



# Public deliberation in the use of health and care data: **Appendices**

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## Appendix A: Methodology

### Sampling and recruitment

A subjective purposive sampling approach has been adopted for this work. This sampling method is commonly used in qualitative research, which does not use randomised sampling but relies on researcher judgement when choosing participants. Participants were identified and selected related to criteria of interest. The goal was not to create a sample with the intention of making generalisations (i.e. statistical inferences), but rather to be reflective of the range of views and experiences that existed within the given population.

To help manage the recruitment process, Ipsos MORI employed the services of Criteria UK - a specialist recruitment agency - to undertake recruitment of participants. Criteria UK were instructed to use an entirely 'free-find' recruitment 'on-street' method. In practice, this means that recruiters go out to different local areas and approach people to take part in the deliberation. This method was judged to be preferable to solely using databases because the people that are approached were less likely to be regular participants in research. Lists, too, can be skewed towards people who are particularly keen to be involved in research. Because of their local area expertise, recruiters were expected to know where to find people with certain characteristics (e.g. parents close to schools or in libraries/local leisure centres, young people within proximity to university campuses).

Minimum quotas, or target numbers, of participants were set, to ensure that the sample suitably reflected the criteria that was judged to be important to include within the deliberative event, and the London population. In this case, it was decided to select criteria based on a mixture of characteristics which are known to influence attitudes (e.g. age, ethnicity, socioeconomic grade), as well as those which reflect likely differences in experiences (e.g. people with children and caring responsibilities, people with long-term conditions). Quotas were then set to ensure that there was adequate representation of the range within these criteria, sometimes reflecting population estimates (e.g. age, ethnicity).

### Quotas

- General public: 100 participants recruited
- Within the 100, a minimum quota of 48 for both male and female
- A mixture of ages:
  - 25 participants aged 18-24 years old
  - 25 participants aged 25-44 years old
  - 25 participants aged 45-64 years old
  - 25 participants aged 65 years old and above
- A mixture of socioeconomic backgrounds:
  - At least 30 from AB<sup>1</sup> socioeconomic grades
  - At least 30 from C1C2 socioeconomic grades, with at least 13 from each group
  - At least 30 from DE socioeconomic grades, with at least 13 from each group
- A minimum of 40 participants from a Black, Asian and Minority Ethnic (BAME) background<sup>2</sup>
- A minimum of 20 parents with children under 16
- A mixture of self-defining health and social care usage – heavy, medium, light – a minimum of 28 participants from each
- At least 20 participants with self-defined long-term conditions
- A minimum of 20 carers<sup>3</sup>
- A mixture of self-defining attitudes towards data – data unconcerned, data pragmatists, data absolutists – a minimum of 30 from each with the final ten people falling across these categories (in line with advice from the Oversight Group)
- Within the 100, participants were recruited from across all five London Sustainability and Transformation Partnership (STP) areas, with 20 participants per area:
  - North East London STP: boroughs include Hackney, Havering, Redbridge, Barking and Dagenham, Newham, Waltham Forest, Tower Hamlets, City of London
  - North Central London STP: boroughs include Barnet, Camden, Enfield, Haringey, Islington

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- North West London STP: boroughs include Brent, Westminster, Ealing, Hammersmith and Fulham, Hounslow, Harrow, Kensington and Chelsea, Hillingdon
- South West London STP: boroughs include Croydon, Kingston Upon Thames, Merton, Richmond, Sutton, Wandsworth
- South East London STP: boroughs include Bexley, Bromley, Greenwich, Lambeth, Lewisham, Southwark
- Within the 100, participants were recruited from all 32 London boroughs – aiming for a minimum of two per borough

Within these quotas, Ipsos MORI instructed Criteria UK to expect higher numbers of BAME participants from North West London STP (in particular from the boroughs of Brent, Newham and Hounslow) and East London (Newham, Tower Hamlets, Redbridge and Waltham Forest).

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### Attitudinal screening

As part of the OneLondon engagement programme, in September and October 2019, Ipsos MORI undertook research with the general public and a broad range of specific groups (capturing the voices of vulnerable, marginalised communities and hard to reach groups) to help inform the design of the deliberation. Analysis of this pre-deliberative research found, overall, 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 of acceptability, and included:

- **‘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

Criteria UK were instructed to ensure all three groups were reflected in the 100 people participating in the deliberative event, to the quota outlined above.

**Exclusions:** To mitigate the risk of some participants being more informed than the general public, individuals who worked in the following industries were excluded:

- Journalism
- Advertising
- Public relations (PR)
- Market Research
- Pharmaceutical industry
- NHS or social care

Exclusions were also set for those who had participated in a market research group discussion or workshop within the past year.

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### Incentive payments

Given the commitment, participants were thanked for their time and help with a payment of £200 per weekend, £400 in total (in line with the current industry payment for this type of event). Participants received their incentive at the end of each weekend. At the end of the first weekend, the distribution of incentives was used to remind participants about the second weekend. Two reminder emails were sent by Ipsos MORI via mail merge, and Criteria UK also contacted participants between weekends, to remind participants of their obligations.

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### Accessibility

Participants were asked at the point of recruitment if they had specific dietary requirements and whether they felt they would need assistance during the four-day deliberation. The venues chosen to host the events catered for most dietary requirements (vegan, gluten free), and were checked to ensure all rooms were accessible via lifts and were wheelchair friendly. Finally, a condition of participating in the deliberation was that people needed to be able to speak English.

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### Deliberative method

As referenced in the main body of this report, a deliberative event was held in London over two weekends (i.e. four days) and referred to throughout this report as the ‘Citizens’ Summit’. The first weekend took place on 1 and 2 February (Days 1 and 2). The second weekend was four weeks later on 29 February and 1 March (Days 3 and 4). This reconvened approach allowed participants enough time to digest the

## Appendix A: Methodology

information received during the first weekend, reflect on the topics outside of the deliberative setting, and complete an assigned homework task (details of which can be found in Appendix F).

Approximately 100 participants took part in the Citizens' Summit throughout all four days. This number changed marginally on each day due to participants being unable to attend. 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 the quotas, 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.

On Day 4 of the Citizens' Summit participants were allocated to working groups. These working groups were formed around four key themes of discussion 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 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 covered within the three days:

- The appropriateness of linking data to enable proactive care, as long as suitable safeguards are in place
- Whether all health and care 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, settling on just one overarching recommendation per working group.

The timings and details of the topics covered in each day of the Citizens' Summit can be found in the discussion guides outlined in Appendix E.

## Appendix B: Questionnaire data

A quantitative element to this work involved the administration of a combined pre and post project participation questionnaire. This questionnaire collected information from participants regarding their knowledge and attitudes on the uses of health and care data. Participants were asked to reflect on their attitudes to each question both before the Citizens' Summit and afterwards. Responses to each question are presented in the tables below.

### Q1. How much, if anything, would you say you know about how health and care data is used?

Response	Before	After
A great deal	1%	57%
A fair amount	12%	43%
Not very much	59%	0%
Not at all	26%	0%
Don't know	2%	0%
<b>Base</b>	<b>95</b>	<b>95</b>

Health and care data can be used for different purposes. For each of the following purposes, please tick the circle that shows how acceptable or unacceptable it would be to you.

### Q2. Different NHS services joining up and using your health and care data for your individual care (e.g. your GP and hospital). This data would be linked directly to you.

Response	Before	After
Completely acceptable	15%	68%
Acceptable	30%	29%
Neither acceptable nor unacceptable	40%	1%
Unacceptable	6%	1%
Completely unacceptable	3%	1%
Don't know	5%	0%
<b>Base</b>	<b>93</b>	<b>94</b>

### Q3. NHS and social care services joining up and using your health and care data for your individual care (e.g. a social worker and a GP). This data would be linked directly to you.

Response	Before	After
Completely acceptable	12%	56%
Acceptable	30%	34%
Neither acceptable nor unacceptable	39%	2%
Unacceptable	10%	4%
Completely unacceptable	4%	3%
Don't know	5%	0%
<b>Base</b>	<b>93</b>	<b>94</b>

## Appendix B: Questionnaire data

**Q4. NHS organisations joining up and using your health and care data for the planning of health and care services. The information given to the NHS organisations would not include your name and address or any contact details.**

Response	Before	After
Completely acceptable	15%	61%
Acceptable	37%	39%
Neither acceptable nor unacceptable	30%	0%
Unacceptable	11%	0%
Completely unacceptable	2%	0%
Don't know	5%	0%
<b>Base</b>	<b>93</b>	<b>94</b>

**Q5. A commercial organisation (e.g. pharmaceutical or tech company), using your health and care data for health research. The information given to the commercial organisation would not include your name and address or any contact details.**

Response	Before	After
Completely acceptable	4%	28%
Acceptable	23%	53%
Neither acceptable nor unacceptable	33%	11%
Unacceptable	25%	5%
Completely unacceptable	13%	3%
Don't know	2%	0%
<b>Base</b>	<b>93</b>	<b>94</b>

**Q6. A Local Authority/Council using your health and care data for the planning and delivery of local services or public health interventions. The information given to the Local Authority/Council would not include your name and address or any contact details.**

Response	Before	After
Completely acceptable	9%	34%
Acceptable	30%	48%
Neither acceptable nor unacceptable	28%	7%
Unacceptable	16%	6%
Completely unacceptable	12%	3%
Don't know	5%	1%
<b>Base</b>	<b>93</b>	<b>94</b>

## Appendix B: Questionnaire data

**Q7. Central government using your health and care data alongside other data for the planning and delivery of national services. The information given to central government would not include your name and address or any contact details.**

Response	Before	After
Completely acceptable	10%	40%
Acceptable	33%	50%
Neither acceptable nor unacceptable	32%	2%
Unacceptable	12%	7%
Completely unacceptable	8%	0%
Don't know	5%	1%
<b>Base</b>	<b>91</b>	<b>92</b>

**Q8. Here are two statements representing either ends of a scale from 1 to 5. Please select a number between 1 and 5 to show where your view fits on this scale.**

Response	Before	After
1 – The main priority for the NHS is treating people when they are unwell	20%	18%
2	13%	8%
3	33%	16%
4	9%	21%
5 – The main priority for the NHS is keeping people healthy in the first place	21%	35%
Don't know	3%	2%
<b>Base</b>	<b>90</b>	<b>91</b>

Bringing citizens together in the way that we are doing for this event is a means of involving the public in decision making. Please answer the following questions based on how you are feeling right now.

**Q9. To what extent do you agree or disagree with the following statement:  
A) I am able to influence decision making around how health and care data is used**

Response	Before	After
Strongly agree	1%	30%
Agree	20%	50%
Neither agree nor disagree	29%	9%
Disagree	36%	10%
Strongly disagree	12%	1%
Don't know	1%	0%
<b>Base</b>	<b>89</b>	<b>90</b>

## Appendix B: Questionnaire data

**Q9. To what extent do you agree or disagree with the following statement:  
B) The public should be involved in decision making around how health  
and care data is used**

Response	Before	After
Strongly agree	20%	66%
Agree	44%	31%
Neither agree nor disagree	30%	1%
Disagree	2%	1%
Strongly disagree	1%	1%
Don't know	2%	0%
<b>Base</b>	<b>89</b>	<b>90</b>

**Q9. To what extent do you agree or disagree with the following statement:  
C) I feel informed about how health and care data is used**

Response	Before	After
Strongly agree	2%	40%
Agree	17%	44%
Neither agree nor disagree	35%	11%
Disagree	34%	3%
Strongly disagree	10%	1%
Don't know	2%	0%
<b>Base</b>	<b>89</b>	<b>90</b>

## Appendix C: Expert biographies

As mentioned in the main body of this report, experts were invited to attend, contribute to, and, in some cases, present at the Citizens' Summit. These experts gave testimony of their work, answered participants' questions, and engaged in discussions relevant to the topic. Experts played a key role in providing balanced information and helping participants to understand the complex nature of what was being discussed.

Name	Biography
<b>Adam Higgins</b>	Adam is senior director for digital health, patient and value solutions at AstraZeneca. He is responsible for leading a healthcare service design team focused on the delivery of digital health programmes in partnership with healthcare and tech. This is with the aim of transforming clinical pathways, improving outcomes for patients and enabling new ways to contract. Programmes are based on prioritised use-cases sponsored by the senior executive team at AZ and focused on respiratory, cardiovascular, metabolic and renal diseases.
<b>Alex Baylis</b>	<p>Alex joined The King's Fund in March 2016, and is assistant director in the policy team, overseeing and leading policy projects on a range of healthcare, care quality and NHS system topics.</p> <p>Before joining The King's Fund he worked at the Care Quality Commission (CQC), where he led development of the framework and approach for inspecting and rating hospitals, and at the Healthcare Commission, where he introduced risk-based regulation in the independent sector. Alex also led CQC's work with the Department of Health on the policy and legal framework for quality regulation, and with the Department and other national bodies to agree roles and responsibilities for responding to serious concerns.</p> <p>Before working in quality regulation, Alex worked in management in two NHS trusts. He has also worked at the Department of Health and at the World Health Organization Regional Office for Europe, Copenhagen.</p>
<b>Amanda Lucas</b>	<p>Amanda Lucas joined Imperial College Health Partners (ICHP) as a programme director in January 2018. In her role Amanda is responsible for enabling the North West London sector to work collaboratively to create value and improve the health and wellbeing of the local population through the design and delivery of complex transformation programmes.</p> <p>Amanda is currently responsible for delivery of Discover, the North West London Health Research Platform which involves a collaboration with North West London NHS Trusts, CCGs, academic partners, primary care and industry to bring new research opportunities and revenue into the sector.</p> <p>Amanda is a former management consultant having spent over 12 years in one of the big four consultancies and then working through her own limited company. She has a track record of Board level engagement and delivery of large and complex programmes across the public sector and health and is an expert in big data programmes.</p>
<b>Amy Darlington</b>	Amy is public engagement lead for OneLondon and a director at Imperial College Health Partners (ICHP). Prior to joining ICHP, Amy held a number of senior roles in communications and engagement across the NHS; working at national, regional and local levels across both provider and commissioning functions. She is passionate about using communications and engagement as a strategic leadership tool and believes both are central to the effective delivery of change, ultimately improving services for patients and the public.
<b>Andi Orłowski</b>	<p>Andi is a health economist and leads the business intelligence function at Imperial College Health Partners (ICHP) which supports the North West London STP, the wider NHS, arm's-length bodies, charities and private industry.</p> <p>Andi is particularly interested in population health analytics, especially how to best address health inequalities and the concept of impactability modelling, finding people most amenable to intervention, and is researching this for his PhD at Imperial College London.</p> <p>Andi is also a senior advisor for NHS England on population health management in the Operations and Information Directorate. Andi works with STPs and ICSs across the country advising and working with them on population health management.</p>

## Appendix C: Expert biographies

Name	Biography
<b>Axel Heitmueller</b>	<p>Axel is managing director of Imperial College Health Partners (IHP) and director of Discover-NOW, the Health Data Research Hub for Real World Evidence. Prior to joining IHP, Axel was executive director of Strategy and Business Development at Chelsea and Westminster Hospital NHS Foundation Trust. He brings a broad range of experience from academia and central government where he was deputy director and chief analyst at the Prime Minister's Strategy Unit in the Cabinet Office and No. 10.</p>
<b>Barbara Reichwein</b>	<p>Barbara is the programme director (multiple long-term conditions) at Guy's and St Thomas' Charity. She leads the Charity's work on social determinants of health and the programme on multiple long-term conditions. Through her work, she is crafting practical demonstrations of how to address social risk factors and prevent ill health in urban places. She cares about prevention, tackling health inequalities and supporting people living with long-term conditions to stay healthy.</p> <p>She previously worked in international development as the director of evidence to action at Marie Stopes International, a global provider of sexual healthcare. Her background is in international business, social enterprises, applied social sciences, youth employment and education. Barbara studied at the London School of Economics, and lives in London with her family.</p>
<b>Ben Page</b>	<p>Ben Page is chief executive of Ipsos MORI. He joined MORI in 1987 after graduating from Oxford University in 1986, and was one of the leaders of its first management buyout in 2000. A frequent writer and speaker on trends, leadership and performance management, he has directed thousands of surveys examining consumer trends and citizen behaviour.</p> <p>From 1987-1992 Ben worked in MORI's private sector business on corporate reputation and consumer research, working for companies like Shell, BAE Systems, Sky TV and IBM. Since 1992 he has worked closely with both Conservative and Labour ministers and senior policy makers across government, leading on work for Downing Street, the Cabinet Office, the Home Office and the Department of Health, as well as a wide range of local authorities and NHS Trusts.</p> <p>He became Chief Executive of Ipsos in the UK and Ireland in 2009.</p> <p>Ben is a visiting professor at King's College London, and a fellow of the Academy of Social Sciences. He serves on advisory groups at The Kings Fund, and the Social Market Foundation (SMF), and is a trustee at the Centre for London and at the Centre for Ageing Better, as well as a patron of Create Streets. He recently served as a commissioner on the Resolution Foundation's Intergenerational Commission. He is a council member of the CBI for London. Ben was named one of GQ's 100 Most Connected Men of 2015.</p> <p>He regularly appears on national TV and radio programmes.</p>

## Appendix C: Expert biographies

Name	Biography
<b>Caroline Cake</b>	<p>Caroline is chief executive officer of Health Data Research UK (HDR UK). She provides strategic direction and leadership for the organisation's delivery programmes.</p> <p>Caroline is committed to supporting the HDR UK community in making the UK the most impactful place to do health data science. She sees HDR UK's inclusive, team-oriented culture, built on the values of transparency, optimism, respect, courage and humility, as being at the heart of building HDR UK as one of the world's leading health data science institutes.</p> <p>Caroline joined HDR UK in 2018 as chief operating officer, where she oversaw the development of the Health Data Research Hubs, the Alliance, the Gateway and the Better Care Programme. With more than 20 years of experience working in commercial organisations, Caroline joined HDR UK from 2020 Delivery. At 2020 Delivery she was a director advising health organisations, universities and central government departments on strategy, transformation, capability building, and delivery planning. Prior to joining 2020 Delivery, Caroline worked at McKinsey &amp; Company and at ICI as a Chartered Engineer. Caroline holds an MBA from Harvard Business School and an MEng from the University of Cambridge.</p>
<b>Cathy Ingram</b>	<p>Cathy is the transformation programme manager for health and social integration at Guy's and St Thomas' NHS Foundation Trust. Cathy qualified as a nurse in 1984 and has a wide range of experience in both acute and community care, specialising in older people and rehabilitation. She previously managed the community rehabilitation teams in Southwark and Lambeth and was responsible for the development of a wide range of new services in the community, many of which are integrated with local social service teams. She has a strong commitment to delivering integrated care centred around the individual and working in partnership to achieve this.</p>
<b>Dan Wellings</b>	<p>Dan works in the policy team at The King's Fund, where his particular areas of interest include patient and staff experience and public perceptions of the NHS and social care system.</p> <p>Before joining The King's Fund in April 2017, Dan was head of insight and feedback at NHS England. The Insight and Feedback team is responsible for the commissioning and running of a number of national surveys including the GP Patient Survey, the Cancer Patient Experience Survey and the Staff Survey. In addition, the team oversees the patient-reported outcomes measures (PROMs) programme as well as the implementation and development of the friends and family test.</p> <p>Dan has also worked as research director at Ipsos MORI, specialising in public attitudes to the NHS and social care. He has a Master's in public health from the London School of Hygiene and Tropical Medicine.</p>
<b>Harpreet Sood</b>	<p>Dr Harpreet Sood is currently NHS England's associate chief clinical information officer and a practicing NHS doctor. Previously he was senior fellow to the CEO of NHS England.</p> <p>Harpreet trained as a clinical doctor at King's College London and Imperial College Business School and practiced as a doctor in East London. Following this he did a Master's Degree in Public Health (MPH) at Harvard University where he focused on international health policy and co-founded a digital health start-up.</p> <p>Post MPH, Harpreet was a Deland Fellow in health policy and management at Brigham and Women's Hospital, a large academic medical centre in Boston. Harpreet's current work at NHS England includes leading on the NHS Digital Academy and working on the Global Digital Exemplar Programme.</p>

## Appendix C: Expert biographies

Name	Biography
<b>Jonty Heaversedge</b>	Jonty is clinical director at Imperial College Health Partners (IChP). He is the chair of a Clinical Commissioning Group in South East London with responsibility for planning and paying for the services local people receive. Most recently he has been working as a medical director within NHS England (London Region), with responsibility for both primary care and digital transformation across the Capital. Jonty continues his clinical role as a GP and also works in education and the media.
<b>Kambiz Boomla</b>	<p>Kambiz has been a GP in Tower Hamlets for 35 years and is a senior lecturer in the Institute of Population Health Sciences at Queen Mary University of London. Prior to this, he was chair to Tower Hamlets CCG IT committee for many years establishing East London CCGs as among the most digitally mature local health economies in the UK. He has also been a member of national Confidentiality Advisory Group of the Health Research Authority and a chair of GPs' City &amp; East London Local Medical Committee.</p> <p>He is heavily involved in the development of the extraction of data from GP clinical systems using new web-based technologies. This information is used for service development, audit, and research. He is clinical lead in the Discovery Data Service Project. Research interests include equitable delivery of digitally enhanced improvement programmes and the governance of information for clinical and third party uses.</p>
<b>Luke Readman</b>	A strategic leader with considerable experience of leading change at the system and institutional level and at the NHS, academic and industry interfaces with a strong commitment to innovation and knowledge transfer. Currently the regional director of digital transformation for NHS London and leading OneLondon Local Health and Care Record Exemplar (LHCRE). Despite the many difficulties faced every day, as the service continues to improve its digital and data infrastructure, Luke remains firmly of the view that there is a remarkable opportunity to improve care through open and collaborative transformation.
<b>Mark Kewley</b>	Mark is a senior policy lead in the London healthcare system, and a director at Imperial College Health Partners (IChP). He has led a range of integration and improvement programmes over the past decade in a variety of roles, including as strategy lead for a hospital foundation trust, as director of transformation in a London clinical commissioning group (CCG), and as director of strategy for an integrated care partnership. Most recently, Mark led work across NHS England, the Greater London Authority and London Councils to produce the London Vision. Prior to joining the NHS, Mark was a senior policy advisor in No.10, advising the Labour and Coalition governments on health policy and public service reform. Mark's work focuses on helping to join up health and care systems to deliver better populations outcomes.
<b>Mike Burgess</b>	Professor Mike Burgess holds a research chair in Biomedical Ethics at the University of British Columbia, Canada, with appointments to the Centre for Applied Ethics, the School of Population and Public Health, and Medical Genetics. He is also the Associate Provost, Strategy for the Okanagan campus. His research has focused on developing approaches to public deliberation, with over 25 events in Canada, Australia, and the US. The majority of these deliberations have been on biobanks, the use of data in health systems and research, and funding decisions in health care.

