OneLondon's Citizens Advisory Group

Public deliberation on access to and charging for London's Secure Data Environment

August 2023

Foreword

Ensuring the voice of the public is heard is central to our work at the London Health Data Strategy Programme. We know we will not achieve our aim to improve the health and wellbeing of Londoners, and solve health and care challenges by using data at scale without working in partnership with our citizens.

That's why we held our Citizens' Summit in 2020 which brought together 100 Londoners to discuss, debate and deliberate the uses of their health and care information by the health and care system in London. We then followed this with a set of deliberations in 2022 focusing on the type of Secure Data Environment (SDE) that should be used in London and whether that should be kept locally controlled or move towards a more pan-London approach. We have enacted recommendations based on this including our first annual report to citizens and establishing the Independent Information Access Group.

Our approach to public involvement has been praised nationally, so when we were fortunate enough to be awarded additional funding to develop a London-wide Secure Data Environment, we wanted to continue this important work. Earlier this year we established the Citizens Advisory Group (CAG) and held our latest round of public deliberations, focusing on what criteria should be used to decide who can access deidentified data and determine how organisations should be charged to access that information. We appreciate that these are not easy topics to grapple with, and would like to express our thanks to the CAG who gave up their time to consider and debate these issues.

This report highlights the key outcomes and recommendations from the three days of discussions and will be invaluable for us in setting the direction for the London Health Data Strategy and Secure Data Environment going forward.

Luke Readman
Director of Digital Transformation at NHS England London Region and Senior Responsible Officer for the London Health Data Strategy

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We would like to thank representatives from the London Health Data Strategy Programme, London Secure Data Environment team and wider system leaders who were present on Day 3 to receive the recommendations from participants: Luke Readman, Axel Heitmueller, Deborah Millington and Jonty Heaversedge.

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

Most importantly, we would like to thank the participants, members of London's Citizens Advisory Group, who gave up two weekends to contribute to a set of complex and challenging discussions, and for their tremendous commitment to making policy recommendations on behalf of Londoners. Finally, we would like to thank members of the OneLondon team and the executive team for their time and effort and working so closely with us to ensure that the process was well-informed and ran smoothly and effectively.

Executive summary

Public trust and confidence in the use of health and care data is paramount. As such, the London Secure Data Environment (SDE) has made a strong commitment to continue to build on the strong track record of public engagement and involvement across the capital to build trustworthiness in data use, particularly through the use of deliberative engagement which has proved so impactful over recent years.

Building on recommendations from previous deliberations, a London-wide Citizens Advisory Group (CAG) has been established and forms part of the London Health Data Strategy governance structure thus directly informing decision making and policy development through advising the Delivery Oversight Group comprising senior representation from each London Integrated Care Board as well as the NHS England regional team and data related programmes.

The group, made up of 102 London residents selected to broadly reflect the wider London population, will work to ensure that credible public input is incorporated into decision-making, the development of policies, and the implementation of programmes.

The inaugural deliberation of the CAG took place across three days on 10 and 11 June and 1 July 2023. This deliberative engagement was led by Imperial Health College Partners (ICHP) and Ipsos and was commissioned by the London SDE team. It addressed two key questions:

- *What criteria should the SDE's IIAGs (Independent Information Access Group) use when deciding to permit direct access to deidentified data, including for non-member organisations?*

- *What criteria should drive decisions about charging, and what are the principles that underpin more complex interdisciplinary partnerships?*

The 3-day process comprised a combination of plenary sessions in which participants listened to expert presentations and were able to ask questions, table discussions in which the issues were debated and discussed at length, and plenary sessions in which facilitators or participants fed back on their tables' views to all participants. Facilitators followed a comprehensive discussion guide throughout the 3-day process to ensure consistent coverage of the same topics across all tables.

Participants initial views on health data use

During spontaneous discussion participants identified several advantages of health data sharing, while also being mindful of data security risks. While deliberating secondary uses of health data, participants once again acknowledged substantial benefits yet expressed concerns about potential data breaches and confusion related to the different levels of data identifiability. Participants also raised concerns regarding the amount of data required to do research, the accuracy of London's health and care data and the potential for research to create unintended consequences.

Participants were most enthusiastic about health data research where they could identify tangible benefits to patients and the public and were in part particularly concerned about for-profit companies accessing health data, however this was often secondary to the overall positive impact of the research.

Participants found reassurance in the concept of researchers accessing data through a secure data environment (SDE). However, concerns persisted regarding the potential risk of data breaches and the possibility of researchers misusing the data.

Participants held differing views on London's position on the National Data Opt-out, ultimately recommending further engagement and communication on the topic.

Principles that should underpin direct access to the London SDE

Participants were generally less comfortable with commercial access due to discomfort around organisations profiting from using patient data. However, while it was common for participants to be less comfortable with commercial access, most indicated that they were willing to accept this assuming several conditions were in place. Suggestions around profit shares, reinvestment of money back into the NHS and discounted charging came up early on, and before the conversation moved onto charging.

Public benefit was the overriding factor in determining whether data accessors should be given direct access to deidentified data in the London SDE. The number of people affected by the condition was very important to participants, as was the extent to which the research could bring about lifesaving or lifechanging benefits to people. Participants were divided on their views around life-limiting conditions that affect a very small number of people and were split on whether the breath of benefit should override the depth of benefit. They landed on both as being equally important. Participants were also supportive of research that could bring about benefits to groups who are currently underserved or overlooked and projects where the benefits could be broader, for example enabling transferrable knowledge or wider learnings.

Participants emphasised the importance of minimising stigma and raised the risk that through some health data research existing health inequalities could be exacerbated. They also flagged that there must be a clear rationale that data held in the London SDE is necessary or beneficial to the research. This was particularly the case when international organisations request access going forward.
In considering how requests should be prioritised, a number of factors were identified including ability to demonstrate broader benefits and demonstrable clear benefits to London or the UK. Participants were supportive of projects that felt more feasible in terms of the application of the findings.

AI research raised lots of questions and was uncomfortable for some and insurance companies were a red line for most. Participants voiced expectations around the need for all organisations to be vetted to check they have the right skills, intentions and a trusted track record, with additional checks and balances for international organisations and in relation to sensitive and/or identifiable data.

Expectations for access criteria

In making decisions about whether direct access to London's SDE should be granted, we expect the following to be demonstrated for each request:

A clear and demonstrable public benefit. This is the most important factor to consider. The level of 'public benefit' should be estimated according to the following factors:

- The breadth of the benefit (volume of people), including the potential impact on wider family members and support networks.
- The depth of the benefit (level of benefit), and whether the benefits are likely to be lifesaving or lifechanging – and how it impacts quality of life (e.g. significantly reduce discomfort)
- The extent to which there will be benefits for groups who are currently underserved or overlooked (i.e., minority groups or people suffering from a little-understood condition)

That the project will create broader benefits such as new understanding, information and/or treatments rather than duplicating past research (i.e. is it an under-researched area or a potentially novel breakthrough?) and/or the project has the potential to create real-world impact.

That existing health inequalities will not be exacerbated through the work, and that no groups will be negatively impacted or harmed. This is particularly important when considering linking of NHS data with non-NHS data e.g. police data.

That there is a clear rationale that data held in the London SDE is necessary or beneficial to the research.

In considering how requests should be prioritised…

- Requests that can demonstrate broader benefits (in addition to public benefit) should be prioritised e.g. those that may reduce operational or financial burden on the NHS, or projects where learnings can be applied in other disease areas.
- Requests that are likely to deliver public (and potentially broader) impact more quickly could be prioritised over those projects where benefits may take longer to be realised, for example, in cases of unexpected health emergencies.
- Regardless of timeframe, anything that is within the NHS priority areas (informed by ongoing engagement with health experts) should be prioritised.
- Requests with clear impact for London or the UK (either in terms of health outcomes or the generation of jobs and investment) should be prioritised over requests that do not directly benefit London/or the UK.
- Projects that are willing to publish their findings (and/or share with NHS) should be considered for priority.

More generally, we expect….

- Organisations to have undergone a vetting process to check they have the right skills (and expertise by experience), intentions and a trusted track record (or with a 'guarantor' with a trusted track record) before they are granted access to the London SDE.
- Organisations to commit in writing to the rules and protocols for access before they are granted access to the London SDE, and to be held accountable for any breaches.
- Requests should clearly state the remit of the project and access should be limited to this, both in terms of type of data needed and for how long.
- The technical system to be able to ensure named individuals can only access what they are authorised to and only for the agreed project duration (time limited access).
- There are to be additional checks and balances in place for projects that are longer term (e.g. six months or longer), using more sensitive data (e.g. mental health data or rare disease data that may be more identifiable) and/or projects being led by international organisations and/or those with no track record. These should include:
- Regular audits to check the data is used for the purpose requested and by the agreed accessors, and
- Quality checks on how analysis is being conducted. These checks should be as efficient as possible e.g., automated/using AI.
- Projects should have to apply again if a company with access is taken over.
- More communication and engagement about London's position on the national data opt-out.
- There to be a way to report any concerns about how the data is being used (e.g. data breaches), in a confidential way.
- Access and charging criteria/rules should be reviewed after one year initially, and then every three-years.

Red Lines

- Under no circumstances should access be granted to insurance companies or marketing agencies.
- The NHS should not let itself be taken advantage of and should ensure it gets a fair return when companies/individuals make big profits from the research based on NHS data.
- Police should not have direct access to health data in the London SDE.
- No access should be given to non-member organisations that cannot cover their costs.

Principles that should underpin charging for direct access to the London SDE.

Notwithstanding some concerns about perceived 'commercialisation' of the NHS, participants generally acknowledged the importance of the London SDE implementing a charging model and supported the introduction of a tiered pricing model.

Once a project has been confirmed by the Independent Information Access Group as being in the public interest, participants widely regarded the type of accessing organisation to be the most influential factor in determining the appropriate charge for a data request. There was a shared sentiment that large commercial entities should incur the highest data access costs, while non-member NHS organisations should be charged the lowest, with charities and universities falling in between.

A strong consensus emerged that the London SDE should distinguish companies based on their ability to pay. Initially participants were split over whether organisations should be differentiated based on the turnover of the company or its profits, but participants ended up opting for turnover-based charges. Participants were generally enthusiastic about the London SDE exploring other value exchange models, such as discounted products, shared IP and discounts based on sharing profits.

Participants acknowledged a potential need for higher fees for accessors seeking more sensitive data, large amounts of data or longer access durations.

Participants were divided on whether international organisations should face higher charges for access. Some felt the location of the accessing organisation should be secondary to its characteristics, reputation, and track record. Others believed working with UK organisations would be less risky and yield additional economic benefits to London, leading them to advocate for lower fees for UK-based organisations.

Once projects have met the access criteria and demonstrated public benefit, participants felt they should be further distinguished based on whether or not they align with NHS priorities. If projects do align with NHS priorities, participants felt they should not only be prioritised for access (see previous chapter) but also considered for a discounted charge.

There was a prevailing view that the charges levied on accessors should reflect the amount of time and resource required of the NHS to acquire, curate, and (if necessary) analyse the necessary data.

Participants were clear that the NHS's costs should always be recuperated. They felt that the London SDE's charging model should incentivise longer-term partnership-building, either through offering discounts or implementing a 'loyalty scheme' for regular users.

Participants felt that access fees should reflect the distinctiveness and quality of the London data set. However, they also recognised that competition in the national and global market may necessitate reduced prices to attract new data users, especially when comparable data could be accessed elsewhere at lower costs.

Initially, some participants felt non-member organisations partnering with member organisations, or higher-paying organisations collaborating with lower-paying ones, should receive a discount on access. Others felt the London SDE should charge according to the rate incurred by the higher-paying partner. In the end, participants recommended that charges should instead be based on who is funding the research.

Participants were split on whether organisations that pay more for access should be given priority access to the London SDE.

Expectations for charging criteria

In deciding how much to charge organisations requesting access to the London SDE, we expect the following principles to be applied…

- Priority should be given within the charging structure to the overall benefit of the project to the NHS, London, and the UK population (primary use case of the data should be factored into charging).
- Profit-making companies should pay the most and non-member NHS organisations should pay the least for access to London's SDE. Charities, non-member local authorities and universities should be charged somewhere in between. However, the SDE should recognise that these distinctions are not

always clear cut (e.g. universities or charities may have high turnover and/or make profit from research in which case they should pay more than charities/universities with lower turnover).
- Large for-profit organisations (measured by turnover) should be charged more up-front than smaller for-profit organisations.
- UK based organisations should pay less than non-UK organisations (to show support for local companies who support the UK economy). Global collaboration should not be discouraged – though there should be higher charges for non-UK organisations if there is no clear benefit back to the UK. There needs to be a clear definition of what is considered 'UK' (this should include where organisations are located, where they pay tax, where their staff are based).
- For projects involving multidisciplinary teams, e.g., NHS and commercial organisations, charges should be applied based on which organisation/s is funding the work. To support this process, requests should be clear about all participating organisations, and which are providing funding.

We expect discounts to be considered for:

- Projects that can demonstrate a clear and realistic aim to save money for the NHS and/or a quantifiable/measurable benefit for the NHS (recognising that this is not always straightforward).
- Projects that are aligned with NHS priorities in London, as set out by the NHS in London. The priorities should be clearly and transparently communicated.
- Projects that have exceptional benefits for patients (a serious disease area, high impact on quality of life). Further work is required to define where benefits are 'exceptional'.

We expect additional charges (on top of the access fees) to be considered for:

- Projects that require more London SDE support than standard data requests (e.g. requiring complex data curation, support with analysis etc)
- Projects that require access for a longer period (e.g., more than six months). Projects may not know their exact timelines at the start and efficiency should be encouraged. Additional charges should be applied at regular review points (every six months).
- Projects that require access to large amounts of data (to reflect that its more labour intensive for the NHS to prepare this data) and/or more sensitive data.
- If the project is purely for commercial reasons and is not benefitting the NHS, we wouldn't expect these projects to be granted access but if they are, this principle (i.e. an additional charge) is important.

More generally, we expect…

- London SDE to take advantage of its bargaining power as and when that exists, e.g., higher rates for projects that can only progress with London data.
- Other value exchange models (beyond fee for access) to be considered to maximise value for the NHS e.g., profit share, discounted products, intellectual property, royalties etc. This should be negotiated up-front to allow greater flexibility for those who can't afford the full up-front access fee.
- Opportunities for longer term strategic partnerships to be explored, e.g., for repeat customers of the London SDE, with a proven track record of delivering benefit to the NHS, in order to encourage and reward these types of users. This is complex and we would like the SDE team to consider how to take this forward in a way which is fair, regularly reviewed, limited and has a clear definition of 'longer-term'.
- There should be opportunities for the NHS to review what it has charged, dependent on changes to the timeframe and changes to the project scope and any potential buy-out of the organisation.

