care data helped to frame and shape the deliberative engagement.

Table 2.2: Stakeholder workshop participants

Name	Organisation	Workshop
Salim Badat	Guy's and St Thomas' NHS Foundation Trust	Social care and safeguarding
Cathy Ingram	Guy's and St Thomas' NHS Foundation Trust	Social care and safeguarding
Zuhaib Keekeebhai	North London Partners; NHS Islington CCG	Social care and safeguarding
Stephen Murphy	Westminster City Council	Social care and safeguarding
Keith Strahan	NHS Digital	Social care and safeguarding

Methodology

Table 2.2: Stakeholder workshop participants

Name	Organisation	Workshop
Rachna Chowla	King's Health Partners	Population health, service planning, quality improvement
Stephen East	Lewisham and Greenwich NHS Trust	Population health, service planning, quality improvement
Fatima Elguenuni	University of East London	Population health, service planning, quality improvement
Ian Goodman	Hillingdon CCG	Population health, service planning, quality improvement
Sandra Iskander	Wandsworth CCG	Population health, service planning, quality improvement
Zuhaib Keekeebhai	North London Partners; NHS Islington CCG	Population health, service planning, quality improvement
Andi Orlowski	Imperial College Health Partners	Population health, service planning, quality improvement
Parashar Ramanuj	Imperial College Health Partners; Central and North West London NHS Foundation Trust	Population health, service planning, quality improvement
Kavitha Saravanakumar	Collaboration of North West London CCGs	Population health, service planning, quality improvement
Graeme Walsh	Public Health England	Population health, service planning, quality improvement
Chris Williamson	Southwark Council	Population health, service planning, quality improvement
Vicky Chico	Health Research Authority	Direct care, sensitive data, research
Stuart Crichton	London Ambulance Service	Direct care, sensitive data, research
Carol Dezateux	Queen Mary University London	Direct care, sensitive data, research
Louise English	University College London	Direct care, sensitive data, research
Natalie Fitzpatrick	University College London	Direct care, sensitive data, research
Manuel Gomes	University College London	Direct care, sensitive data, research
Sian Howell	Southwark CCG	Direct care, sensitive data, research
Phil Koczan	NHSX; Professional Records Standards Body (PRSB)	Direct care, sensitive data, research
Anna Kolliakou	King's College London	Direct care, sensitive data, research
Amanda Lucas	Discover-NOW Health Data Research Hub for Real World Evidence	Direct care, sensitive data, research
Rob Marr	North London Partners	Direct care, sensitive data, research
Denise McCoy	Public Health England	Direct care, sensitive data, research
Catherine Meaden	Google Health	Direct care, sensitive data, research
Ross Stone	AstraZeneca	Direct care, sensitive data, research

Methodology

Deliberative Citizens' Summit

The deliberative event was held over two weekends in central London locations. The event was named the OneLondon Citizens' Summit on uses of health and care data. The first weekend took place on 1 and 2 February, referred to going forward, as Day 1 and Day 2. The second weekend was four weeks later; on 29 February and 1 March (Day 3 and Day 4). This reconvened approach allowed participants enough time to digest the information they had received on the first weekend, reflect on the topic outside of the summit setting and complete an assigned homework task⁸.

A quantitative element to this project involved the administration of a combined pre and post project participation questionnaire for participants. This questionnaire collected information from participants regarding their knowledge and attitudes on the uses of health and care data. Additionally, a feedback form was administered to participants at the end of Days 1 and 2 (helping to inform the design of the second weekend). Details of these questionnaires can be found in Appendix G.

Approximately 100 participants were recruited to take part in this engagement⁹. Participants were recruited using a face-to-face on-street method, meaning recruiters approached members of the public in different local areas. Participants were recruited from across all five London Sustainability and Transformation Partnership (STP)¹⁰ areas and from across all 32 London Boroughs. Quotas were also set based on demographic characteristics such as gender, age, socio-economic group, ethnicity, and health status reflective of London's population. Other quotas included a minimum number of parents with children under the age of 16, a mixture of self-defining health and social care users (i.e. heavy, medium and light usage), and a minimum number of carers. Additionally, participants were recruited to reflect a range of attitudes to data sharing. Three attitudinal categories were developed during the exploratory research:

- **'Data unconcerned'** – those who have little concern about how their data is collected and used
- **'Data absolutists'** – unwilling to provide personal information despite the potential benefits
- **'Data pragmatists'** – who make decisions on whether to share personal information on a case-by-case basis – dependent on the benefits

These quotas were set to ensure participation of individuals from a range of backgrounds reflective of the areas they came from and the broad diversity of London. Further details on the recruitment process, including a full demographic breakdown of participants is included in Appendix A.

In recognition of their time and to cover any expenses incurred through attending the Citizens' Summit, such as travel or childcare, participants were provided with an incentive payment: £200 for taking part in the first weekend, and a further £200 for returning for the second (a total of £400 for taking part in both weekends).

Subject matter experts were invited to attend, contribute and, in some cases, present information about their area of work; details are included in Appendix C. These experts played a key role in providing information to participants through presentations, contributing to discussions, answering questions, and helping participants understand the complex nature of what was being discussed. Prior to the Citizens' Summit, experts were briefed to only join participant discussions when invited, to answer specific questions or to provide context, to give a balanced view at all times, and to provide fact rather than opinion.

The Summit comprised a combination of plenary sessions in which participants listened to expert presentations and were able to ask questions, table discussions in which the issues were debated and discussed at length, and plenary sessions in which facilitators fed back on their tables' views to all participants. The timings and details of the topics covered each day can be found in the discussion guides in Appendix E.

Facilitators followed a comprehensive discussion guide throughout the two weekends of the Citizens' Summit to ensure that the same topics were covered consistently across all tables. Materials underwent several iterations with the OneLondon team before being signed off. On Days 1, 2 and 3 participants were allocated to ten tables of approximately ten participants per table. Allocations were made based on the demographic and attitudinal information outlined in Appendix A, ensuring a mixture of key characteristics (e.g. age, gender, ethnicity, and differing attitudes towards data usage). Participants were mixed up and allocated to different tables for each day to ensure they were exposed to as many differing points of view and arguments, whilst also minimising the impact of 'group-think' or social desirability bias.

Methodology

On Day 4 of the Citizens' Summit, participants were allocated to working groups. These working groups were formed around four key themes of discussion that had been covered over the previous three days, including:

- Access and control in health and social care
- Data use to support planning and quality improvement in health and care, and also wider public services
- The use of data in research and development
- Public and political involvement in ongoing governance and oversight

In addition to these four working group themes, participants were asked to form recommendations for two 'banked' topics, including:

- The appropriateness of linking data to enable proactive care, as long as suitable safeguards are in place
- Whether all NHS organisations across London should contribute data to, and be able to access data from, a single database in the same way (rather than each organisation making its own decision about what to do on behalf of its patients)

The overall aim of these working groups was to culminate in approximately six clear recommendations for OneLondon (from each of the four working groups and two verified from the 'banked' topics). In order to set the scene for the working groups, and so that Summit participants knew what they were working towards, facilitators helped to steer each group in terms of what a recommendation could look like. For example, a statement of the group's expectation, followed by a prioritised list of their operating principles, conditions, assurances required, and/or caveats. Participants were instructed to limit the number of conditions of their recommendation to around eight, forming one overarching recommendation per working group.

Workshop with marginalised and vulnerable communities

To ensure the deliberative process engaged with and heard from a range of different voices, including marginalised and vulnerable groups, a full day workshop was convened in order to critique and, if necessary, build on the recommendations formed through the Citizens' Summit. This followed previous social research with marginalised and vulnerable communities completed by Ipsos MORI as part of the OneLondon engagement programme in September and October 2019. These findings helped to inform the design of the deliberation - most notably that there were no common group-

characteristics within or between groups that appeared to influence views and opinions. Rather, attitude towards data was a key driver towards acceptability.

The workshop aimed to engage with representatives of communities who experience the greatest difficulty in accessing healthcare and/or who may have poorer outcomes from care and treatment, including those who are disproportionately impacted by stigma. Experts, including those on the Oversight Group, advised that - due to reasons around psychological safety - it would not be appropriate to invite those from certain vulnerable and marginalised communities into a large-scale engagement exercise, however, ensuring they were able to feed into and inform the process was key. While there are limitations to the approach, the workshop helped to engage vulnerable individuals whose insight may have otherwise been missed, and helped ensure a wider range of voices were included in the process overall, strengthening the advice to policymakers.

The recruitment, design and delivery of this workshop was supported by Working with Everyone, an organisation specialising in providing a voice to communities who are often under-represented in public engagement. The individuals involved in the workshop included:

- Current or former drug users
- People who are homeless
- Domestic violence survivors
- Survivors of sexual assault
- Adult survivors of childhood sexual abuse and exploitation
- Gypsy, Roma and Traveller communities
- Migrants and refugees
- Sex workers
- Former prisoners

Facilitators followed a discussion guide throughout the workshop and workshop materials outlined the information provided during the Citizens' Summit, early findings from the Citizens' Summit (i.e. reasoning that led to recommendations), and the recommendations formed. The recommendations were tested with workshop participants to understand whether there were additional considerations/conditions specific to their lived experience that might not have emerged through the Citizens' Summit. Further information relating to the marginalised and vulnerable communities workshop, including the discussion guide, is included in Appendix E.

Methodology

Strengths and limitations of the approach

As with any chosen methodology, there are strengths and limitations specific to the Citizens' Summit.

- Deliberation is a robust qualitative approach where participants are given the information, time and space to explore and weigh-up real-world benefits, concerns, risks and constraints associated with an issue. It is well-suited to inviting the public to consider complex and unfamiliar issues in depth so that public views can meaningfully inform policy-making. It is used increasingly to build acceptable policy responses to questions where the issues at stake are more nuanced than a simple 'agree' / 'disagree' dichotomy. Recent examples include a 100-person citizens' assembly on constitutional change in Ireland (including policy on holding a referendum on abortion); and a 100-person citizen's assembly convened by the UK Parliament to explore policy responses to climate change. In this citizens' summit 100 participants were recruited, using on-street recruitment in each of the 32 London boroughs, so that the group was reflective of the diverse population of London; and attitudinal factors were considered so that the group had a mixture of views in relation to data sharing.
- The deliberative format of the OneLondon four-day Summit facilitated a genuine conversation that empowered participants to learn about the way that the NHS and social care are structured, and how this impacts practical aspects of information sharing. It enabled participants to explore the levels of acceptability of using and accessing health and care data for different purposes. A mix of plenary sessions with experts and in-depth table discussions supported participants to weigh-up benefits and concerns, and to consider the trade-offs that were agreeable to ensure their expectations could be met in a real-world context. These activities and in-depth discussions support the emergence of an informed 'mini-public', which is unlike the form of discussion generally encountered through focus group methods, or quantitative approaches. However, the group is therefore reliant on receiving balanced information and hearing a range of views. This deliberation used an expert Oversight Group to develop the materials and ensure balanced content. During the deliberation, experts were asked to present facts rather than advocate a position; with mechanisms for participants to ask questions and receive answers on any aspect of the materials.
- A feature of deliberations, this one included, is that the interactions between participants change over the course of the two weekends, as they become more familiar with the topic area and more familiar and

trusting of one another. At the beginning, participants were generally comfortable stating opinions; but by listening to others over the course of iterative group discussions and plenary, participants increasingly began to share opinions and their reasoning. This supported participants to respectfully challenge and self-moderate as groups, enabled people to more explicitly recognise and respect that other people have different experiences and perspectives, and that they legitimately form different points of view. It is in this context that the views and reasoning set out in the report should be understood.

- Although we are confident that the group was appropriately diverse and thus reflective of the London population, the Summit was held in two central London venues meaning that travelling to these, over two separate weekends, may have discouraged some people from taking part.
- Whilst the work is robust, and the size of this deliberation is large relative to other comparable data deliberations, it does not represent an opinion poll of Londoners' views about data sharing. Further work will be required to share with other Londoners what this mini-public recommended and why, to test the wider acceptability of policy across the region.

The following relate to limitations of the approach used for the marginalised and vulnerable communities workshop.

- Throughout the workshop, there was an overall feeling that participants did not have enough time to reflect on what was being discussed and unpack the nuances in relation to the information they were given. With this considered, two days may have been more appropriate to allow more time for information provision, discussion time, and reflection. That said, it may have been difficult to keep participants engaged for this length of time
- The number of participants who attended the workshop (approximately 20) is another limitation to the method used. Although this increased the likelihood of each participant being able to voice their views, a smaller number overall reduces the likelihood of these views being reflective of the communities that were represented at the workshop
- Whilst workshop participants provided their views as people with lived experiences, we must recognise that their views do not necessarily reflect the range and diversity of those from the various communities. It should also be noted that these participants regularly attend workshops of this nature, particularly within the health and care space, so they are arguably more informed by virtue of this



3

Navigating this report

Navigating this report

Structure of this report

The report follows the structure of the four-day deliberation, which is visually displayed in Figure 3.1.

- Chapter 4 details findings from across discussions on Day 1 about expectations of a health and care service and the role of data
- Chapter 5 covers access and control in health and care, discussions that spanned over the afternoon of Day 1 (health) and the morning of Day 2 (social care). It also includes the access and control working group's recommendation (Day 4), as well as considerations from the marginalised and vulnerable communities workshop
- Chapter 6 details the use of de-personalised data for proactive care, which was discussed on the afternoon of Day 2
- Chapter 7 reports on the use of de-personalised data for health and care planning and improvement, which was discussed on the morning of Day 3. It also includes the planning and improvement working group's recommendation (Day 4), as well as considerations from the marginalised and vulnerable communities workshop
- Chapter 8 covers the use of de-personalised data for research and development, discussed on the afternoon of Day 3. It also includes the research and development working group's recommendation (Day 4), as well as considerations from the marginalised and vulnerable communities workshop
- Chapter 9 covers ongoing involvement in policy-making and oversight, a new theme that was discussed as part of one of the four working groups on Day 4. This chapter details the group's discussions and its recommendation, as well as considerations from the marginalised and vulnerable communities workshop
- Chapter 10 details findings from a final discussion about consistency across London on the afternoon of Day 4

Interpretation of findings

Applying criteria used in the social science literature¹¹ to determine the credibility of qualitative research findings, we can be confident that the principles and views presented in this report are credible and valid due to the following strategies used in this deliberation: accounting for bias, meticulous record keeping and systematic analysis, validation and data triangulation. The culmination of this deliberation is this report which provides detailed and nuanced evidence on how participants' views, concerns, aspirations and expectations can be used to inform London-wide policy.

This report uses the conventions of qualitative social science reporting:

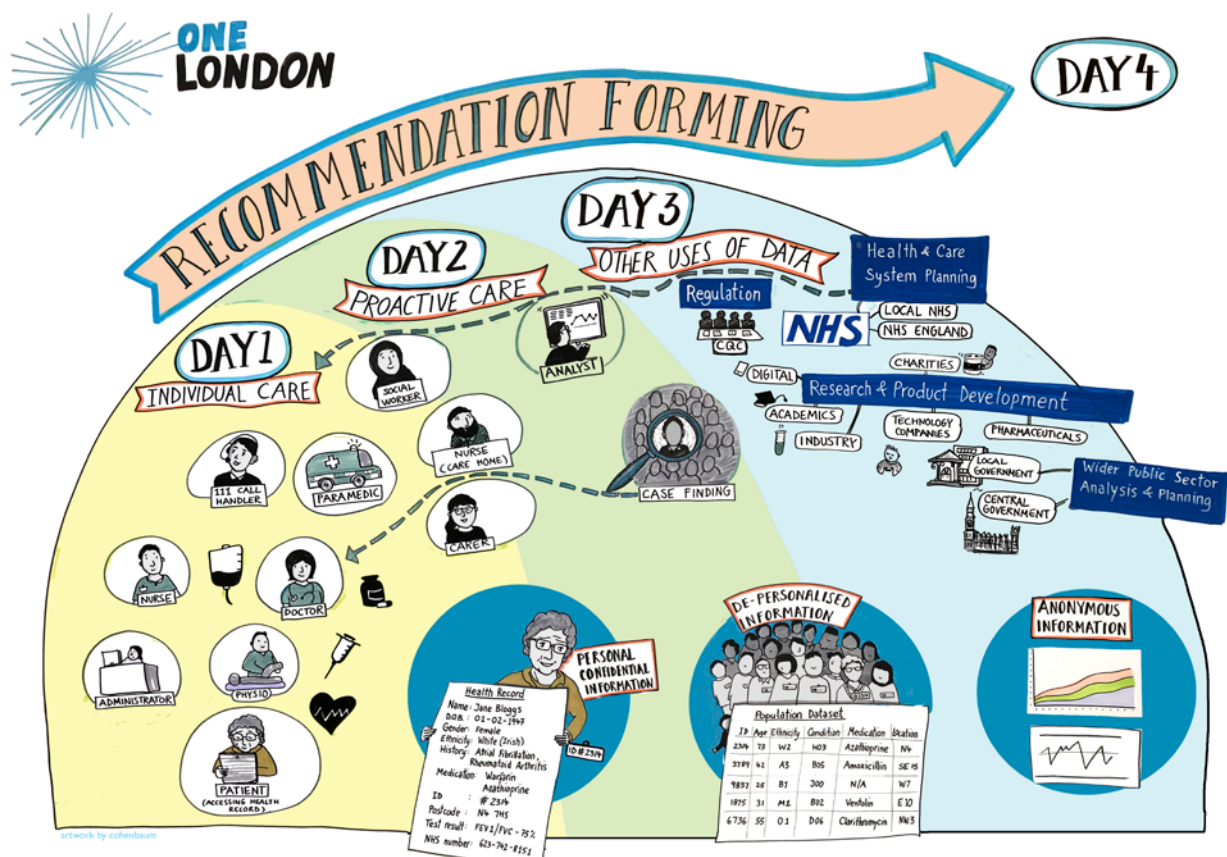
- An indication via "a few" or "a limited number" to reflect views which were mentioned infrequently, and "many" or "most" when views are more frequently expressed. The use of "some" to reflect views which were mentioned some of the time, or occasionally. Any proportions used in the reporting should be considered indicative, rather than exact.
- This report focusses on perceptions rather than facts. Throughout the deliberation, participants had some misconceptions around facts, and had low awareness of how the NHS uses data for planning and research. This report indicates where perceptions of participants are reported, and where an analysis of the implications of these perceptions is offered.