## Appendix C: Expert biographies

Name	Biography
<b>Murat Soncul</b>	<p>Murat worked as an oral surgeon and completed a doctorate in healthcare technology before undertaking a number of leadership roles in the NHS in London working on digital health transformation. He worked as the head of information governance and later as the data protection officer for South London and Maudsley NHS Foundation Trust for 16 years. Murat led the information governance working group to enable the digital strategy for health and care partners in South East London and was part of the leadership team in the OneLondon Local Health and Care Record Exemplar as the IG lead. He currently works as the head of privacy and data protection in Government Digital Service. Murat is one of the vice-chairs of the Confidentiality Advisory Group at the Health Research Authority. Murat's professional interests include ethical and fair use, sharing and linking of personal data to support digital innovation to improve public services whilst making sure individuals' rights under data protection and privacy legislation are protected.</p>
<b>Sam Everington</b>	<p>Sir Sam Everington has been a GP in Tower Hamlets since 1989 in the Bromley by Bow Partnership. The centre has over 100 projects under its roof supporting the wider determinants of health. The social prescribing delivered at the centre, is now part of a network of 2,000 across the country and is about to be put in every general practice in the country. He is chair of Tower Hamlets CCG, clinical lead of his STP and chair of the 32 London CCG Chairs. This means he holds and manages the government's health budget for a population of two million.</p> <p>Sam is a member of BMA Council and vice president of the BMA. In 1999 he received an OBE for services to inner city primary care in 2006, The International Award of Excellence in Health Care and in 2015 a knighthood for services to primary care. He is a member of the Ministerial National NHS Property, NHS Resolution and East London foundation Trust boards and is Fellow and Honorary Professor of Queen Mary University of London and Vice President of the Queen's Nursing Institute. He has previously been a member of GMC Council, Cabinet appointed Ambassador for Social Enterprise, acting chair of the BMA, adviser to shadow cabinet ministers between 1992 and 1997 and national advisor to NHS England's New Models of Care project. He is a trained woodcarver, day skipper, and speaks Norwegian. He trained originally as a cadet pilot in the RAF and lives with his wife and five children in the Tower Hamlets, East End of London. He works as a GP two days a week.</p>
<b>Sanjay Gautama</b>	<p>Sanjay is a consultant anaesthetist at St Mary's Hospital, Paddington - Imperial College Healthcare NHS Trust - since 2000. His specialities include paediatric anaesthesia (lead for the Trust), major vascular anaesthesia and peripheral nerve blockade. He trained on St Thomas' and UCH/Middlesex rotations including sub-speciality training at Royal Children's, Melbourne, Great Ormond Street, the Royal Brompton and the Royal National Orthopaedic Hospitals. He is also chief clinical information officer (clinical lead for IT) and has been a Caldicott Guardian (clinical lead for information governance) for Imperial for the past decade. In addition, he is chief clinical information officer and clinical IG lead for North West London and the Discover-NOW digital innovation hub, and represents North West London at OneLondon Level 1 and Level 2 boards and also the Transformation Portfolio Board for London.</p>

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Name	Biography
<b>Stuart Crichton</b>	<p>Stuart is the chief clinical information officer (CCIO) for the London Ambulance Service. A practising paramedic with 28 years of experience in prehospital medicine, his current focus is bringing the Trust's digital strategy to life. One of Stuart's first digital projects was the introduction of iPads for clinical staff, enabling the move from paper to digitise work flows at the patient's side.</p> <p>Stuart is also responsible for the development of all clinical systems including the Trust's Computer Aided Dispatch (CAD) system and electronic patient care records. Putting both patient and user experience at the heart of everything he does, Stuart is passionate about bringing everyone with him on the journey. This year Stuart has also been undertaking the Nye Bevan programme at the NHS Leadership Academy. Stuart lives in London with his wife, stepdaughter and a very old German Shepherd.</p>
<b>Tim Hubbard</b>	<p>Tim is Professor of Bioinformatics and head of the Department of Medical &amp; Molecular Genetics at King's College London. He is an associate director of the London site of the new UK national virtual health data institute, Health Data Research UK (HDR UK). He is also head of genome analysis at Genomics England, the company set up by the Department of Health to execute the 100,000 genomes project, which aims to mainstream the use of whole genome sequence analysis for treatment in the NHS. Until 2013 he was head of informatics at the Wellcome Trust Sanger Institute where he was one of the organisers of the sequencing of the human genome. In 1999 he co-founded the Ensembl project to analyse, organise and provide access to the human genome and from 2007 led the GENCODE project to annotate the structure of all human genes. He has long been an advocate of open data for science and society, however working with health data, he believes that research needs to take place within trusted research environments to protect patient privacy and provide transparency on data use. He received his BA from Cambridge University, and PhD from Birkbeck College, University of London.</p>

## Appendix D: Case studies and handouts

All stimulus and presentations used throughout all four days of the Citizens' Summit is available at [www.onelondon.online/citizenssummit](http://www.onelondon.online/citizenssummit)

Figure D.1: Case studies for roles-based access (RBAC)

### Case study 1 – Cancer

- Tom has been diagnosed with lung cancer and also has a history of substance misuse and depression.
- His cancer doctor needs all of the information about his test results and diagnostics to inform decisions about Tom's treatment.
- A care administrator is tasked with collating this on behalf of the doctor. In order to do this they need access to Tom's medical information.
- Having reviewed the information, Tom's doctor suggests that Tom needs chemotherapy and an appointment should be scheduled asap. A bookings clerk needs to contact Tom to arrange this.

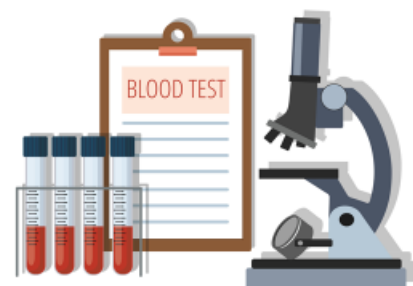


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### Case study 2 – Test results

- Mary works full time and finds it hard to get time off to go to the doctor, but has been having bad headaches.
- She books a Saturday appointment to see her GP.
  - *What information does the receptionist need to book the appointment?*
- She has to have some blood tests done in a local clinic.
  - *What information does the person taking her blood need?*
- A week later she rings the GP practice for her results.
  - *Who should be able to give her the results?*



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## Appendix D: Case studies and handouts

### Case study 3 – Diabetes



- Ian has type 2 diabetes, schizophrenia and is on medication for back pain. His schizophrenia means he is not very good at keeping track of his blood sugar level.
- His GP has referred him to the hospital as his foot has sores that won't heal (this is a common risk of diabetes).
- He has to have his foot partially amputated
  - *What does the anaesthetist and surgical team need to know?*
- He needs physiotherapy to learn how to walk
  - *What does the physiotherapist need to know?*



Figure D.2: Handout for RBAC considerations

### HANDOUT B: Things to think about...



Burden  
on NHS

Safety

Quality

Privacy

Convenience

Joined-up  
care

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## Appendix D: Case studies and handouts

Figure D.3: Case studies for social care

### Case study 4 - Bill (residential care home)

- Bill lives in a residential care home. He moved there when his wife died as a social worker assessed him and didn't think he should live alone.
  - *What information did the social worker need?*
- He takes about 8 pills a day for various things (he doesn't know what as the carers give them to him).
- One night he has a fall and needs to go to hospital for a few days.
  - *What information does the hospital need to look after him?*
- He is sent home with pain killers which must be taken with food and instructions to go to his GP to have his stiches taken out in a week.
  - *What information does the care home need?*
  - *What information does the GP need?*



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### Case study 5 – Mrs Jones (care at home)

- Mrs Jones finds it hard to wash and get dressed and is increasingly forgetful. The care assessor who was sent by the council developed a care plan with Mrs Jones and her social worker.
  - *What information does the care assessor and social worker need?*
- The care plan means that Mrs Jones will have carers from a local provider to visit her twice a day to help.
  - *What information does the local provider need?*
  - *What information do the carers need when they visit?*
- One day Mrs Jones found it hard to breath so she went to hospital by taxi. She was admitted and put on antibiotics for a chest infection.
  - *What information does the local care provider need whilst she is in hospital?*
- She is sent home and has to keep taking her antibiotics for two weeks. Before her discharge from hospital, her care plan is updated by the social worker.
  - *What information does the social worker need?*
  - *What information does the local provider need?*
  - *What information do the carers need?*

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## Appendix D: Case studies and handouts

### Case study 6 – Sue (nursing home)

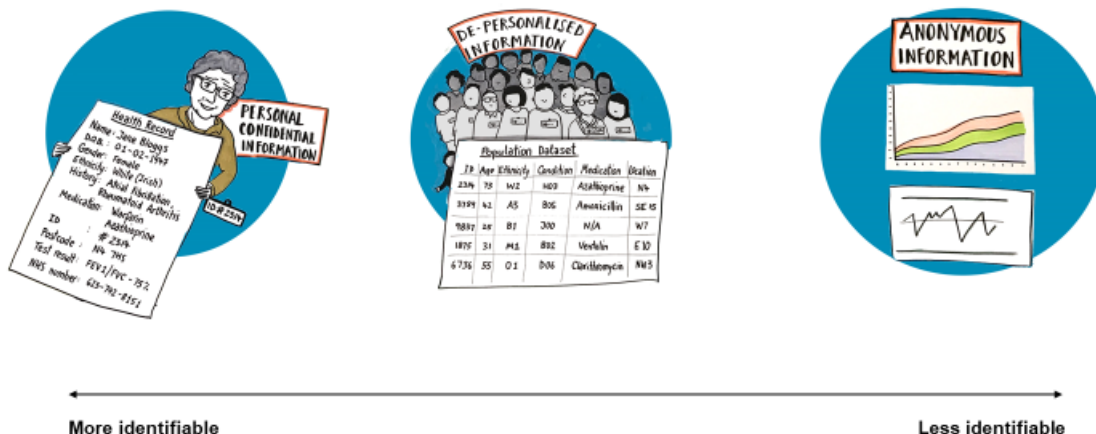


- Sue has advanced Parkinson's disease. She needs a lot of care so she lives in a nursing home. She had a history of depression earlier on in her life and this is included in her GP notes.
  - *What information do the nursing staff need day to day?*
  - *What information do the other care staff need day to day?*
- Sue has previously agreed with nurses and doctors what she wants to happen as she approaches the end of her life.
  - *Who needs to have access to this information?*



Figure D.4: Spectrum of identifiability handout

### HANDOUT C: Spectrum of identifiability



## Appendix D: Case studies and handouts



Figure D.5: Case studies for de-personalised information and proactive care

### Case study 7: Atrial Fibrillation identification

**Atrial Fibrillation (AF)** is a condition that causes an irregular heart rate.


It is **one of the leading causes of strokes**, if not detected and treated.

Many people **don't know** they have AF.


**Analysis of patient data (case-finding):**


- By looking at de-identified information about a whole population, analysts can identify the characteristics of those most at risk of AF. This will allow GPs to identify the patients in their population who are most at risk.
- At-risk patients are then invited for a test at a GP surgery.
- Those who have the condition can then be put on medication to reduce the likelihood of a stroke.



### Case study 8: Coordinating care for the frail

- As we become more frail we also become more vulnerable to health crises.
- Health guidance recommends that people who are frail receive additional support through a care plan to help prevent a health crises.
- However identifying frailty is complex. It involves looking at multiple aspects of a medical record across 36 areas of need, for example: medication and mobility (see Handout C). The more needs a patient has, the more likely they are to experience frailty.
- By analysing the de-identified information of a whole population, we can identify those at highest risk of frailty. These people can then be offered more support.
- A frailty flag can be applied to a patient's health record to alert healthcare staff that they are vulnerable.
- Healthcare staff, such as doctors, nurses and paramedics, are able to see the frailty flag and take appropriate action to ensure the right level of support is offered.



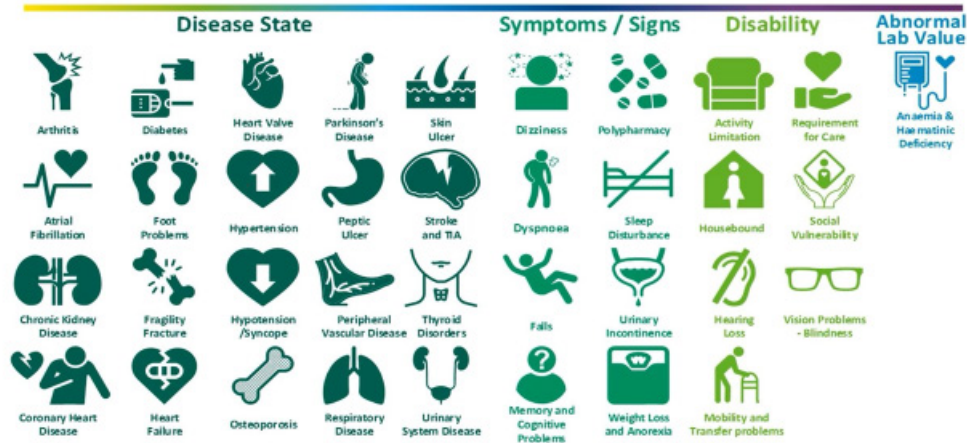


## Appendix D: Case studies and handouts

### Case study 8: Coordinating care for the frail



#### Electronic frailty index



### Case study 9: Preventing onset of type 2 diabetes



- The number of people living in the UK with type 2 diabetes has more than doubled in the last 20 years to 4.7 million.
- Type 2 diabetes is one of the leading causes of stroke and heart disease
- Through changes to diet and lifestyle it has been demonstrated that we can prevent people from becoming type 2 diabetic.
- Obesity is responsible for 80-85% of someone's risk of developing type 2 diabetes.
- Using population level data (weight or BMI) we can identify people at risk of type 2 diabetes. They can be contacted by their GP practice and offered help and support to reduce the risk of onset.



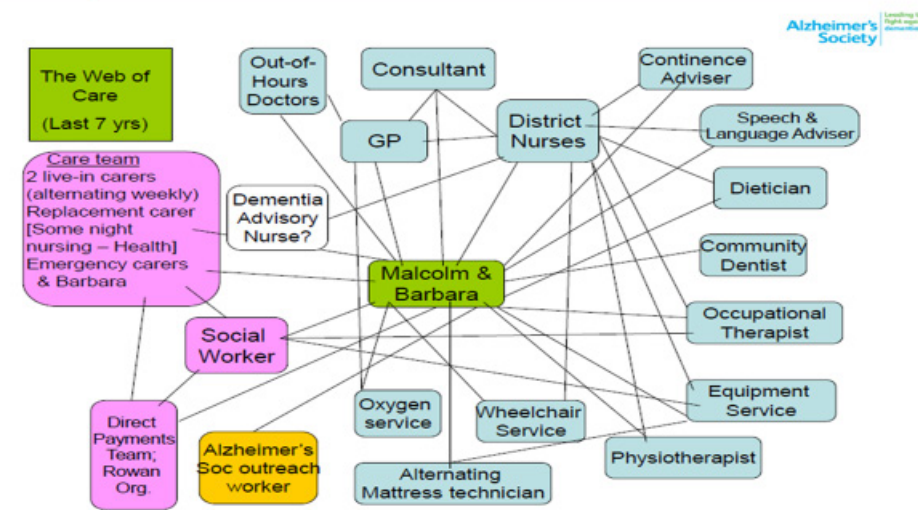
## Appendix D: Case studies and handouts

Figure D.6: Case studies for planning services

### Case Study 1 – Improving care of people with complex needs

- Some people have **many** long term health problems at once, which require a lot of **different** kinds of support.
- We know these patients and their supporting networks often have to manage these very **complex webs** of care themselves because **services do not ‘join up’**.
- Staff in organisations providing this care want to use **data about patients** to **understand** patterns of care and redesign services to reduce this.
- They need **access to data** filtered for people with 3 or more conditions and lots of **detailed information** about their care (e.g. from GP records (conditions and appointments) hospital records (about admissions and appointments)).
- Some areas of London have **datasets** like this, while **others do not**. Where areas **do** give approval, cooperation can take a long time (18 months) to get access.

### Case Study 1 – Improving care of people with complex needs



## Appendix D: Case studies and handouts

### Case study 2 – Planning diabetes services

- Commissioners **plan services** based on the resources (£, staff, buildings, technology, etc.) and the **needs** of their population.
- **Evidence** tells us that diabetes patients benefit through **education** on their condition in group meetings with a **self-management** trainer.
- Commissioners heard from GP practices that some patients who could **benefit** were not using services like these. Their diabetes **worsens** and they need more care.
- Commissioners want to **understand** whether there were patterns and **investigate** why people didn't attend. To do this, they needed to see **demographic information**, and where people live.
- The commissioners want to use this information to **decide how to allocate resources**. One option might be investing in setting up a new service, but this requires either new resources or the reallocation of them from somewhere else.



### Case study 3 – Local council

- Air pollution '**hot-spots**' are found at places like busy roads and junctions.
- Research tells us that people who spend time in these places are more likely to have **emergency hospital admissions**, for things like **asthma exacerbations or heart attacks**.
- A council wants to **improve** the health of a local neighbourhood and thinks **changing the road layout** might help, **by changing patterns of air pollution** so that hot-spots are reduced or moved.
- This costs a significant amount of money, so they want **evidence** that this is having **an impact on health** in this neighbourhood.
- They also want to take into account people's existing conditions, so need **information** from the GP record about: recorded diagnoses of diseases, hospital visits, a person's home postcode.



## Appendix D: Case studies and handouts


Figure D.7: Information provision on health data research


### What is health data research?

Health data comes from a variety of sources, but all relates to peoples' interaction with the health and care system in some way – for example as an **NHS patient, a participant in a clinical trial, being involved in a genomics initiative or as a blood donor.**

It is used for research and development to find patterns and links, to improve people's lives through better public health and healthcare to:

1. better **predict** disease, as early as possible
2. **prevent** disease
3. better predict the **right treatment for the right person at the right time**
4. develop **new treatments and cures** for disease












Figure D.8: Legal basis for health data research

### There is a legal basis for using depersonalised data for research

Organisations must have a valid, legal reason to process personal data for research purposes. This is called a 'legal basis'.

GDPR (European Data Protection Act that has been adopted by Parliament) provides a legal basis for using data for medical Research

Any use or disclosure of confidential patient information for research and planning must be for the purpose of improving or benefitting health and care.

Confidential patient information is when two types of information from your health records are joined together:

- Something that can identify you
- Something about your health care or treatment

Information must never be disclosed for marketing or insurance purposes without explicit consent.








## Appendix D: Case studies and handouts

Figure D.9: The five safes framework



## Appendix D: Case studies and handouts

Figure D.10: Case studies for health data research

### Case study 4 – Reviewing eye scans

A doctor from a London-based NHS specialist eye hospital is facing an urgent clinical problem: *“The number of eye scans we’re performing is growing at a pace much faster than human experts are able to interpret them. There’s a risk that this may cause delays in the diagnosis and treatment of sight-threatening diseases, which can be devastating for patients.”*

The NHS hospital partners with a globally recognised technology company to explore whether machine learning technology can be trained to identify signs of eye disease and recommend how patients should be referred for care. The researchers employed by the tech firm work alongside clinicians to review thousands of historic de-personalised scans within the hospital setting. No data is downloaded or leaves the hospital.

The researchers discover technology that can recommend the correct referral decision for over 50 eye diseases with 94% accuracy, matching world-leading eye experts. It is hoped that the technology could revolutionise the way health professionals carry out eye tests. Although clinicians would still have to review scans, the technology would allow them to spot conditions earlier and prioritise patients with the most serious eye diseases before irreversible damage sets in.

### Case study 5 – A&E attendances

A UK-based University wants to conduct research to understand the circumstances around cases where patients visit A&E for problems that could have been managed by a GP, in order to identify potential solutions that might reduce unnecessary A&E visits, ensuring patients are able to receive the right care, in the right place.

To undertake this research, the University requires access to depersonalised data for all patients who had one or more A&E visit over a 12-month period, including clinical information (e.g. the reason for the visit to the A&E department, reason for discharge) and patient information (e.g. age group, gender and ethnicity).

The University submits an application to the NHS explaining how the study will benefit health and social care. This is reviewed by an independent body that includes patient representation. The University must also show how it will keep the data safe, for example providing evidence that the data will be hosted in a secure environment. Once approved, the University is sent the depersonalised data it needs for the study.

## Appendix D: Case studies and handouts

### Case study 6 – New drug for diabetes

A clinical researcher (a researcher who designs and runs clinical trials) based in the NHS is working with a pharmaceutical company (companies that make medicines, such as GlaxoSmithKline, Pfizer, AstraZeneca) to trial a new innovative drug that is designed to manage diabetes when a patient also has cardiovascular disease (CVD), e.g. heart disease or stroke.

To see if it is possible to run a trial, the clinical researcher and pharmaceutical company need to undertake a feasibility study to understand how many people might benefit from this type of new treatment and further understand the group of patients that could be invited to participate in the trial.

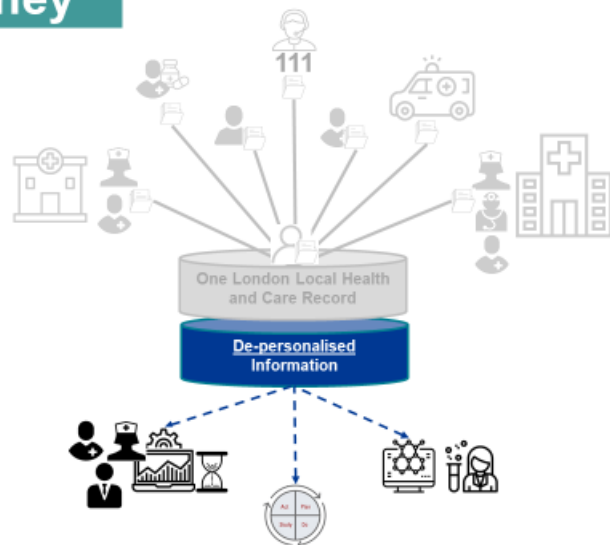
They are granted access to depersonalised data in a secure NHS setting so they can look at how many people are living with diabetes who also have CVD, and who meet certain criteria (e.g. age, what current medications they are on) relevant for the trial. From this information they are able to see that it is worth progressing with the trial.

Figure D.11: Costs of health data research

### Doing all of this costs money

#### What is it that costs money?

- Acquiring
- Curating
- Storing
- Securing
- Analysing



## Appendix D: Case studies and handouts


Figure D.12: Health research perspectives

### Academic researcher

Academics, often working within an university, undertake health research with a view to finding new discoveries that can improve health / healthcare and contribute to a growing knowledge base. Research is usually undertaken with the intent of publishing the results (e.g. in a dissertation or peer-reviewed journal article).

Benefits and motivations	Concerns
Making new discoveries that improve the health and / or healthcare of the population	How do we carry out health research in a trusted way?
Contributing to global knowledge and understanding	How do we ensure that controls on health data do not prevent us carrying out research?
Research can generate funding grants which enables further research and supports academic institutions	How do we balance a need for transparency with the fact that lots of research is published in journals that require a fee to access?


### Commercial involvement in research



Pharmaceutical company conducting research on **de-personalised data** working **with academic researchers** as well as **NHS clinicians** and data controllers.

We have worked studies that involve improving understanding around the journey of Type 2 Diabetes patients. We aimed to develop new services or treatments that help provide the right care, for the right patient, at the right time.

Benefits	Concerns
Improve understanding of the challenges within the care pathway	Transparency vs protecting intellectual property
Justify a new service, treatment or process that can improve health	Public perception and reputation
Improve: <ul style="list-style-type: none"> <li>- Outcomes for patients</li> <li>- Efficacy of the system</li> <li>- Speed at which treatment is developed</li> </ul>	Transparency and clarity – to gain public trust

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## Appendix D: Case studies and handouts

### NHS trust perspective



What does current evidence tell us about what might constitute a fair partnership?  
How do we ensure that partnerships are transparent and accountable?

Benefits and motivations	Concerns
Academics and companies have skills that are beneficial to the NHS (e.g. research and evaluation methods, statistical tools, and proprietary technologies)	Reputation (from misreporting of NHS 'selling you data' to the commercial data companies)
Prestige and research income, as well as creating an environment for 'cutting edge' innovation	Ethical issues of machine learning / AI types of technologies
Development of actual technologies, tools and techniques that can bring patient benefit	Concerns about research collaborators pushing beyond the boundaries of the approved research proposal
Opportunity to negotiate reduced prices of resulting technologies for the trust, London system, and potentially the NHS overall	Concerns about getting challenged by the Information Commissioner's Office



### Charity perspective



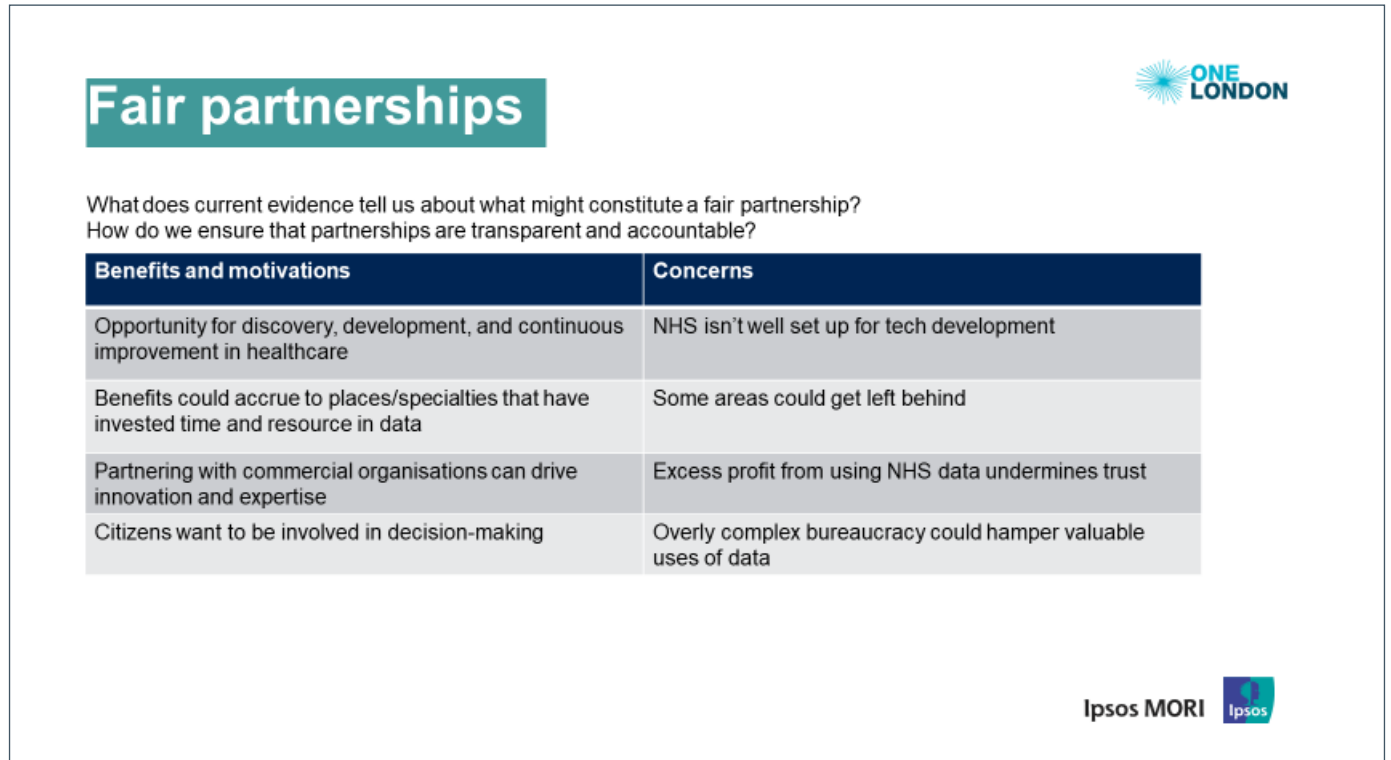
What does current evidence tell us about what might constitute a fair partnership?  
How do we ensure that partnerships are transparent and accountable?