Background and methodology

Background

Introduction and background

Public trust and confidence in the use of health and care data is paramount. As such, the London Secure Data Environment (SDE) has made a strong commitment to continue to build on the strong track record of public engagement and involvement across the capital to build trustworthiness in data use, particularly through the use of deliberative engagement which has proved so impactful over recent years.

London has invested resources in ongoing deliberative discussion with Londoners which has helped the system to understand public expectations through exploration of trade-offs and constraints, and used these insights to shape and develop the policy and governance arrangements that underpin data access and use across the capital.

Building on recommendations from previous deliberations, a London-wide Citizens Advisory Group (CAG) has been established and forms part of the London Health Data Strategy governance structure thus directly informing decision making and policy development through advising the Delivery Oversight Group comprising senior representation from each London Integrated Care Board as well as the NHS England regional team and data related programmes.

The participants comprise 102 Londoners reflective of the capital's richly diverse population (see sample on page 14) and, subject to ongoing funding, will come together up to three times a year to deliberate key dilemmas and issues facing London's health data strategy programme, with an initial focus on research and development as part of the SDE programme (as this is the funding source for the initial deliberation).

The participants will help to ensure meaningful, diverse, and considered public voices are embedded into decision making, policy development and programme implementation to ensure trusted used of data.

The intention is that the 102-person deliberation will run for a term of three years. Participants will take part in a series of 'mini deliberations' throughout that period on key issues facing the London Health Data Strategy programme, with an initial focus on the London SDE but not exclusively.

This report focuses on the content of and findings from the inaugural deliberation which was held in person over three days in June and July 2023 with all 102 members. All members attended the first deliberation to ensure that everyone received an introduction to the LHDS programme and the related concepts and context to enable a firm foundation of knowledge for future deliberations. It also provided an opportunity for participants to meet each other and start to form as a group.

The topics for the inaugural deliberation focused on the criteria that informs decision making about who/what is granted direct access to the London SDE, and what principles should underpin the charging for that access.

Methodology and sample

Overview of the process and topics of deliberation

Building on recommendations from previous deliberations[1], a OneLondon Citizens Advisory Group (CAG) has been established which will be part of the London Health Data Strategy governance structure, and directly inform decision making and policy development through advising the Delivery Oversight Board.

The group, made up of 102 London residents, selected to broadly reflect the wider London population, will work to ensure that credible public input is incorporated into decision-making, the development of policies, and the implementation of programmes.

The inaugural deliberation of the CAG took place across three days on 10 and 11 June and 1 July. This deliberative engagement was led by Imperial Health College Partners (ICHP) and Ipsos and was commissioned by the London SDE team. It addressed two key questions:

- *What criteria should the SDE's IIAGs (Independent Information Access Group) use when deciding to permit direct access to deidentified data, including for non-member organisations?*
- *What criteria should drive decisions about charging, and what are the principles that underpin more complex interdisciplinary partnerships?*

The design of this deliberative exercise was closely informed by the London Health Data Strategy Programme team, whose input into the discussion guide and stimulus material helped to ensure the engagement process was robust, rigorous, accessible, and relevant.

Deliberative engagement

Deliberative methods work best on challenging issues where there is no simple 'correct' answer but rather a range of possible options, with associated strengths, drawbacks, and complexities. The criteria for accessing health data and the charging model employed by the London SDE are intricate areas that require decision-makers to make complex judgments and consider ethical trade-offs. These judgments involve finding a balance between various competing factors, such as patient privacy, clinical quality, and financial and legal considerations.

Making such judgements requires time and consideration and deliberative methods provide an opportunity for participants to engage in a thoughtful and well-informed discussion over an extended period. By considering balanced information on a topic, and grappling with multiple potential solutions and perspectives, participants can reach a series of nuanced recommendations, as they did on day three of this process.

The process design

The 3-day process comprised a combination of plenary sessions in which participants listened to expert presentations and were able to ask questions, table discussions in which the issues were debated and discussed at length, and plenary sessions in which facilitators or participants fed back on their tables' views to all participants. The timings and details of the topics covered each day can be found in the discussion guides in the appendix.

Subject matter experts – including several members of the London SDE team - were invited to attend and contribute to the process; details are included in the appendix. These experts played a key role in

[1] Public deliberation in the use of health and care data, Accessible at: https://www.onelondon.online/wp-content/uploads/2020/06/Public-deliberation-in-the-use-of-health-and-care-data.pdf

providing participants with information through presentations and answering questions at the discussion tables. Prior to the Summit, the experts were instructed to only join participant discussions when invited, to answer specific questions or offer contextual information, to maintain a balanced view throughout, and to provide factual information rather than personal opinions.

Facilitators followed a comprehensive discussion guide throughout the 3-day process to ensure consistent coverage of the same topics across all tables. The materials used underwent several iterations with the London SDE team before being finalised.

On days 1 and 2, participants were allocated to twelve tables of approximately ten participants per table. A facilitator was stationed at each table to moderate the discussion through the day. Table allocations were selected to ensure a mixture of key characteristics (e.g. age, gender, and ethnicity). The table allocations were different on days 1 and 2 to ensure participants were exposed to a variety of differing viewpoints and arguments. This approach aimed to minimise the potential influence of "groupthink" or social desirability bias.

On day 1 of the process, participants received an introduction to different uses of health and care data and reviewed three examples for how deidentified data can be used beyond direct care. They then learned more about SDEs and the 'six safes' that govern data use in London and were presented with an overview of London SDE's proposed process for decision-making around access and its current position on the national data opt-out. After learning more about different types of data user (including commercial and academic data users), participants spent the remainder of the day considering a range of fictional data access requests and ranking them according to how likely they would be to approve the access requests and how they would prioritise projects for access.

One day 2, participants reviewed another set of fictional access requests – this time focused on more novel uses of data – and were asked to share their feelings about each example and make a judgement on they should be prioritised for access. In the afternoon of day 2, participants moved on to discussing charging for direct access for non-members. They received a presentation on the costs associated with maintaining an SDE and the findings from previous public engagement on how accessors should be charged for data. They then revisited the fictional requests covered on day 1 of the process, alongside two additional examples, and placed the requests on a spectrum representing how much participants thought they should be charged.

In-between the second and the third day of the deliberation, the Ipsos and Imperial College Health Partners team devised a set of draft expectations based on a high-level analysis of the data collected across days one and two. These draft expectations were ratified with table facilitators.

On day 3, participants were divided into 2 groups of 50: one of these groups focused primarily on access criteria while the other addressed charging. The groups of 50 were initially split into four groups of 12/13 to closely review the draft recommendations. Smaller groups of 12/13 were then merged into two groups of 25, where amendments were compared and agreed changes implemented (based on consensus). Later the two groups of 25 merged to a group of 50 where expectations were voted on.

The recommendations approved by each group of 50 were presented to the plenary for whole-group feedback, after which final changes were made in groups of 50. At the end of the day, the final expectations from each group of 50 were voted on by all participants.

The final recommendations of each group are outlined in standalone sections of this report. A more detailed account of the timings and topics covered each day can be found in the discussion guides in the appendix.

Sampling and recruitment

To manage the recruitment process, Ipsos worked with Criteria UK - a specialist recruitment agency. Criteria UK recruited 102 participants to join the CAG and take part in this first deliberation using a mixture of face-to-face recruitment and recruitment via databases held by Criteria. The CAG started with 102 members on day 1, with 96 participants completing the whole 3-day process.

Participants were recruited from across all five London Integrated Care Systems and from across all 32 London Boroughs. Quotas were also set based on demographic characteristics such as gender, age, socio-economic group, ethnicity, and health status. Other quotas included a minimum number of parents with children under the age of 16, a mixture of self-defining health and social care users (i.e. heavy, medium and light usage), and a minimum number of carers. Additionally, participants were recruited to reflect a range of attitudes to data sharing, using three categories developed during past Ipsos and ICHP research[2]:

- **'Data unconcerned'** – those who have little concern about how their data is collected and used

- **'Data absolutists'** – unwilling to provide personal information despite the potential benefits

- **'Data pragmatists'** – who make decisions on whether to share personal information on a case-by-case basis – dependent on the benefits

These quotas were set to ensure participation of individuals from a range of backgrounds reflective of the areas they came from and the broad diversity of London. A full demographic breakdown of participants is included below.

In recognition of their time and to cover any expenses incurred through attending the Citizens' Summit, such as travel or childcare, participants were provided with an incentive payment of £120 per day (£360 in total for all three days).

Recruitment criteria	*CAG profile*
Total numbers	102
Gender	52 female and 50 male
Age	38 participants aged 18-39 (with 13 aged 18-25); 33 participants aged 40-59; 31 participants aged 60+ (with 8 participants aged 70+)
Socioeconomic background	30 participants from AB socioeconomic grades; 44 participants from C1C2 socioeconomic grades; 28 participants from DE socioeconomic grades
Ethnicity	41 participants from a BAME background
Parental status	26 participants with children under 16
Self-defined health and social care usage	33 heavy users of health and care services; 28 light users; 41 medium users
Long term conditions	48 participants with long-term physical or mental health conditions
Caring responsibilities	25 participants with regular (unpaid) caring responsibilities for a friend or family member
Self-defined attitudes towards data	36 'data absolutists'; 40 'data pragmatists'; 26 data unconcerned
Place of residence by ICS	21 participants from North Central London ICS; 20 participants from North East London ICS; 21 participants from North West London ICS; 19 participants from South East London ICS; 21 participants from South West London ICS
Place of residence by borough	Participants from all 32 London boroughs were present

[2] Public deliberation in the use of health and care data: Appendices. Accessible at: https://www.onelondon.online/wp-content/uploads/2020/06/Appendices.pdf

Participants' initial views on health data use

Participants' initial views on health data use

Chapter summary

- During spontaneous discussion participants identified several advantages of health data sharing, while also being mindful of data security risks.
- While deliberating secondary uses of health data, participants once again acknowledged substantial benefits yet expressed concerns about potential data breaches and confusion related to the different levels of data identifiability.
- Participants also raised concerns regarding the amount of data required to do research, the accuracy of London's health and care data and the potential for research to create unintended consequences. Concerns were also raised concerns regarding the use of artificial intelligence and the risks of cyberattacks and data breaches. AI emerged as a more prominent concern than it has in previous deliberations on health data, including our 2019 deliberation on the use of health and care data in London.
- Participants were most enthusiastic about health data research where they could identify tangible benefits to patients and the public.
- Participants were particularly concerned about for-profit companies accessing health data, however this was often secondary to the overall positive impact of the research.
- Participants found reassurance in the concept of researchers accessing data through a secure data environment (SDE). However, concerns persisted regarding the potential risk of data breaches and the possibility of researchers misusing the data.
- Participants held differing views on London's position on the National Data Opt-out, ultimately recommending further engagement and communication on the topic.

At the start of day one, participants heard a series of presentations and explored a number of case studies to help them develop their understanding of what health and care data is, different types of health and care data and how health and care data is collected, stored and accessed for purposes beyond direct care. They were invited to share their spontaneous reflections in the early stages of the workshop.

In spontaneous discussion participants identified several advantages of health data sharing, while also being mindful of data security risks

Participants' initial responses on health data sharing, before learning about Secure Data Environments, show that although there is enthusiasm for sharing health data, there is also concern regarding the use of their data and potential security issues.

Convenience, accessibility and innovation were the main positive themes identified by participants. There was a shared sentiment among several participants that health data sharing could enhance the health and well-being of London residents, primarily due to individuals' data being more readily available to clinicians across the system. Participants responded positively to the expectation that increased data sharing would prevent them needing to retell their medical history to multiple healthcare professionals. In spontaneous discussion participants primarily focused on uses of data for direct care.

Data security and data protection were the main risks identified by participants. Participants expressed concerns about the security of their data, who would be granted access to their data and under what conditions.

While deliberating secondary uses of health data, participants once again acknowledged substantial benefits yet expressed concerns about potential data breaches and confusion related to the different levels of data identifiability

Following a presentation on the use of health and care data in service planning, improvement, population health management and research, concerns were raised around breaches of personal data. There was some confusion too about the different types of personal data, especially de-identified data. Some participants also expressed concern that de-identified data, including sensitive medical information, could potentially be reidentified.

"You may have something you don't want the rest of the world to know, someone who's got a virus, like HIV virus. They're fine, they're ok, but it's nobody else's business other than their own." *(Table 1, Day 1).*

In general, however, participants were reassured by the knowledge that data would be de-identified before being used for secondary purposes. Participants also acknowledged that secondary data uses could enable high quality research and planning, leading to service improvements and the development of new and lifesaving treatments. Furthermore, there was some agreement among different tables about the merits of moving to a digital environment, considering the risks associated with paper records.

"As long as it's going to help someone, I don't mind… If it was like a pharmaceutical company or someone that was in the health sector, I wouldn't mind but if it was like… a bank I wouldn't want them to give my details." (Table 5, day 1)

Participants also raised concerns regarding the amount of data required to do research, the accuracy of London's health and care data and the potential for research to create unintended consequences

Participants voiced concerns around the amount of data needed to address a research question – particularly when this felt excessive. Others were concerned about the potential insufficiency of data, both in terms of accuracy and quality, to perform high-quality research that could effectively guide health decisions. Additionally, participants were concerned about the risk of stigmatisation as a result of research, leading to adverse outcomes and challenges for specific groups. This concern was especially pronounced in the context of the frailty case study, where participants feared individuals could be unfairly labelled as 'frail' and consequently be treated differently in healthcare settings.

"Just because someone is older, doesn't mean that all old people suffer from the same medical conditions. In this country, people reach a certain age, and we start to generalise and make assumptions based on people's age." (Table 7, Day 1)

There was further concern about who will have access to the data and whether it will be shared with third parties. There was a strong fear that personal conditions and/or lifestyle choices, flagged on health records, could ultimately be used to the detriment of the individual. Data users that evoked the least trust were pharmaceutical companies and for-profit organisations.

Participants were most enthusiastic about health data research where they could identify tangible benefits to patients and the public

When reviewing a series of case studies (which included research on identifying individuals at risk of frailty, research on asthma prevalence, and a diabetes drug trial feasibility study), participants identified several distinct advantages of health data research. These included:

- The potential for research to result in new or improved treatments that could save or change lives.

- The potential for health data research to offer improved quality of care for communities deemed 'vulnerable' or under-served within the existing system.
- The potential for NHS data to inform policy decisions (for instance, policies relating to air pollution)
- The potential for health data research to inform how resources can be efficiently allocated within the health and care system.

"It's all to our benefit, why would you not want your information to be shared...I wouldn't see the problem." (Table 8, Day 1)

Participants were particularly concerned about for-profit companies accessing health data, however this was often secondary to the overall positive impact of the research

There was positivity about using health data in clinical trials and in drug development. However, opinions were initially mixed about commercial organisations being involved in these activities. Some felt unsure due to a lack of trust around the motives of for-profit companies, whereas others recognised the benefits to the NHS of having them involved, due to their spending power and expertise. Collaborations with pharmaceutical companies were perceived as a potential avenue for freeing up NHS resources to concentrate on other priorities.