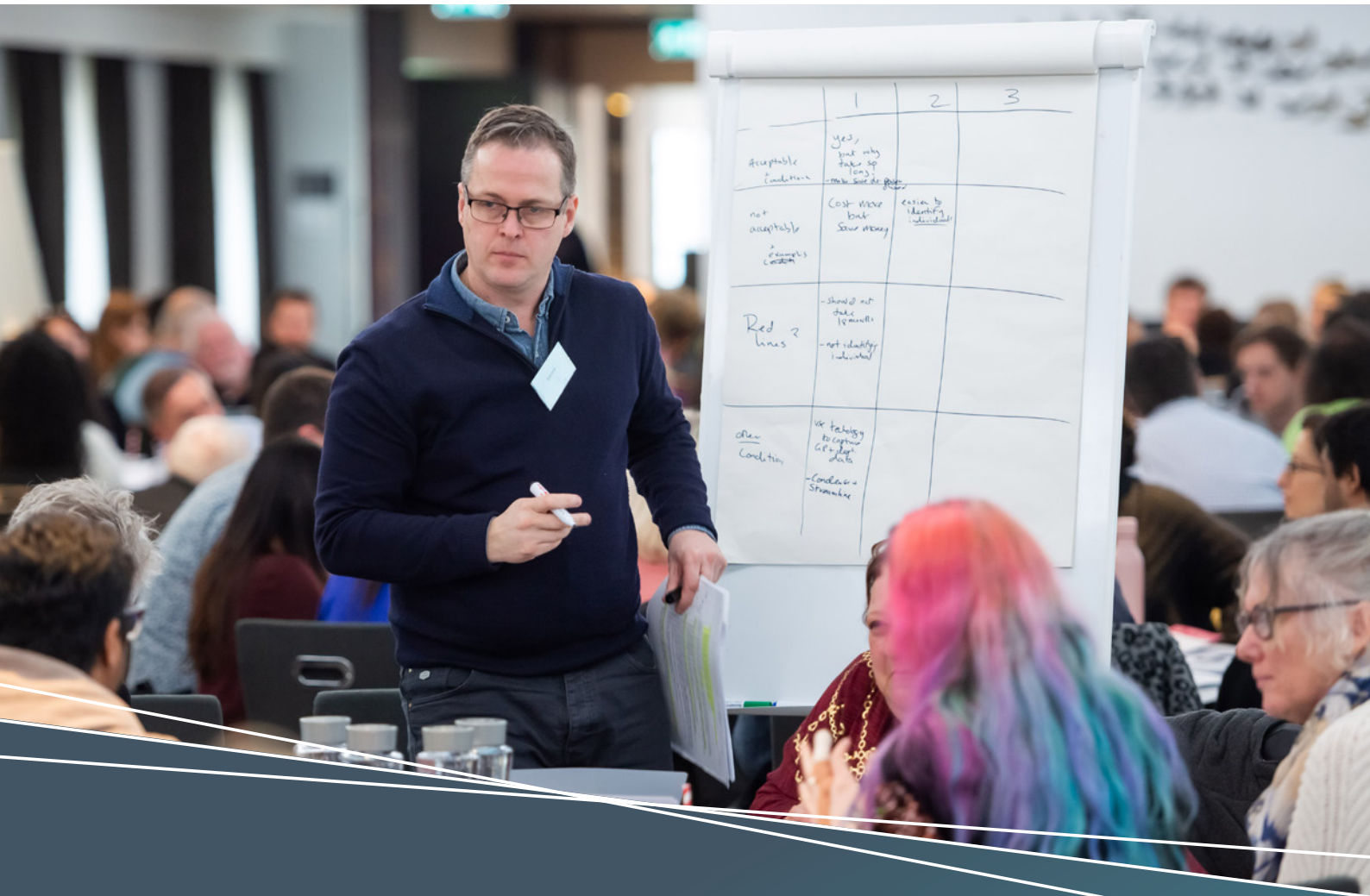
Stylistic conventions

We have used the convention of describing the word data in the singular rather than plural, plus the terminology around patient data recommended by Understanding Patient Data¹² (e.g. talking about individual care rather than clinical care or direct care; and describing data as either personally identifiable or de-personalised).

Navigating this report

Figure 3.1: Infographic showing the format of the four-day OneLondon Citizens' Summit¹³





4

Expectations of a health and care service and the role of data

Expectations of a health and care service and the role of data

Session overview

The Citizens' Summit began with an introduction to the NHS and social care. This session aimed to provide the necessary context for the entire four-day Citizens' Summit. It was anticipated that participants were likely to have varying degrees of prior knowledge and understanding of the system, and how it is organised and run. It was therefore important to provide them with the same basic level of understanding.

Information provision

A presentation highlighted the wide range of organisations involved in delivering health and care and the reality that many are run as independent organisations, for example, GP practices, some care homes and home care agencies. It was explained that the care team is made up of a whole host of individuals, not always solely clinicians.¹⁴

Participants were surprised by the enormity and complexity of the system, the organisations involved, and how it is run

As they learnt about the wide range of health and care organisations involved, there were participants who were particularly surprised to hear that:

- **GPs are independent contractors incorporated as distinct legal entities rather than being part of a statutory NHS organisation**
- **Social care is funded by local authorities, and not the NHS**

There were spontaneous questions, even at this very early point, as to whether organisations providing care have access to a centralised database.

"At the point when you go to one doctor, they have all your information in one place. Is that how it works?"

(Female, from Wandsworth, Day 1)

Initial questions raised by participants following the introduction to the NHS and social care

- What does this mean for privatisation of the NHS?
- Are services accessing our data when they need it?
- Does this mean social care isn't paid for by the taxpayer?

Expectations of a health and care service included one which is joined-up and shares information, and is focussed on prevention

Participants were asked to think about their own expectations of a health and care service, and how it should be run – whether it should be a service that responds to people's needs (i.e. to fix you when you are ill), or one that attempts to keep people well (i.e. by anticipating need and intervening). Figure 4.1 provides a summary of participants' expectations of a health and care service.

There was **a strong sense that the service is currently predominantly a 'sickness service'**, designed around attending to people in crisis and those who are unwell, rather than one to serve people who are healthy and well. There was a sense that the service should meet both aims.

This linked to **an expectation that services should ideally be more preventative**, attempting to do more to educate and encourage people to look after themselves. Whilst there were examples provided by participants of how the NHS currently does this (the health check at age 40, breast and cervical screening), there was also **a sense that there were opportunities not currently being utilised**. Examples of smoking and dietary advice to prevent diseases like diabetes were provided here.

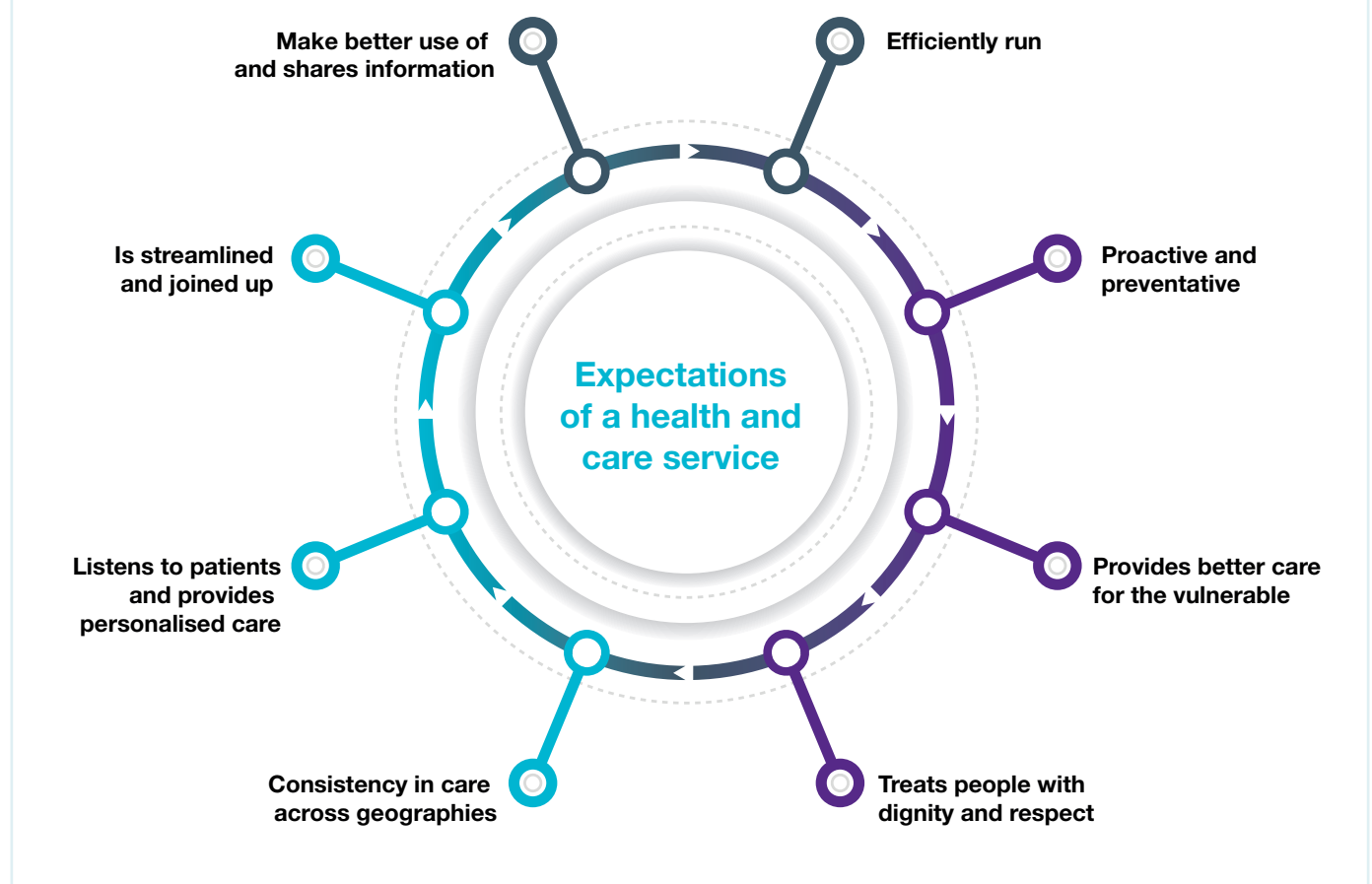
"I agree with that as well, it should be more about preventing, we wait until we get ill then it's like, what will the NHS do."

(Female, from Harrow, Day 1)

There was also a sense that **the health service should be more proactive**, by finding out how people are and checking in with people to provide a 'holistic' service. Mental health and mental health services were viewed as examples of where the system currently fails to do this in a way that it should.

Expectations of a health and care service and the role of data

Figure 4.1: Expectations of a health and care service



Knowledge of how the system currently plans care was limited

Many lacked awareness of how the health and social care system currently plans the services it provides. **Planning was perceived to be driven by available funding**, with resources differentially allocated based on the size of an area: most talked with references to London boroughs. It was assumed that the larger, more populated areas were allocated more money. There was also an assumption, raised by some, that **the system must use information, data and local insight** to plan how to use and distribute services and resources. However, this was still perceived to be linked to the availability of funds.

“They must get figures every year to see what trends are for those periods of times and when it might be at capacity. The powers that be at the top look at the area, a city compared to rural would be different. A lot of it will come down to resource, money and funding.”

(Male, from Bromley, Day 1)

There was some suggestion that research, too, must feed into planning decisions and that planning is based on need and means testing, especially the case for social care services.

“The demographic of that area, like how many young children, older, child-bearing age people. You need to anticipate your services. The same way if they decide if they’re going to close a school. They’ve done calculations to see if the population will need those services.”

(Female, from Enfield, Day 1)

Expectations of a health and care service and the role of data

Though there was some awareness of drug development and the role of clinical research

While not the focus of this discussion (although included on subsequent days), participants discussed the process of how the NHS operates beyond individual care and the role it plays in the development of new treatments. When asked how new treatments, drugs, products and services make their way into the NHS, while some had little idea, **others talked about animal testing, followed by clinical trials.** Private sector organisations and drug companies were assumed to dominate this space. There were occasional mentions of the National Institute for Health and Care Excellence (NICE), which decides whether drugs should be approved and upper limits on price per Quality-adjusted life-year (QALY). And some talked about how drug reps go into GP surgeries to sell products to the NHS.

GPs were assumed to hold the most patient data

When the discussion moved on to explore what health and care information people thought was held about them, why and by whom, **GPs were assumed to hold a lot of information about people,** including demographic information (contact details, ethnicity), blood type, current and previous conditions, medications, test results, previous medical appointments, vaccination history and health-related behaviours previously disclosed (smoking, alcohol consumption, drug use). There was **a sense that GPs held information gathered for, and disclosed by, individuals over the years.**

There was an assumption that this information (GP held data and notes) was accessible to other services

With some references to a 'centralised database', many presumed that hospitals, walk-in centres and the NHS 111 service would be able to access information held by GPs about their patients.

"GPs, A&E, the whole service. If I go to A&E and I'm unconscious, I'd hope they'd know I was allergic."

(Male, from Greenwich, Day 1)

This assumption was linked to **a fundamental expectation that relevant information would need to be accessible to prevent mistakes which could compromise patient safety.** The reliance on patients, or their family members, to provide vital information, such as which medications they are on, was viewed as inadequate given language barriers and the reality that people may be forgetful or have conditions which affect their memory.

[Reflecting on whether an NHS walk-in centre should have access to medical records] "If they haven't got your records, there might be some medication you take that isn't good with another medication. They could give you this medication, and it could have devastation. You have people where English isn't their first language, or people with dementia, or very forgetful like me. I had to put my medication in my phone because I take so much, I couldn't remember it."

(Male, from Westminster, Day 1)

Some shared positive experiences of joined-up data systems.

"They do link up. I spent a lot of time hospitalised last year, and I'd go to the hospital, go to the GP, and all my notes are all there. My doctor sees everything."

(Male, from Barnet, Day 1)

But as participants discussed this further, and shared personal experiences, they began questioning whether information was joined-up.

"I would assume also that the information that they have at the GP, the hospital can see it too. I'm not sure, because sometimes when you go to the hospital, they ask so many questions, but you think, how can you not know? Don't you have all my information? It is exhausting because you're in so much pain and still need to explain it."

(Female, from Merton, Day 1)

Expectations of a health and care service and the role of data

Participants were surprised to hear that data is not more joined-up, although for some this confirmed their concerns that the system is too fragmented

Following an informative video produced by the Professional Records Standards Body and Understanding Patient Data, and a further presentation which demonstrated that there is not one single record about a person's health and that information is fragmented and under the legal control of different organisations, participants reflected that **they were surprised that services were not all currently joined-up when it came to data.**

Given that this was one of their expectations, this worried many. It was described as 'frightening' and 'astonishing' by some, with reference to urgent situations where information might be needed but where the patient was not able to provide this.

Participants assumed that information held in different organisations' records was relevant to the service provided

Participants moved on to an interactive exercise where they were allocated cards representing different data, ranging from basic demographics to types of medical information. They were asked to sort the cards, categorising which information should be captured in a GP, hospital and social care record.

Participants decided whether **information should be held in each record based on a need-to-know basis, linked fundamentally to safety and the relevance of the information to the care being delivered.** For example, medication was deemed necessary to be captured in a hospital record if it affected the reason a patient was in hospital. Similarly, mental health information was deemed as necessary to be included within a social care record if it meant that staff could treat a person in an understanding way, as well as protecting themselves.

Generally, **it was suggested that GP records should contain most information**, except for irrelevant information (i.e. financial records).

"It should all be in the GP records - fertility records, detailed records, sexual health records."

(Male, from Southwark, Day 1)

Though some participants felt it was important that **very private information (i.e. sexual health) should not be shared with a GP** without the patient's consent.

"They have sexual health clinics that have no link to the GP. They are there to keep it private."

(Female, from Hammersmith & Fulham, Day 1)

It was **generally considered that hospital records should include most information.** The important factor here was the reason for being in hospital and the necessity of relevant information. Participants often talked about how staff would need access to key information if patients came into hospital unconscious.

Overall, **less information was deemed necessary for inclusion in a social services care record**, though there was a sense that a summary of the most important medical information (i.e. medications) would be useful for care staff to have access to. At this point, a link was made between social services and private and third-party organisations, which made some feel hesitant about the sharing and storing of information.

The session ended with three short lightning talks from experts, outlining why people may need to access information, different reasons why data is used, the benefits of joining-up information, and some of the challenges. A short question and answer session with the speakers followed, along with a presentation which explained the rules and regulations in place around the uses of data. The distinction was made that these differ where people are providing care directly to a person, and where information is used for other purposes like planning and research. The national data opt-out was also introduced at this point.

Final reflections on the potential uses of data, again centred around **safety and necessity.**

*[Reflecting on whether paramedics need information]
"Yes. I was short of breath and dizzy. I was all over the place, a lot of information I couldn't give to you. Something could be really important. They might want to give me medication that conflicts with something I have already taken. Any point of emergency should know everything about you."*

(Male, from Havering, Day 1)

Expectations of a health and care service and the role of data

Considerations for future communication approaches

- **It is important to consider how informed the public are about the complexities of the health and care system.** Participants typically assumed that the health and care system was simpler than it is and were surprised to hear it is made up of so many organisations operating independently. Therefore, they perceived the system to be more joined-up in terms of the services it provides, and the data used to inform these services
- **An explanation of what social care is and how it works, is essential to engaging the public about this issue, as the public are likely to be less informed about who provides these services and who is involved.** Social care was less understood compared to health care because participants had less experience with the types of services provided by social care. Even those who had experience did not know how the system worked fully. Also, it was often associated with negative perceptions about local authorities, care homes and carers. Participants were also less knowledgeable about the different roles within social care, meaning they were not as clear about the relevance or importance of different social care staffing roles
- **Receiving good care and timely access to services is important to people.** When discussing their expectations, participants' primary expectation was that they would be able to access services as and when they needed to
- **Access to information was deemed acceptable at this point where it was necessary for staff to have this and where safety would otherwise be compromised.** This means that it is important to explain to the public the reasons why certain services (and the staff working within these) require information in order to deliver safe care



5

Access and control in health and care data

Access and control in health and care data

Session overview

On Days 1 and 2, after an initial introduction and discussion about what health and care data is and how it is used, participants moved on to consider who should have access to what information for the purposes of individual care. Discussions focused first on health settings, before moving onto social care.

Through a series of expert presentations, exercises and case studies, participants explored Roles Based Access Control. This is the concept of grouping job roles into categories, with each category allowing different levels of access to health and care data. In doing this, participants identified the controls, or safeguards, that would need to be in place so that access to joined-up information to support individual care was trustworthy.

Information provision

An initial presentation explained that:

- Previous research shows that the public expects health information to be shared for the purposes of individual care
- There is a policy dilemma around how to ensure information is routinely shared where it is needed, but with the right access controls to make people feel that the system is secure
- Teams of people deliver care to individuals and need information to do this, but only information that is relevant to the task they need to do
- Staff could access data for purposes other than individual care and treatment, whether negligently or deliberately, but there are controls in place to limit this

Participants were introduced to the concept of Roles Based Access Control (RBAC), a way of managing access to health and care data by giving staff varying permissions to see different types of information. The RBAC spectrum ranges from the option of no differentiation in access between different roles (at one end) to the option to create lots of different RBAC levels (at the other). The initial discussions were focussed on health data only.

Participants began by spontaneously considering who should have access to what health information. They were asked to group different job roles into those that

should have access to 'all' information, those that should have access to 'some' (for example, a summary of health conditions, medicines, allergies and adverse reactions), and those that should only have 'basic' access (basic demographic data such as name, address and age).

Following this exercise, a further presentation reiterated what they had heard earlier on: that there is no such thing as a single health and care record. The potential consequences of this fragmentation of information were raised, as well as the opportunities presented by joining up data. The presentation also highlighted that non-clinical staff are often part of a care team. With this additional context, participants returned to their table discussions to review how they had initially grouped the different job roles. To help with this, they considered:

- Three case studies that demonstrated how the wider care team may need access to information. This included an individual who had been diagnosed with cancer, someone who needed a GP appointment and blood test, and an individual with diabetes who needed surgery and physiotherapy, who also had been diagnosed with schizophrenia
- A graphic summarising some of the trade-offs involved in making decisions about access to data - safety, quality, burden on the NHS, privacy, convenience and joined-up care - was also shared. Participants were invited to explore these trade-offs; for example, if they expressed a desire that only doctors could see information, they were challenged to think through what this might mean for creating additional burden on the NHS and the potential reduction in convenience for patients (for example, GP receptionists no longer being able to confirm simple blood test results).

Access and control in health and care data

Overall, there was support for joining up health data and allowing access for health professionals

Overall, participants wanted to ensure that health professionals had access to the **data they needed to do their jobs well**. When participants considered the different trade-offs around joining up and allowing access to information, **safety and high-quality care were generally thought to be more important than other factors such as privacy**.

“Privacy is fine, but you have to be alive. If something goes wrong with privacy there’s a comeback. If something goes wrong with safety, that could be final.”