Benefits and motivations	Concerns
Learn more about the patterns of disease to inform the programmes we run, and the initiatives we fund	People might question why we are trying to make use of joined up health data at all; or think we are doing it in order to
Some of our work is nationally and internationally relevant, and doing research is good for our reputation as a thought-leader	People might criticise us for trying being more focused on research for it's own sake rather than research to change the improve health locally
We fund our own work, but publishing research or knowing about disease might make us more competitive in finding other funding partners	People might criticise us for being focused on gaining more funding and grant income for our work



## Appendix D: Case studies and handouts


Figure D.13: Partnerships



## Appendix D: Case studies and handouts

Figure D.14: Governance and oversight guidance

Action and accountability



Much of the work of public sector policy-makers is about deciding what is the right thing to do, doing it, and then being held to account for doing it properly. We need to understand your expectations about how this happens for Londoner's joined-up data.


Setting the rules that guide our action  
 [Developing the policy]

Applying the rules in action  
 [e.g. approving safe projects]

Checking the rules work and are being followed  
 [Holding system to account]

Questions we are grappling with, and where we want to know your expectations:

- Who needs to be involved in these stage to make them feel acceptable and trustworthy?
- What specific roles should the public play in any (or all) of these stages?



Designing the rules







Citizens' Summit Public co-design workshop	Board of managers and experts with patient representative	Ongoing public advisory group
<ul style="list-style-type: none"> <li>• <b>Benefit:</b> mix of people, large scale, participative, consider the public view not just patient view</li> <li>• <b>Concern:</b> relatively hard to convene, costly to prepare and run, drop-out over time</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Benefit:</b> part of regular decisions, challenge to managers, develop expertise</li> <li>• <b>Concern:</b> only 1 or 2 people, less diverse, need particular skills, become 'professional patients'</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Benefit:</b> test and develop ideas over time with same group who become expert</li> <li>• <b>Concerns:</b> risk of selection bias and under-representation, become 'professional patients'</li> </ul>



## Appendix E: Discussion guides

### Citizens' Summit Day 1 discussion guide

Saturday 1 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
9.30 - 10.00	<b>Arrival and registration</b>	<p>Participants arrive at etc. venues St Paul's</p> <ul style="list-style-type: none"> <li>• Participants sign consent form on arrival with Host</li> <li>• Participants handed tracking questionnaire, asked to complete this by Host in advance of 10am start, and told to hand to their table moderator</li> <li>• Participants given name sticker to wear, with table number shown on it (including a RED dot if they have not consented to filming)</li> </ul>
10.00 - 10.30	<p><b>Introduction</b> <b>Warm up</b></p> <p>Plenary and then tables</p>	<p><b>Ipsos Chair to welcome the room to the event (5 mins):</b> Introducing OneLondon, expert commentators, observers, moderators, note takers and film crew. Explains this is day 1 of 4, reminds of dates and provides high level overview of 4-day process (nods to patient data flow diagram on the walls). Chair to explain that we are going to give people a lot of information throughout the course of the weekend, so bear with us. Also covers housekeeping, plus breaks, toilets (we have breaks but you are obviously welcome to leave the room to use these as and when you need to) and fire alarm.</p>
10.05		<p><b>Mike Burgess to introduce the process (5 mins):</b> Emphasising it's a citizens' summit that brings 100 Londoners into a detailed conversation about the use of health and care data across the capital. Nod to the role of the public and the role of processes like this in policy making and introduces ground rules.</p>
10.10		<p><b>Mark Kewley to introduce the OneLondon LHCRE and the role of this process within the wider plans (5 mins):</b> Covering why it has chosen to use this process to engage with the public, how the information we collect over the four days will be used. Explain how we would like the room to make recommendations to inform the policy going forward – and how we may even do this as early as this afternoon. To include 1-min Mayor's video.</p>
10.15		<p><b>Table introductions and ice breaker (15 mins)</b></p> <ul style="list-style-type: none"> <li>• Facilitator introduces themselves and the table's note taker, thank you for coming. Collects permission to audio record the discussion.</li> <li>• To introduce us all to each other, facilitator asks participants to turn to the person next to them and spend 30 seconds each finding out about each other (name, where they live and with whom), and also one interesting fact about each other. Participants then introduce their neighbour to the table (10 mins).</li> <li>• Facilitator asks the table to look at the ground rules that Mike previously introduced, on the flip chart, and to check that they are happy with these or whether they'd like to add or change anything. Facilitator to edit ground rules in a different colour (5 mins).</li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 1 discussion guide

Saturday 1 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
10.30 - 11.25	<p><b>Expectations of health and care services</b></p> <p>Plenary and then tables</p>	<p><b>Dan Wellings, The King's Fund presentation (10 mins):</b> Introduction to the NHS and social care, highlighting the range of organisations involved (including all the private organisations) and the reality that many are private / independent organisations (e.g. GP practices, care homes and home care etc.). Explain that the care team is made up of a whole host of individuals (with examples). Nod to relevant part of patient data flow diagram.</p> <p><b>Table discussions (45 mins in total)</b></p>
10.40		<ul style="list-style-type: none"> <li>• Table reflections on what they've just heard (15 mins) <ul style="list-style-type: none"> <li>– How familiar were you with the way the NHS and social care is run and organised nowadays?</li> <li>– Was there anything in that presentation that was new or surprising to you?</li> <li>– Does it leave you with any questions or concerns?</li> </ul> </li> </ul>
10.55		<p>Facilitator to ask participants to generate a list of their own expectations of a health and care service, thinking about things like how should it feel when receiving care or being treated, who the service is for, the role of the public in this, as well as how it is run – for example should it be a sickness service that responds to people's needs (i.e. to fix you when you are sick), or one that attempts to keep people well (i.e. by anticipating need and intervening). Facilitator flip charts expectations to refer back to during other sessions.</p> <p>Highlight that: 1. We don't just encounter the NHS as patients or carers; it is also an expression of solidarity where we have expectations for the way other people are treated/supported. 2. Health and care services rely on more than just the provision of care; there are a whole set of often unseen processes required as the foundation - such as people working to plan what services are offered and where they go; and people trying to learn about diseases and treatments to be able to create new treatments, products and services for the future.</p> <ul style="list-style-type: none"> <li>• <b>Follow up questions (if not already covered):</b> <ul style="list-style-type: none"> <li>– How do you think the NHS and social care system currently plans which services it provides?</li> <li>– How do you think the NHS and social care system decides where people receive their care and support?</li> <li>– How do you think the NHS makes decisions about how to treat/ manage different diseases and conditions?</li> <li>– And how do you think new treatments, drugs, products and services make their way into the NHS?</li> </ul> </li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 1 discussion guide

Saturday 1 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
11.25 - 11.45	<b>BREAK</b>	Facilitators to explain to participants that they must be back promptly for a 11.40 start. Encourage participants to look the patient data diagram. During the break, chair to go around the tables' flip charts for ground rules and see if any new ground rules have been added in a different colour. If they seem sensible/agreeable, add to the other flip charts and notify moderators.
11.45 - 13.15	<p><b>What is health and care data, and how can it be used?</b></p> <p>Tables, then plenary, then tables and then lightning talks, and then back to tables. Closing on Q&amp;A to the panel.</p>	Facilitators to welcome tables back and explain that we'd now like to look at what health and care data is, and how it is - and can be - used. Before we hear from some of the expert commentators, we'd now like to have an initial discussion around people's understanding of how health and care services use information.
11.45		<p><b>Table discussion (15 mins)</b></p> <p>Spontaneous discussion:</p> <ul style="list-style-type: none"> <li>• What health and care information do you think is held about you, why and by whom?</li> <li>• How joined up do you think health and care services are when it comes to using information?</li> <li>• And how joined up do you think health and care services should be?</li> </ul>
12.00		<b>Plenary - Chair introduces video showing some of the ways that data are used: PRSB/UPD video (2 mins)</b>
12.02		<p><b>Murat Soncul's first presentation (5 mins):</b> The main thing you need to know about health and social care data is that you don't have a record - it's in lots of fragments, under the legal control of different organisations, such as GPs, hospitals, community services, mental health trusts, care providers.</p> <p>There are lots of different reasons why people need to see different bits of this information - and you'll hear more about that in a moment. The law sets up different rules and regulations to control what can be accessed for different purposes. Different purposes of seeing data are treated differently, what is seen, by whom and with what protection.</p>
12.07		<p><b>Table discussions (25 mins in total to include the card sort)</b></p> <p><b>Table reflections on what they've just heard (5 mins):</b></p> <ul style="list-style-type: none"> <li>• What, if anything, surprised you?</li> <li>• What concerns, if any, do you have about what you have just heard?</li> <li>• Anything you are unsure or unclear about? (Jot down on flipchart as questions for expert commentators)</li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 1 discussion guide

Saturday 1 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
12.12		<p>Facilitator to split tables in half (i.e. groups of five) and provide health and care data sorting cards and handout which has three columns/ categories (GP record, Hospital record, Social services care record) – (20 mins)</p> <ul style="list-style-type: none"> <li>• Participants to work in pairs and sort the data cards into the categories based on what information should be captured in a GP record (5 mins)</li> <li>• Participants to work in pairs and sort the data cards into the categories based on what information should be captured in a hospital record (5 mins)</li> <li>• Participants to work in pairs and sort the data cards into the categories based on what information should be captured in a social services care record (5 mins)</li> </ul>
12.32		<p>Facilitator to flip chart what the pairs of participants thought should be captured in a GP/Hospital/social services care record and then to provide hand out which shows what is actually captured within each record (5 mins)</p> <p><b>Plenary, lightning talks (10 mins):</b> Chair introduces the idea of a move towards more joined up health and care data, and panel provides different views around what this means in terms of opportunities and risks. Panel lightning talks (3 mins each) highlighting the different reasons why data are used, the benefits of joining up information but also some of the challenges.</p> <ul style="list-style-type: none"> <li>• <b>Sam (3 mins)</b> - GP talking about individual care and why he needs to share information with other people; benefits and concerns.</li> <li>• <b>Stuart (3 mins)</b> - Technical limitations - systems don't all talk to each other; and not all practitioners agree to do this, they have objections and/or don't think their patients want it. This makes being a paramedic hard given that we need to make clinical decisions and often have only limited info available. We really need something that makes it easy for other providers (GPs and hospitals) to share info that we can view if and when we need to give you care (this could be 999 emergency, and/or when you call up 111 to get more routine help).</li> <li>• <b>Axel (3 mins)</b> - talking about other uses of data beyond individual care e.g. planning, research</li> </ul>
12.42		<b>Q&amp;A with Sam, Stuart, Axel and Murat – (5 mins)</b>

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Saturday 1 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
12.47		<p><b>Murat's second presentation (5 mins)</b></p> <p>The rules and regulations are different for these different types of purpose of data use.</p> <p>Where people provide care directly to a person</p> <ul style="list-style-type: none"> <li>• they need to see relevant and proportionate personally identifiable information</li> <li>• there are duties to protect information, and duties to share information</li> <li>• they do not need to ask for your explicit consent – you can request that data controllers do not share, which needs to be registered but not enacted</li> </ul> <p>Where people need info for other purposes like planning and evaluation</p> <ul style="list-style-type: none"> <li>• They do not need to know it is 'you', so are not routinely allowed to see personally identifiable information</li> <li>• They can see de-personalised info without your consent (because we don't know it is you)</li> <li>• If they need to see identifiable info they would generally need to have your explicit consent (e.g. if you were to take part in a pilot, evaluation etc.)</li> <li>• A national opt-out means you can request that no identifiable information is shared for any secondary purpose</li> </ul>
12.52		<p><b>Table discussions (15 mins)</b></p> <ul style="list-style-type: none"> <li>• Any reflections on what you have just heard?</li> <li>• What interested you most?</li> <li>• What, if anything, did you find concerning?</li> <li>• Can you think of any opportunities or risks associated with using data in some of the ways described? (Flip chart)</li> <li>• Do you have any questions about anything you have just heard that you would like to ask the panel? Facilitator to explain that we are likely to only take one or two questions from each table and that she/he is more than happy to ask questions on behalf of people. Equally people can ask questions themselves. Facilitator to flip chart the table's questions and ask them to prioritise the most important to ask. Facilitator to add the unanswered questions to the Graffiti wall.</li> </ul>
13.07		<p><b>Q&amp;A to the panel – Murat, Sam, Stuart, and Axel (8 mins)</b></p>
13.15 - 14.05	<b>LUNCH</b>	<p>Facilitator to ask people to come back promptly for a 14.05 start, and to suggest people sit in different seats around the table.</p> <p>Over lunch, chair and moderating team spend some time collating and theming questions on the graffiti wall, with the aim of being able to answer these directly after lunch.</p>

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### Citizens' Summit Day 1 discussion guide

Saturday 1 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
14.05 - 15.20	<p><b>Access and control – providing care to an individual (health setting) Part 1</b></p> <p>Tables, then plenary, then tables, then plenary, then tables.</p>	<p><b>General Q&amp;A moderated by the chair following lunch (5 mins)</b></p> <p>Facilitator to welcome the table back after lunch and to explain that we'd now like to focus on the entire healthcare team and who has access to what information. Reflecting on the range of patient data we looked at before lunch but for this session, just focussing on access to information within the healthcare setting. Explain that we will do a similar exercise for social care settings tomorrow morning.</p>
14.10		<p><b>Table discussions (10 mins)</b></p> <ul style="list-style-type: none"> <li>• When you think of the entire healthcare team, who do you think of?</li> <li>• Who do you think has access to your health data or records?</li> <li>• What kinds of information do you think they can access and why?</li> </ul>
14.20		<p><b>Mark Kewley's presentation – round 1 (5 mins):</b> Stating clearly that we are focusing specifically on the health setting and who has access to what information. Reflecting on a couple of key findings from previous research (Insights report/pre-deliberative research) and how this links to organisation, as well as public expectations. Describing the different aspects of a control environment: legal frameworks (Common law, implied consent), employment and professional conditions, personal controls and technological controls (i.e. highlight the variance in practice – smart cards, RBAC, configured technical infrastructure based on role). Describing how that plays out now in a world of predominantly paper records.</p> <p>To include intro to control environment (the fact that we have a broad model in mind, others do something different – stuff from less differentiated to more). Technical and feasibility constraints. 'we need this to be something that you think is trustworthy'</p>

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Saturday 1 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
14.25		<p><b>Table discussions (15 mins including card sort)</b></p> <p>Table reflections on what they've just heard:</p> <ul style="list-style-type: none"> <li>• What do you think to what you have just heard?</li> <li>• Anything unclear or confusing?</li> </ul> <p>Facilitator to split the table into three mini groups, allocate a third of the cards to each group (i.e. they categorise different cards) and have each group devise their own means for categorising different roles. The exercise is about grouping roles which are seen to be similar in terms of the amount of data people should be able to access (all, some, none).</p> <ul style="list-style-type: none"> <li>• Think about how much you trust each type of role to see your data</li> <li>• Think about what reassurances or safeguards Londoners would need to see in place for the system to feel trustworthy</li> </ul> <p>In doing the exercise, facilitators to encourage mini groups to think about the range of reasons why different people might need to access different data, including patients in this.</p> <p>Facilitator: Ask mini groups to report back on how they categorised their (third of the) roles. Spark discussion (i.e. "Is everyone happy with this? Why/Why not?"). Write up the groupings on the flip chart – under three columns: All, Some, None (and any new categories devised by participants).</p>
14.40		<p><b>Sanjay's presentation – round 2 (10 mins):</b> Explaining who makes up a care team and how roles, such as receptionists, have always been central to the team and had access to data (i.e. who opens letters from the hospital). Explaining the complexity of the issue: things to consider include privacy, convenience (for patients and staff), safety and burden on the NHS (trade-off triangle). Reiterate the fact that there is mass variation across the country (and within London too), meaning some providers are much more relaxed about this (consequences of this) and some are too cautious (consequences of this). Suggest that it seems sensible to develop some levels or hierarchy of control which allows for the safe delivery of care but also ensures that people aren't accessing excessive information that they don't need to see. Also nod to what may or may not be feasible (a sensible number of roles vs a long list of roles).</p>
14.50		<p><b>Q&amp;A – (5 mins)</b></p>

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Saturday 1 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
14.55		<p><b>Table discussion (25 mins):</b></p> <p>As outlined in the presentation, providing members of a care team (some who are not clinically trained and registered professionals but instead provide a supporting and administrative role), with access to certain pieces of patient data, relevant to their role, is necessary to provide safe and coordinated care.</p> <ul style="list-style-type: none"> <li>• How you do feel about this?</li> <li>• What, if anything, worries you?</li> <li>• Does anything you have heard make you think differently about who accesses your information? If so, why?</li> <li>• What would need to be in place for you to be comfortable with different people accessing your information for different reasons?</li> </ul> <p>Facilitator to provide 1) HANDOUT A showing how a range of different people who might need to access information ('Why different people need access?' quotes), and 2) case studies, drawing on the trade-offs outlined in Sanjay's presentation. As participants discuss the handout and patient case studies. If needed remind them of the legal (can be fined, sent to prison if you break the law), employment (can be fired) and professional (can be struck off) obligations and sanctions where rules are broken. Also that technology can ensure that people only see what they are meant to see.</p> <p>For each case study, think about what the issues are and to what extent they are at play here (privacy, convenience, safety, burden on staff and efficiency). Facilitator to also provide HANDOUT B. Ask participants to discuss:</p> <ul style="list-style-type: none"> <li>• How comfortable, or uncomfortable are you with this?</li> <li>• What factors are most important here (privacy, convenience, patient safety, burden on staff and efficiency)?</li> <li>• What factors are less important here (privacy, convenience, patient safety, burden on staff and efficiency)?</li> </ul> <p>Facilitator note: if people are struggling to consider the trade-offs, and are very strongly of the opinion that (for example) GP receptionists shouldn't see any personal information, you need to provide challenge around what this means for ease of gaining test results, taking burden away from GPs who are already very stretched etc.</p> <p>Facilitator to ask the table to rank the case studies in order of most to least comfortable, capturing their reasoning in doing so.</p>
15.20 - 15.40	<b>BREAK</b>	Facilitators to explain to participants that they must be back promptly for a 15.35 start. Encourage participants to look the patient data diagram.

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Saturday 1 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
15.40-16.00	<p><b>Access and control – providing care to an individual (health setting) Part 2</b></p> <p>Tables</p>	<p><b>Table discussions (20 mins):</b></p> <p>Facilitator asks the whole table to work up the three mini group categorisations into something they, as a table, are happy with</p> <ul style="list-style-type: none"> <li>• Group to reflect on their own categories (their earlier groupings) and the roles within these, using trade-offs discussed</li> <li>• Table to land on something that reflects what is important to them and (they feel) is feasible to implement</li> <li>• Experts roaming the room, assisting tables around feasibility of the options /answering Qs</li> </ul> <p>Facilitator to capture (on flip chart):</p> <ul style="list-style-type: none"> <li>• What were the most important factors at play (privacy, convenience, patient safety, burden on staff and efficiency) as the table agreed on the groupings?</li> <li>• What made the participants change their mind and move roles around (i.e. bumping them up, keeping them where they were, or dropping them down the hierarchy)?</li> <li>• What would need to be in place for participants to have trust in the system in delivering this?</li> <li>• What sort of things might persuade you to grant more access (i.e. move people from having no access to some)?</li> </ul>

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Saturday 1 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
16.00-16.25	<p><b>Access and control – providing care to an individual (health setting) Part 3</b></p> <p>Plenary</p>	<p><b>Plenary (20 mins):</b> Chair to invite a representative from each table to spend two mins reporting back to the room on their discussions: agreed and proposed categories, difficult decisions that they had to make, across the board what was important to them in deciding whether or not to give different roles access to information. Also state where they (patients) sit in this and why.</p> <p><b>Show countdown on the screen.</b></p> <p>Summary (5 mins): After we have heard from all ten tables, chair to make an assessment on where the room is at. For example, if there is divergence (and why) and to assess the temperature of the room in relation to what is important to people (referring back to the trade-offs).</p> <p><b>If tables were very similar:</b> Chair to ask the room if we want to make a recommendation about a model going forward, and the assurances that are needed to make this model trustworthy.</p> <p><b>Note to Chair:</b> The voting question infers testing public acceptability of designating a small number of categories (as opposed to not doing so), per se, and not what these categories should be specifically.</p> <p><b>Possible vote on:</b> Should we devise a small number of categories (i.e. around four) of roles for the entire care team which defines the level of access to information different roles have, or should we have no variation between roles in the care team meaning anyone with access to the system can see all of the information held about people?</p> <ol style="list-style-type: none"> <li>1. Devise a small number of categories of roles</li> <li>2. No variation between roles in the care team in terms of access</li> <li>3. I am unsure / I need more information</li> </ol> <p><b>OR... Chair and OneLondon team to devise a question that would capture the discussions around access and control.</b></p>
16.25 - 16.30	<p><b>Summary</b></p> <p>Plenary</p>	<p><b>Chair to close the day, covering the following (5 mins):</b></p> <ul style="list-style-type: none"> <li>• Today has been about providing you with a lot of information to inform the discussion over the whole of the 4 days. Nod back to the patient data flow diagram</li> <li>• And to get you familiar with the range information and different perspectives you need to help you discuss and form opinions on these issues</li> <li>• Tomorrow we ask you to continue to think in a citizen-minded way, as we move on to explore your expectations of information being shared to join up health and social care services, and to support services which anticipate people's needs rather than waiting for them to arise.</li> </ul>

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### Citizens' Summit Day 2 discussion guide

Sunday 2 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
9.30 - 10.00	<b>Arrival and registration</b>	<p>Participants arrive at etc. venues St Paul's</p> <ul style="list-style-type: none"> <li>• Participants given name sticker to wear, with table number shown on it (including a RED dot if they have not consented to filming)</li> <li>• Participants allocated to different tables to the previous day to expose one another to different views and to mix up the deliberation</li> </ul>
10.00-10.15	<p><b>The role of deliberation and reminder of the citizens' summit process</b></p> <p>Plenary and then tables</p>	<p><b>Ipsos Chair to welcome the room back to day 2 (5 mins):</b></p> <p>Chair welcome back and summarises what happened on day 1 (we discussed your expectations of a health and care system, how data are used and who has access to information). Reminds people about why we are here and that we ask for them to continue to think in a civic-minded way. Chair provides an overview of the topics that we will discuss today (your expectations of information being shared to join up health and social care services, and to support services which anticipate people's needs rather than waiting for them to arise), and introduces relevant part of the patient data flow diagram. Also covers housekeeping, plus breaks, toilets and fire alarm.</p>
10.05		<p><b>Table introductions (10 mins) (Because people are on new tables. Facilitator to go around the table asking for)</b></p> <ul style="list-style-type: none"> <li>• Each person to introduce themselves (name, where they live and with whom)</li> <li>• Each person to report back on the one piece of information that they learnt yesterday that they were most surprised about?</li> <li>• Do you have anything to add to the Chair's summary of day 1?</li> <li>• Do you have any unanswered questions? Facilitator to encourage participants to put these up on the graffiti wall if he/she can't answer them there and then. (Questions collected and analysed for consideration on how to address for Day 3 and 4).</li> </ul>
10.15 - 11.30	<p><b>Access and control – providing care to an individual (care setting) Part 1</b></p>	<p><b>Cathy Ingram's presentation (10 mins):</b> Stating clearly that we are now focussing on the social care setting. Describing some of the main care settings (care home, nursing home, care at home) and the health information that is relevant in each – also that care providers only tend to receive care plans but highlighting that some care homes do receive discharge summaries from hospital. Explain (briefly) what information these settings tend to receive from the health system and why this is (i.e. technology and complex systems limits just sharing certain information; fears from Caldicott Guardians about sharing hospital letters with social care as could be misused; worries over safeguarding information being available to care providers. Touch on IG standards and care quality standards.</p>

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### Citizens' Summit Day 2 discussion guide