"As long as this drug is good and does what it says on the tin, I don't mind if [access is] given. If the pharmaceutical company pay the NHS, if they're efficient, they will spend it for our benefit." (Table 10, Day 1)

There was some distrust in pharmaceutical companies due to a perception that they are driven by financial motivations, and profit making, rather than helping patients and improving healthcare. Participants were also concerned about the NHS having to pay high fees for drugs produced by companies using UK health data. Universities, by comparison, were more trusted. From an early-stage participants voiced expectations that the NHS should levy charges for data access and that necessary incentives should be in place for the NHS to share data with private entities.

"What I tend to find is the scientists who do the research get the cures, but the drug companies will develop the drug for solely the financial side of it." (Table 6, Day 1)

"The NHS has to get value from it and whether that's actual money or reduced cost of drugs that's the thing that is critical. They must get value for their data." (Table 5, Day 1)

Participants found reassurance in the concept of researchers accessing data through a secure data environment (SDE)

After discussing the potential uses of health data in London, participants were presented with an overview of secure data environments (SDEs). The presentation covered what SDEs are, the 'six safes' that ensure their safety[3], and the history of trusted research environments in London.

Participants were reassured by the idea of researchers accessing data through the SDE. They were almost unanimous in preferring this approach – often referring to the reading library used as an analogy - over the traditional practice of sending datafiles to researchers. They found comfort in knowing that data use would comply with the six safes and not leave the secure environment.

Some participants who had previously been more skeptical shifted their perspective on data use in London after learning about the SDE, appreciating the added protection and privacy that the SDE offers.

[3] The 'six safes' are six rules that govern how SDE data is stored and accessed, and by whom. For more information on the 'six safes' see page 19 of this report: https://www.onelondon.online/wp-content/uploads/2022/10/A-deliberation-on-Londons-health-and-care-data_FINAL.pdf

Participants were optimistic about the potential opportunities that could arise from consolidating all Londoners' health and care data into a single environment. They recognised the transformative potential of this approach, offering new avenues for research and insights into improving health and care outcomes across the city.

"A safe data environment is definitely better." (Table 7, day 2)

"The infrastructure around the data, the security is pretty robust [in an SDE]. Even if the data is hacked, it can't be assigned to a specific individual. Even if there was a breach, I think you would still be safe on an individual level." (Table 7, day 2)

However, concerns persisted regarding the potential risk of data breaches and the possibility of researchers misusing the data

Participants still expressed concerns about the potential for human error or malicious actions that could compromise the correct functioning of the London SDE. For instance, they were worried about the risk of someone taking unauthorised pictures of the data within the environment or deliberately manipulating or altering the data.

To address these concerns, participants believed that ensuring proper staff training and adherence to a clear protocol for data use would help the London SDE to minimise the likelihood of errors and unauthorised access. Additionally, participants emphasised the importance of imposing severe sanctions in case of any data breaches, which would act as a deterrent and promote responsible data handling.

Despite the widespread view that the London SDE offers a more secure model for data use, participants acknowledged that it would not be possible to eliminate all risk associated with heath data research. Therefore, their concerns about potential risks and vulnerabilities persisted, even though they recognised that the London SDE's features helped mitigate some of these risks.

"They seem to have taken lots of precautions, they've got six, but it's like you can lock your doors and windows but a burglar will get in." (Table 1, Day 1)

Participants also expressed concern about the potential consequences of any breaches due to the large volume of data stored within the London SDE. There was a related concern that hackers might be incentivised to target the system due to the vast amounts of data held within it. Moreover, given the volume of data held in the London SDE, participants highlighted the possibility of rogue researchers or for-profit companies exploiting the data to conduct very powerful research for potentially harmful purposes, such as creating addictive drugs or conducting research not aligned with health objectives.

The awareness that the London SDE could be utilised to foster new and innovative research also raised some concern - in particular about the potential implications of AI projects. Participants raised concerns that researchers might lack full control over AI projects and apprehensions that AI algorithms could be used to reidentify individuals. Additionally, participants displayed some unease about the automated deidentification process, fearing that it might not be entirely foolproof, potentially leaving certain individuals identifiable within the London SDE.

Participants raised queries about whether the LSDE would be accessed in a physical environment, through approved devices or through researchers' personal computers. Some expressed concern about the idea of remote access, fearing an increased risk of data breaches, such as unauthorised photography of data, and the lack of ability to closely monitor accessors in such scenarios.

Apart from the enhanced security and safeguards provided by the technical infrastructure and rules of the SDE, participants commonly advocated for additional assurances. They emphasised the need for a 'human element' in overseeing the SDE and governing access to it. This anticipation of the importance of governance and human discretion pre-empted the subsequent discussions about the SDE's access criteria.

"Wouldn't there be [additional] safeguards? Don't they have to jump through hoops first, before they can use it?" (Table 3, Day 1)

Participants held differing views on London's position on the National Data Opt-out, ultimately recommending further engagement and communication on the topic

Participants were encouraged to share their reflections on London's position on the National Data Opt-Out of confidential information being used for research and planning, which is that the opt-out should not apply to SDE data due to its 'effectively anonymous' nature. There were two prevailing views concerning London's interpretation of the opt-out.

One viewpoint was supportive of London's position given the robust data security measures in the SDE and the rigorous controls protecting the data. Those who held this view believed that these safeguards minimise the risk of reidentification to such an extent that it should no longer be a major concern. Additionally, those who held this view highlighted the risk associated with a significant number of individuals opting out of having their data included in the SDE, which could undermine the accuracy and comprehensiveness of the data. This, in turn, might skew research results and diminish the overall value of the data to researchers, by extension reducing the potential impact of the SDE on improving the health of Londoners.

"I'm ok because you can't get accurate data sets for the reason that if a lot of people opt out you don't get a true representation of the population so you're missing out on a hell of a lot of benefits." (Table 4, Day 1)

Particular concerns were raised regarding the possibility that certain demographic groups might be more inclined to opt out, which could potentially lead to research becoming less relevant to them. To address these concerns, participants inquired about the feasibility of forecasting the number of individuals in London who might choose to opt out and the demographics to which they would belong.

"If the required data has not been given over… then there will be gaps in the data required by the medical professionals to make the right decisions. Why not just remove the opt out option altogether? If it's only going to lessen the quality of medical advice because of the gaps, it can only be detrimental." (Table 7, Day 1)

"I'm quite torn, I get why they would not want the opt out and the reasoning of it then skewing any research purposes. I personally am very comfortable with it, but the idea of nobody being able to opt out, I don't know how well that would go down." (Table 6, Day 1)

The opposing viewpoint, on the other hand, was not aligned with London's position on the opt-out. This view was underpinned by the principle that individuals should have the autonomy and choice to decide how their personal data is used, irrespective of the safeguards in place.

"I feel a bit cheated; I opted out but now I know my data hasn't completely been deleted." (Table 11, Day 1)

Some who held this view expressed heightened concern about the lack of control over sensitive data (particularly mental health data) being stored in the SDE without the ability for individuals to opt out. These apprehensions were accentuated during discussions on day two when participants were presented with a fictional data access request concerning the linkage of NHS and police crime data to address domestic abuse. In such instances of perceived invasiveness, participants strongly believed that individuals should have the option to opt out of having their data included in the SDE.

"I think if there's enough people contributing, there's an awful lot of data… People have contributed this data and they might not be aware of it if their opt out is disregarded- [we need to consider] fairness for everybody, for the suppliers [of data], the people collating the data and the people who are using the information and benefiting." (Table 3, Day 2)

Suggestions were put forward about an opt-in mechanism, which some felt would be preferable to ensure a higher level of individual control over the data. Although this idea was quickly challenged (both by those who agreed and disagreed with London's position), given the risk that this could result in insufficient data being available in the SDE, which could limit the scope and impact of valuable health data research in London.

"I don't like this opt out business, it's like don't give me the information and then I have to look through it to opt out, I should have to look through the information to opt in rather than having to opt out. " (Table 4, Day 1)

"The problem of opting in is that even if you don't have a problem with it, you won't go out of your way to opt in, but with an opt-out system you need to have a strong view in order to be motivated to opt out." (Table 2, Day 1)

Regardless of individual participants' position on the opt-out, there was a near-unanimous consensus that greater transparency, communication, and engagement were crucial regarding the implementation of the opt-out policy. Participants felt this would help to build public trust in whatever position London ends up adopting.

"It needs to be made public information that that is the case, make it completely clear, so it can't come out in the future and people say, "well I didn't agree to that." (Table 1, Day 1)

"There needs to be more communication and engagement about London's position regarding the opt-out." (Table 2, Day 3)

On day three of the process, despite not reaching a consensus on what London's opt-out position should be, participants were able to agree on the importance of engaging and communicating more about the opt-out policy. This became the recommendation that participants collectively developed.

Principles that should underpin direct access to the London SDE

Principles that should underpin direct access to the London SDE

Chapter summary

- The question agreed for deliberation was '*What criteria should the Independent Information Access Group (IIAGs) use when deciding to permit direct access to deidentified data, including for non-member organisations?*'.
- Participants were generally less comfortable with commercial access given that these organisations will profit from using patient data. However, while it was common for participants to be less comfortable with commercial access, most indicated that they were willing to accept this assuming several conditions were in place.
- Suggestions around profit shares, reinvestment of money back into the NHS and discounted charging came up early on, and before the conversation moved onto charging.
- Public benefit was the overriding factor in determining whether data accessors should be given direct access to deidentified data in the SDE. The number of people affected by the condition was very important to participants, as was the extent to which the research could bring about lifesaving or lifechanging benefits to people. This said and participants were divided on their views around life-limiting conditions that affect a very small number of people.
- Participants were also supportive of research that could bring about benefits to groups who are currently underserved or overlooked and projects where the benefits could be broader, for example transferrable knowledge or wider learnings.
- Participants emphasised the importance of minimising stigma and raised the risk that through some health data research existing health inequalities could be exacerbated.
- There must be a clear rationale that data held in the London SDE is necessary or beneficial to the research. This was particularly the case when international organisations request access going forward.
- In considering how requests should be prioritised, a number of factors were identified including the ability to demonstrate broader benefits and demonstrable clear benefits to London or the UK.
- Participants were supportive of projects that felt more feasible in terms of the application of the findings.
- AI research raised lots of questions and was uncomfortable for some and insurance companies were a red line for most.
- Participants voiced expectations around the need for all organisations to be vetted to check they have the right skills, intentions and a trusted track record, with additional checks and balances for international organisations and in relation to sensitive and/or identifiable data.

Deliberation question

Future access to the London Secure Data Environment (SDE) is governed by Independent Information Access Groups comprising members of the public as well as various professionals (for example, clinical, research and information governance expertise). There is a London-wide Independent Information

Access Group (IIAG) and five Data Access Committees for each of London's Integrated Care Systems (ICSs).

While previous public engagement and deliberations in London suggest the public expect there to be independent data access groups in place, with a range and balance of membership[4], there is little understanding of public expectations around the criteria such groups use to make decisions about access requests.

Additionally, findings from previous public engagement in London have been grounded in the reality of NHS analysts facilitating access. Given that this approach is resource intensive, costly and could create a bottleneck for research, the intention is to offer *direct access* to deidentified data in the London SDE for non-members who have the appropriate capabilities and credentials. Organisations that contribute data or provide infrastructure (NHS, local authorities etc.) will be members of the SDE.

The question agreed for deliberation was thus:

What criteria should the IIAGs use when deciding to permit direct access to deidentified data, including for non-member organisations?

Through a series of facilitated discussions, and using fictional data access request, participants discussed the multiple trade-offs concerning how decisions should be made, such as the scale of public benefit, commercial gain (for the NHS or others) and the credentials of the accessor.

Participants were generally less comfortable with commercial access

In line with previous public engagement, there was more concern around commercial organisations accessing the data directly, in comparison to non-member NHS partners, universities or charities [5]. The prevailing reason for this was discomfort with the idea of commercial organisations profiting from using patient data, though other less common reasons included a worry that they might reuse data for other purposes (facilitators needed to remind people that access was via the London SDE and for an agreed purpose and timescale). Where international commercial organisations were involved, there were questions about their motivations: solely financial or health related too.
While it was common for participants to be less comfortable with commercial access, most indicated that they were willing to accept this assuming the following conditions were in place:

- Demonstrable public benefit from the project
- The data was assured to be secure, and approved users were coming to the London SDE to access it (the data was not shared with them)
- The NHS would (also) financially benefit from the project or partnership.

The involvement of NHS individuals or organisations in commercial partnerships, as demonstrated in some of the fictional data access requests, provided extra reassurance to some.

Suggestions around profit shares, reinvestment of money back into the NHS and discounted charging came up early on, and before the conversation moved onto charging

As noted above, there was widespread recognition that commercial companies will stand to gain financially when using NHS data. This was uncomfortable, hence the ability for the project to

[4] Discover-NOW Citizens Advisory Group Deliberation 1, Report. Accessible at: https://imperialcollegehealthpartners.com/wp-content/uploads/2021/03/Discover-NOW-Citizens-Advisory-Group_Deliberation-1_Report_Feb2021.pdf

[5] Public deliberation in the use of health and care data. Accessible at: https://www.onelondon.online/wp-content/uploads/2020/07/Public-deliberation-in-the-use-of-health-and-care-data.pdf

demonstrate public benefit became even more important (see below). During discussions around commercial access, and before the conversation moved onto one about charging during the second workshop, participants spontaneously suggested several ways that the NHS could stand to benefit financially:

- discounted or free products later down the line
- a share in the profits if the research was successful and led to new drugs, medical devices, or other interventions.

[When discussing a data access request from a commercial organisation about using AI to detect signs of stroke on brain scans] ***"There would be a need to negotiate that there would be a significant discount for NHS use of the application, since the NHS helped to develop it."*** (Table 2, Day 1).

There was often an expectation voiced around the need to reinvest money back into the NHS, particularly where the company was international given the perceived additional financial benefits to the companies involved from global sales.

[When discussing a data access request from a Large US health tech company developing an AI algorithm to more accurately detect breast cancer] ***"Again, there's more opportunity to get money from this. They'll be even more people to benefit in the US, I imagine, so if they're going to benefit, they should invest in the NHS in turn for what they're going to gain in the future".*** (Table 2, Day 2).

[When discussing a data access request from a Large US health tech company developing an AI algorithm to more accurately detect breast cancer] ***"This data is unique in the UK, no one else has got this data so it's incredibly valuable. It must be taken forward, but there must be a benefit, because it's a unique set of the data, they should be charged for the use, it could be access to the AI, or the NHS could sell it to the world. This is a good case for using the data."*** (Table 6, Day 2).