(Female, from Enfield, Day 2)

Initial questions raised by participants following the introduction to Roles Based Access Control

- Why isn’t data currently joined up?
- What happens in emergencies?
- If you were unconscious, how quickly can a hospital access our records?
- Can I access my own health records?
- How much will this cost?
- What are the benefits in terms of a centralised system?
- Who decides what goes in?

For many, **convenience** was an acceptable reason for data to be shared more widely. For example, if a receptionist was able to give test results so that patients could call for them rather than needing an appointment. In addition, allowing access to data could lead to **better decisions and more joined-up care** which would benefit the patient and the health service. They also suggested it would mean that patients would need to explain their symptoms or condition less often, which would be better for the person receiving care.

As mentioned previously, in chapter four, there are occasions when allowing access was seen to be particularly important, as participants believed information about medications and pre-existing conditions could help with diagnosis and treatment:

- For staff required to make **emergency decisions** about care such as paramedics (particularly relevant as the patient may not be able to impart the information themselves)
- **Safeguarding for patients and staff** if they are at risk (for example, due to the mental health of the patient)
- **People at particular risk or in need of additional support or care** (for example, older people and those at the end of life)

Some groups suggested that an individual’s data could be flagged in these latter cases.

Access and control in health and care data

Concerns were raised that were important, but ultimately less important than safety

When discussing access and control, participants also talked about joining up health and care data. There were concerns raised by participants, and these are summarised in Figure 5.1.

However, on balance the **benefits of joining up data between hospitals and GPs, for example, were seen to outweigh these risks**. In addition, some saw benefits to centralised records, including **back-ups** in case of fire or loss, albeit with a corresponding risk of what would happen if the database **crashed**.

Figure 5.1: Concerns raised about joining up health services

Hacking Concern that data could be hacked and used for identity fraud, spamming, identifying vulnerable people or finding out when they are in hospital to rob their house. Concern increases where datasets have more data.	Inaccurate information Concerned that incorrect records or out-of-date information could lead to wrong assumptions. For example, some participants said they had been invited to an asthma check but did not have asthma.	Data being ‘sold on’ Some were concerned spontaneously about the use of data to target marketing, or being used by companies to make a profit, especially if that had no benefit to the NHS (for example, using it to sell insurance).
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It was important that staff saw only the information that they needed

Although safety and high-quality care were more important to participants than privacy, privacy nonetheless remained important. There was a view that staff should only access data on a **‘need to know’** basis. For many participants, the key determinant of what data a staff member should have access to was **needing access to the data to do their job well**. Many emphasised the importance of sharing just enough data, so that staff have sufficient information to do their job well but no unnecessary or excessive information.

This was important in order to protect **privacy** and to ensure that staff focused on information that was **relevant**. For these reasons, participants largely thought that more specialist staff (such as physiotherapists, pharmacists and radiographers) would only need access to ‘some’ health data that related to the particular condition they were investigating, along with safeguarding information, and not ‘all’ health data.

Qualifications and training were a key differentiator of who should be able to access what data

Participants suggested that **staff should only have access to the data they are qualified to understand**.

- Participants were broadly comfortable with staff who are **medical professionals, responsible** for diagnosing and treating conditions, or who would ‘be held responsible’ for errors, having access to all of their health information (for example, GPs or consultants)
- In contrast, those who were **‘following orders’** that others gave them rather than making decisions about a patient’s treatment (for example, administrative staff and receptionists) and those providing ‘care’ rather than being medical professionals (for example, health care assistants) were perceived to require less information

Some were concerned that if people with less training had more information, they might start to make decisions they were not qualified to make.

“On the grounds that the ‘All’ are professional people. Their job description is a tad bit higher. A healthcare assistant works under most of these professionals.”
(Male, from Brent, Day 2)

Access and control in health and care data

Other factors also affected trust in different job roles and who should have access to what data

Alongside this distinction and levels of qualification, **some roles were naturally more trusted than others**. GP receptionists were discussed at length, partly because they were associated with working in open plan locations, and therefore any information they have access to could be overseen or overheard by other patients. In addition, there were concerns that administrative staff may 'gossip' or that their location within the community meant patients may know receptionists personally or via other people. Equally, other participants had known their GP receptionists for a long time and trusted them.

Another factor was the type of contract staff held. Agency or temporary staff were generally trusted less as they were thought to have 'less to lose'. However, in a life-threatening situation, most participants would choose to allow these staff to have access to their data as safety overrode their other concerns.

Participants therefore broadly agreed with some form of Roles Based Access Control

Given these **distinctions that participants drew between job roles**, there was broad agreement that some roles should have access to more information than others, and that a small number of levels should therefore be defined.

"I agree with the different levels. I don't believe everybody needs to see everything, just because they work in a hospital. I think it should be need-to-know, who needs to see."

(Female, from Hammersmith & Fulham, Day 1)

Several groups discussed the important role of **deciding who sees what**. They suggested GPs would be well placed to decide this, as the GP is one of 'the most powerful positions in the NHS'.

However, this view was not universal, with several participants expressing the view that they were happy for information to be accessed more widely, and that they trusted a wider range of roles to have access to their data.

"My gut reaction is that we don't need all the different roles, in the ultimate analysis, if lots of other people can see my record, I'm not really all that bothered. It's not like financial records, where they could commit fraud."

(Male, from Hillingdon, Day 1)

The type and amount of information being accessed also mattered

The level of comfort around data being accessed was affected by the **type of information** in question. Data that participants were more concerned about included information about self-harm, alcoholism, mental health, sexual health, fertility, abortion, drug abuse, HIV/AIDS. They were worried that it might become a **barrier to seeking help** – i.e. if people are concerned about who has access to this sensitive information, they may consequently not use services that they need. A few suggested that there should be **greater choice** for individuals around who should have access to this more sensitive data, i.e. that they should be able to choose who can and cannot access it.

"I'm mildly allergic to morphine, and I want that to be shared. But if I had an abortion when I was young, I wouldn't want that to be shared anywhere."

(Female, from Islington, Day 1)

A few groups questioned the amount of information that would be accessed. They suggested that the **detail of what is discussed** in a GP appointment would not need to be shared, as long as the conclusion or diagnosis was available to those who need it. A couple of groups mentioned that being able to see the full record of what appointments you had might be overly intrusive. They did not think that all staff should be able to see how many times a person had accessed a service before as they did not think it was relevant.

Participants expected controls to be in place

Expert presentations outlined that controls were in place to safeguard people's information. This was important and reassuring for participants.

Particular controls that were expected are shown in Figure 5.2.

"He mentioned that every healthcare individual has their own login, and it's tracked – that's quite reassuring."

(Male, from Enfield, Day 1)

Access and control in health and care data

Figure 5.2: Controls to safeguard people's information

Tracking of who accesses data The use of personalised logins to track who accesses what data was reassuring for many participants.	Serious consequences It was also reassuring to participants that there were deterrents in place if staff do not use the data as intended, albeit recognising that this would only be detected after the abuse of data.	Staff training Some participants thought staff should be trained on how to handle the data, although others were not sure that it was worth the time it would take to train all staff.	Confidentiality agreements Some thought staff should sign these agreements in order to access the data.	Background checks Extensive checks on staff before allowing them to access data would increase trust in Roles Based Access Control.
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There was movement towards allowing greater access than participants had initially been comfortable with

The examples given in the presentations and the case studies encouraged people to think more broadly about how access to health data could be helpful. In general, from the initial exercise where participants grouped job roles into who they thought should see ‘all’, ‘some’ or ‘basic’ information; having received further context about the importance of the wider care team and through reviewing the case studies and deliberating the trade-offs, they **became more comfortable with allowing greater access** to data.

“Generally speaking, we’ve moved more people over to access more information as a whole, and I think that’s justifiable looking at the examples we just looked at here. I would have never thought they needed this information, but when you think about it, for example, the patient with diabetes, maybe it’s better if the physiotherapist does know the patient’s background.”

(Male, from Hillingdon, Day 1)

This was particularly the case for administrative staff, where many participants began to recognise why members of the wider care team might need access to information and became more willing to allow this in order to make services **run more efficiently** and **reduce the burden** on GPs and doctors. Even so, limits remained: for example, some thought receptionists should have access to, and be able to share, negative test results, while positive tests results should be delivered by a healthcare professional so that questions could be answered.

Information provision about social care

On the morning of Day 2, the discussion moved onto **access and control in social care settings**. Participants listened to a presentation describing what social care services do, how healthcare and social care staff work together, and explaining the different settings in which social care services are provided and the different roles in a social care team.

The presentation outlined why social care services need access to some patient data in order to develop care and support plans for individuals. Participants were reminded that different people in a care team need access to the data, but with differing levels of access and under strict controls. It was asserted in the presentation that staff in those teams **need to know about an individual** to deliver effective care, but should **only see what is relevant** to the task they need to do. Examples of joined-up information included detail for a care worker **about how or when to administer a person’s medication** as part of their care plan, or a hospital discharge summary. Participants’ attention was drawn to some of the trade-offs around who should have access to what data: difficulty defining what is relevant; rights to privacy versus professionals communicating effectively; the amount of differentiation between roles needed to maintain public trust whilst maintaining efficiency for all.

On their tables, participants completed an exercise assigning different social care roles to having access to ‘all’ or ‘some’ of their data, or basic information only. Case studies were provided to highlight different examples for further discussion.

Access and control in health and care data

Many of the same considerations emerged for social care as for health settings

In many respects, the discussions about Roles Based Access Control within social care **mirrored the themes that emerged from the Day 1 discussions about health settings.**

In general, there was acceptance of some joining-up of health and care data. Many participants spontaneously thought a social worker would need information about conditions, medication and so on in order to 'do their job' and ensure people get the right services and care. They raised the point that if a carer knew about previous conditions, they would be more vigilant and better prepared to catch problems early. At times, the trade-off between safety and privacy was weighted more strongly towards safety; for example if the individual was not able to remember details of their condition and medication.

"I think that first and foremost safety should be at the forefront. Even though there may be less trust, I think more people having access to your information comes down to safety."

(Female, from Harrow, Day 2)

Participants differentiated between types of staff in a care setting, thinking that some should have more access to data than others. As with staff in a health setting, this again followed a similar hierarchy, with more access given to those coordinating care, giving orders and instructions than to those receiving and acting on these.

"We were saying that the level of access should depend on specific roles and responsibilities... There should be a hierarchy of roles. For example, supervisors should be responsible for day to day knowledge and feed the information down. The care workers may not need the full access, but only what's relevant."

(Female, from Harrow, Day 2)

Other considerations from the discussion about health settings also applied to care settings, for example:

- It was important that **staff saw only the information that they needed**
- **Qualifications and training were a key differentiator** of who should be able to access what data
- The **type and amount of information** being accessed mattered
- Participants **expected controls to be in place**

However, there were a number of important differences in how these considerations were thought to play out in social care compared to health settings.

Participants were generally more reticent to join up data between health and social care

Despite earlier voiced expectations that services should be joined up, there were some perceived features of social care that meant the considerations led to a greater reticence to join up health and care data:

- **Many staff are not clinically qualified:** there was a perception that care workers largely assist people with care needs such as dressing and washing, and do not have clinical qualifications, and as such there was some concern about sharing health data in case they make a judgement about medical needs that they are not qualified for

"There are people who are not fully medically qualified, and they have access to a lot of medical data. That's the part which I am not comfortable with."

(Participant, Day 2)

- **The size of the care team, higher turnover and the use of temporary staff:** some participants were concerned that data would be shared more widely due to the larger number of people involved in social care, partly due to high turnover. In contrast, others thought this made it more important to share information effectively

Access and control in health and care data

“I didn’t mind a social carer knowing my information. You don’t only get one social carer for the rest of your life. It’s a combination of people. The amount of people who know my information, if you have seven or eight, with all your information getting passed around through the years, I start feeling uncomfortable.”

(Female, from Lambeth, Day 2)

- **The involvement of the private sector:** there was limited concern about information being accessed by the private sector, and whether conflicts of interest related to profit-making meant that data would be mis-used

“Safety is the most important thing compared to privacy, but the issue is that private care companies are for profit, rather than care. They may squeeze the service and cut costs.”

(Participant, Day 2)

On balance, joining-up health and care data was thought to be important to ensure safety and high-quality care, however the caveats on who has access to what data were particularly strong for social care.

Recommendation forming

On Day 4 a quarter of participants were allocated to a working group tasked with developing a recommendation for access and control in health and care. They were shown a summary of the key themes discussed across the ten tables on Days 1 and 2, and had input from working group experts. They were also shown an example of Roles Based Access Control in order to understand what it could look like in practice, and an example hospital discharge summary to demonstrate what information could be shared with social care.

Using this stimulus, the working group developed an initial recommendation with supporting conditions in their own words. They then presented this to the Summit and received feedback from all participants. They then revised the recommendation and conditions reflecting this feedback, and presented a final version back to the Summit.

Developing the draft recommendation

The key issues and trade-offs the working group deliberated are described in detail below.

We expect health and care data to be accessed and used by those who need information to perform their role with the following conditions

Overall, participants expected both health and care data to be accessed for the purposes of individual care. However, this did not mean all staff having access to all information, and so it was limited to **those who need the information to perform their role**. There were also a number of conditions that participants wished to attach to the overall recommendation around who should access the data and safeguards that should be in place, which would enhance their trust in the approach.

On a need-to-know basis

This emphasised that staff should **only have access to the information they need** to perform their role, and no more. Two particular scenarios in which the ‘need-to-know’ basis was relaxed were when there was a high level of urgency or threat to a person, or when they were particularly vulnerable.

“I think the roles-based access is spot-on but there’s always going to be an urgent case outside of that, where it would be necessary... The emergency services needs a caveat. In case of emergency, break glass, get the information.”

(Male, access and control in health and care working group, Day 4)

A senior person or group that authorises the level of data

There was a view that the working group could make recommendations about their expectations, but that they could not categorise job roles themselves, given their level of knowledge. They therefore spent some time considering who should decide the level of data that different job roles can access and concluded it should be a senior person or group of people, who can be held accountable.

Background checks for any staff being given access

An important condition was that staff should have background checks before being allowed access to the data.

Access and control in health and care data

Mandatory, annual training

The working group also reflected that there should be training on safely accessing the data, which would be mandatory for all staff and take place annually, to ensure regular updates.

Additional safeguards

There were other aspects of the control environment that had been outlined in Days 1 and 2, which provided reassurance about the safety of the data. This included the need for passwords, contracts and confidentiality agreements. Again, to build trust in the processes around access, the working group wanted these additional safeguards to be in place.

Serious consequences for misuse

Recognising that these would only apply after data had been misused, the working group thought that having serious consequences for misuse would deter people from accessing and using data inappropriately. These consequences included sanctions and penalties, such as losing their job.

Checks/audit trail built in to find out who is looking at which data

Again, having a system of checks, including an audit trail that would allow access to data to be tracked, was an important part of the reassurance the working group required to allow their information to be joined-up.

Vital information flagged and available to all

The working group considered some information to be vital, and therefore specified that this should be available to all roles. For example, an allergy was important for safety and should be flagged to be easily accessible to all staff, and not just certain roles.

Draft recommendation

After the period of deliberation, the working group developed the following draft recommendation and conditions.

Draft recommendation:

We expect health and care data to be accessed and used by those who need information to perform their role with the following conditions

Draft conditions:

- On a need-to-know basis – principles are: level of urgency/threat and level of vulnerability
- A senior person or group that authorises the level of data
- Background checks for any staff being given access
- Mandatory, annual training
- Additional safeguards, e.g. passwords, contracts, confidentiality agreements
- Serious consequences for misuse (deterrents, penalties, sanctions)
- Checks/audit trail built in to find out who is looking at which data
- Vital information should be flagged and available to all, e.g. allergies to medication, end of life decisions

Access and control in health and care data

Feedback on draft recommendation

When the draft recommendation was presented back to the whole Summit, most participants supported the recommendation to some extent, with only 2% of participants saying they could not support any part of the recommendations. However, nearly half thought it was missing some considerations.

To what extent, if at all, do you support this recommendation?

1. I fully support all parts of this recommendation



2. I support most parts of this recommendation, but think that it is missing some considerations



3. I support parts of this recommendation, but think other parts need more work



4. I support most parts of this recommendation, but think that it is missing some considerations



The main feedback included:

- A question from the Chair about the **number of roles** that were thought to be appropriate by the working group
- Whether **annual training** was frequent enough and what would happen for new staff joining an organisation or temporary staff
- The need to define what was meant by **'serious consequences'**
- A query about **temporary staff** and whether the conditions would apply equally to them, or if there might be differences
- When talking about relaxing access, for example in an emergency, there were questions about how that could be **practically responded to** and **who would define** if it was an emergency
- A question about how categories would be **reviewed** over time
- Linked specifically to social care, whether the group had taken into consideration how the recommendation would work across **lots of organisations and different types of organisations**, and how access would be practically monitored, to ensure accountability

Final recommendation

Taking on feedback from the wider Summit, the draft recommendation was amended by the working group so that the wording would be self-explanatory and to group together similar conditions to simplify the recommendation. In addition, more material amendments were made to the recommendation to reflect the feedback received during the plenary session and on post-it notes. These more material amendments included:

- Clarification that there should be **three to five roles**, reflecting that participants had been keen for there to be differentiation between different job roles, but that having a large number of roles seemed unwieldy and difficult to administer. Importantly, the group did not feel qualified to define the categories, or which roles sat within these, and stated that this should be decided by a senior person or group
- Instead of mandatory, annual training, this condition was amended to **'mandatory training on induction, repeated regularly and checked'**. This addressed the point that staff starting a new role should receive training, and that annual training may not be frequent enough in some cases. It was also felt that training should be checked to ensure it is completed
- **'Appraisals'** was added to the additional safeguards, as another mechanism through which to check access is appropriate

Access and control in health and care data

- Clarification that **serious consequences for misuse** would apply to both individuals and organisations
 - An additional stipulation was added around the **checks and audit trail**, to ensure that they are reviewed regularly
 - A condition was added that there should be **mechanisms for raising concerns**, such as a whistle-blowing policy
 - No change was made in response to the point about **social care** involving many different types of organisations, since the working group thought that the condition of it being on a '**need-to-know**' basis already made provision for this
- The feedback was fed into the revised and final recommendation and conditions. The following was presented back to the Summit.

Recommendation:

We expect health and care data to be accessed and used by those who need information to perform their role, with the following conditions:

Conditions:

- A senior person or group should authorise the level of data a staff member can access, for a small number of categories (three to five)
- Data should only be accessed on a need to know basis, which needs to take into account the level of urgency/ threat posed and vulnerability of the patient
- Safeguards should be applied, including:
 - Background checks for any staff being given access
 - Mandatory training on induction, repeated regularly, and checked
 - Additional safeguards e.g. passwords, contracts, confidentiality agreements, appraisals
- There should be accountability, including:
 - Serious consequences for misuse (deterrents, penalties, sanctions), for the individual and the organisation
 - Checks and an audit trail should be built in to find out who is looking at which data, and this should be reviewed regularly
 - There should be mechanisms for raising concerns e.g. whistle-blowing policy
- Vital information should be flagged and available to all e.g. allergies to medication, End of Life care decisions

Access and control in health and care data

Considerations from workshop with marginalised and vulnerable communities

Participants in the workshop were presented with a summary of the information given to participants at the Citizens' Summit, alongside direct quotes from the access and control working group, demonstrating the group's thoughts and reasonings behind the recommendation.

Overall, participants in the workshop with marginalised and vulnerable communities **supported the Citizens' Summit recommendation about access and control**. They thought that different staff should have **different levels of access**, and agreed that **safety was more important than privacy** when deciding who should be able to access what information. Other details were also similar, such as thinking information should be accessible in **emergency** situations, and **greater trust in registered and qualified healthcare professionals** in comparison with administrators, or those providing care rather than diagnosis and treatment.