Sunday 2 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
10.25		<p><b>Jonty Heaversedge's presentation (5 mins):</b> Introduce the idea of standardising access to certain information for different roles to facilitate safer, more efficient care (i.e. as a GP, I need social care workers so know information about patient's medication). Use the example of the care plan (which states purely transactional information such as administer medication, help with washing) vs the hospital discharge summary (which includes summary of reason for hospital admittance, treatment or procedures in hospital and list of medication). Introduce trade-offs here (privacy, convenience, safety, burden on staff and efficiency). Jonty to emphasise that the discussion does require trade-offs, with concrete examples.</p>
10.30		<p><b>Q&amp;A to Jonty and Cathy (5 mins)</b></p>
10.35		<p><b>Table discussions (25 mins)</b></p> <ul style="list-style-type: none"> <li>• What do you think to what you have just heard?</li> <li>• Anything unclear or confusing?</li> <li>• Introduce 3 case studies which introduce data challenges, trade-offs, and includes the role of the social worker in each <ul style="list-style-type: none"> <li>– Bill lives in a residential care home</li> <li>– Mrs Jones receives care at home</li> <li>– Sue lives in a nursing home</li> </ul> </li> <li>• Can you think of the benefits of data being accessed by the staff roles in these examples? If so, what are they?</li> <li>• What concerns might Londoners have about how the data is being used/accessed?</li> <li>• What would need to happen/be put in place for Londoners to feel confident about how the data is handled? Why do you think this?</li> </ul> <p>Facilitator to provide case studies 4, 5 and 6 and draw on the trade-offs outlined in Jonty's presentation. For each pen portrait, think about what the issues are and to what extent they are at play here (privacy, convenience, safety, burden on staff and efficiency). Ask participants to discuss:</p> <ul style="list-style-type: none"> <li>• How comfortable, or uncomfortable are you with this?</li> <li>• What factors are most important here (privacy, convenience, safety, burden on staff and efficiency)?</li> <li>• What factors are less important here (privacy, convenience, safety, burden on staff and efficiency)?</li> </ul> <p>Facilitator note: if people are struggling to consider the trade-offs, and are very strongly of the opinion that (for example) low skilled care workers shouldn't see any personal information, you need to provide challenge around what this means for people's safety (medication errors), efficacy of running services (knowing when people are out of hospital and back home to be added back on the rota)</p> <p>Facilitator to ask the table to rank the case studies in order of most to least comfortable, capturing their reasoning in doing so.</p>

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Sunday 2 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
11.00		<p><b>Table discussions (card sorting exercise) (15 mins):</b></p> <p>Facilitator asks the whole table to work up the three mini group categorisations into something they, as a table, are happy with</p> <ul style="list-style-type: none"> <li>• Group to reflect on their own categories (their earlier groupings) and the roles within these, using trade-offs discussed</li> <li>• Table to land on something that reflects what is important to them and (they feel) is a feasible solution to implement</li> <li>• Experts roaming the room, assisting tables around feasibility of the options /answering Qs</li> </ul> <p>Facilitator to challenge participants to draw out the reasons underpinning the decisions about who goes where</p> <ul style="list-style-type: none"> <li>• Facilitator to capture (on flip chart): <ul style="list-style-type: none"> <li>– What were the most important factors at play (privacy, convenience, patient safety, burden on staff and efficiency) as the table agreed on the groupings?</li> <li>– What made the participants change their mind and move roles around (i.e. bumping them up, keeping them where they were, or dropping them down the hierarchy)?</li> <li>– What would need to be in place for participants to have trust in the system in delivering this?</li> <li>– What is an appropriate solution to this given what you have heard?</li> </ul> </li> <li>• After we spoke about this yesterday for healthcare, we've been thinking about the different reasons that you wanted to give different staff roles different levels of access. Here are some of the reasons that we think we heard yesterday: <ul style="list-style-type: none"> <li>– A healthcare professional needs to know something to support your healthcare</li> <li>– A decision needs to be made on patient care</li> <li>– It will save your life</li> <li>– Safety of your care</li> <li>– Making healthcare more useful and convenient</li> <li>– Level of training professionals have for care provision</li> <li>– Level of training professionals have on privacy and security</li> </ul> </li> <li>• Do you think these reasons reflect what you were telling us yesterday? In what ways? What is missing?</li> <li>• How do these reasons compare for healthcare and social care? Why?</li> </ul>

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Sunday 2 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
11.15		<b>Plenary (20 mins)</b> Chair to invite a representative from each table to spend 2 mins reporting back to the room on their discussions (focusing on the reasons underpinning decisions about who should see what social care data, drawing out any differences between NHS and social care).
11.35 - 11.55	<b>BREAK</b>	Facilitators to explain to participants that they must be back promptly for a 11.50 start. Encourage participants to look the patient data diagram and opportunity for tables to clarify any questions with experts.
11.55 - 12.15	<b>Access and control – providing care to an individual (care setting) Part 2</b>	<b>Summary (20 mins):</b> After we have heard from all ten tables, chair to make an assessment on where the room is at. For example, if there is divergence (and why) and to assess the temperature of the room in relation to what is important to people (referring back to the trade-offs). Chair and OneLondon to decide where to take the room – to include getting reasoning from people who do not want to differentiate between roles.
12.15 - 13.05	<b>Access and control – proactive care – Part 1</b>  Plenary, then tables, then plenary Q&A	<b>Jonty Heaversedge's presentation (10 mins):</b> Providing an overview of what proactive care is, with some examples, and how technology and joined up care and information is enabling us to do (i.e. new possibilities). Outline in the context of the preventative agenda. Explain that proactive care is aimed at the individual (i.e. direct care), but we are looking for people before they get acutely unwell (i.e. we need to look at people in a population dataset rather than a person who has turned up to a clinic). Include detail about the benefits, but also concerns (including: algorithms can drive false positives, false negatives, equalities impact, and might become intrusive/nannying)
12.25		<b>Q&amp;A (5 mins)</b>
12.30		<b>Table discussions (10 mins)</b>  Table reflections on what they've just heard: <ul style="list-style-type: none"> <li>• What do you think about what you have just heard?</li> <li>• Anything unclear or confusing?</li> <li>• Is anything surprising to hear, or new to you?</li> <li>• What do like about what you have heard?</li> <li>• What, if anything, concerns you?</li> </ul>

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Sunday 2 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
12.40		<b>Andi Orlowski's presentation (10 mins):</b> Presentation to explain that big data are helpful but how no system is fool-proof thus it is technically possible to triangulate data and identify people if you really want to and try hard, however the sanctions are severe. As well, where data are all in one place, in a big data set, this might become more of a target for cyber-attacks. However, on the flip side, this also allows us to invest more in state of the art infrastructure. Introduce the kinds of people are involved in proactive care (analysts) and the types of controls in place, describing for example the application process to get access to this information in NW London and the level of identification of the data that tend to be used. Explain the 'grey area' around consent/data use for proactive care – i.e. that it falls between individual care and secondary data uses; however, the data sharing rules for individual care (implied consent) apply.
12.50		<b>Q&amp;A (5 mins)</b>
12.55		<b>Table discussions (10 mins)</b> <b>Table reflections on what they have heard</b> <ul style="list-style-type: none"> <li>• What are your reflections on what you have just heard?</li> <li>• Is anything surprising to hear, or new to you?</li> <li>• What do like about what you have heard?</li> <li>• What, if anything, concerns you?</li> </ul>
<b>13.05 - 13.45</b>	<b>LUNCH</b>	Facilitators to explain to participants that they must be back promptly for a 13.45 start. Encourage participants to look the patient data diagram.
<b>13.45 - 15.20</b>	<b>Access and control – proactive care – Part 2</b>  Tables, then plenary and then vote	Facilitators to explain that we'd like to now look at a number of different examples of 'proactive care'. Flag diagram showing identifiable info, de-identified info and anonymous information. Facilitator to provide HANDOUT C on spectrum of identifiability to refer to throughout case study discussions.  Case studies 7, 8 and 9 showing data uses for a few different examples (e.g. AF, frailty, preventing diabetes) (15 mins).  For each case study: <ul style="list-style-type: none"> <li>• What appeals to you about this?</li> <li>• What concerns you?</li> <li>• What are the most important factors at play here (privacy, burden on the system and quality) and what is of most /least importance?</li> <li>• What questions does this example raise?</li> </ul>

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Sunday 2 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
14.00		<p><b>General questions about proactive care interventions (15 mins)</b></p> <ul style="list-style-type: none"> <li>• Yesterday, and this morning when we talked about social care, the information being shared and used would be personally identifiable. Now we are talking about the use of de-personalised information. Does this make this anymore or less acceptable?</li> <li>• The case studies emphasis the idea of preventative care, by using de-personalised data to anticipate people who would benefit from additional support before they reach a crisis. This differs from the health system responding to people once they become sick. How do you feel about this?</li> <li>• The data used by analysts to identify people at risks, also contains de-personalised data about people who might not be at risk and, therefore, won't receive any proactive care:             <ul style="list-style-type: none"> <li>– How acceptable is this?</li> <li>– What reassurances would be needed for Londoners to be comfortable with this?</li> <li>– Can you think of any examples which Londoners might find unacceptable?</li> </ul> </li> <li>• As we heard, in Andi's presentation, because this data is being used for the purpose of providing targeted support to those individuals who need it, health providers want to use the same legal justification for joining up and using the data as they do when they use the patient data for delivery of individual care. This means that organisations would rely on implied consent, rather than asking everyone directly for their consent to use their de-personalised data in this way.             <ul style="list-style-type: none"> <li>– How acceptable is this?</li> <li>– What reassurances would Londoners need to be comfortable with data being used in this way?</li> </ul> </li> <li>• Are there any questions for the expert commentators about this proposed use of patient data?</li> </ul> <p>Facilitator note: If people are struggling with the concept of data sharing here, and the identification, please remind them that this is not showing information about who you are (it is de-personalised), and reassure them that the only re-identification happens for the people who are then contacted by the healthcare services.</p>

## Appendix E: Discussion guides

### Citizens' Summit Day 2 discussion guide

Sunday 2 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
14.15		<b>Plenary Q&amp;A (10 mins):</b> Chair to take questions from the room and pose these to Andi and Jonty.
14.25		<b>Table discussions (10 mins):</b> Facilitator to encourage table to form a view on whether they think the use of patient data for proactive care purposes using the implied consent model is acceptable or not.
14.35		<b>Plenary (30 mins):</b> Chair to invite a representative from each table to spend a few minutes (maximum of 3 mins) reporting back to the room on their discussions in relation to proactive care – benefits, concerns, and whether they think it is acceptable to continue to deliver proactive care under the implied consent model.
15.05		<b>(15 mins) Vote on</b> Do the <b>benefits</b> of using <b>de-personalised information</b> to find candidates for proactive care outweigh the <b>concerns</b> that people have about their information being processed in this way?  <ol style="list-style-type: none"> <li>1. Yes, the benefits outweigh the concerns</li> <li>2. No, the benefits do not outweigh the concerns</li> <li>3. I am unsure / I need more information</li> </ol> <p>Followed by a summary from the chair off the back of the vote. For example, does the room want to make a recommendation now on this going forward? Or summarising that there are differing views so we will return to this later in the process. Chair to ask people to clearly write down on a post-it note their reason, condition or caveat to explain their vote and/or what would need to be in place for the system to operate in a trustworthy way. And to stick these up on the 'vote wall' – on the left if they voted yes, on the right if they voted no and in the middle if you are unsure/feel you need more information.</p>
<b>15.20 - 15.40</b>	<b>BREAK</b>	Facilitators to explain to participants that they must be back promptly for a 15.35 start. Encourage participants to look at the patient data diagram.
<b>15.40 - 16.25</b>	<b>Access and control – operating across London</b>  Plenary, then tables, then plenary and then vote	<b>Amy Darlington's presentation (10 mins):</b> Reminding people of all of the topics covered over the weekend. Remind people that there is no single NHS record that all people who work within health and care organisations can (and should be able to) access. Provide some indication of the % of GP practices and hospitals that are joining up data locally, or at least some examples of areas which are more joined up than others. Explain that this whole exercise is supporting the establishment of policy to support the joining up of health and care data for different purposes, but that in doing so we need to understand whether the public expect information to be consistently joined up or whether organisations should be able to decide.

## Appendix E: Discussion guides

### Citizens' Summit Day 2 discussion guide

Sunday 2 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
15.50		<p><b>Table discussions (20 mins):</b></p> <ul style="list-style-type: none"> <li>As we heard in the presentation, we need to establish what the public expect in terms of whether there should consistency across London, or whether organisations should continue to decide if and how they share data. <ul style="list-style-type: none"> <li>What are your thoughts in response to this, given everything that we have talked about over the last two days? Facilitator to ask for a show of hands to see where the table is at.</li> <li>What are the arguments for consistency?</li> <li>What are the arguments for allowing organisations to decide if/how they share data?</li> </ul> </li> <li>What are the important considerations the NHS should keep in mind when formulating policy to support the joining up of health and care data for different purposes? – Flip chart. If list is long, ask participants to prioritise their top five.</li> </ul>
16.10		<p><b>Plenary (10 mins):</b> Chair to go round each table and to have them list their top five operating principles which someone writes up on screen so that the whole room can see.</p>
16.20		<p><b>(5 mins) Vote on</b> 'Should there be a consistent approach across London for health and care data use, or should organisations continue to make different choices about what information they share with whom and for which purposes?</p> <ol style="list-style-type: none"> <li>There should be a consistent approach across London</li> <li>Organisations should continue to make their own choices separately about what information they share with whom and for which purposes</li> <li>I am unsure/ I need more information</li> </ol> <p><b>Followed by</b> a summary from the chair off the back of the vote. For example, does the room want to make a recommendation now on this going forward? Or summarising that there are differing views so we will return to this later in the process. Chair to ask people to clearly write down on a post-it note their reason, condition or caveat to explain their vote and/or what would need to be in place for the system to operate in a trustworthy way. And to stick these up on the 'vote wall' – on the left if they voted yes, on the right if they voted no and in the middle if you are unsure/feel you need more information.</p>

## Appendix E: Discussion guides

### Citizens' Summit Day 2 discussion guide

Sunday 2 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
16.25 - 16.30	<p><b>Summary</b></p> <p>Plenary</p>	<p><b>Chair to close the day, covering the following (5 mins):</b></p> <ul style="list-style-type: none"> <li>• Today has been about providing you with more information to inform the discussion over the whole of the 4 days</li> <li>• And to get you more familiar with the range of information and different perspectives you need to help you discuss and form opinions on these issues</li> <li>• We now have four weeks for you to go away and reflect on what you've heard, before coming back for our final weekend at County Hall</li> <li>• <b>NB: facilitators to administer tracking questionnaire and evaluation questionnaire</b></li> <li>• <b>Administer incentives</b></li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
10.00-10.35	<p><b>Introduction and scene setting</b></p> <p>Plenary then table discussions</p>	<p><b>Ipsos Chair to welcome the room back to the event (5 mins):</b>            'Story so far' summarising what was covered on days 1 and 2 and where we are in the process (referring to the patient data diagram provided in packs). Where we are going in days 3 and 4: moving away from direct and proactive care uses of data, through to the secondary uses such as planning and improvement and research and development. Where we need to arrive in the outcomes for day 4: recommendations for OneLondon. If applicable, mention the media presence and introduce experts who are going to be observing throughout the day. Reintroduce the housekeeping, breaks and toilets. Finish with a note about ground rules before introducing the table discussion.</p> <p>Patient data flow diagram placed in a prominent position in the room and digital versions left up on the two furthest screens throughout the whole of the two days. Also in day 3 and 4 pack, right at the front.</p>
10.05		<p><b>Table introductions and ice breakers (30 mins)</b></p> <ul style="list-style-type: none"> <li>• Facilitator introduces themselves and the table's note taker, thank you for coming. Collects permission to audio record the discussion.</li> <li>• To introduce us all to each other, facilitator explains we have new table arrangements. Participants introduce themselves around the table (5 mins).</li> <li>• Tables to reflect on weekend 1 as a group – what stuck in their mind? What questions do they want to explore today? (5 mins)</li> <li>• Tables to discuss the homework task (20 mins)               <ul style="list-style-type: none"> <li>– What conversations did they have and with whom?</li> <li>– What data cans did they listen to and what issues, questions or concerns did they raise?</li> </ul> </li> </ul>
10.35 - 11.10	<p><b>Use of de-personalised data for health and care planning and improvement and the diameter of trust – part 1</b></p> <p>Plenary presentation, then tables</p>	<p><b>Mark Kewley's presentation (5 mins):</b>            Outlining that during the end of the previous weekend we introduced the idea of 'de-personalised data', and that all of the data uses we are referring to today would use this type of data (though in some cases data would be completely anonymous). Explain what this is, how it is protected, and provide one or two examples. Point to some of the media articles around the use of data which could be identified, but then clearly state a) how difficult it would be to do this, and b) that it would be a breach of the law.</p> <p>Frame the intent for the whole of the day's discussion to be around: What would make the use of this kind of data for different purposes more or less trustworthy?</p>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
10.40		<p><b>Alex Baylis' presentation (10 mins):</b> How planning and improvement happens across health, social care and public health.</p> <ul style="list-style-type: none"> <li>• Quality improvement in providers</li> <li>• (touch on) Regulation</li> <li>• Commissioning, Planning and reconfiguring services</li> <li>• Public health</li> <li>• Worked example of the role of data in planning and improvement</li> <li>• How does data go from patient/citizen -&gt; analysis -&gt; decision</li> <li>• Who is involved – roles and orgs</li> <li>• Also to make the point that the value from this data use is only fully appreciated when there is consistency in providers sharing their patient's data (i.e. data quality)</li> </ul> <p>Throughout: articulate what happens now vs what would be ideal. Bringing out the potential of more joined up data, i.e. planning based on supply (now) vs planning based on demand and supply (future); planning in silo, i.e. with just A&amp;E data (now) vs planning with the 'whole person' in mind (future); planning based on outputs (now) vs planning based on outcomes (future).</p>
10.50		<p><b>Ipsos Chair:</b> explain that we're now going to go to table discussions about what we've just heard and to gather questions for a panel of people who are involved in these kinds of processes.</p> <p><b>Table discussions (10 mins)</b></p> <p>Table reflections on what they've just heard</p> <ul style="list-style-type: none"> <li>• How familiar were you with the way the NHS and social care planning and improvement takes place?</li> <li>• Was there anything in that presentation that was new or surprising to you?</li> <li>• Does it leave you with any questions or concerns to address to the panel?</li> </ul> <p>Facilitators to encourage participants to note down their questions on post it notes and place them on the group's flip chart. Facilitator to ask their groups to prioritise questions.</p> <p>Facilitator to ask the questions of the panel on behalf of group (in a bid to be brief).</p> <p>Any remaining questions added to graffiti wall to be potentially addressed in plenary later in day.</p>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
11.00		<p><b>Q&amp;A in plenary with panel</b> - Alex, Luke, Jonty - (10 mins) (Alex to share questions from his table first, before going on stage to respond to other questions)</p> <p><b>Ipsos chair:</b> explain that we're now going to break for 15 minutes before sitting down to discuss some concrete examples and case studies of planning and improvement.</p>
11.10 - 11.25	<b>BREAK</b>	Facilitators to encourage participants to return prompt, and round up in the breakout areas to ensure participants are back in their places by 11.25 prompt.
11.25 - 12.00	<p><b>Use of de-personalised data for health and care planning and improvement and the diameter of trust – part 2</b></p> <p>Table discussions</p>	<p>Facilitators to welcome participants back from break.</p> <p>Clarify if there is anything that group is still unclear about or want to put our hands up and call experts over to our table about.</p> <p>Explain that this session involves discussing case studies of the use of this kind of depersonalised data. Remind them again of the depersonalised data definition Mark used – data that has had information such as names and address removed.</p> <p>In each of these, the OneLondon team are very interested in three things:</p> <ul style="list-style-type: none"> <li>• Whether you'd expect health and social care providers to be sharing data to join up and use in this way. This will help to engage providers of care (such as GPs and hospitals) who have historically not shared data for these purposes. We know that sometimes they are reluctant to for a range of reasons. <ul style="list-style-type: none"> <li>– A belief that their patients may not support the use of their data in these ways;</li> <li>– Liability for their patients' privacy being breached after they share data onwards;</li> <li>– That the data will be used to assess their performance.</li> </ul> </li> <li>• Whether you think the case is a legitimate use of the data. This will help to guide them on the decisions about the kind of work that is done using the data they build.</li> <li>• What organisations you are comfortable with being involved – how far we want to share data for improvement and planning purposes – the 'diameter of trust'. Point participants to 'circle of trust' diagram in their packs</li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
11.25 - 12.00 continued		<p>Next: Introduce the three case studies that have the uses of depersonalised data for planning and improvement:</p> <ol style="list-style-type: none"> <li>1. Health staff improving care for people with Long term multiple conditions</li> <li>2. Planners thinking about changing services for diabetes patients</li> <li>3. Local council and changing the road transport system to tackle air pollution</li> </ol> <p>Facilitators to work through cases, spending c.8 mins on each, asking the following specific questions in each one of the group, keeping those three elements in mind – expectation of providers, legitimate uses, and the diameter of trust across organisations. Facilitators to capture, extension of the diameter of trust they are willing to accept and red lines on flipcharts.</p>
11.30		<p><b>Planning and improvement case study 1:</b> Health staff improving care for people with Long term multiple conditions</p> <ul style="list-style-type: none"> <li>• Do you expect different NHS organisations to contribute depersonalised data about patients to support this kind of work for people with complex needs?</li> <li>• What are the advantages and disadvantages of doing this?</li> <li>• Is it right that some parts of London can have this analysis and improvement and others can't?</li> </ul>
11.38		<p><b>Planning and improvement case study 2:</b> Planners thinking about changing services for diabetes patients</p> <p>Local commissioning organisations do not provide care to any individual directly, but it is their job to make sure that the right services are in place, and that services are suitable for everyone who needs them.</p> <ul style="list-style-type: none"> <li>• What are the advantages and disadvantages of using de-personalised patient data to make decisions about which services to commission? (If necessary remind participants that this data is de-personalised so it is difficult but not impossible to re-identify people. Some data might not be complete / might be incorrect – is it better to make a decision on some data or no data? How would they feel if a service was changed or moved so that it was more convenient on average, but some current users might be inconvenienced?)</li> <li>• Do you expect commissioners to be able to access person-level depersonalised population data to inform their planning decisions?</li> <li>• IF NECESSARY: Are there any conditions you could add to make it more acceptable?</li> <li>• What factors are important in making this feel trustworthy?</li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
11.46		<p><b>Planning and improvement case study 3:</b> Local council and changing the road transport system to tackle air pollution</p> <ul style="list-style-type: none"> <li>• How do you feel about public sector organisations outside of the NHS, like public health teams in local councils, working with the NHS to derive insights from person-level depersonalised population data?</li> <li>• What considerations might determine if it is ok to link health data with non-health information, and why? Think about data a council might have or could get from other sources such as air pollution measures, bin collection data, or information about people in receipt of welfare benefits? <ul style="list-style-type: none"> <li>– Facilitator note: bin collection data includes information about people who ask for help with putting their bins out, which is thought to be an indicator of frailty; and benefits claimant information might highlight the links between health outcomes and the loss of universal credit.</li> </ul> </li> <li>• What are the benefits and concerns?</li> <li>• What factors are important in making this feel trustworthy?</li> </ul>
11.54		<p>To end the session, prepare to feed back in plenary. Facilitators to capture on flip chart (5 mins):</p> <ul style="list-style-type: none"> <li>• Were these examples as described acceptable?</li> <li>• Were there conditions that made the examples more acceptable?</li> <li>• Any red lines about unacceptable uses of data for planning/improvement?</li> </ul> <p>Do you think that health and care organisations should be expected to contribute depersonalised data on your behalf to enable this type of planning and improvement?</p>
12.00 - 12.30	<p><b>Use of de-personalised data for health and care planning and improvement and the diameter of trust – part 3</b></p> <p>Plenary conversation</p>	<p><b>Ipsos chair to bring room back together</b> explaining that the next thirty minutes are going to be used for feeding back from tables. But we will be wrapping this up tomorrow.</p> <p>Facilitators at each table to spend 2.5 minutes, reporting back to the room on their discussions (parameters of acceptability with safeguards and conditions, extension of the diameter of trust they are willing to accept, red lines). Facilitators should cover the whole range of the views on their table – giving a sense of how split the table was too (25 mins)</p>
12.25		<p><b>Ipsos chair to respond (5 mins):</b> to comment on outcome of the facilitators' feedback, judge convergence/divergence and summarise the key considerations that will feed into Day 4.</p> <p>Chair to reassure the room that this discussion doesn't end here: because it's complicated, and because we expected it to raise lots of questions, we have designed a part of tomorrow to revisit this before we move to making recommendations about the use of de-personalised data for these types/other types of uses</p>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
12.30 - 13.15	LUNCH	Facilitators to explain to participants that they must be back promptly for a 13.15 start. Encourage participants to look at the patient data diagram.
13.15 - 13.50	<p><b>Use of de-personalised data for research and innovation – Elements of a Trusted Research Environment</b></p> <p>Plenary presentation, then tables</p>	<p><b>Caroline Cake's presentation (5 mins):</b> What is R&amp;D, who does it, why is it important; and why does linked data offer a new type of opportunity. Include the benefits and risks of doing research [use examples].</p> <p><b>Amanda Lucas's presentation (5 mins):</b> Explain legal basis and introduce concept of five safes. Explicitly call out that there isn't a consistent approach i.e. to safe settings (HES versus GEL model) and remind participants that NHS may need to partner with commercial or state funded bodies to ensure safe storage - does not mean they can access data.</p>
13.25		<p>Facilitators to explain that previous public research suggests that the public, in principle, support research and development because of the benefits that come with this, and we have just heard some of these in the presentations. We now need to focus on the practicalities of how different people involved in research can access the data in a trustworthy way.</p> <p>Explain that there is a framework that data controllers and data users can use to provide assurance about how data is accessed. It is used by a number of secure labs including the UK Data Service. Facilitator to show the 'five safes framework' slide. Facilitator to spend a few minutes talking through the framework on the slide.</p> <p>NOTE TO FACILITATOR: As participants react to trusted research environment case studies, constantly refer to the 'five safes' framework to establish whether such a framework, or particular elements of it, increases trustworthiness. Also whether certain conditions (i.e. those relating to a safe setting) absolutely do need to be met.</p> <p>Explain that we are now going to look at four different case studies which present different possible research projects and people and organisations involved, looking to access health and care data.</p> <p>Facilitator to explain that we need their input around what might increase trustworthiness for each example of de-personalised data being used for research and development purposes.</p> <p>Facilitator to work through the three case studies, spending around 6 minutes on each one. As participants are discussing the safe people, write up on a flip chart their principles for what makes it more/less acceptable in terms of the people accessing data. Also probe and note down the things that would increase trustworthiness (for each).</p>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
13.30		<p><b>Trusted research environment case study 4: Reviewing eye scans</b></p> <ul style="list-style-type: none"> <li>• Do you have any initial thoughts on the case study? Any concerns or questions? How acceptable / unacceptable is this example?</li> <li>• If unacceptable: why do you say that?</li> <li>• What would make you feel more comfortable about this? <ul style="list-style-type: none"> <li>– Moderator can change actors to probe further: For example, what if this was an eye charity rather than a global technology firm, or a new UK-based start-up business? Would that make a difference to how acceptable this is? Why?</li> </ul> </li> <li>• Are there any conditions that you would apply that would make this more acceptable? Or any elements you would change that would make this more acceptable? Refer to five safes to help people draw these out – does this example feel like it has safe people? Is it a safe project? Is the setting safe? Is the data safe? Are the outputs safe?</li> <li>• Would it be different if the company was not allowed direct access to the data but instead, they could pay for an NHS analyst to do the data for them? Why do you feel the way you do?</li> </ul>
13.36		<p><b>Trusted research environment case study 5: A&amp;E attendance</b></p> <ul style="list-style-type: none"> <li>• Do you have any initial thoughts on the case study? Any concerns or questions? How acceptable / unacceptable is this example?</li> <li>• If unacceptable: why do you say that?</li> <li>• What would make you feel more comfortable about this? <ul style="list-style-type: none"> <li>– Moderator to probe further on whether or not the sending of depersonalised data is a concern for people or not.</li> </ul> </li> <li>• Are there any conditions that you would apply that would make this more acceptable? Or any elements you would change that would make this more acceptable? Refer to five safes to help people draw these out – does this example feel like it has safe people? Is it a safe project? Is the setting safe? Is the data safe? Are the outputs safe?</li> </ul>
13.42		<p><b>Trusted research environment case study 6: New diabetes drug</b></p> <ul style="list-style-type: none"> <li>• Do you have any initial thoughts on the case study? Any concerns or questions? How acceptable / unacceptable is this example?</li> <li>• If unacceptable: why do you say that?</li> <li>• What would make you feel more comfortable about this?</li> <li>• Are there any conditions that you would apply that would make this more acceptable? Or any elements you would change that would make this more acceptable? Refer to five safes to help people draw these out – does this example feel like it has safe people? Is it a safe project? Is the setting safe? Is the data safe? Are the outputs safe?</li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
13.50 - 14.25	<b>Use of depersonalised data for research and development - fair partnerships, part 1</b>	<b>Axel's presentation (5 mins):</b> Explanation of the value of health data and the cost of maintaining / curation, the benefits and also the potential risks / concerns, models that are in play.
13.55	Plenary then tables, lightning talks, then tables and Q&A	<p><b>Table discussion (5 mins)</b></p> <p>Table reflections on what they've just heard:</p> <ul style="list-style-type: none"> <li>• What do you think to what you have just heard?</li> <li>• Anything unclear or confusing?</li> </ul> <p>Facilitator to tease out potential questions from participants to ask at Panel Q&amp;A. Participants should also be encouraged to note down any questions they may have on post-it notes.</p>
14.00		<p><b>Plenary, lightning talks (10 mins):</b> Chair to introduce the idea that the NHS works in partnership with a range of individuals and organisations focused on using NHS health data for research and development purposes. Panel will provide different views around what this means in terms of opportunities and risks. Panel lightning talk (2 mins each) highlighting the different reasons why individuals/ organisations form NHS partnerships (highlighting benefits for all parties, motivations, concerns – including transparency).</p> <ul style="list-style-type: none"> <li>• <b>Tim Hubbard (2 mins)</b> – Academic researcher talking about how and why partnerships are formed with the NHS to support academics research.</li> <li>• <b>Adam Higgins (2 mins)</b> – Commercial researcher (from AstraZeneca) talking about how and why partnerships are formed with the NHS to support commercial research (i.e. development of new drugs/treatments).</li> <li>• <b>Harpreet Sood (2 mins)</b> – Representative from the NHS to talk from the NHS perspective about fair partnerships.</li> <li>• <b>Barbara Reichwein (2 mins)</b> – Representative from a Health Charity giving their perspective about fair partnerships.</li> </ul>
14.10		<p><b>Table discussion (5 mins)</b></p> <p>Table reflections on what they've just heard:</p> <ul style="list-style-type: none"> <li>• What do you think to what you have just heard?</li> <li>• Anything unclear or confusing?</li> </ul> <p>Facilitator to do further teasing out of potential questions from participants to ask at Panel Q&amp;A. Participants should also be encouraged to note down any questions they may have on post-it notes.</p>
14.15		<b>Q&amp;A with Panel (Axel, Tim, Adam, Harpreet, Barbara) - (10 mins)</b>
14.25 - 14.40	<b>BREAK</b>	