Public benefit was the overriding factor in determining whether data accessors should be given direct access to deidentified data in the London SDE

When participants assessed fictional data access requests across workshop one and two, it was clear that the extent to which the project sought to bring about public benefit was the most important factor to consider. For the most part, public benefit was seen to be the overriding factor, regardless of the kind of organisation requesting access (i.e. commercial companies included here), where the organisation was based (i.e. outside of London, international companies included here), and the fact that the organisation would likely profit from using the data. In most situations, though not all, participants were happy to trade these factors off so long as it was clear that the project would bring about public benefit. In its broadest sense, public benefit meant one or a combination of the following:

- the prevention of diseases and conditions in early stages.
- speeding up access to treatments or diagnoses.
- finding new cures or treatments, thus saving lives or improving quality of lives.

The importance participants placed on demonstratable public benefit was evident as they discussed the data access requests, they were less likely to approve. These tended to be those where the public benefit was vague, unconvincing, or less tangible.

[When discussing a data access request from a small Swedish medical devices company wanting to conduct a feasibility study around chronic back pain] ***"This is not a free lunch is all I'm saying, and this is written as though it's a free lunch. I have to see some benefit to the NHS to making that data available."*** (Table 5, Day 1).

The number of people affected by the condition was very important to participants

Where the condition or disease was seen to affect large numbers of people, participants placed a lot of emphasis on the importance of these projects going ahead.

"[When discussing a data access request about a ICB in Southwest England requesting access to deidentified data in relation to adolescent mental health] ***"Yeah, I'd say mental health affects everyone, everyone probably knows various people that have mental health, it's like a big thing with that one. Like a really big problem in England, I would say."*** (Table 5, Day 1).

[When comparing three data access requests] ***"Number 3*** [a Large US health tech company developing an AI algorithm to more accurately detect breast cancer] ***has a potentially greater benefit to more people."*** (Table 4, Day 4).

This meant that even where the company proposing to conduct the research was commercial and/or international - or not based in London (see sections which follow) – where the condition was seen to affect a lot of people, most were supportive. Two examples of this were as follows:

- A data access request from a large healthcare AI company based in the UK requesting access to data to use AI to detect signs of stroke on brain scans. Participants were immediately drawn to the potential to bring about benefits to large numbers of people, at the same time recognising the financial strain that the identification and treatment of strokes place on NHS services.
- A data access request from a Large US health tech company developing an AI algorithm to more accurately detect breast cancer. Participants recognised the scale of the problem, with large numbers of women (both domestically and globally) affected by breast cancer, thus the potential to diagnose this sooner and more accurately was very appealing to people.

The extent to which the research could bring about lifesaving or lifechanging benefits to people was also important, although participants were divided on their views around conditions that affect a very small number of people

In addition to bringing about benefits to large numbers of people, participants were also very supportive of research focussed on bringing about benefits to people which are likely to be lifesaving or lifechanging, although they recognised that this could be hard to define. These were conditions or diseases with significant adverse effects on quality of life, and where treatment of those patients was financially burdensome for the NHS. They highlighted that these conditions don't only affect the patient but also their family members, carers and support networks. Examples included stroke, chronic back pain and Motor Neurone Disease.

[When discussing a commercial data access request about using AI to detect signs of stroke on brain scans] ***"Strokes can completely ruin your quality of life. Anything they can do to pick it up."*** (Table 1, Day 1).

[When discussing a data access request from a UK medical research charity in partnership with a UK pharmaceutical company, evaluating the effectiveness of a new drug treatment for Motor Neurone Disease] ***"In some ways the treatment is so expensive, of someone living with MND day to day, I think that outweighs the cost of not doing it."*** (Table 1, Day 2).

Conversely, there were participants who deprioritised conditions which affect small numbers of people (Motor Neurone Disease), even though the impacts of these were felt to be life limiting. They perceived the costs associated with the investment required to pursue the research (particularly where the company was looking for NHS resource to support the project) to outweigh the potential benefits (particularly given these would be to smaller numbers of people).

[When discussing a data access request from a UK medical research charity in partnership with a UK pharmaceutical company, evaluating the effectiveness of a new drug treatment for Motor Neurone Disease] ***"So my point really was, it's very resource intensive and the benefit is to a very small number, even though it's a massive benefit to them, maybe it's a lower priority."***(Table 3, Day 2).

Participants were supportive of research that could bring about benefits to groups who are currently underserved or overlooked

Participants also spoke of the importance of encouraging research which has the potential to bring about benefits for groups who are currently underserved or overlooked. Mental health (as per one of the fictional data access requests) was an example of this, as was Motor Neurone Disease given that it affects small numbers of people so was perceived to require funding to progress treatment options.

"[When discussing a data access request about a ICB in South West England requesting access to data in relation to adolescent mental health] ***"I think it is a real issue. I do tutoring of GCSE kids and within the last 5 years about 7 of them have committed suicide, so much so that there is going to be an inquest. I think it's a really bad situation and there is a definite need."***(Table 6, Day 1).

As well, when participants discussed the linking of police data with health data, in relation to domestic abuse, despite a lack of trust from some in the police to be involved (see below), they were keen to see an otherwise overlooked area being tackled through data use.

Participants supported access to data for projects where the benefits could be broader, for example transferrable knowledge or wider learnings

Participants were drawn to projects they perceived to offer translatable learnings, either to other diseases and/or for other healthcare systems globally, as well as projects which were perceived to reduce financial pressures and/or operational burden on the NHS. Examples of these included:

- A project concerning a Large US health tech company developing an AI algorithm to more accurately detect breast cancer**.** Participants assumed that learnings from this could be applied to other types of cancer.

- A project concerning a commercial data access to use AI to detect signs of stroke on brain scans. Participants assumed that the AI model could be applied to other disease areas such as cancer.

- A project concerning a UK medical research charity in partnership with a UK pharmaceutical company, evaluating the effectiveness of a new drug treatment for Motor Neurone Disease. Participants were hopeful that findings might be transferrable to other rare diseases such as Parkinson's disease.

The importance of minimising stigma and ensuring the risk that existing health inequalities may be exacerbated is reduced

As participants discussed two particular fictional data access requests, concerns were raised around the potential for discrimination, as well as the risk of stigmatising people and exacerbating existing health inequalities. This was a concern and made the fictional access requests far less appealing.

- *An NHS Integrated Care Board in South West England requesting access to deidentified data to identify trends between mental health service referrals and wider determinants of health, with a focus on adolescents:* Some participants raised concerns over children being labelled, which could adversely impact negatively on them in the future. Additionally, some participants questioned the ethics of this kind of data use given that adolescents won't have consented to their data being used in this way.

- *Several London Integrated Care Boards and a regional police force, supported by a UK-based AI company requesting access to deidentified data (such as free text police data) to mine so that it could be coded and then linked to deidentified health data, to detect trends to help determine the predictors of A&E attendance following a police intervention relating to domestic abuse safeguarding concerns for either adults or children:* Discussion around this request evoked suspicion with some participants perceiving the example to be one of profiling. Additionally, and given the very sensitive nature of the police data in particular, participants questioned the ethics of using data in this way, with some noting the lack of consent and the fact that some people may have previously opted out.

Incidentally, the use of non-NHS data in these examples was more contentious and raised questions around the motivations of, and trust in, the other bodies involved. As seen in other health data public engagement, the diameter of trust was important here [6].

"It may break the trust people have in the health services or professional services, that it's going to be shared with the police or beyond." (Table 1, Day 2).

There must be a clear rationale that data held in the London SDE is necessary or beneficial to the research

Participants were encouraged to think about data access requests outside of London, for example those coming from other regions of the NHS, non-London universities, national and international charities and commercial organisations. Participants were clear that there would always need to be a rationale as to why London's population data is needed. For example, as they discussed a fictional data access request depicting an NHS Integrated Care Board in Southwest England requesting access to deidentified data to identify trends between mental health service referrals and wider determinants of health, with a focus on adolescents, there were questions raised over the similarity of the demographics in London and the South West. For example, participants spontaneously highlighted that the overall demographics were different, thus non-comparable, and teenagers' experiences in London will be different to those in more rural areas.

As well, participants were curious as to why international companies would want to access London's data set. Alongside the justification for *why* the data is needed, participants commonly spoke of the need for London or the UK to receive some sort of financial incentive and wider benefits such as knowledge.

There were occasional suggestions to add clauses into contracts to ensure that data users were committed to ensuring that the benefits would be realised in London/the UK more widely.

"[When discussing a data access request from a large US pharmaceutical company wanting access to data to determine how effective an anti-Covid drug is] ***"We should insert a clause in any contracts to make sure there are benefits to the NHS."*** (Table 11, Day 1).

[When discussing a data access request from a small Swedish medical devices company wanting to conduct a feasibility study around chronic back pain] ***"Yeah I don't think I'd be bothered about the country so much, I just think that there should be something that will help London."*** (Table 5, Day 1).

In considering how requests should be prioritised, a number of factors were identified including the ability to demonstrate broader benefits (beyond public benefit) and clear benefits to London and/or the UK

Participants were encouraged to voice which factors they would use in deciding how to prioritise data access requests. These were:

[6] Public deliberation in the use of health and care data. Accessible at: https://www.onelondon.online/wp-content/uploads/2020/07/Public-deliberation-in-the-use-of-health-and-care-data.pdf

- Those **requests that can demonstrate broader benefits** (in addition to public benefit) such as reduced burden for the NHS.
- Those requests that **are likely to deliver public (and potentially broader) impact more quickly**.
- Those requests with **a clear impact for London or the UK**, either in terms of the health outcomes or the generation of jobs and investment.

Participants were supportive of projects that felt more feasible in terms of the application of the findings

Ability to follow through with the research findings was a factor which some used in deciding whether they found a data access request acceptable, or in prioritising data access requests.

Participants raised the importance of official bodies, such as the NHS, police, or social services, taking forward the findings from the research and efficiently implementing changes. There was some doubt raised to this effect - driven by a lack of faith and trust - in the ability of the police to do so. As well as concern about the ability of the NHS to translate research findings given the current pressures on services.

[When discussing a data access request from a Large US health tech company developing an AI algorithm to more accurately detect breast cancer] ***"I'm all for early detection and saving lives, but loads of people will be given a diagnosis that cannot be treated."*** (Table 9, Day 2).

[When discussing a data access request from a private consultancy working with an NHS Integrated Care Board to support GPs to identify people at risk of hypertension] ***"This sounds amazing however logistically how is the NHS going to support 4 million people when we know there's long waiting lists to see a doctor and specialist."*** (Table 8, Day 1).

AI research raised lots of questions and was uncomfortable for some

Given that supporting AI will be a priority for the SDE in London, several of the fictional data access requests introduced the idea of AI and algorithms.

There were some clear positive associations with these technologies, such as efficient savings, particularly with regards to freeing up NHS clinicians in the context of workforce challenges and current NHS pressures.

[When discussing a data access request from a Large US health tech company developing an AI algorithm to more accurately detect breast cancer] ***"In a way they'll free up the radiologists' time by using AI, so they can bring forward more tests."*** (Table 2, Day 2).

However, more often than not participants had questions about the technology, and it was clear that these were being driven by a lack of understanding, trust and fear.

- There were participants who were worried about the involvement of algorithms in clinical decision making.

"I'm not keen on algorithms at all, a lot of them have gone very wrong. They can really hurt people rather than help them. The one that stands out to me is the one with the Post Office, people's lives were ruined." (Table 1, Day 1).

- There were also participants who were fearful that AI (robots) would replace humans and jobs would therefore be lost.
- Finally, and in the context of discussions about patient data, some perceived data to be *more* identifiable with AI involved given the perception that free text data is commonly used, and larger

volumes of data will be mined. This led to suggestions around the need for patient consent (or for London to apply the National Data Opt-Out) when using data in this way.

Insurance companies were a red line for most

Previous public engagement on behalf of OneLondon[7] and others[8] [9] has concluded that the public are against deidentified health and care data being accessed for insurance and marketing purposes. The public tend to agree that this type of research doesn't serve a health purpose or benefit.

The same was true here, with participants generally uncomfortable about insurance companies being given access to the deidentified London SDE data given the perception that requests would be driven by commercial gain, with no wider benefits to patients, the population, or the NHS.

"[When discussing a data access request about an insurance company wanting access to data] ***"It doesn't say what the motivation for the insurance company is, if we go back to is it in the public interest, [I] would say no…it's in the corporation's interest."*** (Table 9, Day 1).

"[When discussing a data access request about an insurance company wanting access] ***"I would say no, because that is strictly for their gain, and there is no benefit to the NHS to providing that information."*** (Table 2, Day 1).

Participants discussed a fictional data access request based around a global insurance company requesting access to deidentified data to explore the correlation concerning air pollution of where someone lives with the likelihood of developing respiratory-related conditions. In doing so, they voiced a lack of trust in insurance companies and their motivations, despite some recognising that the research findings might be useful to the NHS. There were questions over whether the money would go back into the NHS and how the NHS would benefit.

Fundamentally participants disagreed with the idea of using postcode data in a way that could result in increased insurance premiums and wider impacts on things like rent and council tax. It felt unfair and discriminatory to penalise people because of where they live, with some flagging that people who live in the most polluted areas are likely to be from poorer backgrounds and thus least likely to be able to afford high premiums.

"This screams discrimination. Our predisposition to certain diseases. If this company can access all the information about South West London, now it's going to be like, 'All the black and Asian people could now have insurance premiums' and I don't think that's fair. It should be the same across the board for everybody. I don't think that's good… The discriminatory potential here, this is like the poster child of what you should not do." (Table 3, Day 1).

Not all participants were completely against insurance companies using deidentified data however, recognising that they would benefit from good quality data to inform their businesses. For this minority, the idea in principle felt justified, however the implications (rising premiums because of where people live) felt unfair. Some indicated that they would be comfortable with insurance companies accessing data so long as agreements were in place stating that people's premiums would not be affected as a result.

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[7] Public deliberation in the use of health and care data. Accessible at: https://www.onelondon.online/wp-content/uploads/2020/07/Public-deliberation-in-the-use-of-health-and-care-data.pdf

[8] The One-Way Mirror: Public attitudes to commercial access to health data Report prepared for the Wellcome Trust. Accessible at: https://www.ipsos.com/sites/default/files/publication/5200-03/sri-wellcome-trust-commercial-access-to-health-data.pdf

[9] Public perspectives on access to health data by non-traditional researchers: findings from deliberative workshops. Accessible at: https://dataloch.org/sites/default/files/2022-07/Public%20deliberations%20on%20access%20to%20health%20data%20by%20non-traditional%20researchers.pdf

Organisations to be vetted to check they have the right skills, intentions and a trusted track record, with additional checks and balances for international organisations and in relation to sensitive and/or identifiable data

As noted above, participants were generally less comfortable with commercial access. For this reason, and additionally where the organisations were international, they expressed a desire to see a thorough vetting process to ensure that those accessing the data had the right skills, intentions, and a trusted track record. They wanted organisations to commit in writing to the rules and protocols for access – and clearly state the remit of the project both in terms of type of data needed and for how long - before being granted access to the London SDE and to be held account for any data breaches.