"You get healthcare assistants that aren't nurses. They'll help so they'll need to know a certain amount but not everything the nurses would need to know."

(Participant from the marginalised and vulnerable communities workshop)

However, the **trade-off between safety and privacy was more complex for workshop participants, since the two were more closely linked**. There was a concern that people might be worried about how widely their information is being accessed, and this **could mean they would not access services when needed**. Examples included specific groups such as refugees or drug users, and specific types of information such as HIV status or living with Hepatitis C.

"I work with refugees and it's important that they are safe. Privacy needs to be respected. Safety has different aspects. Many people may not access care if they don't feel comfortable. Therefore, their safety is everything."

(Participant from the marginalised and vulnerable communities workshop)

Linked to this, there were **concerns about prejudice and people being discriminated** against as a result of this type of information, which again led to greater reticence in joining up more sensitive data.

"I've been treated for Hepatitis C twice and I wouldn't want everyone to know that. With some people, you'll be treated with prejudice for that."

(Participant from the marginalised and vulnerable communities workshop)

Workshop participants also mentioned **the role of the patient**, in terms of expecting person-centred care and having some level of control or knowledge about who had been accessing the data. For example, there was a concern about correcting inaccurate information or being able to audit who looked at their information.

"If we had access to the data ourselves, we could see this nurse looked at the data, wouldn't we be a better person to raise those sort of concerns?"

(Participant from the marginalised and vulnerable communities workshop)

Considerations for future communication approaches

- **If communicating about RBAC, communications that emphasise how teams work together to provide care to patients would be helpful.** As participants learnt more about how individuals work together in a care team, they were more understanding of why different types of staff might need access to information. Without this understanding, members of the public will likely question why specific types of staff would need access to their information
- **It should be made clear to patients and the public that there are controls in place for who sees what data.** Those able to access data would be approved, and there would be a series of individual and system-level controls safeguarding their data. Such safeguards were particularly reassuring to participants
- **When joining up data between health and social care, distinctions in the views of each need to be reflected in communications.** For example, where a registered nurse in a social care setting has access to information this can likely be easily explained in relation to the nurse's qualifications. However, greater reticence towards social care around unqualified staff, the size of the care team and its more temporary nature should be borne in mind in communications, to reassure the public that their information is safeguarded



6

Use of de-personalised data for proactive care

Use of de-personalised data for proactive care

Session overview

On the afternoon of Day 2 the Summit was introduced to the concept of using data for proactive care. This means using de-personalised datasets to identify people who are at risk of developing more severe illness, and providing earlier intervention and/or preventative treatment. This is a move away from treating illness towards promoting health as part of a more preventative approach. Proactive care requires joined-up data from across the system, de-personalised information on a whole population, and expert analysts to identify characteristics or patterns of activity that are linked to disease development.

Information provision

An expert presentation outlined what proactive care is and why it is done, with examples to illustrate the potential added value of joined-up de-personalised data. The presentation explicitly stated that:

- It is only possible to do proactive care with joined-up data from across different care settings
- Not everyone will benefit but it is necessary to analyse data for a whole population to identify those who may benefit from proactive intervention
- There is uncertainty regarding how this use of data should be categorised: it is understood to be within the remit of 'individual care', however this is a grey area given that not everyone will benefit

Following a question and answer session, a further presentation outlined:

- The specifics of who is involved in proactive care (teams of analysts)
- The kind of data they can access (de-personalised data)
- An explicit explanation that data is not always accurate

Case studies (atrial fibrillation case finding, co-ordinating care for the frail, and preventing onset of type 2 diabetes) were used to further draw out views around the acceptability of using de-personalised data for this purpose. Participants were encouraged throughout the discussion to think about the relevant trade-offs when assessing acceptability:

- Proactive care is considered to be 'individual care' because anyone could benefit, but what about the privacy of those who do not?

- Whether the protections of privacy feel adequate to justify the benefits for the people who go on to receive direct care?
- Should the system try to anticipate people's needs in this way, or continue to only react when problems become severe?¹⁵

The concept of de-personalised data caused some initial confusion, however once explained it was deemed as low-risk

There were several areas of confusion and requests for clarification among participants. These were subsequently answered in question and answer sessions with experts.

- What de-personalised data is and what this means
- Whether the national data opt-out, which had been introduced during Day 1, would cover this proposed use of data
- Whether private medical data is included within proactive care analysis
- How the reidentification process works

Initial questions raised by participants following the introduction to the use of de-personalised data for proactive care

- What is de-personalised data? What does it mean?
- Can you opt-out?
- What about private health care data? Is this included?
- How do they know which patients to target?

Once this was explained and understood, **participants were largely of the opinion that de-personalised data was low risk**, in that as long as they could be reassured that there would be no negative consequences for individuals, they were happy for data to be used in this way. Even if this meant that it would only help a minority of people. However, whilst they recognised that the data is de-personalised, they were clear that it is still the data of individuals and therefore should be treated appropriately.

Use of de-personalised data for proactive care

The preventative aspect of proactive care was positively received

Participants were **positive about this data use and recognised the potential cost savings** and time saved for healthcare professionals.

“Of course it is, we know the funds going into the NHS are diminishing, the funding to the NHS has been reduced by a third, so if it will benefit then I’m for it and a lot of people are, we don’t want an American system.”

(Male, from Brent, Day 2)

They talked about the limited funds within the NHS and therefore **the need for a preventative approach to treating people**.

“We’re trying to promote health, so this is a step that we can take in order to promote health as opposed to just responding to illnesses. I can support that agenda.”

(Male, from Southwark, Day 2)

Participants also discussed reducing the burden on the NHS over time, and the potential longer-term benefits to healthcare professionals associated with proactive care.

“As long as it is there to benefit the system, the patients and the NHS. It will take the burden off NHS in the long-term. If they can suspect who is prone to get a disease, they can take action and be proactive. It saves us money from medicine, treatment and social care. It has a knock-on effect.”

(Female participant, Day 2)

One table was particularly keen to see that this work was happening across London, with a concern that this ‘service’ might not be available in some boroughs. **The need for consistency to ensure fairness and equity for all was therefore important.** This extended across London as well as beyond to the rest of the country. Across the Summit, there was some recognition that the larger the dataset, the increased opportunities.

But there were some concerns about over-reliance on data, and potential data inaccuracies

As participants worked through case studies exploring different applications of proactive care, questions and concerns were highlighted:

- **Some cautioned a move towards a system that is over-reliant on data.** The importance of retaining elements of a personal service, with doctors spending time talking to patients, was raised
- Knowledge ascertained in the presentations that the data isn’t always accurate created **anxiety among participants that decisions might be made as a result of using inaccurate information.** Consequently, people could be incorrectly flagged for intervention, contacted, and be put under unnecessary unease

Participants wanted reassurances about those working with NHS data

Presentations and discussions reassured participants that analysts working on behalf of the NHS would always be trained and skilled professionals. It was also reassuring for participants to learn that there are harsh sanctions in place to deter people from misusing data.

There was an assumption that this will increase workload, and they wanted to know how the NHS would cope

Although initially proactive care was viewed as having the potential to save time and money for the NHS, as participants understood more through the case studies and discussions, they had questions about the implications. This **included the ability of the NHS to cope, with the assumption that it would create more work.** Participants spoke of:

- GPs not having enough time to action the results of the analysis. If GPs are not able to utilise the data, then the analysis would be a waste of time and money

“I think that if this gets put into place, we need more doctors and more time.”

(Female participant, Day 2)

- Doctors requiring extra training as a result of having to act on the analysis

Use of de-personalised data for proactive care

Compassionate and sensitive communication was paramount

A dominant theme in discussions around proactive care was communication with patients. Participants spoke of **the need for sensitive and compassionate communication**, specifically:

- **Contact should not be relentless.** There were similarities made between this and NHS reminders about flu vaccines, with the caveat that the number of times a patient should be contacted would need to be kept to a minimum
- **The importance of the wording of letters or other forms of communication.** Examples used in the case studies sparked concerns about how words like 'frail' could be received, with the potential for this to cause anxiety and alarm. Similarly, communications about being flagged as overweight (i.e. pre-diabetes), could be very sensitive to some

"It needs to be that people aren't being called to say that 'you have a disease', but rather that it's a check."

(Female participant, Day 2)

- **The need for ongoing support following communications.** For example, if people are advised they need support plans and they may have to pay for this

Proactive care and risk identification will rely on patient engagement and there should be an opt-out either for being contacted, or taking action as a result

There were some discussions over whether risk identification is enough. **Participants spoke of the engagement required on the part of patients.** Whilst participants were positive towards the idea of identifying people who are at risk, or would benefit from intervention, they also recognised that this relied on patients being willing and able to take on the advice and change their behaviour accordingly.

This linked to a moot point about **the ethics of doing proactive care.** While many recognised that they would want to know if they were at risk of developing a condition, there was caution that some patients may not.

"I have known people who don't want to know they're ill."

(Male, from Richmond, Day 2)

Some tables went as far as to suggest that **there should be an opt-out associated with the outcome of doing proactive care.** This could take the form of opting out of being contacted following the analysis that identifies you as at risk or opting out of having to take action (for example, making an appointment to see a doctor or go for a screening test).

Overall acceptance for de-personalised data to be used in this way came with conditions

Most participants concluded that they were content with the use of de-personalised data for proactive care purposes. This acceptance, however, came with several conditions:

- **Data must not be shared with, or sold to,** insurance companies or for marketing purposes

"As long as they don't sell it to companies that call you up. The ones where you get multiple phone calls asking whether you've had an accident."

(Female, from Westminster, Day 2)

- **Data should not be used by policymakers for reasons which are not in the public's interest.** Whilst this was not precisely defined, there were examples provided

"We don't want the Secretary of State to use this statistic to make a policy and give less money to the government and more cuts to the NHS."

(Male, from Brent, Day 2)

- There need to be **severe punishments for misuse**
- There should **be reassurances and information about the process for de-personalising data:** who is involved and how is this done

Use of de-personalised data for proactive care

“Who’s going to have the responsibility to strip down the information and what’s going to happen if it’s not stripped down properly?”

(Participant, Day 2)

Towards the end of discussions, and with most comfortable about the use of de-personalised data for proactive care, there were still **questions about the national opt-out and whether this covers data use for proactive care**. When participants were informed that it does not currently cover proactive care, this created **a need for transparency**.

“As we’ve discussed more of this, we’ve become more onboard. I suppose the more we know about it, the more we accept it.”

(Male participant, Day 2)

Recommendation forming

The process of forming a recommendation on the use of de-personalised data for proactive care differed to that for other topics. It was only possible to bring back a certain number of issues to Day 4 to discuss at length within the themed working groups. It was decided that proactive care did not require further deliberation, as the use of de-personalised data for this purpose was generally uncontroversial. At the end of the proactive care discussion, and as part of the closing of Day 2, the Summit was invited to express a vote on three questions.

Whether the benefits of using de-personalised information for proactive care outweigh the concerns

The Citizens’ Summit was asked to stand, before considering the following question:

Based on everything we’ve heard, do the benefits of using de-personalised information to find candidates for proactive care outweigh the concerns that people have about their information being processed in this way?

1. Yes, the benefits outweigh the concerns
2. No, the benefits do not outweigh the concerns
3. I am unsure / I need more information

From standing, the Summit was asked to sit down if their answer was: ‘Yes, the benefits outweigh the concerns’. All but two people sat down. The two participants who remained standing said they did so because they needed more detail about access and passing on information, and about whether the data would be sold to make money.

Whether there is support for the use of de-personalised data for proactive care, so long as the right safeguards are in place

The question was modified, and the Summit was asked whether it would support the use of de-personalised data for proactive care, so long as the right safeguards are in place. The room was asked to stand again and for those in support to sit down. This time all but six people sat down. Two of the six who remained standing were those who had remained standing in the previous vote. A handful of the six were asked why they were still standing. Several did not think that the addition of safeguards was necessary, given the level of identification of the data being used. One participant specified that they thought the Secretary of State should make the commitment - a “cast iron guarantee” - to not sell on data.

Whether all GPs and hospitals should be expected to contribute data for proactive care

Finally, the Summit was asked whether it agreed or disagreed with the following statement: “Londoners think all GPs and hospitals should be expected to put information about you into a place where we can do proactive care”. Those who agreed with the statement were asked to sit down, and two people remained standing. When asked why this was, one questioned why it is that some GPs don’t already do so. An expert attendee, who was also a GP, provided the explanation that many GPs are reluctant to share information about their patients because they are concerned that their patients wouldn’t want them to. In doing so, he also emphasised the importance of events like this Summit where the public is invited to express their expectations.

Use of de-personalised data for proactive care

Considerations for future communication approaches

- **The public are likely to respond positively to activities which seek to take a preventative or proactive approach to tackling health issues and challenges.** Participants were generally in favour of proactive care as they perceived it as leading to, and focusing on, health benefits for people. Many questioned why proactive care was not being carried out more consistently
- **However, there may be some people who are less in favour of this approach to health and care, which should be handled with caution.** A minority of participants expressed that they would not like to be informed if they were at greater risk of developing a disease and/or would like to have a choice about being part of such interventions. Here, there was an expressed need for an opt-out for those who would rather not be contacted. There were also considerations raised about how people should be informed as the result of a proactive care intervention, with compassionate and sensitive communication being absolutely necessary
- **There are reassurances that the public requires in relation to proactive care.** These included the process for de-personalising data, the punishments for misuse of data, and the assurance that data will not be sold on to third parties



7

Use of de-personalised data for health and care planning and improvement

Use of de-personalised data for health and care planning and improvement

Session overview

On Day 3 participants moved on to discuss the use of de-personalised data for reasons beyond individual care and treatment. This part of the deliberation focussed on the use of de-personalised data for health and care planning and improvement. This includes:

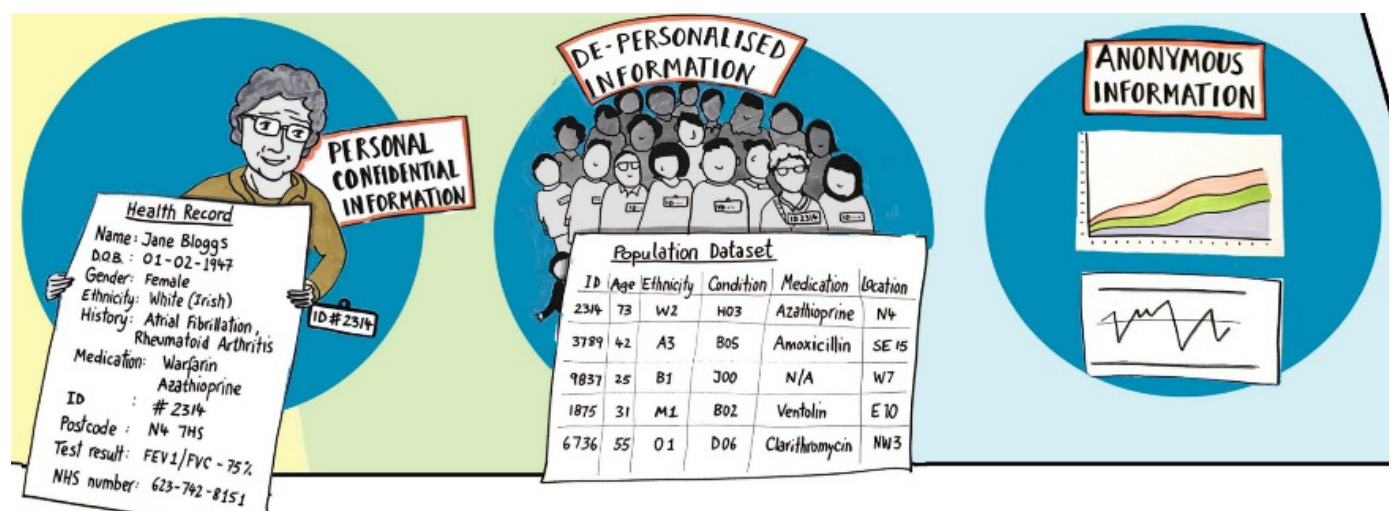
- Understanding what care and treatment patients need
- Predicting what services will be needed in the future, so funding and resources can be put into place
- Understanding the outcomes of patient care to make sure people are being cared for safely and effectively (including quality improvement and regulation)

Information provision

At the start of Day 3, and to frame the subsequent discussions about the use of de-personalised data for planning and improvement, and in research and development, a presentation explained what is meant by de-personalised data. It acknowledged that this is a contentious issue, pointing to recent news coverage^{16,17,18}. Defining de-personalised data as data where identifiable information (e.g. name, address, date of birth) has been removed and replaced with less specific fields (e.g. an identification number), the presentation highlighted that this data is useful because it is rich in enough information to enable patterns to be identified. It clarified that the more information attached, the more unique the record is. And it cautioned that in theory it is possible to infer someone's identity from their de-personalised information, although this requires access to the data, some prior knowledge about the individual, effort and some skill, and is illegal. It was important to clarify that de-personalised data does not mean that it is completely anonymous. Visual aids were used to demonstrate this distinction, including the artist's sketch in Figure 7.1.

A second presentation then introduced the idea of planning and improvement in health and care services, highlighting the different purposes data might be used (planning, quality improvement and regulation), and the organisations and teams of people involved (national and local commissioners, public health teams, local councils and regulators).¹⁹

Figure 7.1 Spectrum of identifiability: personally identifiable, de-personalised and anonymous



Use of de-personalised data for health and care planning and improvement

There was a lack of awareness about how the health and care system plans, with few recognising the role of local councils and public health teams in this

Participants struggled to make sense of this topic. This was predominantly because **they were unfamiliar with the planning process** of the NHS, leading most to continue to think in terms of proactive care (covered on Day 2, see chapter 5). There was also an **assumption that, to some extent, this type of planning using data happens anyway**.

Participants were **surprised to learn that public health sat within the remit of their local authority**. This raised various questions including how funding is split between health and public health at a local level, the possibility of local variation in the allocation of resources, and health inequalities as a result of using local population data to inform decisions.

The introduction of local councils, too, raised concerns, including **a lack of trust in their systems and processes**, the people involved, and suspicion **that they might share or sell data onto third parties**.

“I don’t know how qualified the local authority are to hold all our data. That would worry me.”

(Female, from Enfield, Day 3)

Since many participants were unclear about where the funding came from and the role of public health teams, they questioned the feasibility of local council involvement in planning and improvement.

“I want to clarify. For cutbacks, how can they cut back when they’re thinking about how to improve this system? It’s my perception that local councils are always looking for how we can cut back to save money on this.”

(Female, from Barnet, Day 3)

Initial questions raised by participants following the introduction to planning and improvement

- How do they prioritise which populations to look at?
- Can the data be shared outside of the NHS, and will it be used for the right purpose?
- Where are the healthcare commissioners in the process? Who employs them?
- When your data is de-personalised, where does the personal stuff stay?
- What level of authority is there at a local council to handle and store health data? For example, how qualified are the analysts involved?
- Who makes the decisions about planning, is it the NHS or those in local councils?
- With so many organisations involved, is it possible to safeguard the data?
- How does the opt-out work?
- Are there plans to publicise the national opt-out?

Overall, and in early conversations, most were positive about using data for health and care planning and found this an acceptable use because it involved de-personalised data

Whilst there were many initial questions over the role of local councils, **most participants were initially supportive of their de-personalised data being used to support planning and improvement** of health and care services.

Use of de-personalised data for health and care planning and improvement

The **reassuring factor here was the level of identification of the data**. Overall, participants continued to view **de-personalised data as relatively low-risk** and thought the benefits of joining up the data would outweigh the concerns.

There were, however, some who were concerned that the **more widely the data was shared, the greater potential for the data to be lost or misused** (for example, by hacking). They therefore wanted assurances that any systems being used to process health and care data were being tested to ensure that they were not accessible to people with malicious intent.