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials																				
14.40 - 15.40	<p><b>Use of de-personalised data for research and development - fair partnerships, part 2</b></p> <p>Plenary presentation and then table discussions</p>	<p><b>Amy Darlington's presentation (10 mins):</b> presentation to introduce actors in a fair and productive partnerships and run through the different elements – benefits, costs, income and conditions. Presentation to also explain the OneLondon needs participants help with the conditions – presenter to frame the various dilemmas from the front of the room to set up table discussions.</p>																				
14.50		<p><b>Table discussion (10 mins)</b></p> <p>Table reflections on what they've just heard:</p> <ul style="list-style-type: none"> <li>• What do you think to what you have just heard?</li> <li>• Anything unclear or confusing?</li> </ul> <p>Facilitator note: ensure that participants understand what is being asked of them here – that we need them to work as civic minded Londoners to consider what is a fair deal for the NHS and for us as a population when working in partnership with other organisations.</p> <p>Facilitator note: In this session moderator should park discussion on whether it is a safe project or setting. Remind participants we have listened to their views in the previous session but didn't know them in advance. Explain only projects that meet their expectations expressed above will be considered, but we had to develop some examples and want to know what a fair deal would look like for each of them</p>																				
15.00		<p><b>Table discussion (40 mins)</b></p> <p>Facilitators to provide handouts for conditions 1, 2 and 3, and spend 3 minutes reading through each in order (10 mins)</p> <p>For each:</p> <ul style="list-style-type: none"> <li>• What do you think to what we've just read?</li> <li>• Anything unclear or confusing?</li> </ul> <p>Facilitator will also use a ready-made grid like the one shown below on the flipchart.</p> <table border="1"> <thead> <tr> <th></th> <th>Income and charging</th> <th>Levels of transparency</th> <th>Distribution of benefits</th> <th>What others?</th> </tr> </thead> <tbody> <tr> <td>1. Why patients visit A&amp;E</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>2. Algorithm for breast cancer detection</td> <td></td> <td></td> <td></td> <td></td> </tr> <tr> <td>3. Clinical trial for diabetes drug</td> <td></td> <td></td> <td></td> <td></td> </tr> </tbody> </table>		Income and charging	Levels of transparency	Distribution of benefits	What others?	1. Why patients visit A&E					2. Algorithm for breast cancer detection					3. Clinical trial for diabetes drug				
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## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
15.00 continued		<p>Facilitator to explain that we don't want to look at this in the abstract so we will now look at some 'data request proposals'. These set out potential organisations that may wish to access depersonalised data for specific purposes and the conditions and potential benefits and risks of access. Explain that we would like participants to step into the shoes of decision makers. We are asking them to judge, based on the conditions we have just looked at, whether or not these requests should be approved, based on what is a fair deal for the NHS and the party requesting access.</p> <p><b>TRADE-OFFS. Note for facilitators:</b> As you work through each proposal, be sure to push and challenge participants on the trade-offs within each of the conditions.</p> <ul style="list-style-type: none"> <li>• <b>Income and Charging:</b> Should a charge be applied to access? If no, how are costs of joining up data covered? If charging is this looking to recover costs or generate income? How should this be distributed if income generated? Would participants treat the chance of making commercial income differently to academic researchers who generate grant funding for publications? Should different organisations be charged differently for their access? If charging are we looking to recover costs or generate income? How should this be distributed?</li> <li>• <b>Transparency:</b> (Probes below relate to different choices – use the moderator notes if needed to decide which are relevant) <ul style="list-style-type: none"> <li>– Commercial issues to consider – what if providing more details about the research meant (i) companies did fewer studies because of risk to loss of IP (leading to less development of new technology). Or (ii) did the work in another country, meaning the NHS loses the income that subsidises the cost of the of the data services platform for other NHS uses?</li> <li>– Cost implications to consider – sending millions of personal letters to 8 million Londoner's costs roughly 30p per letter which is around £2.4m. Is this feasible / acceptable?</li> <li>– Privacy issues to consider – it is possible that someone other than the intended recipient could read the letter and find out information about them (e.g. sexual health information) that has been included in a research study.</li> </ul> </li> <li>• <b>Distributing the benefits:</b> Is it ok for only those NHS organisations that participated in the partnership to get the benefits of the research, or should it be for the NHS as whole? Consider costs of curating and storing data, and that some benefits may only be realised by those areas that have joined up health and care data (e.g. new algorithm). When considering distribution of benefits probe participants on whether this is the 'public benefit' and / or potential financial benefit also.</li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
15.05		<p>Facilitator to hand out Proposal 1 and to read through it with the table. Facilitator to also provide condition handout and ask participants to consider questions on the handout as they work through each proposal (10 mins - for each proposal).</p> <p><b>Proposal 1: Here we have a UK-based University requesting access with the hope of developing solutions that could reduce unnecessary visits to A&amp;E. Thinking as a decision maker:</b></p> <ul style="list-style-type: none"> <li>• Pointing to the conditions handout: What are the most important conditions to consider here?</li> </ul> <p>Facilitator to use flip chart to record key conditions for each proposal as the table works through it. FACILITATOR NOTE: draw on trade-offs to explore peoples' expectations</p> <ul style="list-style-type: none"> <li>– What charges should be made to research projects to access/ use the data: should there be any charges at all, and if so, are these equal for all parties (e.g. academic, charity, company)? Should it be free to encourage research, should they just seek to cover costs of collecting and maintaining the data or should the NHS seek to make money?</li> <li>– What should be done with the outputs of successful research: how should we consider access to, and distribution of, the findings from a successful piece of research based on Londoner's joined-up NHS data? Specifically, should the NHS look to get a benefit either financially or in kind (i.e. by getting discounts on any product/service produced as a result) – or both What should be done with the outputs of successful research: how should we consider access to, and distribution of, the findings from a successful piece of research based on a population data asset Londoner's' joined-up NHS data?</li> <li>– How should we make clear what research is taking place: what type of record of projects should be made available, and to what level of detail?</li> <li>– What other issues are important to Londoners: what do you think needs to be considered by the NHS when entering into these partnerships? What would make them fair?</li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
15.05 continued		<ul style="list-style-type: none"> <li>Looking back on what we have considered, how acceptable is this data request?</li> </ul> <p>IF ACCEPTABLE:</p> <ul style="list-style-type: none"> <li>Why is it acceptable? (Prompt for income/charging, distribution of benefits, transparency, other)</li> </ul> <p>IF REJECTED:</p> <ul style="list-style-type: none"> <li>Why have you rejected this request? (Prompt for income/charging, distribution of benefits, transparency, other)</li> <li>What would need to change to make this more acceptable and trustworthy?</li> <li>If the table cannot come to an agreement on accepting the request, facilitators to note any divergence within the tables to revisit during the last five minutes and highlight at the plenary.</li> </ul> <p>Facilitator to hand out Proposal 2 and to read through it with the table.</p>
15.15		<p><b>Proposal 2: Here we have a US-based technology company requesting access with the hope of developing an algorithm that could potentially enhance breast cancer detection. Thinking as a decision maker:</b></p> <ul style="list-style-type: none"> <li>Pointing to the conditions handout: What are the most important conditions here?</li> </ul> <p>Facilitator to use flip chart to record key conditions for each proposal as the table works through the it. FACILITATOR NOTE: draw on trade offs to explore peoples' expectations</p> <ul style="list-style-type: none"> <li>What charges should be made to research projects to access/use the data: should there be any charges at all, and if so, are these equal for all parties (e.g. academic, charity, company)? Should it be free to encourage research, should they just seek to cover costs of collecting and maintaining the data or should the NHS seek to make money?</li> <li>What should be done with the outputs of successful research: how should we consider access to, and distribution of, the findings from a successful piece of research based on Londoner's joined-up NHS data? Specifically, should the NHS look to get a benefit either financially or in kind (i.e. by getting discounts on any product/service produced as a result) – or both?</li> <li>How should we make clear what research is taking place: what type of record of projects should be made available, and to what level of detail?</li> <li>What other issues are important to Londoners: what do you think needs to be considered by the NHS when entering into these partnerships? What would make them fair?</li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
15.15 continued		<ul style="list-style-type: none"> <li>Looking back on what we have considered, how acceptable is this data request?</li> </ul> <p>IF ACCEPTABLE:</p> <ul style="list-style-type: none"> <li>Why is it acceptable? (Prompt for income/charging, distribution of benefits, transparency, other)</li> </ul> <p>IF REJECTED:</p> <ul style="list-style-type: none"> <li>Why have you rejected this request? (Prompt for income/charging, distribution of benefits, transparency, other)</li> <li>What would need to change to make this more acceptable and trustworthy?</li> <li>If the table cannot come to an agreement on accepting the request, facilitators to note any divergence within the tables to revisit during the last five minutes and highlight at the plenary.</li> </ul>
15.25		<p>Facilitator to hand out Proposal 3 and to read through it with the table.</p> <p><b>Proposal 3: Here we have a UK-based pharmaceutical company requesting access with the hope of gaining access to patients to trial a new diabetes drug. Thinking as a decision maker:</b></p> <ul style="list-style-type: none"> <li>Pointing to the conditions handout: What are the most important conditions here?</li> </ul> <p>Facilitator to use flip chart to record key conditions for each proposal as the table works through the it. FACILITATOR NOTE: draw on trade offs to explore peoples' expectations</p> <ul style="list-style-type: none"> <li>What charges should be made to research projects to access/use the data: should there be any charges at all, and if so, are these equal for all parties (e.g. academic, charity, company)? Should it be free to encourage research, should they just seek to cover costs of collecting and maintaining the data or should the NHS seek to make money?</li> <li>What should be done with the outputs of successful research: how should we consider access to, and distribution of, the findings from a successful piece of research based on Londoner's joined-up NHS data? Specifically, should the NHS look to get a benefit either financially or in kind (i.e. by getting discounts on any product/service produced as a result) - or both?</li> <li>How should we make clear what research is taking place: what type of record of projects should be made available, and to what level of detail?</li> <li>What other issues are important to Londoners: what do you think needs to be considered by the NHS when entering into these partnerships? What would make them fair?</li> </ul>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
15.25 continued		<ul style="list-style-type: none"> <li>Looking back on what we have considered, how acceptable is this data request?</li> </ul> <p>IF ACCEPTABLE:</p> <ul style="list-style-type: none"> <li>Why is it acceptable? (Prompt for income/charging, distribution of benefits, transparency, other)</li> </ul> <p>IF REJECTED:</p> <ul style="list-style-type: none"> <li>Why have you rejected this request? (Prompt for income/charging, distribution of benefits, transparency, other)</li> <li>What would need to change to make this more acceptable and trustworthy?</li> <li>If the table cannot come to an agreement on accepting the request, facilitators to note any divergence within the tables to revisit during the last five minutes and highlight at the plenary.</li> </ul>
15.35		<p>Facilitator to ask table to reflect on the decisions they have made (pointing to the flip charted grid, the conditions they have considered and the reasons underpinning these - including referring to flip charted content. (5 mins)</p> <p>We've been talking through a range of proposals in relation to fair partnership and access to depersonalised health data. Can we, as a table, come to an agreement on the conditions of usage and any additional assurances you might need in order for the conditions to feel acceptable and trustworthy (FACILITATOR NOTE: draw on trade-offs to explore peoples' expectations):</p> <ul style="list-style-type: none"> <li>What charges should be made to research projects to access/use the data: should there be any charges at all, and if so, are these equal for all parties (e.g. academic, charity, company)? Should access be free to encourage research and if so how does the NHS cover the costs of joining up data, should charging just seek to cover costs of collecting and maintaining the data or should the NHS seek to make money?</li> <li>What should be done with the outputs of successful research: how should we consider access to, and distribution of, the findings from a successful piece of research based on Londoner's joined-up NHS data? Specifically, should the NHS look to get a benefit either financially or in kind (i.e. by getting discounts on any product/service produced as a result) - or both?</li> <li>How should we make clear what research is taking place: what type of record of projects should be made available, and to what level of detail?</li> <li>What other issues are important to Londoners: what do you think should be part of the rules to ensure we set up a trusted research environment?</li> </ul> <p>Facilitator to take note of the areas of agreement and diversion for reporting back during plenary</p>

## Appendix E: Discussion guides

### Citizens' Summit Day 3 discussion guide

Saturday 29 February – 10am - 4.30pm

Time	Discussion structure	Questions and materials
15.40 - 16.20		<p><b>Plenary (40 mins):</b> Chair to go round each table and invite facilitators to spend 3 minutes reporting back to the room on their discussions (trusted research environments and fair partnerships). (30 mins)</p> <p>Facilitators be prepared to feedback on table views about:</p> <ul style="list-style-type: none"> <li>• What makes the use of depersonalised data for R&amp;D purposes more / less trustworthy?</li> <li>• Does the five safes framework increase trustworthiness – are there any particular conditions that participants feel need to be met?</li> <li>• What charges should be made to research projects to access data: should there be any charges at all, and if so, are these equal for all parties? Income generation or cost recovery? Views on distribution?</li> <li>• How should we make clear what research is taking place: what type of record of projects should be made available, and to what level of detail? NOTE TO FACILITATORS: probe on trade offs here</li> <li>• What should be done with the outputs of successful research: how should we consider access to, and distribution of, the outputs of successful research from a population data asset?</li> <li>• What other issues are important to the public: what do you think should be part of the operating model of a fair partnership and why?</li> </ul>
16.10		<p>Chair and Amy to spend 10 minutes at a room level, addressing where there is convergence / divergence (and why) and to assess the temperature of the room in relation to what is important to people (referring back to the trade-offs).</p> <p>Ends with a summary of what key considerations would need to be in place to maintain public trust, from what we have just heard. Chair to reassure the room that this discussion doesn't end here: because it's complicated, and because we expected it to raise lots of questions, we have designed a part of tomorrow to revisit this.</p>
16.20 - 16.30	Close	<p>Chair to bring day to close. Thank participants for their contribution (patient diagram up on screen). Explain that we'll need to conclude our citizens' summit with an interesting and interactive session tomorrow, where we need their help in forming recommendations. Stress we need participants to return on Sunday for a prompt start.</p>

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Roles Based Access and Control)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Welcome and scene setting, inc. key questions addressed</b>	<b>10.00 - 10.35</b>	<ul style="list-style-type: none"> <li>Welcome by the Chair (5 mins)</li> <li>Explain the purpose of today (develop recommendations that will be presented to the room and shared with a panel in the afternoon).</li> <li>Recap what has been discussed so far (with reference to the patient diagram).</li> <li>Explain the area (proactive care) that we are not bringing back, but we will have a chance later to voice our expectations around that.</li> </ul> <p><b>Key questions to answer (10 mins): Need to cover...</b></p> <ul style="list-style-type: none"> <li>National Opt-out - it's not an Opt-in</li> <li>Why is this happening only in London / what is happening elsewhere?</li> <li>Address where data is already joined up (and good things are happening), and where it isn't (and why - because of fragmented organisations etc). Joined-up datasets are the exception</li> <li>De-personalised data (Mike)</li> </ul>	Cover off some of the overarching questions where responses are required to frame the day
<b>Groups locate to four working group stations</b>	<b>10.15 - 10.20</b>	<b>5 minutes for participants to find their group</b>	
<b>Recommendation forming in working groups (round 1)</b>	<b>10.20 - 11.15</b>	<p>Start in mini groups</p> <p>Facilitator introduction to cover (5 mins)</p> <ul style="list-style-type: none"> <li>Our topic is access and control in health and social care (who sees what information and under what safeguards or conditions)</li> <li>We have collated the views on the area from the previous three days (on posters and handouts) and it's now time to use this to inform your recommendation forming</li> </ul>	Cover off some of the overarching questions where responses are required to frame the day

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Roles Based Access and Control)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Recommendation forming in working groups (round 1)</b>  Continued	10.20 - 11.15	<ul style="list-style-type: none"> <li>Please stress to participants that in forming their recommendation, and concise list of conditions, they are to recognise that they have had the opportunity to contribute towards the earlier discussion as individuals. This meant that people shared their own views, experiences, hopes and concerns. This has all been helpfully captured and got us to the point we are at now. Now this session, and task, is about working as a select group of informed people to act on behalf of both the summit and Londoners. This means that people need to think and act together as citizens, to develop a statement of their expectations to inform policy making.</li> <li>Make it clear to participants to make no assumptions about how their health and care data will be used and what policies and practices will be in place (for example safeguarding, training, controls and so on). If there is something that participants think is important, essential, or even as a condition or red line, please stress that they need to get this down on paper (i.e. capture it within their recommendation and/or set of conditions).</li> </ul>	
	10.25	<b>Revisiting deliberation (reviewing stimulus) - (10 mins)</b>  Ask participants to review the information on posters or on handouts	
	10.35	<b>Prompt on the following - (10 mins)</b> <ul style="list-style-type: none"> <li>Does this seem a fair reflection of the conversations you had?</li> <li>Is there anything missing?</li> <li>Do you have any thoughts on the four-tiered operating model?</li> <li>For social care delivery staff (domiciliary care worker, home helps), the 'summary' access would be in the form of a discharge summary (SHOW EXAMPLE) which is an extract from the whole care record and necessary to do their job (i.e. can be used in combination with the instructional care plan)</li> </ul>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Roles Based Access and Control)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
Recommendation forming in working groups (round 1)	10.45	<p><b>Recommendation forming - (30 mins)</b></p> <ul style="list-style-type: none"> <li>You now need to form a recommendation (statement of expectation) Refer to recommendation forming guidance</li> </ul> <p>Facilitator: You may need to start participants off with an example. Encourage participants to use their own language and reflects what people have voiced as expectations on day 1. Example...</p> <p><i>“We expect health and care data to be accessed and used by those who need information to perform their role, on a need to know basis...”</i></p> <ul style="list-style-type: none"> <li>Then, what are the conditions that should be applied to this for Londoners to feel comfortable and trust this (set of conditions)</li> </ul>	
Break	11.15 - 11.30		
Recommendation forming in working groups (round 1)	11.30 - 12.00	<p><b>Working groups (30 mins) (same across all groups)</b></p> <p>The two sub-groups come back together forming a single working group. Each sub-group presents back their recommendation (including operating principles, conditions, assurances required, and/or caveats) to the whole group (10 mins)</p> <p>Whole group votes on which version they like, or agrees to create a new recommendation (facilitated). Use a show of hands to agree which operating principles, conditions, assurances, and/or caveats they want to add (20 mins)</p> <p>One of the facilitators writes up the recommendation onto four large posters in the colour assigned to the group (for identification purposes), ready to stick up around the room in plenary.</p> <p>Agree who will present back – facilitators will encourage a selection of the summit participants to do this, however we have to also be open to supporting them where they ask for it.</p>	Participants discuss at the working group level and decide on the recommendation to present to the room

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Roles Based Access and Control)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
Recommendation presentation (round 1)	12.00-13.00	<p><b>Plenary session (60 mins)</b></p> <p>The four working groups come together as a whole room:</p> <ul style="list-style-type: none"> <li>Representatives from Group 1 explain to the room that they have been looking at access and control in health and social care, presents back to the room their initial recommendation (5 mins) <ul style="list-style-type: none"> <li>Room comments and raises questions (10 mins)</li> </ul> </li> </ul> <p>The room is asked to vote on level of support (voting technology will be used) for each recommendation. The recommendation is up on screen and the Q is 'To what extent, if at all, do you support this recommendation?'</p> <ol style="list-style-type: none"> <li>I fully support all parts of this recommendation</li> <li>I support parts of this recommendation, but think that it is missing key considerations</li> <li>I support parts of this recommendation, but think other parts of it need more work</li> <li>I currently do not support any part of this recommendation. It needs more work</li> </ol> <p>Then, the room is asked to vote for the condition which they least favour (answer options are the conditions in full).</p>	
Lunch	13.00 - 13.45	Participants welcomed to walk around and browse each station, add comments using post-it notes as they do so	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Roles Based Access and Control)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Recommendation forming in working groups (round 2)</b>	<b>13.45-14.15</b>	<p><b>Working groups (30 mins)</b></p> <p>Working groups go back to their stations and, as an entire group, take on board comments and questions. Reflecting the comments/questions, facilitators moderate discussion and support working groups to reach final recommendation. This might include changing the wording of the recommendation all together, tweaking it, and/or adding or removing operating principles, conditions, assurances or caveats (15 mins).</p> <p>Once the group are happy with their recommendation, the facilitator initiates an open vote (5 mins).</p> <ol style="list-style-type: none"> <li>1. All of those who support the recommendation in full put their hands up.</li> <li>2. All of those who do not support the recommendation in full put their hands up. Facilitator asks those with their hands up for second show of hands to why they do not support it in full.</li> </ol> <p>Facilitator moderate discussion where the group are given the opportunity to tweak the recommendation (10 mins)</p>	<p>Participants take on board comments from room and revise recommendations</p> <p>Working group participants vote on recommendation to ensure that it is endorsed by all members</p>
<b>Recommendation presentation (round 2)</b>	<b>14.15-14.35</b>	<p><b>Plenary session (20 mins)</b></p> <p>Each working group presents back final recommendations (5 mins per working group)</p> <p>During the presentations, the recommendation will be shown on the screen to the room.</p>	<p>Participants present revised recommendations to room</p>