At the same time, participants had elevated concerns about privacy and data security when they discussed more sensitive data (i.e. that of children), or data that was perceived to be more identifiable (i.e. in relation to Motor Neurone Disease given it is a rare disease and linked free text police and health data). Particularly in the context of commercial access, though more generally too for any kind of access request coming from a non-NHS member, they called for additional checks and balances for projects dealing with more sensitive data and where data access was required for a longer period of time.

"[When discussing a data access request about a ICB in Southwest England wanting to access data in relation to adolescent mental health] ***"Because it's children, you want to be extra safe, and you need to be even more sure that it's not re-identifiable."*** (Table 2, Day 1).

Expectations for access criteria

Expectations for access criteria

In-between the second and the third day of the deliberation, the Ipsos and Imperial College Health Partners team devised a set of draft expectations based on a high-level analysis of the data collected across days one and two. These draft expectations were ratified with table facilitators, before being presented to participants at the start of the third day. The 50 participants working on the access criteria expectations initially discussed them in four groups of 12/13. Smaller groups of 12/13 were merged into two groups of 25, where amendments were compared and agreed changes implemented (based on consensus). Later the two groups of 25 merged to a group of 50 where expectations were voted on in situations where there were alternative versions of the same expectation, or where new expectations had been previously added.

Next the consolidated set of expectations from the access criteria group of 50 was presented to the 50 participants working on the charging criteria, for their feedback. The access criteria group of 50 looked at this feedback and made decisions about tweaks to the expectations accordingly. At the end of the day, the final expectations from the access criteria group of 50 were voted on by all participants.

Voting results

The final expectations on access criteria received a high level of support from participants with 88% of participants declaring their support for all or most of the recommendations. A further 8% indicated that they supported some of the expectations, while only 4% did not support any of the recommendations.

The full results were as follows:

To what extent, if at all, do you support these recommendations concerning criteria to support decision making about requests for direct access to deidentified data within the London SDE?

The final set of expectations

The final set of expectations on charging, ratified by the participants at the end of day three, were as follows:

In making decisions about whether direct access to London's SDE should be granted, we expect the following to be demonstrated for each request….

A clear and demonstrable public benefit. This is the most important factor to consider. The level of 'public benefit' should be estimated according to the following factors:

- The **breadth of the benefit** (volume of people), including the potential impact on wider family members and support networks
- The **depth of the benefit** (level of benefit), and whether the benefits are likely to be lifesaving or lifechanging – and how it impacts quality of life (e.g. significantly reduce discomfort)
- The **extent to which there will be benefits for groups who are currently underserved or overlooked** (i.e. minority groups or people suffering from a little-understood condition)

There was widespread agreement on this expectation with very few changes between the draft and the final expectation. When the groups of 25 came together, references to the impact on wider family members was added, as well as the impact on quality of life and reduction in discomfort.

Participants did highlight the difficulty both in defining public benefit and predicting the benefit of research before it has been conducted. Again, when participants discussed whether breadth of the benefit (volume of people) should override depth of the benefit (level of benefit) during Workshop 3, they returned to the same dilemma that they had debated previously. There were concerns that by focussing on scale of impact, there is a risk that rarer disease areas will be excluded and there were participants who were fundamentally against this. For this reason, a prevailing view was that *both* the breadth and depth of benefit should be considered in gauging public benefit, as well as considering how to avoid overlooking minority groups (i.e., the third bullet point in the expectation).

That the **project will create broader benefits such as new understanding, information and/or treatments** rather than duplicating past research (i.e. is it an under-researched area or a potentially novel breakthrough?) and/or the project has the potential to create real-world impact.

This expectation did not change between draft and final and was uncontested by participants. Some spoke of capacity building for the NHS as an important wider benefit.

That **existing health inequalities will not be exacerbated** through the work, and that no groups will be negatively impacted or harmed. This is particularly important when considering linking of NHS data with non-NHS data e.g. police data.

This expectation did not change between draft and final and was uncontested by participants.

That there is a clear rationale that data held in the London SDE is necessary or beneficial to the research.

This was a new expectation that participants created during Workshop 3, in recognition of discussions on the previous two days around how unique and special the London SDE dataset will be, regarding the population demographics and size of the dataset. There was some concern that the SDE will be overburdened with requests accordingly and recognition that might not always be necessary to use London's data. One group therefore devised an expectation around the need for data accessors to justify that the London dataset is necessary or beneficial to the research, and this was voted on to include in the final expectations by the other groups working on access.

In considering how requests should be prioritised…

Requests that can demonstrate broader benefits (in addition to public benefit) should be prioritised e.g., those that may reduce operational or financial burden on the NHS, or projects where learnings can be applied in other disease areas.

This expectation was uncontested in its draft form, and the only addition was put forward by one of the groups was to add 'operational or financial burden on the NHS' (where previously it read 'reduce burden on the NHS or save the NHS money'). This was ultimately the result of one group's suggested addition to specify the cost savings to the NHS and others agreed with this addition hence the change was implemented.

Requests that are likely to deliver public (and potentially broader) impact more quickly could be prioritised over those projects where benefits may take longer to be realised, for example, in cases of unexpected health emergencies.

This expectation remained similar between the draft and final version, with the exception of one group's addition (which was voted for to include) for 'in cases of unexpected health emergencies', having reflected on how vaccine development projects would have needed to happen at pace during the Covid-19 pandemic. And the group of 50 voting to change 'should' to 'could' given agreement that it would depend on the situation. There was some disagreement, when one of the groups of 25 came together, about the risk that those managing the SDE will lose sight of major benefits which might be more long-term, by focussing on short term gain.

Regardless of timeframe, **anything that is within the NHS priority areas** (informed by ongoing engagement with health experts) should be prioritised.

This additional expectation was added by participants in Workshop 3. In recognition that NHS resources in London are limited, a suggestion was put forward (that was later voted on and added) to prioritise projects which could alleviate pressures on the NHS the most. Participants had ideas about how this could be done, and suggestions put forward around consulting health experts on which projects would alleviate pressures on the NHS, hence the final wording around ongoing engagement with these.

Requests with **clear impact for London or the UK** (either in terms of health outcomes or the generation of jobs and investment) should be prioritised over requests that do not directly benefit London/or the UK.

The draft version of this expectation was not changed at all, however there was some debate within smaller groups about whether priority for access should be given to requests that can demonstrate clear benefits to London, and additionally would benefit the UK. While others assumed that if there were benefits to London, there would naturally be benefits to the UK.

Participants came round to recognise that the expectation specified London *or* the UK and thus were comfortable with keeping it as it was.

Projects that are willing to publish their findings (and/or share with NHS) should be considered for priority.

This addition came about through a discussion in one of the groups about the need for transparency, however not everyone was on board with this initially given the worry that this would discourage some commercial organisations (who might otherwise need to keep commercially confidential information out of the public domain) from accessing the data. The expectation was softened to include the caveat that the project would be willing to share the findings with the NHS and when groups merged to 25, and later to 50, participants voted to keep this.

More generally, we expect…

Organisations to have **undergone a vetting process** to check they have the right skills (and expertise by experience), intentions and a trusted track record (or with a 'guarantor' with a trusted track record) before they are granted access to the London SDE.

This expectation changed slightly between draft and final, with the addition of the brackets specifying a guarantor, given the recognition that new organisations would not necessarily be able to provide a track record. While this was added as an alternative, not all participants agreed with it as it was felt to be unfeasible to assume that all would be able to put forward a guarantor.

Organisations to **commit in writing to the rules and protocols** for access before they are granted access to the London SDE, and to be held accountable for any breaches.

This expectation did not change between draft and final and was uncontested by participants.

Requests should clearly state the remit of the project and access should be limited to this, both in terms of type of data needed and for how long.

This expectation did not change between draft and final and was uncontested by participants.

The technical system to be able to ensure named individuals can only access what they are authorised to and only for the agreed project duration (time limited access).

This new expectation was crafted in one group, and later voted on in the groups of 25 and 50, due to an acknowledgment about the importance of having the technical ability to ensure that only named individuals can access the authorised data and only for the agreed period.

There are to be **additional checks and balances in place** for projects that are longer term (e.g., six months or longer), using more sensitive data (e.g. mental health data or rare disease data that may be more identifiable) and/or projects being led by international organisations and/or those with no track record. These should include:

- Regular audits to check the data is used for the purpose requested and by the agreed accessors, and
- Quality checks on how analysis is being conducted.

These checks should be as efficient as possible e.g. automated/using AI.

This expectation was worked up from its draft form to include additional considerations for projects being led by international organisations and/or those with no track record. As well, participants in one group specified that these checks should include audits and quality checks, and these additions were voted on in the groups of 25 and 50. One group suggested that automation should be explored, given the perceived burden of manual checks and again, this addition was voted on in the groups of 25 and 50.

Projects should have to apply again if a company with access is taken over.

This new expectation came about during a discussion in one of the groups about how companies might change their focus if they are acquired by other companies and so they would need to reapply for access if this were to happen, albeit perceived to be rare. This addition was later voted on by the groups of 25 and 50.

More communication and engagement about London's position on the national data opt-out.

It was highlighted in one group that in the context of London's interpretation of the opt-out, the terminology in itself is very misleading given that there is no opt-out. As flagged earlier, there was no consensus when discussions circled back to the opt-out (following the information they had received on day 2), but participants were keen to see more work done on this. For some, this was about communicating and educating people, whereas for others it was more about deeper engagement.

There to be a way to report any concerns about how the data is being used (e.g., data breaches), in a confidential way.

In one of the groups participants suggested the idea of an anonymous whistleblowing process, where staff could report misuse of data from other staff for example. This was later crafted as an expectation and had unanimous support from the groups of 25 and 50.

Access and charging criteria/rules should be reviewed after one year initially, and then every three-years.

This new expectation was added in recognition that the criteria may become outdated over time. There was some debate about how frequently to do this, as some participants highlighted that it would be costly and resource intensive to initiate a review (they assumed that the public would be brought together as they had been for this deliberation), so the consensus was to review the criteria initially after one year and then subsequently every three years.

Red lines

Under no circumstances should access be granted to insurance companies or marketing agencies.

This expectation did not change between draft and final however one of the groups of 25 did propose softening the rules on insurance companies given that there may be health benefits to some research undertaken by them. In the group of 50, 15 of 50 voted for this, however 35 of the 50 voted to keep the expectation as it was (i.e. with the wording 'under no circumstances') and thus it remained unchanged.

The NHS should not let itself be taken advantage of and **should ensure it gets a fair return** when companies/individuals make big profits from the research based on NHS data.

This new expectation was added by one of the groups of 12/13, after a discussion about how the NHS should always receive a fair return when commercial companies are making big profits from the research based on NHS data. The group wanted to solidify this concern and so created a red line to this effect. There was near unanimous agreement to keep this expectation when the group of 50 voted on it.

Police should not have direct access to health data in the London SDE.

This new red line was added as a result of participants in a couple of the groups of 12/13 discussing their concerns about the police directly accessing data in the London SDE. One group suggested that this would be made more acceptable by only allowing the police to have access if they did so via an academic institution, however this was later discounted as it felt like this could be a risky loophole. All but 5 people of out 50 voted to the police not having direct access to health data in the SDE.

No access should be given to non-member organisations that cannot cover their costs.

This new red line was added following feedback from the group working on the charging criteria, and this was unanimously voted in by the group of 50.

Principles that should underpin charging for direct access to the SDE

Principles that should underpin charging for direct access to the London SDE

Chapter summary

- The question agreed for deliberation was "What criteria should drive decisions about charging, and what are the principles that underpin more complex interdisciplinary partnerships?"
- Notwithstanding some concerns about perceived 'commercialisation' of the NHS, participants generally acknowledged the importance of the London SDE implementing a charging model and supported the introduction of a tiered pricing model.
- Once a project has been confirmed by the IIAG as being in the public interest (see previous chapter), participants widely regarded the type of accessing organisation to be the most influential factor in determining the appropriate charge for a data request. There was a shared sentiment that large commercial entities should incur the highest data access costs, while non-member NHS organisations should be charged the lowest, with charities and universities falling in between.
- A strong consensus emerged that the London SDE should distinguish companies based on their ability to pay. Initially participants were split over whether organisations should be differentiated based on the turnover of the company or its profits, but participants ended up opting for turnover-based charges.
- Participants were generally enthusiastic about the London SDE exploring other value exchange models, such as discounted products, shared IP and discounts based on sharing profits.
- Participants acknowledged a potential need for higher fees for accessors seeking more sensitive data, large amounts of data or longer access durations.
- Participants were divided on whether international organisations should face higher charges for access. Some felt the location of the accessing organisation should be secondary to its characteristics, reputation and track record. Others believed working with UK organisations would be less risky and yield additional economic benefits to London, leading them to advocate for lower fees for UK-based organisations.
- Once projects have met the access criteria and demonstrated public benefit, participants felt they should be further distinguished based on whether or not they align with NHS priorities. If projects do align with NHS priorities, participants felt they should not only be prioritised for access (see previous chapter) but also considered for a discounted charge.
- There was a prevailing view that the charges levied on accessors should reflect the amount of time and resource required of the NHS to acquire, curate, and (if necessary) analyse the necessary data. Participants were clear that the NHS's costs should always be recuperated.
- Participants felt that the London SDE's charging model should incentivise longer-term partnership-building, either through offering discounts or implementing a 'loyalty scheme' for regular users.

- Participants felt that access fees should reflect the distinctiveness and quality of the London data set. However, they also recognised that competition in the national and global market may necessitate reduced prices to attract new data users, especially when comparable data could be accessed elsewhere at lower costs.
- Initially, some participants felt non-member organisations partnering with member organisations, or higher-paying organisations collaborating with lower-paying ones, should receive a discount on access. Others felt the London SDE should charge according to the rate incurred by the higher-paying partner. In the end, participants recommended that charges should instead be based on who is funding the research.
- Participants were split on whether organisations that pay more for access should be given priority access to the London SDE.

Deliberation question

There are significant costs associated with establishing and maintaining a pan-London SDE. The initial investment costs, spread across the first three years, are projected to be approximately £17 million, and the annual costs thereafter in the region of £3-5 million. The London Health Data Strategy Programme (LHDSP) intend to recoup these costs by charging non-member organisations (organisations that do not contribute data to the London SDE such as pharmaceutical companies, academic institutions and charities). Initially, any funds generated will be used to recover the costs of initial investments, however it is possible that over time a surplus could be generated.

Previous public engagement has demonstrated clear support for accessors contributing an up-front fee, and there has been clear endorsement for implementing a tiered pricing model for accessing data [10]. It has not yet been made clear, however, how pricing tiers should be defined.