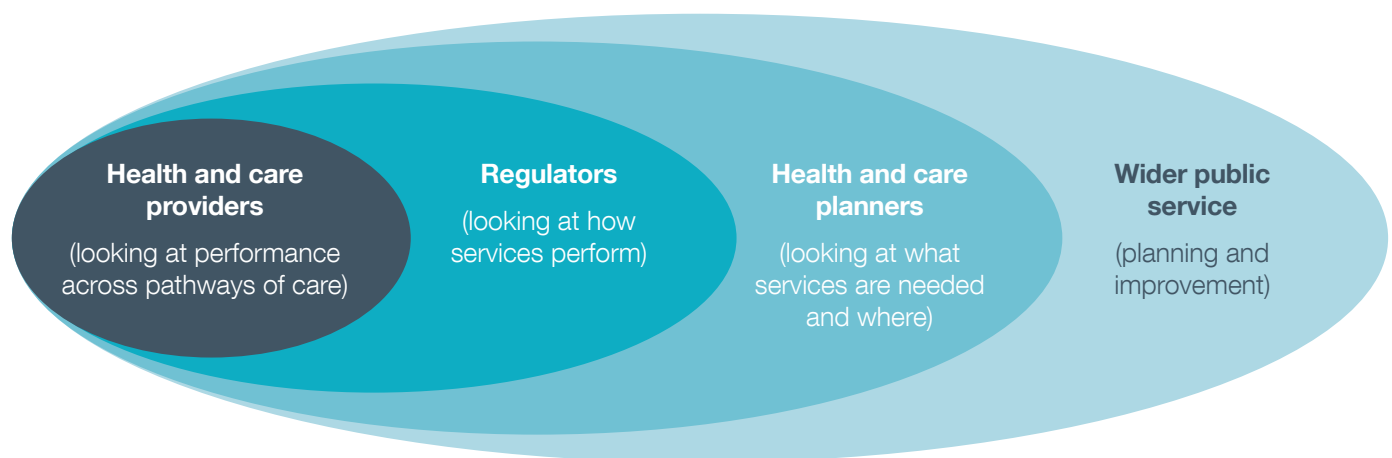
“Does the NHS employ hackers? They would be useful for minimising the chance that information could be reassembled.”

(Male, from Hillingdon, Day 3)

Further information provision

Participants were given three case study examples to illustrate how de-personalised data could be used in different contexts: health staff improving care for people with multiple long-term conditions; commissioners thinking about changing services for diabetes patients; and a local council considering changing the road transport system to tackle air pollution. Facilitators were briefed to draw out the levels of acceptability of data being used by organisations that move further away from health and care settings.

Figure 7.2: Diagram used as part of the stimulus to portray the diameter of trust



Using de-personalised data to improve care and planning within the NHS was widely endorsed

When considering the two health case studies, which related to improving care for people with multiple conditions and planning care for people with diabetes, participants were very supportive of using data to support decision-making. They **expected the NHS to be using data in this way** because it:

- Leads to **wider societal benefits and greater good**, including preventing people getting unwell
- Enables the **NHS to be more efficient** / save money / spend money where it is most needed
- Ensures **services are fair and equitable**

Because de-personalised data was considered low-risk, participants felt that the potential for harm would be limited. Though a couple of tables were **mindful of the ‘slippery slope’**, cautioning that the next step would be for the NHS to suggest it would be acceptable to use personal data.

“It sounds good in theory and in terms of ‘this is how it starts.’ But over periods of time, could it be used in the same way? You’re trying to build up data. It makes sense now. But there’s something in my mind that makes me wonder what the next stage would be.”

(Male, from Southwark, Day 3)

Use of de-personalised data for health and care planning and improvement

There was concern about postcode lotteries, coupled with an expectation that healthcare providers should be contributing to datasets to avoid variation across London

The first case study (improving care of people with multiple long-term conditions), illustrated how approaches could vary in different parts of London.

There was an expectation from many that all health and care providers should contribute data on behalf of their patients. The fact that some providers might not do so was a cause for concern as most participants wanted to avoid a 'postcode lottery', and felt it was important to have a single approach across the region.

"I think it should happen across London too, it's weird one borough might, and another wouldn't... If you're moving from one borough to the other, you might not be aware of those differences in standards. I'd imagine it would have an impact on most people as everyone wants the best healthcare service."

(Female, from Richmond, Day 3)

There was general acceptance for using data to allocate resources, so long as the data is accurate and complete

The second case study (planning diabetes services), introduced the idea that data might be used to plan the allocation of resources. Some found this completely acceptable, with no conditions or caveats. Others were comfortable, in theory, with configuration of services based on planning data if the majority would find it more convenient, and if those who were inconvenienced could still get to the services. For these participants, **it was important that the NHS did not take away services that people rely on.**

However, the case study also raised some concerns about the quality of the data being used to make such decisions. Some participants questioned whether the data would be accurate and complete. They thought that the quality of the data could impact on the quality of the decision-making.

"My problem is the opt-out clause. If 50% of the people of London opt out, how accurate are these reports?"

(Male, from Merton, day 2)

The importance of the triangulation of insight and knowledge

As with discussions about proactive care, some participants raised concerns about the NHS becoming over-reliant on data, highlighting the importance of the triangulation of insight and knowledge. They wanted **assurances that decisions would continue to be based on local knowledge and interactions with patients, as well as their data.**

Local council use of data was still a concern, because of a lack of clarity around their role in planning coupled with a lack of trust

The third case study (local council use of health data) concerned some participants. Whilst some suggested that if it could genuinely improve public health then that would be a good use of their joined-up data, others were sceptical of the role of local councils in using health data to plan public health interventions. The involvement of local councils was deemed by these participants as 'intrusive', with **an overall lack of trust** (fears that data would be sold), and participants questioning:

- **The added value of health data.** In the example given, participants thought that the link between air pollution and health was already proven and that the council should be able to use its own air quality data. This meant they questioned why local health data, for example, showing illness linked to pollution, such as hospitalisations from asthma, would be required for this particular purpose

"If the science naturally shows that a certain amount of pollution has a negative impact on people's health, why does the local council need more evidence? If they just take a pollution meter to that hotspot and say this will affect people's health."

(Male, from Richmond, Day 3)

- **The qualifications and governance of the council staff involved** and whether they would be able to understand the data and be able to analyse it

"It's about how many people access that data. It's quite easy for someone to have a friend on the council."

(Male, from Richmond, Day 3)

Use of de-personalised data for health and care planning and improvement

Participants wanted specific safeguards

Whilst the use of data for planning and improvement was broadly accepted where it was being used for health and care purposes, in order to increase trustworthiness **participants expected to see a number of safeguards in place**. Specifically, they wanted the NHS to ensure:

- **The systems where their data is stored are secure.** Where it was being used beyond delivery of individual care, they wanted the data to be stored in a de-personalised format
- **That information could not be passed onto insurance and marketing companies.** This could be handled by specifying rules around the exact purpose of the data
- **People accessing data are trained in using it appropriately.** The training should encompass how to make good decisions based on the data, and rules about protecting people's information
- **People accessing data should only be able to see the data they need (and nothing else)**
- **Transparency about how data is being used, and an audit trail of which individuals are using the data.** Participants wanted to be able to find out how many people are accessing the data, who is using it and for which purposes

There were mixed views about the national data opt-out

There were discussions about the importance of the national data opt-out across this part of the deliberation. There were mixed opinions about whether or not an opt-out is necessary:

- **Those who deemed it unnecessary, and in favour of complete datasets for good decision-making**
- **Those who called for better promotion of the opt-out,** and the importance of this for those who are uncomfortable with their data being used beyond individual care

An important point raised on a couple of the tables was around communication. Recognising that their views had changed over the course of the Summit, becoming increasingly positive about de-personalised data use for different purposes, these participants were concerned that with a lack of information, people would opt-out.

“For this type of thing [health planning and improvement], I don’t think there should be [an opt-out]. I think this is all for people’s benefit and to actually make the system more efficient... It takes us back to the first weekend. In our discussion, a lot of us ended up saying we were very resistant to data being used for anything, and then by the end of the weekend, we were all very pro. If you’re Joe Public, and you haven’t had all of this, then they might choose to opt out.”

(Male, from Enfield, Day 3)

Recommendation forming

On Day 4 a quarter of participants were allocated to a working group tasked with developing a recommendation for use of de-personalised data for health and care planning and improvement. They were shown a summary of the key themes discussed across the ten tables on Day 3, including thoughts, quotes, and questions from participants, and had input from working group experts.

Using this stimulus, the working group developed an initial recommendation with supporting conditions in their own words. They then presented this to the Summit and received feedback from all participants. They then revised the recommendation and conditions reflecting this feedback, and presented a final version back to the Summit.

Developing the draft recommendation

The key issues and trade-offs the working group deliberated are described in detail below.

De-personalised health and care data should be shared and used by relevant bodies to plan and improve services to demonstrably benefit health in London (or Londoners)

Overall participants in the working group were comfortable with de-personalised data being used for these purposes. While **the phrasing of the recommendation initially started as “we expect”, it was amended to “data should be used” to strengthen the intent.**

Use of de-personalised data for health and care planning and improvement

In initial discussions, there had been less comfort with local councils having access to joined-up data. An expert provided some additional examples of public health initiatives which might be led by local councils and would benefit from the use of health data. Consequently, **the group became more open to data being shared with councils as well as being used within the NHS, if certain conditions were satisfied.** Of importance to the group was the idea of **demonstrable benefits.**

“For me, if this information is used, there has to be some sort of identifiable improvement for using it. So, we can clearly see the process and the end result.”

(Male, planning and improvement working group, Day 4)

The group also noted that not everyone living in London would consider themselves a Londoner, but that their data might still be used in planning and improvement. Consequently, it chose to reference both London and Londoners in the recommendation.

However, the group also wanted to apply conditions to the use of de-personalised data for planning and improvement, as outlined below.

Data should be accurate

Accuracy was seen to be important. The group was comfortable that the data might not be 100% accurate. The group therefore discussed **the importance of data that is sufficiently accurate to ensure good decision-making.**

Must sign up to five safes framework

The five safes framework²⁰ was discussed as an appropriate way to ensure that people’s data was accessed responsibly and in a controlled way.

Some wanted to add a condition that only people who were qualified to do so could analyse the data. However, others thought that was a lower priority to include, as they thought it was self-evident.

Shared for an agreed purpose

The group’s main condition was that the **data must be used to improve the health of Londoners** – it did not want the data used for other purposes. Some thought it was important for this to be transparent, and for Londoners to be aware of how their data was being used to benefit them.

Defined items / bits of data should be shared

The group discussed whether it wanted only the specific data required for planning to be used, or a

full de-personalised dataset. Some were concerned that providing access to a sub-set of the data would create more work for the NHS, as it would have to extract only the data required by the council. However, others thought this would be important to limit the data accessed by councils as they were concerned about the council having ‘too much’ information.

“I’ve got visions of the chief executive [of the council] having access to all the data and I find that a bit worrying.”

(Male, planning and improvement working group, Day 4)

Data does not leave the health system – does not leave the ‘home’ organisation

There were particular concerns about a council selling on health and care data, and the group wanted measures in place to prevent this from happening. The **wording of the condition within the recommendation: “does not leave the ‘home’ organisation” was intended as a safeguard, where ‘home’ referred to the organisation(s) that had collected the data,** and meant health and care services should not provide access to information (particularly to private companies) with no ability to maintain control over how it is used. Having penalties, enshrined in law, was thought to be particularly important for assuring people that their data would be handled appropriately.

“Providing that the council don’t go on to share it with other companies. We’re giving the information for them to use but not pass on or share with a third party.”

(Female, planning and improvement working group, Day 4)

People should have an opt-out option, also an option to opt back in

Although some noted the need for the opt-out, most in the group were not particularly concerned. Their bigger concern was the data becoming unusable because too many people opt out. They therefore wanted **an assurance that people could opt back in if they wanted to.**

There should be legal penalties for misuse

There was an expectation that strict penalties were needed to discourage misuse of the data. These would need to go beyond fines given that this might not be a strong enough deterrent. As such, participants spoke of dismissal proceedings.

Use of de-personalised data for health and care planning and improvement

The organisations that are sharing data should be specified

The group discussed the importance of data only being used for agreed purposes and being accessed only by people working directly on agreed projects. Some questioned whether planning would be an ongoing process, but the group was more comfortable with access being time-limited. It also wanted the data securely removed from council systems once the work was complete.

“I’ve worked with councils and afterwards the data is just hanging around.”

(Female, planning and improvement working group, Day 4)

There should be a defined process for accessing the data

The group raised the importance of a defined process that anyone accessing the data would need to go through before being able to access it.

Draft recommendation

After the period of deliberation, the working group developed the following draft recommendation and conditions:

Draft recommendation:

De-personalised health and care data should be shared and used by relevant bodies to plan and improve services to demonstrably benefit health in London (or Londoners).

Draft conditions:

- Data should be accurate
- Must sign up to five safes
- Shared for an agreed purpose
- Defined items / bits of data should be shared
- Data does not leave health system – does not leave the ‘home’ organisation
- People should have an opt-out option, also an option to opt back in
- There should be legal penalties for misuse
- The organisations that are sharing data should be specified
- There should be a defined process for sharing the data

Use of de-personalised data for health and care planning and improvement

Feedback on draft recommendation

When the draft recommendation was presented back to the whole summit, most participants supported it to some extent, with no participants saying they could not support any part of the recommendation. However, nearly half thought it was missing some considerations.

To what extent, if at all, do you support this recommendation?

1. I fully support all parts of this recommendation

37%

2. I support most parts of this recommendation, but think that it is missing some considerations

49%

3. I support parts of this recommendation, but think other parts need more work

14%

4. I support most parts of this recommendation, but think that it is missing some considerations

0%

The main feedback included:

- The **importance of allowing access to relevant information only and ensuring insurance companies could not access the data**
- Whether it was practical for the data to remain in the 'home' organisation, **so long as de-personalised data only went to 'approved' third parties with appropriate safeguards** and encryption in place
- **How the data access would be 'policed'**, and who would decide which organisations could have access to the data
- Whether the focus should be London / Londoners or **whether the benefits should be made available to the wider NHS**
- Requests for the conditions to be tightened up, for example, **clarifying who would agree an 'approved purpose' for data access**
- The **difficulty of establishing if the data was accurate**

Final recommendation

Using the feedback, the working group made some final amendments to the recommendation and supporting conditions, specifically focussing on tightening up the language to reflect their intentions.

- **The word 'should' was replaced with 'must'** to make the recommendation around the use of de-personalised health and care data to plan and improve services even stronger. For those who were less certain about this, the point about ensuring a national opt-out was clarified so that they were not required to agree to their data being used in this way
- **The group decided to drop the reference to 'Londoners'**, as on reflection it worried this could be misinterpreted as only those born and bred in London. The reference to 'London' was retained however, despite feedback from the rest of the Summit that benefits should be for the wider NHS. Incidentally the group assumed this would happen anyway but wanted to **specify 'London' in the final recommendation, to ensure that it remained at the heart of any accrued benefits**

Use of de-personalised data for health and care planning and improvement

- After some discussion, the group agreed to remove the requirement to keep the data in the 'home' organisation, so long as it was confident that enough safeguards were in place. It agreed that all parties signing up to the five safes and committing to only using data for the agreed purpose, should achieve this

The feedback was fed into the revised and final recommendation and conditions. The following was presented back to the Summit.

Recommendation:

De-personalised health and care data must be shared and used by relevant bodies to plan and improve services and demonstrably benefit health in London.

Conditions:

- Ensure the data being shared is accurate
- All parties must sign up to the 'five safes' in order to access/use data
- Data is shared for an agreed purpose (not for general analysis)
- Only data relevant to the specific analysis are shared
- Shared data must be held securely by all agreed recipients
- Maintain the national 'opt out' option, but also provide an option to opt 'back in'
- There should be legal penalties for misuse of the data (e.g. selling on to 'third parties')
- The organisations that are sharing/using the data should be stated and published somewhere for the public to see
- There should be a defined process for sharing the data that is published somewhere for the public to see

Considerations from workshop with marginalised and vulnerable communities

Workshop participants were presented with a summary of the information given to participants at the Citizens' Summit, alongside direct quotes from the planning and improvement working group which demonstrated the group's thoughts and reasonings behind the recommendation.

Overall, **there was a similar level of acceptance for using de-personalised data to plan and improve services** within the health and care service, and an appreciation for what data can offer.

"If you know you've got a large number of people who have got tuberculosis, then you need that service. That would be an advantage to know the condition."

(Participant from the marginalised and vulnerable communities workshop)

However, as with the Citizens' Summit, there was also **a level of discomfort in council staff having access to de-personalised data**. Some of the reasons for this mirrored those in the Citizens' Summit, namely a **lack of trust in the people** who work in councils and the 'local' environment people work within.

Other **reasons appear specific to these communities:**

- The sense that the wider the data is shared, the greater chance of different departments (housing) and wider agencies (the Home Office) finding out about people (those seeking asylum, homeless people)

"That's the thing about what's the role of health services. It's a principle that our health professionals are confidential about our personal information."

(Participant from the marginalised and vulnerable communities workshop)

- **Vulnerable people could be at increased risk of identification** because of specific sets of circumstances

Use of de-personalised data for health and care planning and improvement

“The people I work with, I fear that they are too identifiable even when de-personalised. There are so many people who are refused for asylum. It’s a group that’s easily identified.”

(Participant from the marginalised and vulnerable communities workshop)

For these reasons, many displayed a preference for anonymous information (rather than de-personalised) to be shared with councils.

“For the council, a lot of it is political, but I would much prefer completely anonymised.”

(Participant from the marginalised and vulnerable communities workshop)

Similar to discussions in the Citizens’ Summit, communities raised **the importance of the need for local intelligence and involving the community**. This is especially important for certain groups, whose data would not appear in the dataset (homeless people for example).

The opt-out was viewed as important to have, however some cautioned how the data will become unusable if many opt-out.

“It’s quite important to have an opt-out but it would totally spoil the data and make it not as usable.”

(Participant from the marginalised and vulnerable communities workshop)

There was **widespread agreement with the recommendation and associated conditions from the Citizens’ Summit**. These seemed sensible and took account of the considerations that were important to people, with a recognition that the context is complex, including:

- The **difficulty of defining ‘accurate’ data** – instead the data should be as accurate as possible
- Although encouraged by a five safes framework, they made the point that **no data is safe, and no people are safe** – they instead called for use of the word ‘appropriate’

A further set of considerations for policymakers was suggested, which would importantly increase trustworthiness among such groups:

- The importance of **establishing a complaints procedure** for the public to use if they learn of data misuse
- Putting in place **end-user** agreements to determine what happens with the data once the primary use is completed
- **Greater transparency around the national data opt-out**, including making this understandable for people who don’t speak English
- **The importance of the NHS agreeing to grant access to only the necessary information** needed for the analysis
- The possibility of an **accountable higher force**

“It’s almost like we need a data tsar. Even English people don’t understand what they’re ticking or why they’re doing it. We do need a data minister or something.”

(Participant from the marginalised and vulnerable communities workshop)

- A need for **greater transparency around the outcomes of using data in this way**

“A lot of these things are done over our heads and there’s no information being shared for various reasons.”