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### Citizens' Summit: Day 4 - Working Group discussion guide (Roles Based Access and Control)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	14.35-15.15	<p>Facilitators to explain that we are moving on now to a discussion about consistency across London. As we have continuously heard throughout the whole of the citizens' summit, for data to be useful for proactive care, for planning and for research and development, it really does rely on the data sets being as complete as possible – i.e. containing the data of everyone, not just of certain people or from certain areas of London. However, given that GP practices hold a lot of information about Londoners, they have an important role to play in this. As do hospitals, and other health and care service providers.</p> <p>Read out: The talking heads cards indicate voices from fictional healthcare professionals holding different views around joining-up their patients' data for reasons beyond their individual care. These voices sit alongside counter views which might challenge the points being made. Let's have a look at these in turn...</p> <p>For each set of talking heads:</p> <ul style="list-style-type: none"> <li>• How do you feel about the opposing perspectives shown here?</li> <li>• Does this raise anything new that you hadn't thought about before now?</li> <li>• Does this leave you with any questions?</li> </ul> <p><b>Read out:</b> There are various different ways that we could develop policy.</p> <ul style="list-style-type: none"> <li>• The first option would be to leave things as they are, with each organisation determining for themselves their own data sharing policies (i.e. the rules they apply within the legal framework); but accepting that there will be healthcare providers (for different reasons, some of which we have just looked at), who will therefore choose not to contribute their data on their patients' behalf to a OneLondon data service.</li> </ul>	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Roles Based Access and Control)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	<p><b>14.35-15.15</b></p>	<ul style="list-style-type: none"> <li>The second option is that these policies are determined and agreed at a sub-regional level (there are five sub-regions in London: NWL, NCL, NEL, SEL, SWL each of circa 2m people); but accepting that sub-regions might choose slightly different arrangements which means that the type of data, and the rules for access could be different between them, and some areas may choose not to put data into a shared OneLondon data service.</li> <li>The final option is that all healthcare providers are required to operate within a single set of policies, and all of them would be expected to contribute their data on behalf of their patients' into a OneLondon data service, that spans the whole of London.</li> </ul> <p><b>Spontaneous discussion:</b></p> <ul style="list-style-type: none"> <li>What do you see as the benefits of each of these options?</li> <li>What do you think might be some of the downsides?</li> <li>Prompts/challenge for participants if needed for healthcare providers being left to make their own decisions:</li> <li>The power and control would remain devolved to individual providers, rather than controlled sub-regionally or centrally. This keeps a lot of responsibility in the hands of the ~1,300 GP practices and ~70 healthcare trusts, but means there is no 'London-wide' commitment to patients about what they can expect in terms of joined up data.</li> <li>This would still mean that if a patient accessed a different service to the one where the information is held, their medical records would not necessarily be available.</li> </ul>	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Roles Based Access and Control)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	<p><b>14.35-15.15</b></p>	<ul style="list-style-type: none"> <li>With this model, there would be limitations to what could be achieved through looking at larger, pan London, datasets in doing proactive care, planning and service improvement, and also in research (given that there would be no central data sets containing joined up information about Londoners).</li> </ul> <p><b>Prompts/challenge for participants if needed for the regional datasets option:</b></p> <ul style="list-style-type: none"> <li>The power and control would be devolved to the 5 sub-regional areas covering up to two million people, rather than controlled centrally. This reduces some of the fragmentation, but reduces the autonomy of GP practices and healthcare trusts. There would still be no guarantee of a 'London-wide' commitment to patients about what they can expect in terms of joined-up data.</li> <li>This would still mean that if a patient accessed a service in a different region of London to the one where they live, their medical records would not be available.</li> <li>With this model, there would be limitations to what could be achieved through looking at larger, pan London, datasets in doing proactive care, planning and service improvement, and also in research. Given that the five datasets would not be joined up.</li> </ul> <p><b>Prompts/challenge for participants if needed for the OneLondon dataset option:</b></p> <ul style="list-style-type: none"> <li>The power to formulate policy would become the same in all areas of London, which would reduce some of the fragmentation and variation of the present. However, this could reduce the autonomy of GP practices and healthcare trusts. So whilst it would make it easier to make a consistent service 'offer' to patients, some GP practices and healthcare trusts may feel disempowered.</li> </ul>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Roles Based Access and Control)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Consistency across London</b>  Table discussions and then plenary vote	14.35-15.15	<ul style="list-style-type: none"> <li>If there was a OneLondon dataset, it would mean great benefits for doing proactive care, planning and service improvement, and also using data to support research. Given that the richer dataset would contain the de-personalised medical records of all Londoners.</li> <li>This would also mean that if a patient was to access a service anywhere in London, their medical records would be instantly available.</li> </ul>	
	15.00	<b>Q&amp;A (5 minutes to clarify anything before the vote)</b>	
	15.05	<p><b>Room to vote:</b></p> <p><b>Chair to read out: Working within the overall legal framework in place across the whole country...</b></p> <p><b>Question 1: 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?</b></p> <ol style="list-style-type: none"> <li>We expect there to be a single set of policies ('rules of the road') across all health and care organisations in London</li> <li>We expect the policies ('rules of the road') to be set at the level of the 5 sub-regional areas in London</li> <li>We expect organisations to make their own policies ('rules of the road') around information sharing</li> </ol>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Roles Based Access and Control)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
	15.10	<p><b>Chair to read out: At whatever level the 'rules of the road' are agreed (within the legal framework)...</b></p> <p><b>Question 2a: To what extent do you agree or disagree with the following statement...</b></p> <p><i>"We expect all health and care organisations in London to contribute 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."</i></p> <ol style="list-style-type: none"> <li>1. Strongly agree</li> <li>2. Agree</li> <li>3. Disagree</li> <li>4. Strongly disagree</li> </ol> <p><b>Question 2b: To what extent do you agree or disagree with the following statement...</b></p> <p><i>"We expect all health and care organisations in London to contribute join-up de-personalised information, as part of a population dataset, to support proactive care, planning and research &amp; development?"</i></p> <ol style="list-style-type: none"> <li>1. Strongly agree</li> <li>2. Agree</li> <li>3. Disagree</li> <li>4. Strongly disagree</li> </ol> <p>Chair to summarise what the votes are suggesting.</p>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (planning and improvement)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Welcome and scene setting, inc. key questions addressed</b>	<b>10.00-10.15</b>	<ul style="list-style-type: none"> <li>Welcome by the Chair (5 mins)</li> <li>Explain the purpose of today (develop recommendations that will be presented to the room and shared with a panel in the afternoon).</li> <li>Recap what has been discussed so far (with reference to the patient diagram).</li> <li>Explain the area (proactive care) that we are not bringing back, but we will have a chance later to voice our expectations around that.</li> </ul> <p><b>Key questions to answer (10 mins): Need to cover...</b></p> <ul style="list-style-type: none"> <li>National Opt-out - it's not an Opt-in</li> <li>Why is this happening only in London / what is happening elsewhere?</li> <li>Address where data is already joined up (and good things are happening), and where it isn't (and why – because of fragmented organisations etc). Joined up datasets are the exception</li> <li>De-personalised data (Mike)</li> </ul>	
<b>Groups locate to four working group stations</b>	<b>10.15-10.20</b>	<b>5 minutes for participants to find their group</b>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (planning and improvement)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
Recommendation forming in working groups (round 1)	10.20-11.15	<p><b>Start in mini groups</b></p> <p>Facilitator introduction to cover (5 mins)</p> <ul style="list-style-type: none"> <li>• Our topic is de-personalised data for use in planning and improving services</li> <li>• We have collated the views on the area from the previous day (on posters and handouts) and it's now time to use this to inform your recommendation forming</li> <li>• Please stress to participants that in forming their recommendation, and concise list of conditions, they are to recognise that they have had the opportunity to contribute towards the earlier discussion as individuals. This meant that people shared their own views, experiences, hopes and concerns. This has all been helpfully captured and got us to the point we are at now. Now this session, and task, is about working as a select group of informed people to act on behalf of both the summit and Londoners. This means that people need to think and act together as citizens, to develop a statement of their expectations to inform policy making.</li> <li>• Make it clear to participants to make no assumptions about how their health and care data will be used and what policies and practices will be in place (for example safeguarding, training, controls and so on). If there is something that participants think is important, essential, or even as a condition or red line, please stress that they need to get this down on paper (i.e. capture it within their recommendation and/or set of conditions).</li> </ul>	<p>Participants able to work in sub-groups, drawing on information and expert input, to develop recommendations around the four themes</p> <p>Expectation around health data to be used to do better planning, for health services and health outcomes, but what are the conditions.</p>
	10.25	<p><b>Revisiting deliberation (reviewing stimulus) - (10 mins)</b></p> <p>Ask participants to review the information on posters or on handouts</p>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (planning and improvement)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
	10.35	<p><b>Prompt on the following - (10 mins)</b></p> <ul style="list-style-type: none"> <li>Does this seem a fair reflection of the conversations you had?</li> <li>Is there anything missing?</li> <li>How do we feel about using something like the fives safes framework to provide assurances for how data are used to plan and improve services?</li> <li><b>When councils comes up (prompt):</b> Social determinants of health (housing conditions; level of education; amount of green space), drive more than 80% of health outcomes, the NHS only drives 20%. To deal with this, the councils are responsible for services related to much of this 80%.</li> <li>BRING IN JONTY TO PROVIDE EXAMPLES OF DATA USES.</li> </ul>	
	10.45	<p><b>Recommendation forming - (30 mins)</b></p> <ul style="list-style-type: none"> <li>You now need to form a recommendation (statement of expectation) Refer to recommendation forming guidance</li> </ul> <p>Facilitator: You may need to start participants off with an example. Encourage participants to use their own language and reflects what people have voiced as expectations on day 3.</p> <p><b><i>“We expect joined up de-personalised health and care data to be used to plan and improve services...”</i></b></p> <ul style="list-style-type: none"> <li>Then, what are the conditions that should be applied to this for Londoners to feel comfortable and trust this use of data (set of conditions)</li> </ul>	
<b>Break</b>	<b>11.15-11.30</b>		

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (planning and improvement)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Recommendation forming in working groups (round 1)</b>	<b>11.30-12.00</b>	<p><b>Working groups (30 mins) (same across all groups)</b></p> <p>The two sub-groups come back together forming a single working group. Each sub-group presents back their recommendation (including operating principles, conditions, assurances required, and/or caveats) to the whole group. (10 mins)</p> <p>Whole group votes on which version they like, or agrees to create a new recommendation (facilitated). Use a show of hands to agree which operating principles, conditions, assurances, and/or caveats they want to add (20 mins)</p> <p>One of the facilitators writes up the recommendation onto four large posters in the colour assigned to the group (for identification purposes), ready to stick up around the room in plenary.</p> <p>Agree who will present back – facilitators will encourage a selection of the summit participants to do this, however we have to also be open to supporting them where they ask for it.</p>	Participants discuss at the working group level and decide on the recommendation to present to the room
<b>Recommendation presentation (round 1)</b>	<b>12.00-13.00</b>	<p><b>Plenary session (60 mins)</b></p> <p>The four working groups come together as a whole room:</p> <ul style="list-style-type: none"> <li>Group 2 explains to the room that they have been looking at de-personalised population information for planning and improvement, presents back to the room their initial recommendation (5 mins) <ul style="list-style-type: none"> <li>Room comments and raises questions (10 mins)</li> </ul> </li> </ul> <p>The room is asked to vote on level of support for each recommendation. The recommendation is up on screen and the Q is 'To what extent, if at all, do you support this recommendation?'</p>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (planning and improvement)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Recommendation presentation (round 1)</b>  Continued	<b>12.00-13.00</b>	<ol style="list-style-type: none"> <li>I fully support all parts of this recommendation</li> <li>I support parts of this recommendation, but think that it is missing key considerations</li> <li>I support parts of this recommendation, but think other parts of it need more work</li> <li>I currently do not support any part of this recommendation. It needs more work</li> </ol> <p>Then, the room us asked to vote for the condition which they least favour (answer options are the conditions in full).</p>	
<b>Lunch</b>	<b>13.00-13.45</b>	Participants welcomed to walk around and browse each station, add comments using post-it notes as they do so	
<b>Recommendation forming in working groups (round 2)</b>	<b>13.45-14.15</b>	<p><b>Working groups (30 mins)</b></p> <p>Working groups go back to their stations and, as an entire group, take on board comments and questions. Reflecting the comments/questions, facilitators moderate discussion and support working groups to reach final recommendation. This might include changing the wording of the recommendation all together, tweaking it, and/or adding or removing operating principles, conditions, assurances or caveats (15 mins).</p> <p>Once the group are happy with their recommendation, the facilitator initiates an open vote (5 mins).</p> <ol style="list-style-type: none"> <li>All of those who support the recommendation in full put their hands up.</li> <li>All of those who do not support the recommendation in full put their hands up. Facilitator asks those with their hands up for 2nd show of hands to why they do not support it in full.</li> </ol> <p>Facilitator moderate discussion where the group are given the opportunity to tweak the recommendation (10 mins)</p>	<p>Participants take on board comments from room and revise recommendations</p> <p>Working group participants vote on recommendation to ensure that it is endorsed by all members</p>

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (planning and improvement)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	14.35-15.15	<p>Facilitators to explain that we are moving on now to a discussion about consistency across London. As we have continuously heard throughout the whole of the citizens' summit, for data to be useful for proactive care, for planning and for research and development, it really does rely on the data sets being as complete as possible – i.e. containing the data of everyone, not just of certain people or from certain areas of London. However, given that GP practices hold a lot of information about Londoners, they have an important role to play in this. As do hospitals, and other health and care service providers.</p> <p><b>Read out:</b> The talking heads cards indicate voices from fictional healthcare professionals holding different views around joining-up their patients' data for reasons beyond their individual care. These voices sit alongside counter views which might challenge the points being made. Let's have a look at these in turn...</p> <p>For each set of talking heads:</p> <ul style="list-style-type: none"> <li>• How do you feel about the opposing perspectives shown here?</li> <li>• Does this raise anything new that you hadn't thought about before now?</li> <li>• Does this leave you with any questions?</li> </ul> <p><b>Read out:</b> There are various different ways that we could develop policy.</p> <ul style="list-style-type: none"> <li>• The first option would be to leave things as they are, with each organisation determining for themselves their own data sharing policies (i.e. the rules they apply within the legal framework); but accepting that there will be healthcare providers (for different reasons, some of which we have just looked at), who will therefore choose not to contribute their data on their patients' behalf to a OneLondon data service.</li> </ul>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (planning and improvement)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	<p>14.35-15.15</p>	<ul style="list-style-type: none"> <li>The second option is that these policies are determined and agreed at a sub-regional level (there are five sub-regions in London: NWL, NCL, NEL, SEL, SWL each of circa 2m people); but accepting that sub-regions might choose slightly different arrangements which means that the type of data, and the rules for access could be different between them, and some areas may choose not to put data into a shared OneLondon data service.</li> <li>The final option is that all healthcare providers are required to operate within a single set of policies, and all of them would be expected to contribute their data on behalf of their patients' into a OneLondon data service, that spans the whole of London.</li> </ul> <p><b>Spontaneous discussion:</b></p> <ul style="list-style-type: none"> <li>What do you see as the benefits of each of these options?</li> <li>What do you think might be some of the downsides?</li> </ul> <p><b>Prompts/challenge for participants if needed for healthcare providers being left to make their own decisions:</b></p> <ul style="list-style-type: none"> <li>The power and control would remain devolved to individual providers, rather than controlled sub-regionally or centrally. This keeps a lot of responsibility in the hands of the ~1,300 GP practices and ~70 healthcare trusts, but means there is no 'London-wide' commitment to patients about what they can expect in terms of joined up data.</li> <li>This would still mean that if a patient accessed a different service to the one where the information is held, their medical records would not necessarily be available.</li> </ul>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (planning and improvement)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	14.35-15.15	<ul style="list-style-type: none"> <li>With this model, there would be limitations to what could be achieved through looking at larger, pan London, datasets in doing proactive care, planning and service improvement, and also in research. Given that the five datasets would not be joined up.</li> </ul> <p><b>Prompts/challenge for participants if needed for the OneLondon dataset option:</b></p> <ul style="list-style-type: none"> <li>The power to formulate policy would become the same in all areas of London, which would reduce some of the fragmentation and variation of the present. However, this could reduce the autonomy of GP practices and healthcare trusts. So whilst it would make it easier to make a consistent service 'offer' to patients, some GP practices and healthcare trusts may feel disempowered.</li> <li>If there was a OneLondon dataset, it would mean great benefits for doing proactive care, planning and service improvement, and also using data to support research. Given that the richer dataset would contain the de-personalised medical records of all Londoners.</li> <li>This would also mean that if a patient was to access a service anywhere in London, their medical records would be instantly available.</li> </ul>	
	15.00	<p><b>Q&amp;A (5 minutes to clarify anything before the vote)</b></p> <p><b>Room to vote:</b></p>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (planning and improvement)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
	15.05	<p><b>Chair to read out: Working within the overall legal framework in place across the whole country...</b></p> <p><b>Question 1: 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?</b></p> <ol style="list-style-type: none"> <li>1. We expect there to be a single set of policies ('rules of the road') across all health and care organisations in London</li> <li>2. We expect the policies ('rules of the road') to be set at the level of the 5 sub-regional areas in London</li> <li>3. We expect organisations to make their own policies ('rules of the road') around information sharing</li> </ol>	
	15.10	<p><b>Chair to read out: At whatever level the 'rules of the road' are agreed (within the legal framework)...</b></p> <p><b>Question 2a: To what extent do you agree or disagree with the following statement...</b></p> <p><i>"We expect all health and care organisations in London to contribute 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."</i></p> <ol style="list-style-type: none"> <li>1. Strongly agree</li> <li>2. Agree</li> <li>3. Disagree</li> <li>4. Strongly disagree</li> </ol>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (planning and improvement)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
	15.10	<p><b>Question 2b: To what extent do you agree or disagree with the following statement...</b></p> <p><i>“We expect all health and care organisations in London to contribute join-up de-personalised information, as part of a population dataset, to support proactive care, planning and research &amp; development?”</i></p> <ol style="list-style-type: none"> <li>1. Strongly agree</li> <li>2. Agree</li> <li>3. Disagree</li> <li>4. Strongly disagree</li> </ol> <p>Chair to summarise what the votes are suggesting.</p>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Welcome and scene setting, inc. key questions addressed</b>	<b>10.00-10.15</b>	<p><b>Welcome by the Chair (5 mins)</b></p> <ul style="list-style-type: none"> <li>• Explain the purpose of today (develop recommendations that will be presented to the room and shared with a panel in the afternoon).</li> <li>• Recap what has been discussed so far (with reference to the patient diagram).</li> <li>• Explain the area (proactive care) that we are not bringing back, but we will have a chance later to voice our expectations around that.</li> </ul> <p><b>Key questions to answer (10 mins): Need to cover...</b></p> <ul style="list-style-type: none"> <li>• National Opt-out - it's not an Opt-in</li> <li>• Why is this happening only in London / what is happening elsewhere?</li> <li>• Address where data is already joined up (and good things are happening), and where it isn't (and why - because of fragmented organisations etc). Joined-up datasets are the exception</li> <li>• De-personalised data (Mike)</li> </ul>	
<b>Groups locate to four working group stations</b>	<b>10.15-10.20</b>	<b>5 minutes for participants to find their group</b>	
<b>Recommendation forming in working groups (round 1)</b>	<b>10.20-11.15</b>	<p><b>Start in mini groups</b></p> <p><b>Facilitator introduction to cover (5 mins)</b></p> <ul style="list-style-type: none"> <li>• Our topic is the use of de-personalised data in research and development – fair and productive partnerships</li> <li>• We have collated the views on the area from the previous day (on posters and handouts) and it's now time to use this to inform your recommendation forming</li> </ul>	Participants able to work in sub-groups, drawing on information and expert input, to develop recommendations around the four themes

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Recommendation forming in working groups (round 1)</b>	10.20-11.15	<ul style="list-style-type: none"> <li>Please stress to participants that in forming their recommendation, and concise list of conditions, they are to recognise that they have had the opportunity to contribute towards the earlier discussion as individuals. This meant that people shared their own views, experiences, hopes and concerns. This has all been helpfully captured and got us to the point we are at now. Now this session, and task, is about working as a select group of informed people to act on behalf of both the summit and Londoners. This means that people need to think and act together as citizens, to develop a statement of their expectations to inform policy making.</li> <li>Make it clear to participants to make no assumptions about how their health and care data will be used and what policies and practices will be in place (for example safeguarding, training, controls and so on). If there is something that participants think is important, essential, or even as a condition or red line, please stress that they need to get this down on paper (i.e. capture it within their recommendation and/or set of conditions).</li> </ul>	
	10.25	<p><b>Revisiting deliberation (reviewing stimulus) - (10 mins)</b></p> <p>Ask participants to review the information on posters or on handouts</p>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
	10.35	<p>Prompt on the following - (10 mins)</p> <ul style="list-style-type: none"> <li>• Does this seem a fair reflection of the conversations you had?</li> <li>• Is there anything missing?</li> <li>• The five safes framework – this feels like a framework that most people, as we understand it, liked this and found it assuring. Can you now frame a recommendation around your expectations for how this is used</li> <li>• Views were more mixed around income and charging and the distribution of benefits</li> <li>• We don't just want to look at income and charging and distribution of benefits in isolation, but how they link together CALL ON AMY AND AXEL FOR HELP WITH THIS</li> </ul>	
	10.45	<p><b>Recommendation forming - (30 mins)</b></p> <ul style="list-style-type: none"> <li>• You now need to form two recommendations (statements of expectation) – one for the conditions of a trusted research environment and one for the conditions of a fair partnership. Refer to recommendation forming guidance</li> </ul> <p><b>Facilitator:</b> You may need to start participants off with an example. Encourage participants to use their own language and reflects what people have voiced as expectations on day 3.</p> <p><i><b>“We expect de-personalised data for research and development to be used in line with the five safes framework”.</b></i></p> <ul style="list-style-type: none"> <li>• Then, what are the specific conditions that should be applied to this for Londoners to feel comfortable and trust this. Reminder of the opt-out (you can add it as a condition if you want to)</li> </ul>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
	10.45	<p><b>Facilitator:</b> You may need to start participants off with an example. Encourage participants to use their own language and reflects what people have voiced as expectations on day 3.</p> <p><i>“We expect a fair and productive partnership to...”</i></p> <ul style="list-style-type: none"> <li>• Income?</li> <li>• Transparency?</li> <li>• Distribution of benefits?</li> <li>• Others?</li> </ul> <p>Then, what are the conditions that should be applied to this for Londoners to feel comfortable and trust this. Reminder of the opt-out (you can add it as a condition if you want to)</p>	
<b>Break</b>	<b>11.15-11.30</b>		
<b>Recommendation forming in working groups (round 1)</b>	<b>11.30-12.00</b>	<p><b>Working groups (30 mins) (same across all groups)</b></p> <p>The two sub-groups come back together forming a single working group. Each sub-group presents back their recommendation (including operating principles, conditions, assurances required, and/or caveats) to the whole group. (10 mins)</p> <p>Whole group votes on which version they like, or agrees to create a new recommendation (facilitated). Use a show of hands to agree which operating principles, conditions, assurances, and/or caveats they want to add (20 mins)</p> <p>One of the facilitators writes up the recommendation onto four large posters in the colour assigned to the group (for identification purposes), ready to stick up around the room in plenary.</p> <p>Agree who will present back – facilitators will encourage a selection of the summit participants to do this, however we have to also be open to supporting them where they ask for it.</p>	Participants discuss at the working group level and decide on the recommendation to present to the room