The question of how to define pricing tiers is technically and ethically complex, requiring the London SDE team to balance financial incentives with the need to support maximum research opportunities. Additional complexities arise when research is interdisciplinary or pursued by more than one organisation (for instance NHS providers collaborating with commercial organisations). Previous engagement in London has not yet addressed these complexities in depth.

The question agreed for deliberation was thus:

What criteria should drive decisions about charging, and what are the principles that underpin more complex interdisciplinary partnerships?

There was clear and widespread support for the adoption of a tiered pricing model

On the whole, participants acknowledged the importance of the London SDE implementing a charging model aimed, at the very minimum, at recouping the expenses involved with establishing and maintaining the London SDE. As highlighted earlier in this report, from day one of the process – before any specific information or stimulus on charging was presented and before participants were prompted on this topic – participants spontaneously put forward suggestions to levy charges on accessors and offered ideas on potential charging mechanisms as a natural extension of the SDE access criteria.

"We need to position ourselves financially in this world market as others will want access to the data. Our data is a valuable commodity." (Table 4, Day 2)

[10] Public deliberation in the use of health and care data. Accessible at: https://www.onelondon.online/wp-content/uploads/2020/07/Public-deliberation-in-the-use-of-health-and-care-data.pdf

Upon being prompted to share their reflections on the proposal for a tiered pricing model that arose from previous public deliberation, apprehensions were raised regarding the potential perception of NHS data being "sold". However, some of these concerns were allayed by the assurance that researchers would be paying for access to the data through the London SDE, rather than being given a copy of the data itself.

"One of the reasons people have issues with the data, there is a perception that the data is being sold." (Table 10, Day 2)

Although participants exhibited broad support for charging accessors, there were concerns about the NHS potentially adopting an excessively commercial approach, potentially at the expense of its core health-related objectives. There was a fear that exorbitant charges could impede research endeavours in London. Participants recognised the need to strike a balance between the financial sustainability of the London SDE and the need to facilitate innovative and impactful research.

"We need to recognise that we have competition, so if we price it highly, people might go elsewhere. So, are we aware of how our competition, basically, has structured their pricing?" (Table 2, Day 2)

The adoption of a tiered pricing model was perceived to address some of these concerns, presenting a fair and transparent approach whereby accessors could be charged varying amounts based on their financial capacity or specific data requirements. Participants supported the idea of implementing an upfront access fee for all non-members, and expressed the sentiment that the NHS should not undervalue its resources. However, it was also observed that the charging model should be structured in a way that does not impede smaller or less affluent organisations from engaging in research. In these respects, participants endorsed principles that have emerged from past engagement on the topic (which were presented to the participants on day 2 [11]):

- It is important that the NHS gets a fair value return.
- There should always be an up-front access fee.
- There should be a tiered pricing model.
- The approach should not exclude smaller/less affluent organisations.

In defining the charging tiers, organisation type was paramount. Participants widely regarded the type of accessing organisation (whether it be a commercial organisation, a charity, a university, or another public body) to be the most influential factor in determining the appropriate charge for a data request. However, it was acknowledged that additional considerations (outlined below) were also crucial in distinguishing between organisations of the same type (for example, differentiating between large and small for-profit companies). One table recommended the London SDE itself follow a similar process when calculating charging rates: start by considering the organisation type, then review other factors.

"You have to separate the fees: a flat rate of fees whether [the organisation is] abroad or here, whether it's a charity [or another organisation] and then you tier it from there [based on] turnover and headcount." (Table 7, Day 2)

Initially, in more spontaneous discussion, there was some resistance to the concept of charging based on organisation type rather than other characteristics of the research project, largely due to the belief that public benefit should be the overriding factor in determining access charges. However, when participants were given the task of comparing and ranking examples based on appropriate charges,

[11] Discover-NOW Citizens Advisory Group Deliberation 2, Report. Accessible at: https://imperialcollegehealthpartners.com/wp-content/uploads/2021/06/20-103669-01-Discover-NOW-Deliberation-2_Report-FINAL.pdf

there was clearly a prevailing consensus that organisation type should indeed serve as a crucial determining factor in the charging structure.

"I would charge [the tech company testing an algorithm designed to detect rare diseases] a lot because they are a private tech company… [if it were a university] I would then charge less. My views would be very different for educational purposes." (Table 4, Day 2)

Several tables were asked to compare two fictional data access requests: one from a large US-based pharmaceutical company and the other from a small London charity. Participants were unanimous that the large US-based company should pay more, due to its greater spending power and profit motive. Another table, when asked to compare a university with a very high turnover and a small commercial startup, maintained that the small company should be charged more.

Across all tables, there was a prevalent view that large commercial entities should bear the highest cost for accessing the data.

"So [the organisation in request 8 'Pharmaceutical company examining outcomes of patients treated with anti-Covid-19 medication'] is a large company. Their motivation is financial. The company may be [working on] Covid but… we have something they want, let's take them. They can afford it." (Table 10, Day 2)

Conversely, participants commonly specified that non-member NHS organisations should be charged the lowest access fees for the London SDE data.

"Could it be something like mates' rates? If the organisation is within the NHS, you'll get mates' rates? You're not situated in London, but you're within the NHS, and it's to do with the nation's wellbeing." (Table 2, Day 2)

Charities and universities were frequently positioned between commercial organisations and non-member NHS organisations, yet no distinct consensus emerged on how to differentiate between these two organisation types. Divergent viewpoints surfaced during the deliberation. On the one hand, participants advocated for universities to be charged more than not-for-profit organisations, due to their potential for substantial profits and large endowments. However, others expressed scepticism toward large charities, which were perceived as offering exorbitant salaries to senior staff.

There were a range of views on whether the turnover of a company, or its profits, should influence how for-profit companies are differentiated

While arguments were made on some tables that all for-profit companies should be charged a uniform rate, the prevailing view among participants was that a more nuanced approach was necessary to differentiate between requests from commercial entities. Two primary models were proposed for making this distinction:

1. Ranking companies based on projected profits, or recovering a portion of any profits made from research
2. Ranking Companies Based on Turnover

When companies secure considerable profits from projects using NHS data, a prevailing perspective emphasised the need for the NHS to recover a portion of this surplus. A similar viewpoint that emerged suggested a charging model that takes into account projected profits. Participants put forward two primary benefits of adopting a profit-based charging model:

- It could lead to greater revenue for the NHS in situations where companies make large profits.
- It could lead to the NHS receiving payment over a longer period of time (if the NHS takes a share of profits from a project) as opposed to a one-off fee.

These perceived benefits convinced some to argue that profit should be the primary variable to determine charges for different companies.

"We need to negotiate a percentage basis from it like 10% of the drug they produce from the result. It would be a better option than collecting a standard fee." (Table 5, Day 2)

Participants also, however, raised risks associated with a profit-based charging model. These included:

- An acknowledgement that accurately forecasting or tracking a company's profits could be challenging.
- Concern about the NHS resources that would be required to successfully negotiate profit-sharing contracts with companies or to effectively track organisations' profits.
- The risk that the company may not make a profit or may only break even after a long period.

"There are a lot of legal fees to do with [taking a profit share] and it would also consume a lot of time… I'd like to explore other options." (Table 3, Day 2)

Turnover of a company was identified in some groups as a more straightforward and consistent metric for comparing commercial entities. This approach was seen as a means to allow the NHS to get a fair deal when working with large for-profit companies, while also reducing barriers to small for-profit companies pursuing research. One table started out supporting a profit-based model but over time, through considering and comparing a set of examples, came to favour turnover as the key differentiator. It was also suggested that an up-front charge based on turnover could be combined with a profit-based fee over time.

"With profits you are not looking at their balance book, it is the potential. Turnover would be a clear indicator. Do they have a track record?" (Table 4, Day 2)

Participants, however, voiced a concern that charging large companies based on their turnover might deter them from accessing the London SDE data and lead them to seek data from alternative sources, potentially depriving London of valuable investments and potential benefits arising from research collaborations.

[When discussing a large pharmaceutical company seeking to examine outcomes of patients treated with anti-Covid 19 medication] ***"We cannot charge really high just because they may make a lot of money, as it might affect their decision [to seek data in London.'"*** (Table 11, Day 2)

In general, a strong consensus emerged that the London SDE should distinguish organisations based on their ability to pay, assessed through factors such as profit, turnover, or a combination of these metrics. There was a widespread view that this principle could also be applied to non-commercial organisations. For example, suggestions were made to charge larger charities more than those in lower income bands, and participants acknowledged that some universities have considerable turnover and profits.

Participants were generally enthusiastic about the London SDE exploring other value exchange models, such as discounted products, shared IP and discounts based on sharing profits

In addition to the SDE exploring profit-based charging options, participants expressed an interest in the SDE considering alternative 'value exchange' models. These models included discounted access or shared intellectual property (IP) of products developed using NHS data. There was a proposal to make organisations eligible for up-front discounts if they committed to other forms of value exchange, thereby reducing immediate research barriers, especially for smaller organisations, while ensuring equitable arrangements for the NHS.

"There could be an agreement that when they make a drug that works, they then sell it back to the NHS. If we give them a good rate, they then give back at a good rate." (Table 4, Day 2)

It was also suggested that a company could be made eligible for a discounted access fee if they were to offer the NHS a share of any future profits resulting from their research. This was thought to allow the NHS to reduce up-front costs (that might inhibit valuable research or price out smaller companies) while still potentially receiving significant financial gains over time.

However, participants did acknowledge that implementing such value exchange models, and determining when to offer up-front discounts in exchange for them, could pose challenges, for instance the requirement of commercial negotiation expertise on part of the NHS and the potential expenses and administrative complexities associated with establishing contracts and implementing the agreed terms.

Participants felt the charging model should account for the amount of data being accessed, the sensitivity of that data and the duration of access required

When prompted for their spontaneous input, multiple tables suggested levying additional fees for accessors requiring substantial amounts of data or access to data over extended periods. Participants believed that longer-term projects could demand more NHS resources over a prolonged duration, potentially limiting resource for other endeavours, and that the benefits from such projects might be realised in the more distant future. Moreover, participants perceived that the longer data is accessed, the higher the risk of potential data breaches, and felt that this elevated risk should be factored into the pricing structure.

"I think that if the long studies are being conducted, they should pay for the length. If it's a short study, they should pay a lesser amount… We are the best in the world at what we do, when we get it right. We can't just be like, 'Oh, okay we'll just accept that.' No, they've come here for a reason. Don't sell ourselves short." (Table 3, Day 2)

"The more data they need, the more should be charged. It's like getting travel insurance." (Table 3, Day 2)

On the other hand, participants expressed concerns that charging based on the amount of data requested or the duration of access could potentially discourage important and complex projects, such as longitudinal research and AI initiatives, which have the potential for transformative impacts.

"I don't think **[duration of access is]** ***a big consideration, because if it's a big and complex project, it's going to take longer to do. You should take it into account, but I don't think it's the top consideration if it's helping people."*** (Table 2, Day 2)

"[I agree that] we want to get as much revenue as we can, but at the same time it should be a fair system. Some need it for six months, others for 3 years. If we make it too expensive, they'll go elsewhere. It was mentioned in the slides that there was going to be competition within the UK and elsewhere as well." (Table 3, Day 2)

Similar arguments were raised concerning the perceived sensitivity of the data being accessed. Participants suggested that accessors seeking more sensitive data should be charged more to account for the higher risk associated with potential data breaches. Participants emphasised the sensitivity of mental health data in this context.

(When considering a Swedish medical devices company wanting to conduct a study around chronic back pain) ***"The data seems so comparatively non-sensitive. The less sensitive the data, the more discount. If for example, the company was a small pharmaceutical firm working on a new anti-depressant, that's a more potentially controversial area and the sensitivity of that data is around mental health."*** (Table 3, Day 2)

Participants were divided on whether international organisations should face higher charges for access

Some participants thought international organisations, especially large ones, should be charged more than UK-based organisations for access to the data.

Participants generally displayed an aversion towards US pharmaceutical companies, expressing a desire to apply higher charges to them. However, this apprehension often coexisted with a more lenient overarching principle that the location of the accessor should not be the primary consideration when determining charging tiers. According to this principle, the key factors (after the type of organisation seeking access) should instead be the purpose of the project (and its alignment with NHS priorities) and where any impact would be felt, regardless of where the organisation is based).

"If you are looking at a request from public health benefit, [the location of the accessor] wouldn't change anything." (Table 11, Day 2)

"80% of the pharma industry is outside of the UK, so why would we want to cut ourselves off from it [through higher charges]?" (Table 6, Day 2)

On the other hand, concerns were expressed about non-UK organisations being subject to different laws and regulations, which could impact data handling and potentially raise data privacy and security issues. There was also a perception that UK-based organisations could bring additional benefits to London, such as the creation of jobs and increased investment, fostering local economic growth and development. These perceived benefits of incentivising UK-based organisations and perceived risks of granting access to non-UK organisations led some participants to maintain that non-UK organisations should be charged more than UK-based organisations.

"USA and other markets have different regulations so it would be difficult to exercise any actions or accountability on it." (Table 5, Day 2)

The London SDE should offer favourable rates to projects that align with NHS priorities

In spontaneous discussion, participants judged public benefit to be an important factor in determining how accessors are charged for data. In some instances, the beneficial impact of a project was considered to carry more weight in determining pricing tiers than the organisation's type.

Participants recognised that establishing an objective framework for ranking projects, or offering discounts, based on their level of public benefit (and assigning costs accordingly) could present challenges. The determination of public benefit might involve complex considerations – including the 'breadth' of benefit, the 'depth' of benefit and any impact on health inequalities – making it difficult to devise a standardised and impartial evaluation method.

Additionally, it was understood that all approved projects would have already demonstrated public benefit during the IIAG approval stage, making this consideration less important at the charging stage.

As a more objective basis for distinguishing projects (in order to assign discounts) alignment with NHS priorities was proposed as an alternative criterion. Participants emphasised that projects commissioned by the NHS, like the fictional request involving a private consultancy working with an NHS Integrated Care Board to identify people at risk of hypertension, should be treated favourably in the charging model due to the high likelihood that such research would respond directly to a priority identified by the NHS.

"I wonder if the measure of benefits might be the NHS priorities… how can it feed into those." (Table 7, Day 2)

Even when considering a request from a large US pharmaceutical company, participants showed a willingness to offer a discounted price due to the research focusing on an area perceived to be a priority for the health system (examining outcomes of patients treated with anti-Covid-19 medication). Another

table suggested that they might have recommended an even lower price for this project had the request been made during the acute period of the pandemic when Covid-19 was a higher priority for the NHS.