(Participant from the marginalised and vulnerable communities workshop)

Use of de-personalised data for health and care planning and improvement

Considerations for future communication approaches

- **It is important to explain the difference between personally identifiable, de-personalised and anonymous data, as well as the different settings each type of data might be used.** Typically, participants were not familiar with the different levels of identification, and required explanation and reminding about the differences between these
- **The public is likely to be sceptical about the role of local councils due to a lack of trust.** Some participants did not trust local authorities to manage health data securely and to not abuse access to data in some way (e.g. sell the data on to a third party or use the information to increase council taxes). Detailed explanation about the different elements and services provided by local authorities was needed to help reassure participants about who would and would not have access to data
- **Knowledge about the role of public health is limited and requires considerable explanation to distinguish its role within local government.** Participants lacked knowledge of where public health was located (i.e. within the local authority) and types of interventions delivered, as well as the information needed to inform these interventions. They were also sceptical about whether public health interventions could achieve the desired outcomes. However, participants were more supportive of types of data use if they felt the outcomes were achievable and beneficial to society



8

Use of de-personalised data for research and development

Use of de-personalised data for research and development

Session overview

On the afternoon of Day 3 participants deliberated the use of de-personalised data for research and development. This was split into two parts:

Part one: participants were asked to think about what research and development is, who does it and why it is important. Alongside this, they were asked to consider the safeguards that should be put in place to ensure that data access for research and development is safe and trustworthy.

Part two: participants were asked to consider what would make a fair and productive partnership between the NHS and organisations wanting to access the data for research or development purposes. This focused specifically on how these organisations should be charged for access (if at all) to health and care data, how much the public should know about the research being undertaken (and the method of informing the public), and how any potential benefits from the research should be distributed.

- Additional safeguards that could be put in place to create a trusted research environment (referred to as the ‘five safes’, see Figure 8.1). The ‘five safes’²¹ is a proposed framework for data controllers and data users to ensure data is accessed in a safe and trustworthy way

At their tables, participants were provided with a handout detailing the potential approach to data safeguarding known as the ‘five safes’. They were also given three case studies illustrating how de-personalised data could be used in different contexts: a tech company working with the NHS to develop artificial intelligence (AI) technology to review eye scans; a university trying to better understand A&E attendances; and a pharmaceutical company working with clinicians looking to develop a new diabetes drug (see Appendix D).

As participants discussed the three case studies, they were continually asked how they felt about each example in relation to the ‘five safes’, and what factors made data access more or less acceptable and why.²²

Information provision

In addition to the presentation and detail about de-personalised data at the start of Day 3 (described in chapter 7), to help frame this discussion, participants were provided with information via two expert presentations.

1. The use of data for research and development, including:
 - What research and development is and how it is used (e.g. to develop new treatments for disease)
 - Who conducts health research (e.g. academics, doctors and innovators)
 - Why health research is important and the opportunities joined-up data offers for research and development (e.g. making new discoveries to improve people’s lives)
2. Ensuring research is undertaken in a trustworthy way, including:
 - The legal basis for using de-personalised data for research, and legal protections (e.g. GDPR)

Initial questions raised by participants following the introduction to the use of data for research and development

- Where is the data stored?
- How does data travel from your GP surgery to where the research takes place?
- How is the use of the data for research policed?
- How does the NHS decide who is trustworthy for it to share data with?

Use of de-personalised data for research and development

Figure 8.1: The components of a ‘five safes’ framework²³ used as part of the deliberative stimulus



Participants recognised the benefits of doing research and were generally accepting of research on the condition that there were direct benefits to the NHS and to patients

In discussing the case studies, participants were attracted to the possibilities of research. Research was seen as necessary given the potential to improve health and people's lives. Research was also viewed as fundamental to improving healthcare for the future. Participants spoke of how there is a need to carry out research to improve our understanding of diseases, to bring about advances in treatment, and new ways of working, particularly around the use of technology (for example, to take the burden off humans). The case study about A&E attendance received positive attention, given this was seen as necessary research to identify people who are using the service when they shouldn't be. This may result in a reduction in pressure on A&E services, which was seen as a good thing. Participants' conditions of acceptance for research taking place was linked to a direct benefit to the NHS, or to patients.

There was initial concern about different organisations accessing the data and their motivations for using the data

When considering the three case studies, participants were **initially cautious of the use of de-personalised data for research and development**. They were quick to refer to examples of recent news coverage provided to them at the start of Day 3, drawing attention to issues around breaches of, or perceived risks around, individuals or organisations abusing data access (e.g. using the data to find new ways to make money from patients), and the uncertainty caused by these risks.

“I don't have a problem with most people seeing it, but somebody might get bribed. You don't know.”

(Female, from Enfield, Day 3)

Participants were quick to make a distinction between different types of organisations conducting research and development:

- Universities and not-for-profit organisations who may use the data for ‘public good’
- Technology and pharmaceutical companies, as for-profit organisations, perceived as less trustworthy due to their drive to ‘make money’

“I think that a university is better than a private organisation which is doing it for profit, but the university is for students to build skills and eventually help the hospital.”

(Male, from Brent, Day 3)

Use of de-personalised data for research and development

As participants moved through the discussions, they began to focus on the risks and safeguards around accessing de-personalised data for research

During the discussions, participants took the opportunity to engage in dialogue with experts in the room (including representatives from not-for-profit and for-profit organisations) and reflected on the information given. They sought to get a more detailed explanation of the anticipated risks of de-personalised data use for research and development, and how these risks are addressed in practice. After this dialogue, most participants **became more open to the idea of for-profit organisations accessing de-personalised data for research. Data being accessed in a safe setting was paramount** for participants and perceived as a key safeguard to mitigate against potential risk. However, there remained a small minority of participants who continued to feel uncomfortable because of the risks. Participants were asked to consider the research environment within which the data is stored, accessed and analysed, and whether this was acceptable to them.

Participants were particularly concerned about data sharing and storage because they associated this with a greater risk of data being hacked, lost or stolen. They **wanted reassurance that the data would remain in a secure environment.**

“As long as the data doesn’t leave the organisation, and it is controlled and kept within that area, it’s fine.”

(Female, from Barnet, Day 3)

Key factors that reassured participants in relation to data access included:

- Research organisations accessing data within a **controlled and secure environment**, such as a hospital or research hub, and the data not leaving this environment
- **Access being supervised** by appropriate NHS staff or conducted by NHS analysts on behalf of the research organisation
- **Contractual arrangements in place** that underpin the data access with consequences for those who break the rules around access (e.g. sharing data outside of the research environment)
- **Data not sent or shared outside of the research environment** (but could be accessed remotely)

De-personalised data provided reassurance around patient privacy, which was reinforced by legislation deterring potential data misuse or negligence

Most participants felt **reassured by the use of de-personalised data**, making this acceptable, whilst providing enough information for it to be useable for intended purposes. Discussions involved weighing up the benefits (e.g. potential to develop new technology to improve healthcare) against the concerns (e.g. breach of privacy). The removal of identifiable information (e.g. names, dates of birth and addresses), combined with other safeguards (i.e. safe and trusted research environment) provided confidence that the data would not fall into the wrong hands or be used for the wrong purposes.

“I think this is about weighing the risks with the benefits and I don’t see any risk. I think the data is kept in a safe environment, with authorisation being required for access to the data.”

(Male participant, Day 3)

However, there were some concerns raised, around the potential for:

- **Computer malfunction** (through a ‘bug’ or virus in the system)
- **Hacking of the data** (and how the data might be used once in the hands of hackers)
- **‘Snooping’** – i.e. people looking at data that is not relevant to the task they have been assigned to do
- **Selling data** on to third parties (to exploit the data for their own financial gain)

“If it’s depersonalised and it comes back to me, what will happen? Will someone show up at my door? What is the danger about somebody somewhere having it?”

(Female, from Harrow, Day 3)

However, threats from viruses, bugs, hacking or snooping were not perceived as being unique to this type of data use. Participants were reassured by experts that the data does not have to be sold on but might involve charging for access in a safe and secure environment instead.

Use of de-personalised data for research and development

Participants expected data access to be granted for research that is likely to result in public good as its primary purpose

As participants talked through the case studies, they reflected on the potential outcomes and benefits of the different examples. This appeared to have a considerable influence on the acceptability of de-personalised data use. For example, participants felt that access to data was acceptable if the research was likely to result in efficiency savings for the NHS or improved outcomes for patients.

“For myself, I think it is very important regarding how they are going to gather information to improve people’s lives. If it is helping detect a disease and help, all this research is so important. I have no problem if it benefits everyone. We just need to accept that it is helpful. I have diabetes and I think if it can help this is important.”

(Female, from Haringey, Day 3)

Participants were **clear that they did not want access to data to be granted for the sole purpose of, particularly commercial companies, making money.** But they did accept that there had to be some financial incentive for commercial companies to be involved.

There was a general expectation that the NHS should be using a consistent approach to safeguarding data for research and development

Overall, participants expected to have **a consistent model to safeguard NHS data for research and development purposes** (i.e. adopting a ‘five safes’ model). There was also an expectation that only de-personalised data should be used in research and development. The use of a model to safeguard data provided assurance that data will be protected in a number of ways:

- **Access by authorised people** who have been sufficiently vetted
- **Accessing of data in a research environment** that reduces the risk of data being transferred outside this environment
- Conduct research **projects that are likely to result in public good**
- Production of **outputs that do not compromise patient identity (i.e. only in anonymous form where re-identification is impossible)**

Further information provision

Participants were presented with information on the value of health data and fair and productive partnerships. This highlighted the cost to the NHS for curating, storing and providing safe access to the data, the potential for societal and economic benefits, and the risks involved. Participants listened to a range of experts from different backgrounds (e.g. academic, commercial, NHS, a health charity) talk about their perceptions of a fair and productive partnership, and were asked to consider three key elements, or conditions, of a fair and productive partnership: income and charging, distribution of benefits and level of transparency.

When discussing these conditions participants were asked to consider specific trade-offs relating to each one.

- **Income and charging:** what charges, if any, should be put in place for accessing the data and should this be equal for all parties, whilst being mindful of the implications this might have on the NHS as a global competitor for medical research
- **Transparency:** how much should the public know about NHS partnerships and how should they be informed, whilst being mindful of the advantages and disadvantages of transparency in relation to commercial contracts and the potential administrative costs to the NHS associated with informing the public
- **Distribution of benefits:** how should the benefits be distributed between the NHS and its partners. Should benefits be distributed directly to the local NHS area who supplied the health data or across the NHS

There were mixed views about whether the NHS should charge for access

Through discussion of what charges, if any, should be put in place and whether this should be equal for all parties, **participants were split in their opinion:**

- Those who favoured charging for access – to recover costs and/or because they believed the NHS should not give away its data for free, particularly when some organisations are likely to make significant profits from using it
- Those who thought access should be free of charge – to limit the financial barriers for all research organisations in accessing the data, in the hope of maximising innovation and the potential benefits (e.g. supporting start-up companies trying to develop novel technologies)

Use of de-personalised data for research and development

Participants who called for the NHS to charge for access to health data felt it was **important the NHS receives an upfront return on investment** in providing access to and maintaining the data. They expected the NHS to recover the costs for supplying the data as a basic charge. There was also the expectation that if research organisations were going to make a profit, some potentially amounting to billions of pounds, then this further justified the NHS to charge.

“It’s good to be charged, because they paid money to make this data, so they deserve to get something out of it. There’s no point selling it for free. Make some money out of it, and bring it back to the NHS.”

(Female, from Enfield, Day 3)

In contrast, those who felt the NHS should not charge for access believed in fully encouraging organisations to undertake research in the hope it would lead to new cures, treatments and products. **Free access to data would therefore remove financial barriers** to potentially innovative research.

“I like the argument for no charge of access. If you are talking about the general good, people having access to it and using it in a way that could benefit collectively... That’s a bit more pure.”

(Male, from Southwark, Day 3)

However, these views were based on the **expectation that the NHS would have a share of the profits from successful research projects**. At this point, participants struggled to identify a clear approach through which the NHS could do this.

If there is a charge, then flexible differential charging was preferred

On the question of whether charges should be applied equally to different research organisations, participants were quick to move towards **a model for differential charging**, with for-profit organisations (i.e. large tech and pharmaceutical companies) paying a higher fee than not-for-profit research organisations (i.e. universities and charities).

“If you’re a non-profit, then the fee shouldn’t be high.”

(Female, from Harrow, Day 3)

However, as the deliberation progressed, some participants raised issues with this distinction and emphasised **the need for more detail in how the NHS should make a judgement on differential charging**. They recognised that for-profit organisations may include small start-up companies that lack resources to pay a higher rate for access. Similarly, other participants acknowledged that universities and charities may also be interested in profit-making.

Thus, participants felt it **important that decision-makers have the ability to be flexible with the charges** and make decisions based on a range of factors, including the type of research organisation, turnover, and the anticipated benefits (e.g. profitability) of the research proposal.

“You could do it by income. Turnover. You could argue it’s the same data. If you have a fixed charge, pharmaceuticals can pay it easily, whereas charities can’t.”

(Female, Westminster, Day 3)

Participants felt that transparency was important, but that this should reflect the use of Londoners’ data as a whole, rather than being specific to, or tailored for individuals

Participants were asked to consider how the NHS should provide details of research projects that use Londoners’ health and care data, and whether Londoners should receive a detailed account, or a summary, of how their data has been used for research and development. They were also asked to reflect on the benefits and concerns around different levels of transparency.

All participants felt there was **some value in transparency around how health and care data is used** by research organisations. In particular, the opportunity for public scrutiny of data use for research and development was perceived as very important. However, there were mixed views about how detailed the level of information made available to the public should be. Whilst some participants felt there should be specific information of how the data of individuals was being used, most felt this level of detail was burdensome to the NHS and individual, and unnecessary – given the number of people expected to look at it and those with the ability to make sense of the information. After some discussion, most participants felt that **the information made available to the public should broadly summarise** the following:

Use of de-personalised data for research and development

- The **research partners** accessing the data of Londoners
- The **types of data** being accessed
- **Purpose of the research** projects being undertaken
- **Outcomes and impacts** of research partnerships

“I think for the purposes of transparency, it is important, but we have to understand there are people in the community who won’t have the time to read these humongous essays, so [the information should be] basic.”

(Female, from Tower Hamlets, Day 3)

Participants were also asked to consider how best to inform Londoners about the research projects and the preferred method of communication, such as public registry, mobile app, website, personal letter. In doing so they were encouraged to think about the potential cost implications to the NHS for different methods of communication, and the trade-off of convenience against cost.

Participants acknowledged early on that **they did not want the communication of this information to come at great cost to the NHS**. They therefore quickly moved to digital methods of communication as they perceived these to be cheaper options, whilst acknowledging that some people may need to receive paper communications. Overall, participants proposed a broad range of communication methods, including:

- **Publishing the information on an NHS website**
- **Developing a newsletter or magazine** to be stocked in GP practices detailing the information
- Publishing the information **through other digital sources**, such as mobile apps and email
- Publishing the information **in local or national newspapers**

“Maybe when they get a new alert, to put it on the NHS website, and this is sent in a massive email out to everyone to know that an update has been done.”

(Male, from Croydon, Day 3)

A minority of participants acknowledged that increasing the level of transparency could have a detrimental impact on the ability for partners to protect intellectual property associated with the research, thereby reducing requests to access data for fear of loss of intellectual property.

Participants were unanimous in their view that the NHS should benefit from the research

Participants were asked to think about the outputs of successful research and how the benefits of the research should be distributed between the NHS and its partners. All participants felt that **the NHS should receive some of the benefits from the research** (i.e. both financial and outcomes-based benefits). For example, by the NHS:

- Receiving **a share of the profits** from new drugs developed by pharmaceutical companies
- Being **granted special access** to any new drug, therapy or treatment for them to use for a set period, or at a discounted price

And stressed that the NHS should be supported by wider government and specialist expertise to negotiate a fair deal

Some participants stressed the **importance of the distribution of benefits being agreed upfront** to ensure that later down the line the NHS would be able to claim its share. They felt that simply charging for access, based on **a differential charging system, would not be comprehensive enough to ensure the NHS got a ‘good deal’** and there needed to be specific remuneration agreements based on the likely stages of success.

“One of my thoughts is, say it’s a small start-up company, they get the cheaper data, develop the drug, and then one of the big pharmaceutical companies buys them. They’ve benefited because they’ve become rich overnight. The drug company benefits. The end user, the NHS, has just charged this rate because of the size of the company they are at the time. I would like to see development goals. There should be caveats should they end up making a large amount of money from it.”

(Male, from Richmond, Day 3)

Some participants questioned whether the NHS had the skills and knowledge to negotiate such deals. They felt that **this should be handled by a Government body to ensure that people with the right expertise** to challenge large commercial research organisations were able to get the best deal for the NHS.

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There were mixed views about whether redistribution into the NHS should be local or national

Participants considered how the benefits (both financial and outcomes-based) should be distributed across the NHS, and whether the local NHS area supplying the data should receive the benefits or whether they should be spread more widely. At this point in the deliberation, **participants were split**, with:

- Those who favoured benefits going back to local NHS areas. They believed it was only 'fair' that the local NHS area be rewarded for investing in the provision of this data and that it would encourage other NHS areas to do the same.
- Those who felt that the benefits should be distributed across the whole of the NHS to ensure that the national population benefited, reducing the chances of deepening health inequalities (for example, if one region has access to treatment but others don't). They also felt that the NHS acting as a collective might generate better bargaining power

"I think it will get very messy if you start doing that. The NHS should be seen as the umbrella organisation, and therefore it just goes into their office."

(Male, from Hendon, Day 3)

Recommendation forming

On Day 4 a quarter of participants were allocated to a working group tasked with developing a recommendation for use of de-personalised data for research and development. They were shown a summary of the key themes discussed across the ten tables on Day 3, including thoughts, quotes, and questions from participants relating to considerations around fair and productive partnerships, and had input from working group experts.

Using this stimulus, the working group developed an initial recommendation with supporting conditions in their own words. They then presented this to the Summit and received feedback from all participants. They then revised the recommendation and conditions reflecting this feedback, and presented a final version back to the Summit.

Developing the draft recommendation

The key issues and trade-offs the working group deliberated on are described in detail below.

We expect a fair and productive partnership to consider the issues around charging, transparency and benefits

Overall, the working group was comfortable with de-personalised data being used for research and development. However, there was a considerable amount of back and forth between participants and experts in the room to clarify a range of different factors relating to a five safes framework. This included clarification of:

- The details around a 'safe setting' and confirmation that the data would be accessed within a controlled, secure and trusted environment where the data would remain and not leave the environment
- The purpose of potential research projects that may be undertaken using de-personalised data and the process for vetting the research proposals to ensure they are trustworthy and likely to benefit society
- Further detail on the process of de-personalising data and type of information contained within the datasets

They also asked for clarification about existing practices for using NHS health and care data for research and development before the discussion moved on to shaping the recommendation.

Use of de-personalised data for research and development

There was general consensus that **the NHS should be actively seeking to generate an income by realising the value of its health and care data** through research and development. Given the financial pressures on the NHS, there is a real opportunity for the NHS to make a profit from its data; money that could go back into the NHS and provide additional income, alongside tax revenue.

“It’s like universities, where some of the leading universities have turned from places of teaching to be more research-focused, with things like think tanks which generate revenue. The NHS could emulate this model.”

(Female, research and development working group, Day 4)

The group wanted to apply conditions to the use of de-personalised data for research and development, as outlined below.

Benefits: shared intellectual property with NHS

The working group wanted to **ensure that the NHS was able to recoup any potential financial benefit** that might be derived from a successful research and development project. Taking a share of the intellectual property that might be generated from research was viewed as the best way to do this, given that each project might be different, and the profitability of the project might be unknown at the time the partnership is being developed.

Benefits: shared across the NHS – to avoid inequalities, maintain British values and the principle of the NHS

Despite a mix of views in discussions on Day 3, the working group concluded that it was **important that any benefits (particularly outcome-based benefits, such as new drugs) are shared across the NHS**, not only within the specific NHS region involved in the partnership. The group was mindful of the potential for inequalities in the provision of NHS care and therefore insisted that the benefits should be widely distributed so the whole of the NHS can benefit.

Charges: recover costs first

Ensuring that the NHS did not lose money in providing access to its data was a priority for the working group. It wanted to ensure, as a minimum, that **the NHS was able to recover the costs of maintaining and providing access to the data** (i.e. collating, analysing and securing the data).