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
Recommendation presentation (round 1)	12.00-13.00	<p><b>Plenary session (60 mins)</b></p> <p>The four working groups come together as a whole room:</p> <ul style="list-style-type: none"> <li>Group 3 explains to the room that they have been looking at the use of data in research and development, presents back to the room their initial recommendation (5 mins)               <ul style="list-style-type: none"> <li>Room comments and raises questions (10 mins)</li> </ul> </li> </ul> <p>The room is asked to vote on level of support for each recommendation. The recommendation is up on screen and the Q is 'To what extent, if at all, do you support this recommendation?'</p> <ol style="list-style-type: none"> <li>I fully support all parts of this recommendation</li> <li>I support parts of this recommendation, but think that it is missing key considerations</li> <li>I support parts of this recommendation, but think other parts of it need more work</li> <li>I currently do not support any part of this recommendation. It needs more work</li> </ol> <p>Then, the room us asked to vote for the condition which they least favour (answer options are the conditions in full).</p>	
Lunch	13.00-13.45	Participants welcomed to walk around and browse each station, add comments using post-it notes as they do so	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Recommendation forming in working groups (round 2)</b>	<b>13.45-14.15</b>	<p><b>Working groups (30 mins)</b></p> <p>Working groups go back to their stations and, as an entire group, take on board comments and questions. (10 mins)</p> <p>Reflecting the comments/questions, facilitators moderate discussion and support working groups to reach final recommendation. This might include changing the wording of the recommendation all together, tweaking it, and/or adding or removing operating principles, conditions, assurances or caveats (20 mins).</p> <p>Once the group are happy with their recommendation, the facilitator initiates an open vote.</p> <ol style="list-style-type: none"> <li>1. All of those who support the recommendation in full put their hands up.</li> <li>2. All of those who do not support the recommendation in full put their hands up. Facilitator asks those with their hands up for 2nd show of hands to why they do not support it in full. Facilitator moderate discussion where the group are given the opportunity to tweak the recommendation.</li> </ol>	<p>Participants take on board comments from room and revise recommendations</p> <p>Working group participants vote on recommendation to ensure that it is endorsed by all members</p>
<b>Recommendation presentation (round 2)</b>	<b>14.15-14.35</b>	<p><b>Plenary session (20 mins)</b></p> <p>Each working group presents back final recommendations (5 mins per working group)</p> <p>During the presentations, the recommendation will be shown on the screen to the room.</p>	<p>Participants present revised recommendations to room</p>

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	14.35-15.15	<p>Facilitators to explain that we are moving on now to a discussion about consistency across London. As we have continuously heard throughout the whole of the citizens' summit, for data to be useful for proactive care, for planning and for research and development, it really does rely on the data sets being as complete as possible – i.e. containing the data of everyone, not just of certain people or from certain areas of London. However, given that GP practices hold a lot of information about Londoners, they have an important role to play in this. As do hospitals, and other health and care service providers.</p> <p><b>Read out:</b> The talking heads cards indicate voices from fictional healthcare professionals holding different views around joining-up their patients' data for reasons beyond their individual care. These voices sit alongside counter views which might challenge the points being made. Let's have a look at these in turn...</p> <p><b>For each set of talking heads:</b></p> <ul style="list-style-type: none"> <li>• How do you feel about the opposing perspectives shown here?</li> <li>• Does this raise anything new that you hadn't thought about before now?</li> <li>• Does this leave you with any questions?</li> </ul> <p><b>Read out:</b> There are various different ways that we could develop policy.</p> <ul style="list-style-type: none"> <li>• The first option would be to leave things as they are, with each organisation determining for themselves their own data sharing policies (i.e. the rules they apply within the legal framework); but accepting that there will be healthcare providers (for different reasons, some of which we have just looked at), who will therefore choose not to contribute their data on their patients' behalf to a OneLondon data service.</li> </ul>	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	<p>14.35-15.15</p>	<ul style="list-style-type: none"> <li>The second option is that these policies are determined and agreed at a sub-regional level (there are five sub-regions in London: NWL, NCL, NEL, SEL, SWL each of circa 2m people); but accepting that sub-regions might choose slightly different arrangements which means that the type of data, and the rules for access could be different between them, and some areas may choose not to put data into a shared OneLondon data service.</li> <li>The final option is that all healthcare providers are required to operate within a single set of policies, and all of them would be expected to contribute their data on behalf of their patients' into a OneLondon data service, that spans the whole of London.</li> </ul> <p><b>Spontaneous discussion:</b></p> <ul style="list-style-type: none"> <li>What do you see as the benefits of each of these options?</li> <li>What do you think might be some of the downsides?</li> </ul> <p><b>Prompts/challenge for participants if needed for healthcare providers being left to make their own decisions:</b></p> <ul style="list-style-type: none"> <li>The power and control would remain devolved to individual providers, rather than controlled sub-regionally or centrally. This keeps a lot of responsibility in the hands of the ~1,300 GP practices and ~70 healthcare trusts, but means there is no 'London-wide' commitment to patients about what they can expect in terms of joined up data.</li> <li>This would still mean that if a patient accessed a different service to the one where the information is held, their medical records would not necessarily be available.</li> </ul>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	14.35-15.15	<ul style="list-style-type: none"> <li>With this model, there would be limitations to what could be achieved through looking at larger, pan London, datasets in doing proactive care, planning and service improvement, and also in research (given that there would be no central data sets containing joined up information about Londoners).</li> </ul> <p><b>Prompts/challenge for participants if needed for the regional datasets option:</b></p> <ul style="list-style-type: none"> <li>The power and control would be devolved to the 5 sub-regional areas covering up to two million people, rather than controlled centrally. This reduces some of the fragmentation, but reduces the autonomy of GP practices and healthcare trusts. There would still be no guarantee of a 'London-wide' commitment to patients about what they can expect in terms of joined-up data.</li> <li>This would still mean that if a patient accessed a service in a different region of London to the one where they live, their medical records would not be available.</li> <li>With this model, there would be limitations to what could be achieved through looking at larger, pan London, datasets in doing proactive care, planning and service improvement, and also in research. Given that the five datasets would not be joined up.</li> </ul>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Consistency across London</b>  Table discussions and then plenary vote	14.35-15.15	<b>Prompts/challenge for participants if needed for the OneLondon dataset option:</b> <ul style="list-style-type: none"> <li>The power to formulate policy would become the same in all areas of London, which would reduce some of the fragmentation and variation of the present. However, this could reduce the autonomy of GP practices and healthcare trusts. So whilst it would make it easier to make a consistent service 'offer' to patients, some GP practices and healthcare trusts may feel disempowered.</li> <li>If there was a OneLondon dataset, it would mean great benefits for doing proactive care, planning and service improvement, and also using data to support research. Given that the richer dataset would contain the de-personalised medical records of all Londoners.</li> <li>This would also mean that if a patient was to access a service anywhere in London, their medical records would be instantly available.</li> </ul>	
	15.00	<b>Q&amp;A (5 minutes to clarify anything before the vote)</b>	
	15.05	<b>Room to vote:</b>  <b>Chair to read out: Working within the overall legal framework in place across the whole country...</b>  <b>Question 1: 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?</b>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Research and Development)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
	15.05	<ol style="list-style-type: none"> <li>1. We expect there to be a single set of policies ('rules of the road') across all health and care organisations in London</li> <li>2. We expect the policies ('rules of the road') to be set at the level of the 5 sub-regional areas in London</li> <li>3. We expect organisations to make their own policies ('rules of the road') around information sharing</li> </ol>	
	15.10	<p><b>Chair to read out: At whatever level the 'rules of the road' are agreed (within the legal framework)...</b></p> <p><b>Question 2a: To what extent do you agree or disagree with the following statement...</b></p> <p><i>"We expect all health and care organisations in London to contribute 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."</i></p> <ol style="list-style-type: none"> <li>1. Strongly agree</li> <li>2. Agree</li> <li>3. Disagree</li> <li>4. Strongly disagree</li> </ol> <p><b>Question 2b: To what extent do you agree or disagree with the following statement...</b></p> <p><i>"We expect all health and care organisations in London to contribute join-up de-personalised information, as part of a population dataset, to support proactive care, planning and research &amp; development?"</i></p> <ol style="list-style-type: none"> <li>1. Strongly agree</li> <li>2. Agree</li> <li>3. Disagree</li> <li>4. Strongly disagree</li> </ol> <p>Chair to summarise what the votes are suggesting.</p>	

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Governance and oversight)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Welcome and scene setting, inc. key questions addressed</b>	<b>10.00-10.15</b>	<p><b>Welcome by the chair (5 mins)</b></p> <ul style="list-style-type: none"> <li>• Explain the purpose of today (develop recommendations that will be presented to the room and shared with a panel in the afternoon).</li> <li>• Recap what has been discussed so far (with reference to the patient diagram).</li> <li>• Explain the area (proactive care) that we are not bringing back, but we will have a chance later to voice our expectations around that.</li> </ul> <p><b>Key questions to answer (10 mins): Need to cover...</b></p> <ul style="list-style-type: none"> <li>• National Opt-out - it's not an Opt-in</li> <li>• Why is this happening only in London / what is happening elsewhere?</li> <li>• Address where data is already joined up (and good things are happening), and where it isn't (and why - because of fragmented organisations etc). Joined-up datasets are the exception</li> <li>• De-personalised data (Mike)</li> </ul>	
<b>Groups locate to four working group stations</b>	<b>10.15-10.20</b>	<b>5 minutes for participants to find their group</b>	
<b>Recommendation forming in working groups (round 1)</b>	<b>10.20-11.15</b>	<p><b>Start in mini groups</b></p> <p><b>Facilitator introduction to cover (5 mins)</b></p> <ul style="list-style-type: none"> <li>• Our topic is the ongoing governance and oversight of data use</li> <li>• We have collated the views on the area from the previous day (on posters and handouts) and it's now time to use this to inform your recommendation forming</li> </ul>	Participants able to work in sub-groups, drawing on information and expert input, to develop recommendations around the four themes

## Appendix E: Discussion guides

### Citizens' Summit: Day 4 - Working Group discussion guide (Governance and oversight)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Recommendation forming in working groups (round 1)</b>	10.20-11.15	<ul style="list-style-type: none"> <li>Please stress to participants that in forming their recommendation, and concise list of conditions, they are to recognise that they have had the opportunity to contribute towards the earlier discussion as individuals. This meant that people shared their own views, experiences, hopes and concerns. This has all been helpfully captured and got us to the point we are at now. Now this session, and task, is about working as a select group of informed people to act on behalf of both the summit and Londoners. This means that people need to think and act together as citizens, to develop a statement of their expectations to inform policy making.</li> <li>Make it clear to participants to make no assumptions about how their health and care data will be used and what policies and practices will be in place (for example safeguarding, training, controls and so on). If there is something that participants think is important, essential, or even as a condition or red line, please stress that they need to get this down on paper (i.e. capture it within their recommendation and/or set of conditions).</li> </ul>	
	10.25	<p><b>Introduce topic of governance from the front (slides 2-3) and first question (slides 4-5) (5 mins)</b></p> <p>On tables, discuss public and patient involvement in designing the rules (20 mins):</p> <ul style="list-style-type: none"> <li>To what extent, if at all, is it important to continue to involve the public in designing the rules for how their joined-up health and care data is used? Why? Probe high level (like today) and/or detail (exactly what each professional can see in the RBAC)</li> </ul>	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Governance and oversight)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
	10.25	<ul style="list-style-type: none"> <li>• There are some examples of how this could be done on the handout (slide 5) or you might have other ideas               <ul style="list-style-type: none"> <li>– What are the advantages and disadvantages of the different ways of involving the public?</li> <li>– Which, if any, would be the best way to ensure you trust that the rules are being designed with Londoner's interests at the centre? (Consider what resources it will take and whether that is necessary)</li> <li>– Introduce holding to account to whole group (slides 6-8) (5 mins)</li> </ul> </li> </ul> <p><b>On tables, discuss who should ensure the rules are working and they are followed as intended (20 mins):</b></p> <ul style="list-style-type: none"> <li>• As we discussed, healthcare officials will definitely have a role. Do you have any questions about this? (moderator be ready to explain Caldicott Guardians, national data guardian etc)</li> <li>• What do you see as the difference between an elected person and an official scrutinising what happens? What are the advantages and disadvantages of each (probe time, independence, expertise, accountability to public)</li> <li>• Who would you ideally want to be involved in overseeing what happens with Londoner's health and care data? Why? Probe for whether Borough, Greater London or national is more important</li> <li>• Which people on the list are less important? Why?</li> <li>• To what extent would additional scrutiny by the people you suggest make you feel more confident that the way your data is being handled / used will be trustworthy?</li> </ul> <p><b>Finally, thinking back to the discussion we had about the role of the public, do they also have a role in scrutinising what happens to their data? What would that look like? (5 mins)</b></p>	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Governance and oversight)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
Break	11.15-11.30		
Recommendation forming in working groups (round 1)	11.30-12.00	<p><b>Working groups (30 mins) (same across all groups)</b></p> <p>The two sub-groups come back together forming a single working group. Each sub-group presents back their current thinking to the whole group about how to involve the public and how to ensure sufficient scrutiny (10 mins)</p> <p>Discuss which are areas of agreement and explore areas of convergence to understand why. Moderator to support whole group to develop a version they agree on. Use a show of hands to agree priorities (20 mins)</p> <p>One of the facilitators writes up the recommendations onto four large posters in the colour assigned to the group (for identification purposes), ready to stick up around the room in plenary.</p> <p>For this group a facilitator should present back so that topic is properly introduced to the room. But a volunteer could do a double-act if they wanted to.</p>	Participants discuss at the working group level and decide on the recommendation to present to the room
Recommendation presentation (round 1)	12.00-13.00	<p><b>Plenary session (60 mins)</b></p> <p>The four working groups come together as a whole room:</p> <ul style="list-style-type: none"> <li>Group 4 explains to the room that they have been looking at governance and oversight, presents back to the room their initial recommendation (5 mins) <ul style="list-style-type: none"> <li>Room comments and raises questions (10 mins)</li> </ul> </li> </ul>	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Governance and oversight)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Recommendation presentation (round 1)</b>	<b>12.00-13.00</b>	<p>The room is asked to vote on level of support for each recommendation. The recommendation is up on screen and the Q is 'To what extent, if at all, do you support this recommendation?'</p> <ol style="list-style-type: none"> <li>1. I fully support all parts of this recommendation</li> <li>2. I support parts of this recommendation, but think that it is missing key considerations</li> <li>3. I support parts of this recommendation, but think other parts of it need more work</li> <li>4. I currently do not support any part of this recommendation. It needs more work</li> </ol> <p>Then, the room us asked to vote for the condition which they least favour (answer options are the conditions in full).</p>	
<b>Lunch</b>	<b>13.00-13.45</b>	Participants welcomed to walk around and browse each station, add comments using post-it notes as they do so	
<b>Recommendation forming in working groups (round 2)</b>	<b>13.45-14.15</b>	<p><b>Working groups (30 mins)</b></p> <p>Working groups go back to their stations and, as an entire group, take on board comments and questions. (10 mins)</p> <p>Reflecting the comments/questions, facilitators moderate discussion and support working groups to reach final recommendation. This might include changing the wording of the recommendation all together, tweaking it, and/or adding or removing operating principles, conditions, assurances or caveats (20 mins).</p>	Participants take on board comments from room and revise recommendations

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### Citizens' Summit: Day 4 - Working Group discussion guide (Governance and oversight)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<b>Recommendation forming in working groups (round 2)</b>	<b>13.45-14.15</b>	<p>Once the group are happy with their recommendation, the facilitator initiates an open vote.</p> <ol style="list-style-type: none"> <li>1. All of those who support the recommendation in full put their hands up.</li> <li>2. All of those who do not support the recommendation in full put their hands up. Facilitator asks those with their hands up for 2nd show of hands to why they do not support it in full. Facilitator moderate discussion where the group are given the opportunity to tweak the recommendation.</li> </ol>	
<b>Recommendation presentation (round 2)</b>	<b>14.15-14.35</b>	<p><b>Plenary session (20 mins)</b></p> <p>Each working group presents back final recommendations (5 mins per working group)</p> <p>During the presentations, the recommendation will be shown on the screen to the room.</p>	Participants present revised recommendations to room
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	<b>14.35-15.15</b>	<p>Facilitators to explain that we are moving on now to a discussion about consistency across London. As we have continuously heard throughout the whole of the citizens' summit, for data to be useful for proactive care, for planning and for research and development, it really does rely on the data sets being as complete as possible – i.e. containing the data of everyone, not just of certain people or from certain areas of London. However, given that GP practices hold a lot of information about Londoners, they have an important role to play in this. As do hospitals, and other health and care service providers.</p> <p><b>Read out:</b> The talking heads cards indicate voices from fictional healthcare professionals holding different views around joining-up their patients' data for reasons beyond their individual care. These voices sit alongside counter views which might challenge the points being made. Let's have a look at these in turn...</p>	

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Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	<p><b>14.35-15.15</b></p>	<p>For each set of talking heads:</p> <ul style="list-style-type: none"> <li>• How do you feel about the opposing perspectives shown here?</li> <li>• Does this raise anything new that you hadn't thought about before now?</li> <li>• Does this leave you with any questions?</li> </ul> <p><b>Read out:</b> There are various different ways that we could develop policy.</p> <ul style="list-style-type: none"> <li>• The first option would be to leave things as they are, with each organisation determining for themselves their own data sharing policies (i.e. the rules they apply within the legal framework); but accepting that there will be healthcare providers (for different reasons, some of which we have just looked at), who will therefore choose not to contribute their data on their patients' behalf to a OneLondon data service.</li> <li>• The second option is that these policies are determined and agreed at a sub-regional level (there are five sub-regions in London: NWL, NCL, NEL, SEL, SWL each of circa 2m people); but accepting that sub-regions might choose slightly different arrangements which means that the type of data, and the rules for access could be different between them, and some areas may choose not to put data into a shared OneLondon data service.</li> <li>• The final option is that all healthcare providers are required to operate within a single set of policies, and all of them would be expected to contribute their data on behalf of their patients' into a OneLondon data service, that spans the whole of London.</li> </ul> <p><b>Spontaneous discussion:</b></p> <ul style="list-style-type: none"> <li>• What do you see as the benefits of each of these options?</li> <li>• What do you think might be some of the downsides?</li> </ul>	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Governance and oversight)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	<p>14.35-15.15</p>	<p><b>Prompts/challenge for participants if needed for healthcare providers being left to make their own decisions:</b></p> <ul style="list-style-type: none"> <li>The power and control would remain devolved to individual providers, rather than controlled sub-regionally or centrally. This keeps a lot of responsibility in the hands of the ~1,300 GP practices and ~70 healthcare trusts, but means there is no 'London-wide' commitment to patients about what they can expect in terms of joined up data.</li> <li>This would still mean that if a patient accessed a different service to the one where the information is held, their medical records would not necessarily be available.</li> <li>With this model, there would be limitations to what could be achieved through looking at larger, pan London, datasets in doing proactive care, planning and service improvement, and also in research (given that there would be no central data sets containing joined up information about Londoners).</li> </ul> <p><b>Prompts/challenge for participants if needed for the regional datasets option:</b></p> <ul style="list-style-type: none"> <li>The power and control would be devolved to the 5 sub-regional areas covering up to two million people, rather than controlled centrally. This reduces some of the fragmentation, but reduces the autonomy of GP practices and healthcare trusts. There would still be no guarantee of a 'London-wide' commitment to patients about what they can expect in terms of joined-up data.</li> <li>This would still mean that if a patient accessed a service in a different region of London to the one where they live, their medical records would not be available.</li> <li>With this model, there would be limitations to what could be achieved through looking at larger, pan London, datasets in doing proactive care, planning and service improvement, and also in research. Given that the five datasets would not be joined up.</li> </ul>	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Governance and oversight)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
<p><b>Consistency across London</b></p> <p>Table discussions and then plenary vote</p>	14.35-15.15	<p><b>Prompts/challenge for participants if needed for the OneLondon dataset option:</b></p> <ul style="list-style-type: none"> <li>• The power to formulate policy would become the same in all areas of London, which would reduce some of the fragmentation and variation of the present. However, this could reduce the autonomy of GP practices and healthcare trusts. So whilst it would make it easier to make a consistent service 'offer' to patients, some GP practices and healthcare trusts may feel disempowered.</li> <li>• If there was a OneLondon dataset, it would mean great benefits for doing proactive care, planning and service improvement, and also using data to support research. Given that the richer dataset would contain the de-personalised medical records of all Londoners.</li> <li>• This would also mean that if a patient was to access a service anywhere in London, their medical records would be instantly available.</li> </ul>	
	15.00	<p><b>Q&amp;A (5 minutes to clarify anything before the vote)</b></p> <p><b>Room to vote:</b></p>	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Governance and oversight)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
	15.05	<p><b>Chair to read out: Working within the overall legal framework in place across the whole country...</b></p> <p><b>Question 1: 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?</b></p> <ol style="list-style-type: none"> <li>1. We expect there to be a single set of policies ('rules of the road') across all health and care organisations in London</li> <li>2. We expect the policies ('rules of the road') to be set at the level of the 5 sub-regional areas in London</li> <li>3. We expect organisations to make their own policies ('rules of the road') around information sharing</li> </ol>	
	15.10	<p><b>Chair to read out: At whatever level the 'rules of the road' are agreed (within the legal framework)...</b></p> <p><b>Question 2a: To what extent do you agree or disagree with the following statement...</b></p> <p><i>"We expect all health and care organisations in London to contribute 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."</i></p> <ol style="list-style-type: none"> <li>1. Strongly agree</li> <li>2. Agree</li> <li>3. Disagree</li> <li>4. Strongly disagree</li> </ol>	

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### Citizens' Summit: Day 4 - Working Group discussion guide (Governance and oversight)

Sunday 1 March - 10am - 4.30pm

Issue	Time allocated	Session format	Key objectives / where we want to get to
	15.10	<p><b>Question 2b: To what extent do you agree or disagree with the following statement....</b></p> <p><i>“We expect all health and care organisations in London to contribute join-up de-personalised information, as part of a population dataset, to support proactive care, planning and research &amp; development?”</i></p> <ol style="list-style-type: none"> <li>1. Strongly agree</li> <li>2. Agree</li> <li>3. Disagree</li> <li>4. Strongly disagree</li> </ol> <p>Chair to summarise what the votes are suggesting.</p>	

## Appendix E: Discussion guides

### Marginalised and vulnerable communities workshop: Discussion Guide

Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
11.15-11.35	<p><b>Introduction and scene setting</b></p> <p>Plenary then table discussions</p>	<p><b>Information Provision:</b></p> <ul style="list-style-type: none"> <li>• April (Chair) to introduce the team (i.e. moderators from April's team, Ipsos MORI team and OneLondon observers) - 2 mins</li> <li>• Chair gives high level indication of what we will discuss today, cover ground rules for the day, etc - 2 mins</li> </ul> <p>OneLondon is an NHS programme supported by the Mayor of London and London Councils.</p> <p>OneLondon is working to join up health and care data in London. There are some huge benefits to this, including faster, safer, more effective care. But equally, we know that people have concerns, like where their information is held, who can see it, and what it is used for.</p> <p>OneLondon recently held a Citizens' Summit with 100 Londoners, in order to understand what people expect in terms of how their health and care information is used.</p> <p>100 Londoners, reflective of the City's diverse population, were recruited off the street across all 32 boroughs to participate in the four-day summit.</p> <p>At the Summit, Londoners set out their expectations and recommendations as to how their health and care information should be used (thinking as citizens, rather than individuals). This included who should have access, data use for service planning and research, and ongoing governance and oversight.</p> <p>OneLondon now wants to test and consider these recommendations with you. We would like you to reflect on these recommendations, letting us know if you support them, providing an explanation as to why or why you don't support them, and letting us know if you think anything is missing.</p> <p>Today's workshop will feed into a final report which will capture your feedback and the recommendations from the Citizens' Summit. This will be published later this Spring.</p> <ul style="list-style-type: none"> <li>• Clip shown from Citizens' Summit, giving more context to how we have got here - 2 mins</li> <li>• Ipsos representative (Michelle) to give a high-level overview of what we mean by 'health and care data' - referring to presentation - 5 mins</li> <li>• Play UPD Video – Providing context to the issues around data not being joined up - 2 mins</li> </ul>

## Appendix E: Discussion guides

### Marginalised and vulnerable communities workshop: Discussion Guide

Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
11.30		<p><b>Table discussion:</b></p> <ul style="list-style-type: none"> <li>• Table introductions - 5 mins           <ul style="list-style-type: none"> <li>– Each participant to give a brief introduction, for example their name and where they have travelled from today.</li> </ul> </li> </ul>
11.35	<b>Roles based access - context</b>	<p><b>Information provision:</b></p> <p><b>Michelle provides context to topic (5 mins):</b></p> <p>The delivery of healthcare often involves teams of people operating within an organisation (e.g. a GP practice) or across organisations (e.g. across the ambulance service and the hospital).</p> <p>Staff in those teams need to know about you to deliver effective care. But people should only see what is relevant to the task they need to do for you.</p> <p>Joining-up health and care information does not mean letting everyone see everything.</p>
11.40		<p><b>Table discussion (10 mins):</b></p> <ul style="list-style-type: none"> <li>• Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>• Who do you think has access to your health data or records?</li> <li>• What kinds of information do you think they can access and why?</li> </ul>
11.50		<p><b>Facilitators present case studies - verbally presenting case studies 1 &amp; 2 relating to access and control in a health setting and a social care setting (5 mins):</b></p> <ul style="list-style-type: none"> <li>• Ask clarification questions after presenting case studies</li> <li>• Refer to prompts in case studies – I.e. What information does the receptionist need to book the appointment?</li> </ul>
11.55		<p><b>Hand out trade-offs slide (Things to think about... slide 5) - Printed on A3 - (10 mins)</b></p> <ul style="list-style-type: none"> <li>• Probe around the trade-offs</li> <li>• Think about how much you trust each type of role to see your data</li> <li>• What advantages are there in each role accessing your data</li> <li>• What disadvantages are there</li> <li>• What factors are most important here (privacy, convenience, patient safety, burden on staff and efficiency)?</li> <li>• What factors are less important here (privacy, convenience, patient safety, burden on staff and efficiency)?</li> </ul>
<b>12.05 - 12.15</b>	<b>Break</b>	
12.15	<b>Recommendation</b>	<b>Background/ explanation of how participants arrived at this recommendation (10 mins)</b>