"If they are doing something the NHS recommends but doesn't have time to do then charge them a little as they are doing something the NHS would like to do." (Table 7, Day 2)

In circumstances where substantial NHS time or resource is required to prepare or curate the data, the NHS should be fairly compensated

There was a prevailing view that the charges levied on accessors should account for the amount of time and resource required of the NHS to acquire, curate, and analyse the necessary data. While the type of organisation and the purpose of the project were generally considered primary factors, the resource intensity was still an important consideration raised on a majority of tables.

When considering a fictional access request involving an NHS Integrated Care Board in South West England linking data to facilitate early identification of adolescent mental health problems, participants were inclined to add additional charges to reflect the high levels of administrative and technical support required to link and curate the requested data.

"Would [the ICB] be using the data independently, or would an NHS analyst have to explain the data as well? That should be an additional cost add to the service… If the NHS had to put a project manager on it, then yes you'll have to pay for that." (Table 1, Day 2)

However, when evaluating a fictional access request presented by a small charity, participants highlighted concerns that additional charges could potentially disadvantage the organisation, given its limited spending power. This apprehension led to the conclusion, expressed by certain participants, that the resource- and time-based charging principle should be secondary to other critical factors, such as the type and size of the accessing organisation.

"If you're going to charge [the charity] and they can't afford it, they'll just get ruled out of acquiring the data… If it costs too much they just won't do it." (Table 6, Day 2)

Participants felt that the SDE's charging model should incentivise longer-term partnership-building

Participants suggested two subtly different potential approaches for how the London SDE could establish strategic research partnerships by rewarding regular customers:

1. Implementing a 'loyalty scheme' that provides incentives or benefits to organisations that frequently access the London SDE data.
2. Offering discounted access to repeat users with a proven track record of productive and responsible collaboration with the London SDE.

"Could there be, like, a library card for frequent users?... You can be, like, a gold customer, with your track record. You might earn brownie points for working with [the London SDE] and get a discount." (Table 2, Day 2)

Participants expect the NHS to consider its bargaining power in different situations and to set prices accordingly

Participants were proud of London's demographic diversity and enthusiastic about past investment in London health data. There was a widespread view that London's health data represents a uniquely valuable resource for researchers and that the charging model should account for the quality and distinctiveness of London's health data – particularly in circumstances where accessors can only conduct their research using London data.

However, participants also recognised that in some circumstances the London SDE might need to consider its position in the national and global market and lower its prices to attract new data users to the

London SDE – especially in situations where other SDEs could offer a similar service for less, or where companies do not stand to gain large profits from a piece of research.

"[It's important to] recognise our bargaining power varies. A big company like Pfizer might say it's cheaper to get the Berlin data than the London data. We need to be competitive and attractive enough to [attract accessors to] come to London to get the data here, not elsewhere." (Table 1, Day 2)

There were different views about how the London SDE should charge multi-disciplinary partnership requests, but participants ultimately favoured charging partnerships based on who is funding the research

In unprompted discussions, participants recognised the necessity for the charging model to account for more intricate scenarios, such as requests made by partnerships comprising both member and non-member organisations or collaborations between companies and public authorities.

Many participants intuitively believed that non-member organisations partnering with member organisations, or higher-paying organisations collaborating with lower-paying ones, should receive a discount on access. This approach was perceived to incentivise constructive partnership-building between researchers and the NHS, promoting collaborative research projects that align closely with NHS aims and objectives.

"[Offering a discount to partnership requests] would certainly incentivise companies to have partnerships with the NHS which may well benefit all of us ultimately." (Table 4, Day 2)

Participants also expressed concern that charging partnerships too high a fee for access could result in the costs being passed on to the NHS partner, leading participants to favour a discounted fee for partnerships between NHS and non-NHS organisations.

There were widespread concerns that non-NHS organisations (particularly for-profit companies) may enter into partnership with the NHS simply to avoid access charges, without genuine intention to meaningfully collaborate. Participants stressed the importance of the IIIAG demanding transparency regarding the nature of any partnership to enable the London SDE to comprehensively understand the motivations of each partner and what they stand to gain from the collaborative work.

"What if they just use NHS, get what they want and cheat them? How do we move forward [with this] in the future?" (Table 11, Day 2)

In light of these concerns, it was suggested that the London SDE might avoid offering a discount and instead charge according to the rate incurred by the higher-paying partner. One table (table 10) suggested that instead of offering a discount to non-members partnering with members, these requests could instead be granted priority access to the London SDE.

"I think it should always go to the highest. That would stop big corporations going to find small charities to save money, to find a loophole to save money. This would block that." (Table 1, Day 2)

Another suggestion proposed by participants – and ultimately the most popular suggestion (see following chapter) was to charge based on who is funding the research. For example, if an NHS organisation is commissioning a company to undertake research, the rate would be lower than if a company were funding the NHS. This approach would serve as a proxy for identifying which organisation will primarily benefit from the research outcome. It was also thought that charging the funder would prevent large companies from establishing 'satellites' to avoid access charges.

It was recognised that it may be challenging to determine who is ultimately funding the research in some cases, and that this would require obligations of transparency at the access committee stage, but participants did suggest some questions for the London SDE to ask to ascertain the "beneficial owner" of the research as demonstrated in the quote which follows:

"What is Google's relationship with [the smaller organisation? Do they own it, are they stakeholders, do they own 50% of it? If they don't own it, are they distinct entities but it's Google that's funding? What is the business relationship with Google, are Google going to market this item, are Google going to take the knowledge and buy out that company? Have they got a deal that in 2 years' time they've got an option to buy that company? Then Google is the beneficial owner." (Table 4, Day 2)

While acknowledging the difficulties in determining who is ultimately financing research, participants concluded by the third day of the process that on the whole they supported the proposal to base partnership charges on the organisation that is funding the research.

Participants were split on whether organisations that pay more for access should be given priority access to the London SDE

While some participants were relatively comfortable with the idea that high-paying accessors may be prioritised for access (particularly in situations where the research is urgent and pressing), the prevailing view across the participants was that it would be unfair to allow organisations to pay for 'fast-track' access. It was thought that this would result in large companies always being at the front of the queue, even if their projects do not prioritise patient need or align with NHS priorities.

"If there's another pandemic and suddenly, [an organisation] needs access to that data, then maybe it would be fair for them to pay more just to get access to it quicker. So, if they want to access data quicker, there should be a clear and fair objective." (Table 11, Day 2)

"There's no integrity. If that's [an organisation's] view on queueing. If they think money can get you to the front of the queue, then what else is going on in their minds that might lead them away from the path of prioritising healthcare?" (Table 2, Day 2)

Expectations for charging

Expectations for charging

In-between the second and the third day of the deliberation, the Ipsos and Imperial College Health Partners team devised a set of draft expectations based on a high-level analysis of the data collected across days one and two. These draft expectations were ratified with table facilitators, before being presented to participants at the start of the third day. The 50 participants working on the charging expectations initially discussed them in four groups of 12/13. Smaller groups of 12/13 were merged into two groups of 25, where amendments were compared and agreed changes implemented (based on consensus). Later the two groups of 25 merged to a group of 50 where expectations were voted on in situations where there were alternative versions of the same expectation, or where new expectations had been previously added.

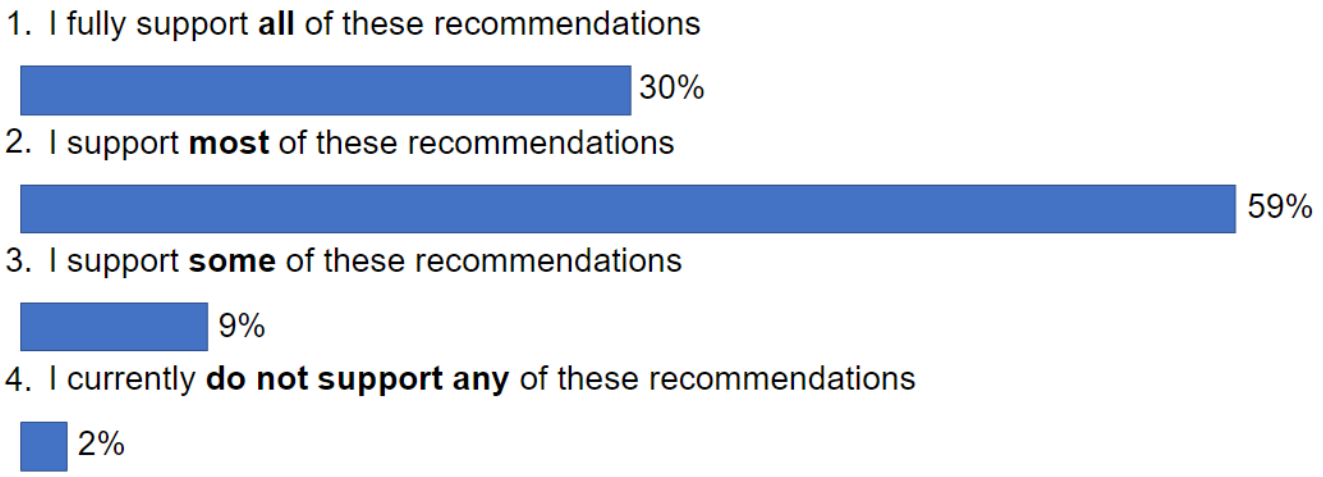
Next the consolidated set of expectations from the charging group of 50 was presented to the 50 participants working on the access criteria, for their feedback. The charging group of 50 looked at this feedback and made decisions about tweaks to the expectations accordingly. At the end of the day, the final expectations from the charging group of 50 were voted on by all participants.

Voting results.

The final expectations on charging criteria received a high level of support. 89% of participants declared their support for all or most of the recommendations, while only 2% did not support any of the recommendations.

The full results were as follows:

To what extent, if at all, do you support these recommendations concerning principles guiding how much organisations should be charged to access deidentified data within the London SDE?



The final set of expectations.

The final set of expectations on charging, ratified by the participants at the end of day three, were as follows:

In deciding how much to charge organisations requesting access to the London SDE, we expect the following principles to be applied…

Priority should be given within the charging structure to the overall benefit of the project to the NHS, London and the UK population (primary use case of the data should be factored into charging).

While acknowledging the potential challenges involved in predicting the outcomes of research, participants expressed a strong desire for 'public benefit' to be included in the charging expectations. This was notwithstanding the fact that a 'public benefit' criterion would also be applied to IIAG's preliminary access decision, underlining the significance participants attached to the London SDE continuously considering the benefits of research to the public and the NHS. This expectation was added by participants to the draft set of recommendations. The group voted for this expectation to encompass UK-wide benefits, not simply benefits experienced in London.

Profit-making companies should pay the most and non-member NHS organisations should pay the least for access to London's SDE. Charities, non-member local authorities and universities should be charged somewhere in between. However, the SDE should recognise that these distinctions are not always clear cut (e.g. universities or charities may have high turnover and/or make profit from research in which case they should pay more than charities/universities with lower turnover).

While there were some queries about the notion of universally charging for-profit companies more, participants were generally in favour of this principle. However, participants emphasised the importance of accommodating differences between for-profit companies, charities, and universities in size and income. This sentiment is reflected in the final version of this expectation which incorporates this qualification. It is also reflected in the following expectation.

Large for-profit organisations (measured by turnover) should be charged more up-front than smaller for-profit organisations.

One the whole, participants supported charging companies with high turnover more than smaller companies. However, there were apprehensions that this could potentially hamper research initiatives or impose an administrative burden on the London SDE team. Notably, in early discussions on day three, some participants leaned towards profit-based charges as opposed to turnover-based charges. Nevertheless, due to the complexities involved in assessing profits and negotiating agreements based on profit sharing, participants ultimately favoured a model based on turnover.

UK based organisations should pay less than non-UK organisations (to show support for local companies who support the UK economy). **Global collaboration should not be discouraged – though there should be higher charges for non-UK organisations** if there is no clear benefit back to the UK. There needs to be a clear definition of what is considered 'UK' (this should include where organisations are located, where they pay tax, where their staff are based).

Participants were divided on the appropriateness of charging UK-based organisations less than those outside of the UK. It was felt that doing so could stimulate UK business and yield health benefits for the country, but there were concerns about the London SDE being too inward-looking and hindering international collaboration. Ultimately, participants ended up supporting this proposal. However, they placed more emphasis on whether the benefits of research would be felt in the UK rather than solely the location of the accessing organisation.

For projects involving multidisciplinary teams, e.g., NHS and commercial organisations, **charges should be applied based on which organisation/s is funding the work**. To support this process, requests should be clear about all participating organisations, and which are providing funding.

Although different views had previously emerged about how best to charge projects involving multidisciplinary teams, by the third day there was broad consensus in favour of charging partnership

requests based on which organisation is funding the research. This approach was deemed as a transparent and fair model for determining costs, ensuring commercial organisations cannot take advantage of other organisations by funding of their research.

We expect discounts to be considered for:

Projects that can **demonstrate a clear and realistic aim to save money for the NHS** and/or a quantifiable/measurable benefit for the NHS (recognising that this is not always straightforward).

Citing the current financial situation of the NHS, participants generally supported the principle of treating money-saving projects favourably, while also stressing the importance of additional non-monetary benefits that could accrue to the NHS. Consequently, the draft expectation was broadened to encompass other "quantifiable/measurable benefits". Nevertheless, participants acknowledged the inherent challenges associated with predicting or quantifying such benefits and raised concerns that granting too many discounts could jeopardise the financial sustainability of the London SDE. Participants argued that this proposed discount, along with the further two discounts listed below, could offer the London SDE a valuable tool to incentivise high-impact research, however they also cautioned against applying too many discounts to protect the London SDE's financial longevity.

Projects that are **aligned with NHS priorities in London**, as set out by the NHS in London. The priorities should be clearly and transparently communicated.

Participants expressed strong support for this principle, believing it would offer a strong incentive for researchers to address urgent health concerns. However, they underscored the need for clear communication of NHS priorities to researchers to be included in the final recommendation to ensure fairness.

Projects that have **exceptional benefits for patients** (a serious disease area, high impact on quality of life). Further work is required to define where benefits are 'exceptional'.

Participants were strongly in favour of incorporating 'public benefit' into the charging criteria. Despite some dissent, the consensus was to limit any potential discount to projects offering "exceptional" benefits, acknowledging that any project that meets the access criteria should inherently provide at least some public benefit. There was, however, lots of debate about what qualifies as 'exceptional' public benefit and who gets to determine this, leading participants to add a suggestion for further work on how this category should be defined. Participants recognised that this expectation closely correlates with the "alignment with NHS priorities" expectation.

We expect additional charges (on top of the access fees) to be considered for:

Projects that **require more SDE support than standard data requests** (e.g. requiring complex data curation, support with analysis etc)

This expectation received a high level of support throughout, with no participants highlighting any drawbacks or proposing any amendments.

Projects that **require access for a longer period** (e.g. more than six months). Projects may not know their exact timelines at the start and efficiency should be encouraged. Additional charges should be applied at regular review points (every six months).