“We’ve got to make sure we cover the costs of what it’s costing the NHS to collate the data. That will cost a lot.”

(Male, research and development working group, Day 4)

Charges: different tiers of charging based on turnover. For example, start-ups, charities, universities, pharmaceutical companies

In addition to recovering costs, the group deliberated **charging a flat fee for access, against differential charging depending on the type of organisation** requesting access to the data. It recognised that charging a flat fee might not be fair for all organisations, particularly universities who it viewed as not-for-profit. The group also recognised that there might be differences between small tech companies and large pharmaceutical companies, and suggested a charge based on turnover to enable the NHS to charge on a case-by-case basis.

Transparency: annual report detailing companies that have accessed and used data, and why, and the impact of this use

The working group wanted to know more about the types of research being undertaken with health and care data; it was **less interested in how individual data was being used**. Discussions focused on reducing the cost of transparency for the NHS. Providing individualised information was deemed undesirable and likely to be costly. The preference was for clear communication about the research that regional NHS data had been used to support. The group suggested an **annual report that could be published online** and in newspapers that detailed at a high level which organisations were accessing the data, the reason, and any outcomes from the research.

Transparency: criteria for vetting – what is the process researchers need to go through to obtain access, and the different process for different types of companies shared for an agreed purpose, should be made available to the public

An additional point of discussion was the importance of understanding the process of the partnerships and the criteria by which research proposals are accepted. The working group felt that alongside knowing what research organisation was using the data, **the public should have a clear understanding of the vetting process for each type of research organisation to access it**.

Use of de-personalised data for research and development

Five safes: needs to be reviewed regularly against the legal and regulatory frameworks that underpin the five safes

The working group felt it was important that safeguards were in place to ensure appropriate and safe use of health and care data for research and development.

The group expected the procedures around the 'five safes' to be reviewed regularly (e.g. annually), to ensure that the regulatory and legal frameworks that underpin the five safes were appropriate and robust enough for the ever-changing technological and data landscape.

Five safes: no access will be granted to insurance companies

The working group was unanimous in its position that access should not be granted to insurance companies. It felt that this would lead to increased premiums for health and travel insurance which was deemed an unacceptable use of the data.

Draft recommendation

After the period of deliberation, the working group developed the following draft recommendation and conditions.

Draft recommendation:

We expect a fair and productive partnership to consider the issues around charging, transparency and benefits. The conditions around...

Draft conditions:

...Benefits:

- Shared Intellectual Property with NHS
- Shared across the NHS – to avoid inequalities, maintain British values and the principle of the NHS

...Charging:

- Recover costs first
- Different charging – different tiers of charging based on turnover. For example, start-ups, charities, universities, pharmaceutical companies

...Transparency:

- Annual report detailing companies that have accessed and used NHS health data (and why), and what the impact of this use was
- Needs to be criteria for vetting – what is the process they need to go through to obtain access – different process for different types of companies shared for an agreed purpose

...Five Safes:

- Needs to be reviewed regularly – needs to be a check on legal and regulatory frameworks that underpin the five safes
- No access will be granted to insurance companies

Use of de-personalised data for research and development

Feedback on draft recommendation

When the draft recommendation and associated conditions were presented back to the Summit, most participants supported it to some extent, with only one participant saying they could not support any part of the recommendation. However, over half thought it was missing some considerations.

To what extent, if at all, do you support this recommendation?

1. I fully support all parts of this recommendation

35%

2. I support most parts of this recommendation, but think that it is missing some considerations

55%

3. I support parts of this recommendation, but think other parts need more work

9%

4. I currently do not support any part of this recommendation, it needs more work

1%

The main feedback included:

- **Broadening the means through which the NHS is able to claim a share of the benefits** from potential research, including royalties, holding shares in companies, recouping a share of the profits and discounts on new products and treatments (developed using NHS data)
- Ensuring that **London is the first place to benefit from research that uses Londoners' data** before the benefits are more widely distributed to the NHS nationally
- Emphasising that the **NHS must recover costs for maintaining the data as a minimum to providing access to London's health and care data**, alongside charging for access to data. There were also calls for access to be granted for a time-limited period through a license or subscription fee
- Ensuring that **differential charging for access to data was reviewed annually** to ensure it was fit for purpose
- Emphasising the **need for a publicly available annual report that is written in plain English**, and also detailing how the NHS is redistributing the financial benefits gained from previous successful research projects
- Reiterating the expectation that the **data should only be used to support research projects that are in the public interest**

Final recommendation

Using the feedback, the group made some final amendments to the recommendation and supporting conditions, specifically focusing on tightening up the language to ensure each condition fully captured the expectations of participants in the Summit. This included the suggestion to amend the recommendation wording, **replacing the word 'consider' with the word 'meet'**. Participants deliberated this wording for some time as they wanted to ensure that it carried the right weight to ensure the recommendation was followed appropriately. They felt the word 'consider' allowed room for policymakers to overlook the conditions, and that 'meet' provided greater onus on policymakers to implement the conditions as they had been set out by the working group.

Use of de-personalised data for research and development

Recommendation:

We expect a fair and productive partnership to meet the following conditions:

Benefits:

- To be shared with the NHS including: shared Intellectual Property, royalties, stake (in companies), profits and outputs (i.e. discount on new drugs)
- To be shared across the NHS –to avoid inequalities (starting with London first), maintain British values and the principle of the NHS

Charges:

- NHS to recover maintenance/usage costs as a minimum
- NHS to charge for access to data (not selling data) for a time-limited period and/or license access to data
- Differential charging (reviewed every year) – tiered charges based on turnover and profit-making (e.g. start-ups, charities, universities, pharmaceutical companies may be charged relative to their turnover and potential to make profit)

Transparency:

- NHS to produce a publicly available annual report (in plain English) detailing who has accessed and uses the data (and why), the impact of the research undertaken, and distribution of any financial benefits to the NHS
- NHS to publish criteria for vetting potential partners – i.e. the process they need to go through to obtain access (e.g. for charities, commercial companies, universities)

Other:

- The ‘five safes’ model must be reviewed regularly – i.e. reviewing the legal and regulatory frameworks that underpin the five safes
- No access to data will be granted to insurance companies
- All accepted research proposals should demonstrate that they are in the public interest

Considerations from workshop with marginalised and vulnerable communities

Workshop participants were presented with a summary of the information given to participants at the Citizens’ Summit, alongside direct quotes from the research and development working group, demonstrating the thoughts and reasonings behind the recommendation.

Workshop participants were **broadly in favour of the recommendation and conditions set out by the working group**, including support for differential charging and the NHS taking a share of the benefits.

“I’d want to create an equitable contract that includes what they’re doing and potential profits, and if at the end of it they’re unwilling I want a small percentage.”

(Participant from the marginalised and vulnerable communities workshop)

However, they wanted to extend the first condition on transparency. They asked for the **publicly available annual report to not only be in plain English but also be available in a range of other languages**, for people who have English as a second language or no English at all.

Workshop participants (particularly those from migrant and refugee communities) were also **uncomfortable with the term ‘British values’**. They were unclear about this choice of wording, feeling that it was not inclusive and has potential negative connotations particularly for people who experience marginalisation and, thus, might not feel represented within the term.

Use of de-personalised data for research and development

Considerations for future communication approaches

- The public is interested in research and the potential role of this to improve health and people's lives as well as processes within the NHS. Participants felt that the NHS should be doing lots of research and working with partners, both to benefit society with the development of new drugs and treatments, but also as an opportunity to generate income
- It is important to distinguish and make clear the difference between data access and data sharing. Participants often confused data access and data sharing, which influenced how they felt about certain types of data use. They were less comfortable with data sharing as they felt this was less secure and that the data could be lost or used for other activities than the intended purpose. However, they were more comfortable with data being accessed as long as it was done so in a secure environment and for appropriate purposes (i.e. according to the five safes framework)



9

Governance and oversight

Governance and oversight

Session overview

On Day 4 a quarter of participants were allocated to a working group tasked with developing a recommendation for continued public involvement in policy development and oversight of these policies relating to the use of health and care data. In planning the deliberation, it was intended that this theme would be covered on the final day, recognising the need for participants to deliberate the other themes before they were asked about ongoing governance and oversight.

Over the course of the Citizens' Summit, participants spontaneously and regularly raised questions about current accountability processes. Where such questions were raised, these were noted, and we explained that this would be covered in more detail on Day 4.

The group received additional information to support the discussion given that it had not been covered as an explicit theme in previous days. The working group was asked to consider:

- Developing the policy, i.e. setting the rules that guide our action
- The approval process for data applications and projects, i.e. applying the rules
- Holding the system to account, i.e. checking the rules work and are being followed

Information provision

Participants were given a framework for thinking about the points at which input could be required: setting rules, applying rules, and ensuring the rules are followed. After an expert presentation providing an overview of typical governance structures, they were introduced to the concept of public involvement in guiding policy-making and continued oversight. A second presentation summarised a range of options and some of the key considerations associated with these models.²⁴

The issue of accountability and 'policing' use of joined-up data was raised spontaneously in discussions on previous days

Over the course of the Citizens' Summit, **participants regularly asked questions about current accountability processes**, and sought assurance that the safeguards they were discussing could be 'policed'. Participants spontaneously deliberated different ways to hold people and organisations to account for their decisions, and for the way they use (or may misuse) joined-up data.

"Who is overseeing that access? Who is monitoring it? What's going to happen if somebody does gain access and pass it on? Are they going to lose their job or is it a jail offence? What are they going to lose, in order to safeguard our information?"

(Female, governance and oversight working group, Day 4)

Participants felt strongly that the public should continue to be involved in decision-making, but that it would be vital to find a way to ensure these were informed views.

There was **broad agreement that ongoing public engagement was important** because of the changing policy and technology landscapes. The fact it was Londoners' data, and that some did not see doctors and other healthcare professionals as impartial, meant they wanted to ensure the public continued to have a say.

"I think it's important to involve the public. We are the ones who are going to be affected."

(Female, governance and oversight working group, Day 4)

Many reflected on their experiences of participating in the Summit. They were conscious that their personal views had changed significantly as a result of their improved understanding of the trade-offs, opportunities and safeguards around data use. Consequently, they were keen to ensure that any future public input would be equally well informed before it influenced decisions.

"I think you have to make sure the public understand fully what they're being asked, otherwise responses are from people who don't understand."

(Female, governance and oversight working group, Day 4)

Governance and oversight

Participants identified four factors of the process that were central to building trust: diversity, information, time and transparency

The stimulus included three different examples of citizen engagement: citizens' summits, similar to the one they were participating in; having citizen representatives on a board; and having an ongoing citizens' advisory group.

Although people were not necessarily wedded to the citizens' summit model, as they recognised that it would be an expensive and resource intensive exercise to repeat, they felt that some aspects of the approach were particularly important. Specifically, diversity, information, time and transparency (as shown in Figure 9.1).

Figure 9.1: Four factors essential to building trust in decision-making



Participants perceived there to be a balance between ensuring people are informed, and them becoming "professionals". Therefore, they wanted to ensure new voices were included. Some thought that a survey could be a good mechanism for a temperature check of the direction of travel, although others were not clear how this approach would ensure that respondents were sufficiently well informed to give a useful view.

"You need to bring in new people on a periodic basis. To test. Otherwise, as it says, we can become professionals and we'll just confirm what we already know."

(Male, governance and oversight working group, Day 4)

The opportunity to work with experts is vital, therefore having citizen representatives, as lay members, on a board of experts was an appealing option

Whilst participants wanted a voice in the decision-making process, they did not necessarily want to make the final

decision. **They felt others would be better qualified to make those judgements, with the knowledge of the public's priorities, concerns and red lines.** It was recognised that this form of public involvement would sit alongside other engagement (for example, an advisory group and ad-hoc activity as needed), however the idea of having a few citizen representatives contributing to a board of experts had instant appeal.

"It's important to have the layers. The healthcare professionals, the experts, the average Joe Bloggs."

(Female, governance and oversight working group, Day 4)

Initially, **they explored the idea of mandating people to participate, to ensure diverse views – in the same way that the public are mandated to jury service. They were not sure whether this would work, or how people might respond.** The role of a lay member was compared with that of a school governor – people thought that the role would be a significant investment of time but could be rewarding.

Governance and oversight

A process for ensuring that these lay members did not have a personal agenda was seen to be vital. To mitigate this risk, an advisory group and ad-hoc engagement was seen to be important. There would need to be clear links between the board and the advisory group, with the citizen representatives on the decision-making board also forming part of the wider citizens' advisory group.

"If you have one or two people representing how many million, what is on their mind is what affects them personally."

(Male, governance and oversight working group, Day 4)

In line with the importance of information and time, working group participants were keen that any lay advisor had enough information to enable them to engage in the discussions.

The idea of a Citizens' Advisory Group was viewed positively by most, although some had concerns about the perceived lack of expert input

For some, the idea of an advisory group to support citizen representatives on a board was immediately welcomed. This was viewed as **a useful mechanism for getting wider input from a group of informed citizens**, without them feeling overwhelmed in the presence of experts who they might defer to.

"For example, if a GP was present on the board, some people look up to the GP and feel a bit intimidated."

(Male, governance and oversight working group, Day 4)

Others had concerns that, without experts in the advisory group (as they had had in the Citizens' Summit to provide information and challenge), there was **a risk that discussions and decisions may not be balanced** (i.e. informed by the benefits as well as concerns or risks). They stressed the **importance of active challenge, including the views of public representatives**, to ensure sessions would be constructive.

"It would be so easy to just complain."

(Female, governance and oversight working group, Day 4)

Some suggested that an advisory group could initially include people recruited, or elected, from this Citizens' Summit, as they would be familiar with the recommendations and reasoning, and therefore best placed to support their development. Important in discussions about who would make up the advisory group was diversity, with the need to involve people from a range of backgrounds including young people.

Going forward, they thought that this **advisory group might meet a few times a year or annually in order to review progress and input**. They anticipated it would meet less frequently than a board to reduce the burden on participants. A high level of attrition, or not enough people attending, was a cause for concern. Convening the group at the request of the board seemed a good way to ensure wider input on issues where needed. Lay members on the board would potentially be recruited from the citizens' advisory group to provide a link between the two layers of governance.

"One of the problems with a public advisory group, is that it is difficult for people with sufficient interest to go to all the meetings. You end up getting the same two or three people."

(Male, governance and oversight working group, Day 4)

As with the other citizen roles, they thought it was **important to rotate members**. They suggested this was done in a phased way so there was cross-over between old and new people to ensure a smooth transition.

In the second part of the session, participants were asked to consider ongoing oversight, i.e. how to ensure the rules are working and being followed as intended. The group considered the roles of health and care managers and clinicians, borough and London-level elected representatives and nationally elected representatives in ongoing oversight. They also reflected on the pros and cons of these different people being involved.

Governance and oversight

A representative group involved in oversight of ongoing data use, with a role for elected representatives to hold the system to account

Participants immediately affirmed **the role for people from health and care backgrounds**, and also thought it would be **important to involve people with other relevant specialisms, for example, scientists and cyber security experts**.

This was still viewed as insufficient, as participants were not sure whether people could be trusted to effectively ‘oversee themselves’. They therefore concluded that there should be **a role for elected representatives to hold the system to account** – especially if or when things went wrong. This was important in creating a trustworthy system.

“I think oversight is the key word there. If something goes wrong, and the mess needs to be sorted out, I think that elected representatives and politicians need to go out and sort the mess.”

(Male, governance and oversight working group, Day 4)

There was some concern that elected representatives would not be familiar with the issues around uses of health and care data. Additionally, some were worried about politicising the NHS. On balance, most thought that these difficulties could be overcome by **ensuring that representatives had sufficient technical support and advice**, especially as they could be held to account through elections if people disagreed with their approach. Many also thought it was unrealistic to try to keep politics separate, given the financial implications of using the data in different ways.

“There might be financial implications so there probably does need to be some representation.”

(Male, governance and oversight working group, Day 4)

At this point, some suggested there was a need **for transparency in enabling citizens to scrutinise the decisions being made on their behalf**. Linking back to discussions around transparency for research and development, whilst recognising that not everyone would be interested, they nonetheless thought that sharing the information online would be a low-cost way to help build trust.

“Online access, it’s cheap. [Then] people can see it easily and don’t have to apply for freedom of information.”

(Female, governance and oversight working group, Day 4)

When it came to potential misuse of data, participants in the group stated **a role for the judiciary and legal system**. They recognised this could mean that new laws would have to be written to enable prosecutions to take place. These laws or regulations should reflect the expectations expressed by the public and experts about acceptable uses of data, making it clear to the courts what would or would not be acceptable.

Recommendation forming

Drawing on the stimulus provided and the subsequent discussion, the working group deliberated the specifics around forming a recommendation and conditions on ongoing policy development and trustworthy oversight in joining up data. Having developed an initial two-part recommendation with supporting conditions in their own words, they presented this to the Summit and received feedback from all participants. They then revised the two-part recommendation and conditions reflecting this feedback, and presented a final version back to the Summit.

Developing the draft recommendation

The key issues the working group deliberated on are described in detail below.

We expect that there are several ways that the public are involved in ongoing policy development

Participants in the working group were all in agreement that several mechanisms should be used in combination to ensure public opinion could influence how their joined-up health and care data was used.

Two to three citizen lay people involved in a decision-making board with health care officials and experts

The working group agreed there was a role for citizen representatives on a decision-making board, potentially recruited from the citizens’ advisory group. They thought **there should be more than one person to ensure a range of views were represented**.

Governance and oversight

This board should be able to check ideas with a citizens' advisory group where people are recruited, in a jury-style way, to be reflective of London, with a lower age limit, supported with the right information to understand the issues

The working group agreed that for this model to work **the advisory group must be recruited to reflect a wide range of backgrounds**. The provision of information was also seen to be vital to ensure that the advisory group was sufficiently knowledgeable to make informed decisions.

"It is great if you can get public advisory going. It's difficult to get enough people to go to the advisory group. If people can go in with enthusiasm, then it would work."

(Male, governance and oversight working group, Day 4)

To ensure diverse representation, some wanted to mandate people to participate, using jury-style recruitment. They thought this would be important, so that the advisory group was made up of more than just people who had a specific interest in the topic. However, others thought it would be important to have people who were interested in the topic so that they would invest time in learning to ensure they could do the role well. On balance, they agreed **that the recruitment for the Citizens' Summit had resulted in a diverse group of people**, and therefore a similar approach to the one used for the Summit might be a good way to get people to participate.

"If it's voluntary you'll end up with the same people all the time. I don't have a vested interest – I haven't seen a GP in three years. Maybe I need to be involved and at some point, I will."

(Male, governance and oversight working group, Day 4)

Participants also discussed practical considerations to encourage a diverse range of people to engage:

- **Expenses should be covered so that people are not out of pocket**, but people should not be paid as this might motivate people to participate for the wrong reasons
- **Ensure that some people, but not all, are current patients** so that they can bring up-to-date experience of the health and care sector to the group
- **Ensure that the time investment is not too great**, potentially just once a year or more frequently if requested by the board

- **Set a minimum age of between 16-18**, given that older people are already more likely to engage given their interaction with the health service

"A wide [age] range, prevention is better than a cure, so getting the younger generation involved."

(Female, governance and oversight working group, Day 4)

These roles should be replaced so that they don't become too stale

There was agreement that over time people would become overly familiar with the technical aspects and could potentially move away from being representative of the public view. Also, the group thought **commitment might diminish if people were expected to sign up for a long duration**. Consequently, they agreed that all roles should be refreshed periodically – potentially every three years, although this wasn't made explicit within the condition.

Surveys should take place with the wider public to gather the wider views of Londoners and test ideas

In situations where the board and the citizens' advisory group didn't agree, it was felt important to harness the views of the wider public to inform decisions or to put ideas out for a vote. Surveys were viewed as an effective means for capturing a wider range of uninformed public views.