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### Marginalised and vulnerable communities workshop: Discussion Guide

Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
12.15 – 12. 45		<p>Present the issues and conditions that participants highlighted during the Citizens' Summit, refer to verbatim comments, give out handouts:</p> <p><b>Main points raised by Citizens' Summit</b></p> <ul style="list-style-type: none"> <li>• Overall, participants at the Citizens' Summit broadly supported access to data in health and care on a need to know basis, because safety / staying alive was viewed as more important than an individual's privacy.</li> <li>• Broadly supportive of people 'having the data they need' but see most roles as "following orders" in which case the order is all that should be required</li> <li>• People worried that even with good rules in place, people can still break rules (the human element)</li> </ul> <p><b>Probes:</b></p> <ul style="list-style-type: none"> <li>• What do you think about this?</li> <li>• Is there anything that you think is missing? (for example, in weighing up the different trade-offs)</li> <li>• What would need to happen/be put in place for Londoners' to feel confident about how the data is handled? Why do you think this?</li> </ul>
12.25		<p><b>Present and discuss recommendation - verbally delivered by facilitator: (15 mins) - See breakdown of time below:</b></p> <p>The Citizens' Summit participants, on behalf of Londoners, suggested the following recommendation and conditions:</p> <p>We expect health and care data to be accessed and used by those who need information to perform their role with the following conditions:</p> <p>Facilitators to read these out one by one and ask probing questions (see below):</p>
12.25		<p><b>(3 mins)</b></p> <ol style="list-style-type: none"> <li>1. A senior person or group should authorise the level of data a staff member can access, for a small number of categories (3 to 5). <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>
12.28		<p><b>(3 mins)</b></p> <ol style="list-style-type: none"> <li>2. Data should only be accessed on a need to know basis, which needs to take into account level of urgency/threat and vulnerability. <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>

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### Marginalised and vulnerable communities workshop: Discussion Guide

Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
12.31		<p><b>(3 mins)</b></p> <p>3. Safeguards should be applied, including:</p> <ul style="list-style-type: none"> <li>– Background checks for any staff being given access.</li> <li>– Mandatory training on induction, repeated regularly, and checked.</li> <li>– Additional safeguards e.g. passwords, contracts, confidentiality agreements, appraisals.</li> </ul> <ul style="list-style-type: none"> <li>• Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>• To what extent, if at all, do you support this?</li> </ul>
12.34		<p><b>(3 mins)</b></p> <p>4. There should be accountability, including:</p> <ul style="list-style-type: none"> <li>– Serious consequences for misuse (deterrents, penalties, sanctions), for the individual and the organisation.</li> <li>– Checks and audit trail built in to find out who is looking at which data, which is reviewed regularly.</li> <li>– Mechanism to raise concerns, e.g. whistle-blowing policy</li> </ul> <ul style="list-style-type: none"> <li>• Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>• To what extent, if at all, do you support this?</li> </ul>
12.37		<p><b>(3 mins)</b></p> <p>5. Vital information flagged and available to all (e.g. allergies to medication, end-of-life decisions).</p> <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> <p><b>Probes to ask after all recommendations have been discussed (5 mins)</b></p> <ul style="list-style-type: none"> <li>• Are there any additional considerations that decision makers need to take on board when implementing these recommendations?</li> <li>• What else would need to be in place for you to be comfortable with different people accessing your information for different reasons?</li> </ul>
12.45 – 13.30	Lunch	

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### Marginalised and vulnerable communities workshop: Discussion Guide

Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
13.30	<b>De-personalised data for planning and improvement - context and recommendation</b>	<p><b>Michelle provides some context to this topic (5 mins)</b></p> <p>In this section we'll be covering how depersonalised health and care data can be used for planning and improving health and care services.</p> <p><b>Michelle to talk through handout/presentation slide covering what is depersonalised data? (5 mins)</b></p> <p>This is de-personalised: identifiers have been removed.</p> <ul style="list-style-type: none"> <li>• It is useful because it is 'rich', so it is possible to spot patterns.</li> <li>• But the more information, the more unique the record.</li> <li>• In theory, it is possible to infer your identify from the record.</li> <li>• This requires access to the data, effort and skill...and doing it is illegal!</li> <li>• De-personalisation therefore does not mean completely anonymous!</li> </ul>
13.40		<p><b>Table Discussion, clarification (5 mins):</b></p> <ul style="list-style-type: none"> <li>• Clarification questions - What do you think to what you have just heard?</li> <li>• Anything unclear or confusing?</li> </ul>
13.45		<p><b>How/why is this data used? (15 mins)</b></p> <p><b>Give out hand out and talk through boxes with examples (slide 15):</b></p> <ul style="list-style-type: none"> <li>• Talk through each box and verbally refer to examples of how depersonalised data can be used for planning and improvement; these will also include details on the different organisations involved and purposes <ul style="list-style-type: none"> <li>– What are the advantages and disadvantages of using de-personalised patient data to make decisions about which services to commission?</li> <li>– If necessary, remind participants that this data is de-personalised so it is difficult but not impossible to re-identify people.</li> <li>– Some data might not be complete / might be incorrect – is it better to make a decision on some data or no data?</li> <li>– How would they feel if a service was changed or moved so that it was more convenient on average, but some current users might be inconvenienced?)</li> </ul> </li> </ul> <p><b>Table facilitators to go through the Five Safes framework (Slide 16)</b></p> <p>Introduction to the five safes at this point, give a high-level explanation on what they are and refer participants to the handout</p>

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Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
14.00	<b>Recommendation</b>	<p>Background/ explanation of how participants arrived at this recommendation (10mins)</p> <p>Present the issues and conditions that participants highlighted during the Citizens' Summit, refer to verbatim comments, give out handouts:</p> <p><b>Main points raised by Citizens' Summit</b></p> <p>Overall, participants recognised the benefits of using de-personalised information for planning and improvement:</p> <ul style="list-style-type: none"> <li>• Leads to wider societal benefits and greater good, including preventing people getting unwell</li> <li>• Enables the NHS to be more efficient / save money / spend money where it is most needed</li> <li>• Ensures services are fair and equitable</li> <li>• Attracted to the use of de-personalised data so this limits the potential harm – it's not like sharing banking data or your home address and contact details</li> </ul> <p>...but recognised and highlighted their concerns:</p> <ul style="list-style-type: none"> <li>• Should not replace talking to people to find out how services can better meet their needs</li> <li>• Using data feels less personal and too top-down</li> <li>• Not everyone will be in the data-set (e.g. pre-diabetic) but important to think of them too</li> <li>• Need to ensure decisions build in local knowledge not just data</li> <li>• There should be one approach across London – we don't think there should be differences between the boroughs on how data is used. Avoid a postcode lottery</li> <li>• Don't take away services people are relying on</li> </ul> <p><b>Probes:</b></p> <ul style="list-style-type: none"> <li>• What do you think about this?</li> <li>• Do you expect health and social care providers to be sharing data to join up and use in this way?</li> <li>• Is this a legitimate use of the data?</li> <li>• Is there anything that you think is missing? (for example, in weighing up the different trade-offs)</li> <li>• What would need to happen/be put in place for Londoners' to feel confident about how the data is handled? Why do you think this?</li> </ul> <p>The Citizens' Summit participants, on behalf of Londoners, suggested the following recommendation and conditions</p>
14.10		<p><b>Present and discuss recommendation - verbally delivered by facilitator: (25 mins) - See breakdown of time below:</b></p> <p>Depersonalised health and care data must be shared and used by relevant bodies to plan and improve services and demonstrably benefit health in London</p>

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Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
14.12		<p>Conditions:</p> <ol style="list-style-type: none"> <li>1. The data being shared is accurate (2 mins) <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>
14.14		<ol style="list-style-type: none"> <li>2. All parties must sign up to the five safes (2 mins) <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>
14.16		<ol style="list-style-type: none"> <li>3. Data is shared for an agreed purpose (2 mins) <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>
14.18		<ol style="list-style-type: none"> <li>4. Only defined items / bits of data should be shared (2 mins) <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>
14.20		<ol style="list-style-type: none"> <li>5. Shared data must be held securely by all agreed recipients (2 mins) <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>
14.22		<ol style="list-style-type: none"> <li>6. Maintain the national opt out option, also maintaining an option to opt back in (2 mins) <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>
14.24		<ol style="list-style-type: none"> <li>7. There should be legal penalties for misuse (E.g. selling on to third parties) (2 mins) <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>
14.26		<ol style="list-style-type: none"> <li>8. The organisations that are sharing data should be specified (2 mins) <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>
14.28		<ol style="list-style-type: none"> <li>9. There should be defined process for sharing the data (2 mins) <ul style="list-style-type: none"> <li>– Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>– To what extent, if at all, do you support this?</li> </ul> </li> </ol>

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### Marginalised and vulnerable communities workshop: Discussion Guide

Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
14.30		<p><b>Probes to ask after all recommendations have been discussed (5 mins)</b></p> <ul style="list-style-type: none"> <li>• Are there any additional considerations that decision makers need to take on board when implementing these recommendations?</li> <li>• What else would need to be in place for you to be comfortable with different people accessing your information for different reasons?</li> </ul>
14.35 –14.45	Break	
14.45	<b>The use of data in research and development (fair and productive partnerships) - context and recommendation</b>	<p><b>Michelle to provide some context to this topic (5 mins)</b></p> <p>Why we do research: In this section we'll be covering how depersonalised health and care data can be used for research and development to find patterns and links, to improve people's lives through better public health and healthcare to:</p> <ul style="list-style-type: none"> <li>• Better predict disease, as early as possible</li> <li>• Prevent disease</li> <li>• Better predict the right treatment for the right person at the right time</li> <li>• Develop new treatments and cures for disease</li> </ul> <p><b>Play video of Axel presenting slides on the value of data - 5 mins</b></p>
14.55		<p><b>Table Discussion, clarification (5 mins):</b></p> <ul style="list-style-type: none"> <li>• Clarification questions - What do you think to what you have just heard?</li> <li>• Anything unclear or confusing?</li> </ul>
15.00		<p><b>What makes a fair partnership (25 mins):</b></p> <p>Facilitators refer to 'What makes a fair partnership?' handout</p> <p>Explanation that data used in research can generate value... However, this costs money... those costs can be recouped</p> <p><b>Talk through the questions that the Citizens' Summit was asked, using high-level handout (blobs)</b></p> <ul style="list-style-type: none"> <li>• What charges should be made to research projects to access data: should there be any charges at all, and if so, are these equal for all parties? Income generation or cost recovery? Views on distribution?</li> <li>• How much should the public know about the research that is taking place? How should we make clear what research is taking place: what type of record of projects should be made available, and to what level of detail?</li> <li>• What should be done with the outputs of successful research: how should we consider access to, and distribution of, the outputs of successful research from a population data asset?</li> <li>• What other issues are important to the public: what do you think should be part of the operating model of a fair partnership and why?</li> </ul>

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Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
15.25		<p>Background/ explanation of how participants arrived at this recommendation (5 mins)</p> <p>Present the issues and conditions that participants highlighted during the Citizens' Summit, refer to verbatim comments, give out handouts:</p> <p><b>Main points raised by Citizens' Summit</b></p> <p>In day 3 of the Citizens' Summit, most agreed with the idea of using de-identified data for research as long as safeguards were in place to ensure people did not receive marketing as a result and their data would not be used to change how much people pay for insurance. There was an expectation that only ethical organisations with a 'safe' track-record can use the data and that their use of the data would be overseen by someone independent. These discussions were also informed by a lot of clarification from experts around the research process and the safeguards</p> <p><b>Probes:</b></p> <ul style="list-style-type: none"> <li>• What do you think about this?</li> <li>• Is there anything that you think is missing? (for example, in weighing up the different trade-offs)</li> <li>• What would need to happen/be put in place for Londoners' to feel confident about how the data is handled? Why do you think this?</li> </ul> <p>The Citizens' Summit participants, on behalf of Londoners, suggested the following recommendation and conditions</p> <p><b>Present and discuss recommendation (25 mins):</b></p>
15.30		<p><b>We expect a fair and productive partnership to consider the issues around charging, transparency and benefits. The conditions around...</b></p> <p>1. <b>Benefits (5 mins)</b></p> <ul style="list-style-type: none"> <li>– Shared Intellectual Property with the NHS</li> <li>– Shared across the NHS – to avoid inequalities, maintain British values and the principle of the NHS</li> </ul> <ul style="list-style-type: none"> <li>• Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>• To what extent, if at all, do you support this?</li> </ul>
15.35		<p>2. <b>Charges (5 mins)</b></p> <ul style="list-style-type: none"> <li>– Recover costs first</li> <li>– Different charging – different tiers of charging based on turnover. For example, start-ups, charities, universities, pharmaceutical companies</li> </ul> <ul style="list-style-type: none"> <li>• Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>• To what extent, if at all, do you support this?</li> </ul>

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Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
15.40		<p><b>3. Transparency (5 mins)</b></p> <ul style="list-style-type: none"> <li>– Annual report detailing companies that have accessed and use, and why. And what is the impact of this use</li> <li>– 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</li> </ul> <ul style="list-style-type: none"> <li>• Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>• To what extent, if at all, do you support this?</li> </ul>
15.45		<p><b>4. They must be in accordance with the 5 safes – no access will be granted to insurance companies. There needs to be reviewed regularly – needs to be a check on legal and regulatory frameworks than underpin the 5 safes. (5 mins)</b></p> <ul style="list-style-type: none"> <li>• Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>• To what extent, if at all, do you support this?</li> </ul>
15.50		<p><b>Probes to ask after all recommendations have been discussed (5 mins)</b></p> <ul style="list-style-type: none"> <li>• Are there any additional considerations that decision makers need to take on board when implementing these recommendations?</li> <li>• What else would need to be in place for you to be comfortable with different people accessing your information for different reasons?</li> </ul>
<b>15.55 –16.05</b>	<b>Break</b>	
16.05	<b>Ongoing roles in policy development / governance and oversight - context and recommendation</b>	<p><b>Michelle to provide some context to this topic (5 mins)</b></p> <p>Participants at the Citizens' Summit were tasked with developing a recommendation on the role of oversight, focusing on ongoing trust.</p> <ul style="list-style-type: none"> <li>• Much of the work of public sector policymakers is about deciding what is the right thing to do, doing it, and then being held to account for doing it properly. We need to understand your expectations about how this happens for Londoners joined-up data.</li> </ul>
16.10		<p><b>Table Discussion, clarification (5 mins):</b></p> <ul style="list-style-type: none"> <li>• Clarification questions - What do you think to what you have just heard?</li> <li>• Anything unclear or confusing?</li> </ul>

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Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
16.15	<b>Hand out stimulus and discuss (15 mins):</b>	<ul style="list-style-type: none"> <li>• <b>Handout: Action and accountability</b> - Setting the rules, applying the rules in action, checking the rules work and are being followed</li> <li>• <b>Handout: How that looks in practice</b> - Examples of how this looks e.g. citizens' summits, board of manager/experts with patient reps, ongoing advisory groups.</li> <li>• What benefits can you see from doing this?</li> <li>• Who needs to be involved in these stages to make them feel acceptable and trustworthy?</li> <li>• What's the best way to ensure we hear from groups who aren't typically involved in these processes? Refer to handout 'Designing the rules'.</li> <li>• What specific roles should the public play in any (or all) of these stages?</li> <li>• What do you see as the benefits of each of these options?</li> <li>• What do you think might be some of the downsides?</li> </ul>
16.30		<p><b>Background/ explanation of how participants arrived at this recommendation (5 mins)</b></p> <p>Present the issues and conditions that participants highlighted during the Citizens' Summit, refer to verbatim comments, give out handouts:</p> <ul style="list-style-type: none"> <li>• Clarification questions - What do you think to what you have just heard?</li> <li>• Anything unclear or confusing?</li> </ul> <p><b>Present and discuss recommendation (20 mins):</b></p> <p>Ongoing governance and oversight in these processes were mentioned by participants, as a result the following recommendation and considerations were proposed:</p>
16.35		<p><b>Ongoing roles in policy development (8 mins):</b></p> <p>We expect that there are several ways that the public are involved in ongoing policy development:</p> <ul style="list-style-type: none"> <li>– There should be a diverse citizens' advisory group where people are recruited to be reflective of London (like we did for today's summit), with a lower age limit, supported with the right information to understand the issues</li> <li>– And 2-3 citizen representatives should also sit on decision-making boards with health care officials and experts, and they need to be recruited (like a school governor) with the skills needed to take part</li> <li>– This role should be time-limited with replacement every three years</li> </ul> <ul style="list-style-type: none"> <li>• Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>• To what extent, if at all, do you support this?</li> </ul>

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Wednesday 11 March – 11.15am-5.15pm

Time	Discussion structure	Questions and materials
16.43		<p><b>Ongoing roles in governance and oversight (8 mins):</b></p> <p>We expect there to be trustworthy oversight of the system of joining-up and using health information, which would include:</p> <ul style="list-style-type: none"> <li>– Health and care officials playing the main role in making detailed decisions</li> <li>– With additional roles for experts from health and care professionals, scientists, and cyber security experts; and people with a range of other backgrounds</li> <li>– 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</li> </ul> <ul style="list-style-type: none"> <li>• Answer any clarification questions - What do you think to what you have just heard? Anything unclear or confusing?</li> <li>• To what extent, if at all, do you support this?</li> </ul>
16.51		<p><b>Probes to ask after all recommendations have been discussed (4 mins):</b></p> <ul style="list-style-type: none"> <li>• Are there any additional considerations that decision makers need to take on board when implementing these recommendations?</li> <li>• What else would need to be in place for you to be comfortable with different people accessing your information for different reasons?</li> </ul>
16.55	<b>Temperature check and close</b>	<p>Chair to spend some time at a room level, to assess the temperature of the room in relation to what is important to people and recognise any standout issues raised in relation to the recommendations.</p> <p>Participants will have the recommendations presented to them once more at the end and hold up cards stating if they: Agree, don't know, disagree - 15 mins</p>
17.10		Thanks and close - 5 mins

## Appendix F: Homework task

**In preparation for the second weekend, participants were asked to reflect on the topic outside of the deliberative setting and complete an assigned homework task.**

### Thinking and talking about the use of health and care data: homework

Before you come back for our second weekend, at etc. venues County Hall, on Saturday 29 February, we have some small tasks for you to complete - labelled 1 and 2. Please complete these tasks and fill in your thoughts and answers.

Please be as complete as you can with your answers.

**Thanks in advance and see you next time!**

#### 1. HEALTH AND CARE DATA CONVERSATION

Please interview a family member or friend. Tell them what you've learned at the Citizens' Summit so far about how health and care data is used. Then ask them these questions:

How would you want this data looked after and safeguarded?

How can you imagine this data being used in future to help you? How about to help other people?

#### 2. RISKS AND BENEFITS OF DATA USE

If you are able to, please visit the following website and have a listen to a few of the data stories <https://www.datacanofworms.com/data-stories>. These are a number of fictional stories; however, they reflect real situations that people may find themselves in.

We would suggest, at the least, that you listen to the following cans:

- "Sarcoma" (treatment and prevention)
- "Meal delivery" (social services)

Tell us three things you found out which interested or surprised you.

Name of the can (i.e. "GP Visit")	What did you like about this story / What are the benefits here?	What did you dislike / What are the concerns here?

If you would like to find out more information about the event and the activities of OneLondon, please visit their website at: <https://onelondon.online/citizenssummit/>

**Thank you! Please bring this back with you for the second weekend.**

## Appendix G: Questionnaires

As mentioned in the main body of this report, a quantitative element to this project involved the administration of a combined pre and post project participation questionnaire. 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 the first weekend (helping to inform the design of the second weekend). Details of these questionnaires can be found below.

### Participant feedback questionnaire

Please provide your feedback on the first weekend of the OneLondon Citizens' Summit on uses of health and care data. It will be used to assess how the summit has gone and what we can improve for the second weekend. All responses are anonymous.

Please tick one circle for each of the following questions.

#### Q1. To what extent do you agree or disagree that you understand the purpose of the summit?

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments:					

#### Q2. To what extent do you agree or disagree that you were provided with enough clear information to enable you to contribute to the discussions?

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Comments:					

## Appendix G: Questionnaires

**Q3. To what extent do you agree or disagree that the information you have been provided with has been fair and balanced?**

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

**Q4. To what extent do you agree or disagree that you have been able to ask questions and get appropriate answers?**

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

**Q5. To what extent do you agree or disagree that you have had enough time to discuss the issues?**

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

## Appendix G: Questionnaires

**Q6. To what extent do you agree or disagree that you have been able to contribute your views and have your say?**

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

**Q7. Overall, how much have you enjoyed the first weekend of the Citizens' Summit, if at all?**

Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Comments:

**Q8. Is there anything else we should take into account when making the final arrangements for second weekend of the summit on 29 February / 1 March?**

Comments:

## Appendix G: Questionnaires

### Combi knowledge and attitudes questionnaire

Welcome and thank you for your interest in this project.

#### What is this document?

We are asking everyone to fill in this short questionnaire.

#### Why are we asking these questions?

We want to understand what you know and have heard about health and care data, as well as how you feel about it.

We would like you to tell us how much you agree or disagree with the statements below at two points in time; in the first 'Before' row please think back and tell us how much you agreed or disagreed with it before you took part in the events. In the second 'After' row, please tell us how much you agree or disagree now after having taken part in the events.

It will take only a couple of minutes to complete.

#### What will this information be used for?

What you tell us will help to ensure we ask the right questions and give you the right information across the events.

We will ask you these questions at different points in the project to understand whether your views change as a result of your involvement.

The questionnaire starts here

Please add your full name below. This will help us to understand whether your views change over our discussions.

#### FULL NAME:

---

The questions below ask about health and care data. By health and care data, we mean information that is routinely gathered about individuals by the NHS and social care services when they receive care.

Please tick one circle for each of the following questions.

---

#### Q1. How much, if anything, would you say you know about how health and care data is used, if anything?

	A great deal	A fair amount	Not very much	Not at all	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Appendix G: Questionnaires

Health and care data can be used for different purposes. For each of the following purposes, please tick the circle that shows how acceptable or unacceptable it would be to you.

**Q2. Different NHS services joining up and using your health and care data for your individual care (e.g. your GP and hospital). This data would be linked directly to you.**

	Completely acceptable	Acceptable	Neither acceptable nor unacceptable	Unacceptable	Completely unacceptable	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q3. NHS and social care services joining up and using your health and care data for your individual care (e.g. a social worker and a GP). This data would be linked directly to you.**

	Completely acceptable	Acceptable	Neither acceptable nor unacceptable	Unacceptable	Completely unacceptable	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q4. NHS organisations joining up and using your health and care data for the planning of health and care services. The information given to the NHS organisations would not include your name and address or any contact details.**

	Completely acceptable	Acceptable	Neither acceptable nor unacceptable	Unacceptable	Completely unacceptable	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Appendix G: Questionnaires

**Q5. A commercial organisation (for example a pharmaceutical or tech company), using your health and care data for health research. The information given to the commercial organisation would not include your name and address or any contact details.**

	Completely acceptable	Acceptable	Neither acceptable nor unacceptable	Unacceptable	Completely unacceptable	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q6. A Local Authority/Council using your health and care data for the planning and delivery of local services or public health interventions. The information given to the Local Authority/Council would not include your name and address or any contact details.**

	Completely acceptable	Acceptable	Neither acceptable nor unacceptable	Unacceptable	Completely unacceptable	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Q7. Central government using your health and care data alongside other data for the planning and delivery of national services. The information given to central government would not include your name and address or any contact details.**

	Completely acceptable	Acceptable	Neither acceptable nor unacceptable	Unacceptable	Completely unacceptable	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Appendix G: Questionnaires

**Q8.** Here are two statements representing either ends of a scale from 1 to 5. Please select a number between 1 and 5 to show where your view fits on this scale.

	1 – The main priority for the NHS is treating people when they are unwell	2	3	4	5 – The main priority for the NHS is keeping people healthy in the first place	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Bringing citizens together in the way that we are doing for this event is a means of involving the public in decision making. Please answer the following questions based on how you are feeling right now.

**Q9.** To what extent do you agree or disagree with the following three statements:

**A) I am able to influence decision making around how health and care data is used**

	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**B) The public should be involved in decision making around how health and care data is used**

	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**C) I feel informed about how health and care data is used**

	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know	Don't know
Before	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
After	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Thank you for taking the time to answer our questions – we hope you enjoy the rest of the event!**

## Appendices - references

1. We have decided not to specify the numbers within these categories given the low proportion of 'As' (i.e. lawyers, head teachers, etc) within the population.
2. This is reflective of the % of Londoners who identify as BAME.
3. A person who looks after, or gives help or support to family members, friends, neighbours or others because of either: long-term physical or mental ill health /disability, or problems related to old age.



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