All Londoners should be educated via an education campaign for the wider public

The importance of education came through as a theme in the discussions, thus was weaved into this draft recommendation. The group recognised how much they had learned over the course of the Citizens' Summit, and that it was important for all Londoners to be informed about how their data was being used and why.

We expect there to be trustworthy oversight of the system of joining-up and using health and care data

Unsurprisingly, participants agreed that **oversight of the system was very important**. In order to build trust in the system, they named a range of people they would want to be involved in the process. The group quickly reached a consensus on this, although there was some debate about the role of politicians in deciding how data is used.

Governance and oversight

Health officials playing the main role in making detailed decisions

Most importantly, the group felt that healthcare professionals should play a major role in oversight.

With additional roles for experts, from health professionals, scientists, cyber security experts, as well as people with a range of other backgrounds (patients, people from the arts and from other sectors)

It was felt that there was an additional role for a range of healthcare professionals, including clinicians, as well as experts from different backgrounds so that varied perspectives could be gathered. It was felt important that other people were included: patients, because they could bring condition-related experience relevant to the data being accessed; and people with different backgrounds, from different sectors (e.g. the arts or manufacturing) to bring an alternative perspective.

A specific role for elected representatives at the London level, to oversee and scrutinise, but not necessarily involved in day-to-day decisions

There was a sense that there was a specific role for elected representatives, but that this needed to be at the London level. While it was important for these elected representatives to scrutinise the process, the group did not think they would necessarily need to be involved in the day-to-day decisions.

Draft recommendation

After the period of deliberation, the working group developed the following two-part draft recommendation and conditions.

Draft recommendation – part one:

We expect that there are several ways that the public are involved in ongoing policy development:

- Two to three lay people involved in a decision-making board with health care officials and experts
- This board should be able to check ideas with a citizens' advisory group where people are recruited, in a jury-style way, to be reflective of London, with a lower age limit, supported with the right information to understand the issues
- These roles should be replaced so that they don't become too stale
- Surveys should take place with the wider public to gather the wider views of Londoners and test ideas
- All Londoners should be educated via an education campaign for the wider public

Draft recommendation – part two:

We expect there to be trustworthy oversight of the system of joining-up and using health information, which would include:

- Health officials playing the main role in making detailed decisions
- With additional roles for experts, from health professionals, scientists, cyber security experts, as well as people with a range of other backgrounds (patients, people from the arts and from other sectors)
- A specific role for elected representatives at the London level, to oversee and scrutinise, but not necessarily involved in day-to-day decisions

Governance and oversight

Feedback on draft recommendations

When the draft recommendations were presented back to the room, participants were supportive of the two parts to some extent.

However, it was clear participants felt that the recommendation was missing some important considerations. At this stage 4% of the room indicated in the vote that they did not support any part of the recommendation.

To what extent, if at all, do you support this recommendation?

1. I fully support all parts of this recommendation



2. I support most parts of this recommendation, but think that it is missing some considerations



3. I support parts of this recommendation, but think other parts need more work



4. I currently do not support any part of this recommendation, it needs more work



The main feedback included:

- People who were positive about the proposals and volunteering personally to sit on the advisory group
- Questions about how the roles would be 'refreshed'
- Whether two or three people sitting on the board would be **sufficient to represent diverse public viewpoints**
- Some wanted to simplify the language, removing the mention of 'lay people' or clarifying who this would be
- Several requested more information about **how the roles would be recruited**
- Questioning **why people specifically from arts backgrounds should be involved**
- Some expressed support for involving **the London mayor** while others thought this could be overly politicising decisions made by the NHS
- The **lack of explicit mention of people from social care backgrounds**

Final recommendations

Using the feedback, the working group made some final amendments to the two-part recommendation and conditions.

For the first part, around ongoing public engagement in policy development, this included:

- Defining a **lower age limit of 17**, with no upper age limit for members of a diverse citizens' advisory group
- **Specifying the means for recruiting representatives** to the decision-making board, by adding a process similar to how school governors are recruited
- Specifying a **time limit** for replacing these roles every three years
- **Removing the reference to surveys specifically**, given that there are other means for gathering insight. However, with a **built-in assumption that the citizens' advisory group would have the power to commission insight gathering exercises** where required

Governance and oversight

On the second part of the recommendation, around oversight, the recommendation was tweaked as follows:

- Changing the **first part to refer to health and care professionals** as it was important to include those with a social care background, as well as health
- **Removing the direct reference to people from the arts, and instead adding a role for people with ‘creative ideas’** to bring challenge and disruption to the board
- **Stating a role for a ‘powerful’ representative at the London level**; someone who has the authority to take action. The group was keen that if this person’s role was to scrutinise, that they would be closely advised; as there was concern that those elected would not necessarily have the expertise. There would also be **a role for the London Assembly** within this

Finally, they **added the condition about transparency** – to inform the public of what is going on and why

Recommendation: ongoing roles in policy development

We expect that there are several ways that the public are involved in ongoing policy development:

Conditions:

- There should be a diverse citizens’ advisory group where people are recruited to be reflective of London (i.e. similar to the OneLondon Citizens’ Summit), with a lower age limit (17 years), supported with the right information to understand the issues.
- Two or three citizen representatives should also sit on decision-making boards with people who work in health and care as well as experts. They need to be recruited (i.e. similar to how school governors are recruited) with the skills to take part
- These roles should be time-limited (and replaced every three years)

Recommendation: ongoing roles in governance and oversight

We expect there to be trustworthy oversight of the system of joining-up and using health information, which would include:

Conditions:

- Experts playing a lead role in making detailed decisions
- With additional roles for experts from the health and care professions, scientists, and cyber security experts, as well as people with a range of other backgrounds who might bring creative ideas
- A specific role for a powerful elected representative at the London level, supported by the right expert advice to hold the system to account, and a role for the London Assembly
- Make sure the accountability process is transparent for all Londoners (should they wish to see)

Governance and oversight

Considerations from workshop with marginalised and vulnerable communities

Workshop participants were presented with a summary of the information given to participants at the Citizens' Summit, alongside direct quotes from the governance and oversight working group demonstrating their thoughts and reasonings behind the recommendation.

This group's considerations were as follows:

- There was broad agreement that the system should be policed by an independent group, a mix of people who know about the subject, from a range of sectors, alongside the public
- There were suggestions that the group approving data requests should contain legal representatives, charity representatives, NHS staff, universities, social care, companies and data experts

"The NHS, if they're going to be holding the information. They should obviously be involved."

(Participant from marginalised and vulnerable communities workshop)

- There was also wide agreement that public representatives should have roles, and that this should include people from marginalised and vulnerable communities

"Well, you've got those patient groups. You can get people from us from minority or stigmatised groups. We should be up there."

(Participant from marginalised and vulnerable communities workshop)

- There was broad agreement too that two or three citizens should sit on a decision-making board, but it was felt important to financially reward those giving up their time

"The problem with voluntary is I keep going to things where other people are being paid, and they're asking me for my expertise, and I'm not getting paid. Everyone at the table should get something in return for their time."

(Participant from marginalised and vulnerable communities workshop)

- It was also agreeable that roles should be refreshed so that the public representation remained balanced and not too biased
- Most felt that three years was too long a period, in the context of data, where there are constantly changes

- It was important to some of the community representatives that the board remained free from politicians. However, the reference to a role for the London Assembly, when it came to oversight of the system was more acceptable, given that the mayor is not a member of parliament. This was described as a 'good compromise'
- Transparency was viewed as important

"Control transparency. You don't need to know meetings but results of meetings."

(Participant from marginalised and vulnerable communities workshop)

- It was also suggested that there should be a government department that looks after and oversees data

"I'm really into the idea of a government department or data tsar who deals with data. Someone who's ultimately responsible. I think we should have a department dealing with this. So that we're all clear, and they publish reports and if you want you can go look at it."

(Participant from marginalised and vulnerable communities workshop)

Considerations for future communication approaches

- **There is a desire for members of the public to be involved in policy development, wider governance and oversight.** Careful consideration should be given as to how to involve the public at all stages of the process
- **It is important that governance and oversight processes engage and involve the diversity of London's population.** There is an expectation to ensure that policy and actions consider the wishes of all Londoners, which requires a diverse range of views
- **Governance and oversight should be open and transparent,** both in terms of the process for setting up these mechanisms and in ensuring that activities are visible to the public. This includes ensuring **efforts are made to make the public aware of governance and oversight arrangements, and information around it** (e.g. who is involved, purpose, activities)
- **Any approach to governance and oversight should be subject to regular review** to ensure it is fit for purpose and able to meet the ever-evolving challenges posed by advances in modern technology



10

Consistency across London

Consistency across London

Session overview

To conclude the Citizens' Summit, participants were asked to reflect on what they had heard throughout the four days of deliberation and to think about the implications of consistency across London for the different purposes of data use (i.e. for individual care, planning and improvement, research and development, proactive care).

Information provision

To support the discussion, participants were presented with fictional quotes from a range of health and care professionals holding different views around the joining-up of health and care data for reasons beyond their individual care. These quotes addressed the different reasons why health and care professionals and organisations might be supportive, cautious and against doing so.²⁵

Participants were asked to consider these views, and the potential benefits and risks in relation to each. Participants then considered three different policy options relating to the consistency of data access and use across London:

- **Option one:** maintain the status-quo and continue to allow each individual organisation to determine its own data sharing policies (being mindful that some might choose not to contribute patients' data)
- **Option two:** determine these policies at STP level (accepting that some STPs might choose different arrangements or choose not to contribute to a cross-London dataset)
- **Option three:** ask all health and care organisations in London to operate within a single set of policies, where they would be expected to contribute their data on behalf of patients into a cross-London dataset

Participants understood why some health and care professionals might be supportive of the status-quo

"Although it is illegal to do so, there have been cases in other countries where de-personalised patient data has been re-identified, and I am just not comfortable with this risk."

GP (fictional quote)

Participants acknowledged that some GPs and other healthcare professionals who held views about not wanting to share patient data were **acting in the best interest of patients and themselves**. For example, fear of potential backlash from patients within their practice who were unhappy about having their data shared.

"If the doctor has protection, he might not be so worried."

(Female, from Bromley, Day 4)

Consistency across London

But participants expected health and care organisations to be sharing data for uses beyond individual care as they believed this would lead to better care for patients

Most participants had clear expectations that health and care organisations should be sharing data for uses beyond individual care. This would result in **better quality data** (meaning subsequent uses of the data would be better informed), as well as helping to **improve care and reduce variance in care and health inequalities for Londoners**. They also felt that consistency would reduce the risk of mistakes.

“I think it should be uniform across London. If different areas are doing different things, then there could be more chances of information being given out that shouldn’t have been given out.”

(Participant, Day 4)

The national data opt-out provided enough assurance for those who may not want their data to be used for purposes beyond their individual care

“Joining up data means that people receive higher quality care and can be treated more safely; and it can save clinicians wasting time chasing information. It also means that we can develop new ways to keep people well and treat them when they are sick.”

Hospital Consultant (fictional quote)

Participants were **quick to point to the national data opt-out** as a process through which those patients who did not want their data involved in uses beyond individual care could choose to do so.

“We are seeing the bigger picture here. We are aware it can be hacked and disappear. As long as we are aware of it, but also aware of the benefit and being included in it... We are making the decision for the whole of London, but they are still making their decision, based on whether or not they want to opt-in or opt-out.”

(Female participant, Day 4)

Overall, consistency was key

There was a considerable expectation from nearly all participants that there should be a single approach to govern how health and care organisations go about sharing data, that all organisations should sign up to. This seemed, in part, a response to the knowledge gained earlier in the Summit, on Day 1, around GP practices and other health organisations operating as independent legal entities operating under contract. Participants expected health and care organisations to act universally (where possible) and ensure that all Londoners have access to the same care.

“I would agree with the last option. A centralised system should be information gathered from all parts. That would benefit everyone.”

(Female, from Ealing, Day 4)

Consistency across London

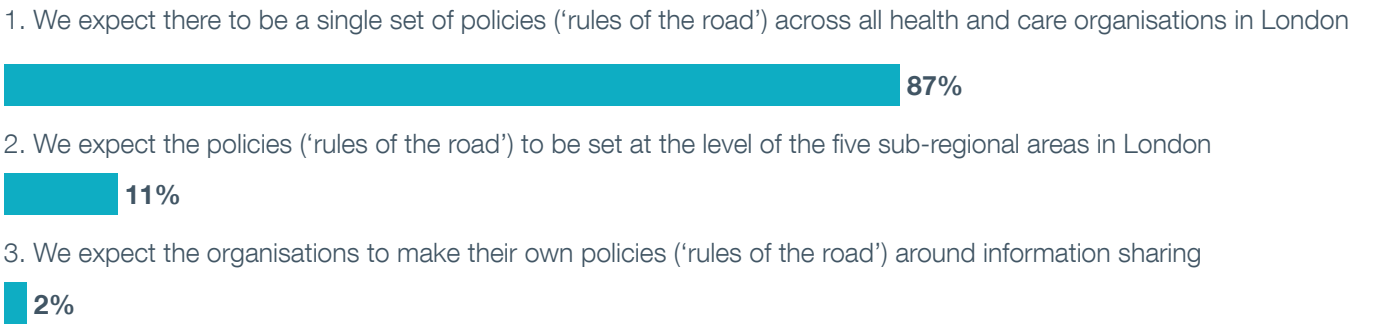
Confirming expectations

There was clear expectation that data should be consistently joined-up across London to support individual care, proactive care, planning and research

Participants returned to plenary for the final time and were asked to vote on three questions relating to consistency across London. The voting was done discretely using electronic voting pads and the results were displayed at the front of the room for all participants, experts and observers to see.

All participants were asked to express their expectations in relation to the following three key questions around the use of health and care data.

Question one: Should all health and care organisations across London follow the recommendations we have developed today (data use for planning and in research), or should they each have the power to make their own decisions about how to use their patients’ data?



Most participants (87%) expressed **that they expected there to be a single set of policies** across all health and care organisations in London. A minority of participants (11%) expected the policies to be set at the STP level, whilst only two participants expected organisations to make their own policies around information sharing.

Consistency across London

Question two: To what extent do you agree or disagree with the following statement: “We expect all health and care organisations in London to join-up identifiable information to support the provision of care to individuals, with staff seeing information relevant to their roles through some sort of role-based access control.”

1. Strongly agree



2. Agree



3. Disagree



4. Strongly disagree



Most participants (97%) agreed to an expectation that **all health and care organisations in London should join-up identifiable information to support individual care** and be used by staff through some form of roles-based access and control model. Only a few participants disagreed with this.

Consistency across London

Question three: To what extent do you agree or disagree with the following statement: “We expect all health and care organisations in London to join-up de-personalised information, as part of a population dataset, to support proactive care, planning and research and development.”

1. Strongly agree



2. Agree



3. Disagree



4. Strongly disagree



Nearly all participants (98%) expressed an expectation that **all health and care organisations in London join-up de-personalised information, as part of a population dataset**, to support proactive care, planning, and research and development. Only two participants disagreed with the statement.

Considerations for future communication approaches

- **The public expects a consistent health and care service across London.** It is important that communication at a local level reflects this expectation, and this should be considered when developing local messaging and branding of data programmes
- **The public wish for a national approach to consistency.** Communication should consider the wider implications, in relation to consistency, beyond the local population. Participants repeatedly called for national joining-up of data to ensure the rest of the country could receive the same services and benefits as London

Glossary

Anonymised data

Data which does not identify individuals either directly or indirectly and where identification is not likely to take place by any means reasonably likely²⁶.

Deliberation

Deliberative engagement focuses upon participants' viewpoints after they have been presented with the opportunity to 'deliberate' the issue(s) in question (as opposed to traditional qualitative methods that seek to understand current viewpoints). The sessions, which usually take the form of an extended workshop, present a range of information, and encourage differing points of view and perspectives to be presented, before considered decisions are finally sought. It can be a useful approach for policy consultations as it allows the public to be involved in decision-making that incorporates a wide range of viewpoints and ideas²⁷.

De-personalised data

This is information that does not identify an individual, because identifiers or identifiable data have been scrambled or removed from the non-identifiable information about the person it relates to. However, the information is still about an individual person and so needs to be protected. It might, in theory, be possible to re-identify the individual if the data was not adequately protected, for example if it was combined with different sources of information²⁸.

Five Safes framework

A set of principles for data access²⁹ to provide assurance for data owners and researchers by using³⁰:

- Safe people - completed by people who have been trained and accredited
- Safe projects - for research projects that deliver clear public benefits
- Safe settings - in a secure setting where it is impossible to remove data
- Safe outputs - where all outputs are checked and confirmed as non-disclosive
- Safe data - when the data to be used has names, addresses and any other variables that would directly identify an individual removed beforehand

General Data Protection Regulation (GDPR)

The General Data Protection Regulation 2016/679 is a regulation in EU law on data protection and privacy for all individuals within the European Union and the European Economic Area. It also addresses the export of personal data outside the EU and EEA areas and all personal data processed by organisations established in the EU³¹.

Governance

Governance refers to the way that organisations, partnerships or networks are managed, and the systems and processes in place for doing this.

Identifiable data

Personal information about identified or identifiable individuals, which should be kept private or secret. It includes the definition of personal data in the Data Protection Act, but also includes data relating to people who have died and information given in confidence under the Duty of Confidentiality³².

Individual care

A clinical, social or public health activity concerned with the prevention, investigation and treatment of illness and the alleviation of suffering of an identified individual³³.

National data opt out

The national data opt-out is a service that allows patients to opt out of their confidential patient information being used for research and planning³⁴.

Oversight

A systematic process of holding policymakers, organisations and partnerships to account.

Planning and improvement

A process that appraises the overall health needs of a geographic area or population and determines how these needs can be met in the most effective manner through the allocation of existing and anticipated future resources³⁵.

Proactive care

Proactive care is a move away from treating illness towards promoting health, by enabling earlier interventions to prevent an individual's health from deteriorating.

Research and development

Research and development in healthcare aims to develop new treatments and medicines, prevent illnesses, improve quality of life, improve our understanding of medical conditions, and understand the emotional and physical support needed for someone living with a medical condition³⁶.

Roles Based Access and Control (RBAC)

A set of rules that govern who (e.g. which health and care professionals) can access health and care information to keep it secure, confidential and ensure it is used appropriately. The level of access is related to the job or role undertaken.

Social care

The term social care covers a range of services provided to help vulnerable people improve their quality of life and assist them with their day-to-day living³⁷.

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7. See table 2.2 for stakeholder workshop participants.
8. Details of the homework task assigned to participants is included in Appendix F
9. 97 participants took part on Day 1, and this number was boosted overnight meaning that 102 participants were present for Day 2. The overall number reduced from 102 to 97 for Day 3, and for Day 4 the total number of participants was 93.
10. STPs are areas covering all of England, where local NHS organisations and councils draw up shared proposals to improve health and care in the areas they serve. Participants were recruited from across the five STPs covering London, including: East London Health & Care Partnership, North London Partners, North West London STP, Our Healthier South East London, and South West London Health and Care Partnership.
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14. For full details of the information and stimulus provided to participants, including presentations at the Summit, visit: <https://onelondon.online/citizenssummit/>
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21. For more detail see blog by Office for National Statistics - <https://blog.ons.gov.uk/2017/01/27/the-five-safes-data-privacy-at-ons/>
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Appendices

Appendices

Appendix A: **Methodology**

Appendix B: **Questionnaire data**

Appendix C: **Expert biographies**

Appendix D: **Case studies and handouts**

Appendix E: **Discussion guides**

Appendix F: **Homework task**

Appendix G: **Questionnaires**

References

Appendices are available to download at:

<https://www.onelondon.online/wp-content/uploads/2020/06/Appendices.pdf>

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