There was some disagreement about whether or not this principle should be included, due to concerns about predicting a project's duration in advance. In light of this, participants proposed including guidance about holding periodic reviews to allow the London SDE to monitor the data usage and requirements of project teams.

Projects that **require access to large amounts of data** (to reflect that its more labour intensive for the NHS to prepare this data) and/or more sensitive data.

There was lots of discussion in the group regarding the potential higher charges for 'sensitive' data. One perspective advocated for the charging model to reflect the heightened discomfort people feel towards certain information and their increased fear of data breaches. An alternative viewpoint argued that the 'sensitive data' category is vague given the inherently sensitive nature of all health data. It was also suggested that the London SDE should be encouraging research on 'sensitive' topics (such as mental health issues or rare diseases), not discouraging them by charging higher access fees. Despite the diverging opinions failing to reach a consensus, the group ultimately voted in favour of including 'sensitive data' in the final expectation.

If the project is **purely for commercial reasons** and is not benefitting the NHS, we wouldn't expect these projects to be granted access but if they are, this principle (i.e. an additional charge) is important.

This expectation received a high level of support throughout, with no participants highlighting any drawbacks or proposing any amendments.

More generally we expect…

London SDE to take advantage of its bargaining power as and when that exists, e.g. higher rates for projects that can only progress with London data.

Participants were eager to ensure that the London SDE received a fair deal for its health data, reflecting its high quality and the diversity of the London population. However, they also expressed concerns about NHS London operating too commercially. In particular there were fears of the NHS in London undercutting other regions for commercial gain. Although no consensus was reached between these perspectives, a middle ground was found in excluding the mention of offering "reduced rates where other SDEs could offer a similar service for less", which was initially included in the draft expectation.

Other value exchange models (beyond fee for access) to be considered to maximise value for the NHS e.g., profit share, discounted products, intellectual property, royalties etc. This should be negotiated up-front to allow greater flexibility for those who can't afford the full up-front access fee.

While there was widespread support for the London SDE considering other value exchange models, groups were divided over the issue of whether accessors offering alternative value exchange models should receive discounted access. In favour of this position, some participants recommended assured discounts for organisations that bring contributions through other value propositions (such as profit share, IP or discounted products), however there was significant opposition to this view from those wanting a guaranteed and sufficient up-front payment for the NHS. Eventually, participants settled on a more flexible stance, delegating the discretion to determine when to negotiate alternative value exchange models and when to adhere to traditional charging models to the SDE team.

Opportunities for longer term strategic partnerships to be explored, e.g. for repeat customers of the London SDE, with a proven track record of delivering benefit to the NHS, in order to encourage and reward these types of users. This is complex and we would like the SDE team to consider how to take this forward in a way which is fair, regularly reviewed, limited and has a clear definition of 'longer-term'.

This draft expectation initially elicited divergent responses. Although participants acknowledged the benefits that the NHS could realise by developing close partnerships with researchers, there were reservations about undermining fair competition. Consequently, participants suggested that the London SDE team give more in-depth consideration to how to foster strategic collaborations with successful researchers without unjustly disadvantaging new users. This was included in the final recommendation.

There should be **opportunities for the NHS to review what it has charged**, dependent on changes to the timeframe and changes to the project scope and any potential buy-out of the organisation.

This expectation was added to the draft recommendations on the morning of day three, after being proposed by one group, and received a high level of support thereafter, with no participants highlighting any drawbacks or proposing any amendments.

Appendices

Appendix: Discussion Guides

OneLondon CAG Deliberation 1: day 1

Saturday 10th July – 10am-4pm. DISCUSSION GUIDE

Prompts in bold text are priority to ask.

Time	Discussion structure	Questions and materials
9.30-10.00	**Arrival and registration**	**Participants arrive at etc venues Mary Ward House** • Participants arrive at the venue, are signed in and given name sticker to wear, with table number shown on it (there will be 12 tables of 8 participants)
10.00-10.15	**Introduction and scene setting** **Plenary.**	**Ipsos Chair to welcome the room to the session:** Introducing the One London/London Health Data Strategy Programme, Ipsos, ICHP, expert commentators, observers, moderators and note takers. Explaining the purpose of CAG and why we have recruited members of the public (their role over this first deliberation and their ongoing role). Explaining this is day 1 of 3, reminding participants about dates and providing a high-level overview of the 3-day process. Also covering ground rules and housekeeping – i.e., breaks, toilets, lunch area and fire alarm.
10:15-10:20	**Importance of public input and reminder of access criteria question**	**Deborah Millington (OneLondon lay representative) presentation (5 mins)** Talking about experience of transitioning from OneLondon Citizens' Summit participant to a lay partner of the OneLondon programme. Stating that they want to be clear that they are making decisions that reflect public expectations.
10:20-10:40	**Meet and greet at tables** **Table discussion**	**Table introductions and ice breaker (<u>20 mins</u>)** • *Facilitator introduces themselves and the table's note taker, thanks participants for coming.* • *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* (<u>10 mins</u>). • *Participants encouraged to express words that come to mind when they think about the NHS using health and care data in London (10 mins)*
10.40-11:10	**The use of health data in planning, improvement,**	**Luke Readman's presentation (<u>10 mins</u>):** To introduce that there are multiple NHS organisations across London, all collecting data at the point of care. This data is joined up into the London Shared Care Record, prevents patients repeating their story. The data has other uses too. When deidentified (explain what this is and how it's done) it can be used in other ways for example in planning, population health management and research. Brief examples used to illustrate different uses. Introduce at high level the benefits and potential risks.

10.50	**PHM and research** **Plenary then table discussion**	**Table discussions (20 mins)** • **What do you think about what you have just heard?** • **Anything unclear or confusing? Anything surprising or shocking?** • Does this match with your prior expectations about how your health and care data is used? • What concerns might Londoners have about their data being used in these ways? • **How do you feel about the use of deidentified data for different purposes?** • Do you have any questions about the presentation or this discussion? *Facilitator to note down Qs to be answered at a later date – if not covered by subsequent information provision.*
11:10-11.25	**BREAK**	**15 mins** *Facilitators to explain to participants that they must be back promptly for a 11.25 start.*
11:25 – 12:05	**Health data use cases to date** **Table discussion**	**Table discussions (40 mins)** Facilitator to present 3 case studies covering different purposes for how deidentified data can be used beyond direct care, and by whom (10 mins per case study). Facilitator to save 10 mins at the end of a discussion comparing and contrasting the examples. • Case study 1: Coordinating frailty care • Case study 2: Asthma services • Case study 3: A new diabetes drug Case study 1 (Coordinating frailty care) Qs: • **How comfortable, or uncomfortable are you with this?** • **Were you previously aware that your health data might be used in this way?** • Is there anything you find surprising or particularly concerning about this example? • **How do you think people across London would feel about their deidentified data being used in this way?** Case study 2 (Asthma services) Qs: • **How comfortable, or uncomfortable are you with this?** • **Were you previously aware that your health data might be used in this way?** • Is there anything you find surprising or particularly concerning about this example? • **How do you think people across London would feel about their deidentified data being used in this way?** • How would you feel if the same data was being used to plan services for a less common condition? Case study 3 (A new diabetes drug) Qs:

		• **How comfortable, or uncomfortable are you with this?** • **Were you previously aware that your health data might be used in this way?** • Is there anything you find surprising or particularly concerning about this example? • **How do you feel about pharmaceutical companies using deidentified data in this way? How would you feel if university researchers/charity researchers were conducting this study instead?** • How do you feel about this data being used to assess the feasibility of a study that is not guaranteed to take place? • How do you feel about the fact data would be accessed in a secure NHS setting? <u>Facilitator asks participants to rank the examples in pairs according to their levels of comfort (10 mins):</u> • **Which examples do you think Londoners would find most and least comfortable about? Why?** • **What questions do these examples raise, if any?** • *(If participants rank the examples differently):* What do you think might be the cause of these differences of opinion? • (*If participants have negative reactions to any of the examples*): What would need to be in place for you to be more comfortable with the proposed use of data? *Where questions are asked about the ability to opt out, tell participants to park these questions as we will be addressing them later in the day.*
12:05-12:30	**SDEs and the six safes** **Plenary the table discussion**	**Rebecca Cosgriff's presentation (7 mins):** To explain what an SDE is, that there are many across the country. Introduce the five safes and provide an example of an SDE in London (DN). **Table discussions (18 mins)** • **What do you think to what you have just heard?** • **Anything unclear or confusing? Anything surprising or exciting?** • **Having heard Rebecca's presentation, how do you feel now about the use of de-identified data being used for different purposes in London? Why?** • We will have a chance to ask questions of specialists this afternoon. Do you have any questions about the presentation or this discussion? <u>*Facilitator to note down Qs to be answered at a later date – if not covered by subsequent information provision.*</u>
12:30-13:15	**Lunch**	**45 mins** *Chair to explain to participants that they must be back promptly for a 13.15 start.*
13:15-13:25	**Introduction to direct access**	**Axel Heitmueller's presentation (10 mins):** On direct access and how decision making around access will be done going forward.

	for non-members **Plenary**	• Explaining the membership model • Explaining the range of non-members likely to be requesting access • Explaining the move away from using NHS analysts, to direct access • Explaining how access requests will be reviewed and approved/rejected. • Explaining the makeup of the IIAGs and their purpose (building on previously set public expectations) • Explaining why there is a need to prioritise direct access requests. Setting the first Q for deliberation (*What criteria should the Independent Information Access Groups (IIAGs) use when deciding to permit direct access to deidentified data, including for non-member organisations?)*
13:25-13:35	**Providing clarity on the opt out in London** **Plenary**	**Luke Readman's presentation (10mins)** • More detail on the NDOO • Overview of the ICO guidance • Overview of London's position and why
13:35-13:55	**Reflective discussion about the change in access in London** **Table discussion**	**Table discussions (20 mins)** Reflecting on presentations (10 mins): • **What do you think about what you have just heard?** • **Anything unclear or confusing? Anything surprising?** • **Do you have any questions about the presentation or this discussion?** *Facilitators to note down areas of confusion or clarification, collect questions for Q&A* (If there is time) Spontaneous discussion (10 mins): • **What are the most important factors Independent Information Access Groups should consider when deciding whether or not to grant data access to a non-member organisation?** *Facilitator to note down some of the key themes that are coming up from the spontaneous discussion.*
13:55-14:10	**Specialist Q&A** **Plenary**	**Plenary Q&A**: Opportunity for participants to ask Qs to allow for any misperceptions to be corrected, and also to provide complete clarity on how access currently works and the proposal for direct access going forward. Facilitators to encourage people on their table to ask Qs they noted down earlier in the day.
14:10 – 14:25	**Break**	**15 mins**

14:25 – 14:40	**Specialist lightning talks** **Plenary**	**Plenary lightning talks (5 mins per talk)** • Data User (commercial) – Talking about what they would want to access the data for and why direct access is appealing as opposed to current process. Talking about their incentives – to support NHS but also commercial gain. • Data Controller (GP) – Talking about importance of protecting data and ensuring it is used for the right reasons, in a safe way. Concerns increase if requests are novel etc. • Data User (clinical/academic)– Talking about the importance of furthering research and sharing concerns about overly-bureaucratic approvals process and also the risk of public backlash if it goes wrong. How do we get the right balance?
14:40 – 15:55	**Working through data access requests** **Table discussion**	**Table discussions (75 mins in total)** Each table will work through a range of data access requests (4 out of a total of 8 requests variably across the groups). The whole group of 100 will be split into two cohorts of 50 and the data access requests will be split between the cohorts as such: **Cohort A:** • **1**: Insurance company to explore correlation between air quality and other predictors in the development of respiratory diseases • **2**: An Artificial Intelligence (AI) algorithm to detect signs of stroke on a brain scan • **3**: Early identification of adolescent mental health problems • **4**: Small Swedish medical devices company wanting to conduct a feasibility study for a chronic back pain device **Cohort B:** • **1**: Insurance company to explore correlation between air quality and other predictors in the development of respiratory diseases • **5**: Private consultancy working with an NHS Integrated Care Board to identify people at risk of hypertension • **6**: Large datasets used to detect patterns which can help plan and allocate resource • **7**: Pharmaceutical company examining outcomes of patients treated with anti-Covid-19 medication Facilitator to ask prompts on each request (10 mins for each). *Request 1 (Global insurance company):* • **How do you feel about this request?** • Are there any factors that make you feel particularly strongly about this request? • **How would you feel if this was a UK-based insurance company?** • **How would you feel if it was instead a local council/the NHS conducting this research to plan interventions?** • How do you feel about the fact the company has agreed to share the findings publicly?

		Request 2 (Large AI company based in the UK): • **How do you feel about this request?** • Are there any factors that make you feel particularly strongly about this request? • **How do you feel about any findings needing to be validated and perhaps not being released for several years?** • **How do you feel about other projects needing to wait whilst this project is undertaken?** • **How would you feel about the company working with an NHS clinician? How would you feel if it was instead a US-based company not working with an NHS clinician?** • How would you feel if the AI company could lead the data curation instead of the London SDE team? • How do you feel about analysts having access to a dataset of this size? *Request 3 (An NHS Integrated Care Board in SW England):* • **How do you feel about this request?** • Are there any factors that make you feel particularly strongly about this request? • **How do you feel about an ICB in SW England leading this research?** • **How would you feel if this project was instead being led by a commercial organisation?** • **How do you feel about linking health data, social care data and education data?** How would you feel if, rather than mental health data, this project was only linking physical health data and education data? • How would you feel if access was required for a shorter period? *Request 4 (Small Swedish medical devices company):* • **How do you feel about this request?** • Are there any factors that make you feel particularly strongly about this request? • **How do you feel about this deidentified data being used for a feasibility study?** • How would you feel if the company was committed to progressing with London as the trial location? Would this make the data use any more or less acceptable? • **This example, as did request 1, involves a commercial organisation. How do you feel about these examples in comparison to those that don't include commercial organisations?** • **How would you feel if the medical devices company was not working with the London university?** How would you feel if the project was led solely by the London university? • How would you feel if this project focused on a less common condition, but one that is life threatening? *Request 5 (A large UK-based private consultancy):* • **How do you feel about this request?** • Are there any factors that make you feel particularly strongly about this request? • **How would you feel if this project focused on a rare disease area, rather than a common one?** • How would you feel if this project focused on an equally common disease area, but one that is not life threatening? • **How would you feel if the private consultancy was not working with an NHS ICB?**

		• How would you feel if access was required for much longer than 6 months? *Request 6 (A group of NHS Trusts in partnership with a nationwide respiratory charity):* • **How do you feel about this request?** • Are there any factors that make you feel particularly strongly about this request? • **How do you feel about linking deidentified healthcare activity and clinical record, social services, council services, education returns, employment data? Do you feel particularly strongly about any of these records?** • How do you feel about analysts having access to a dataset of this size? • Would you feel differently if the research was being carried out by analysts at the charity, rather than NHS analysts? • **How would you feel if this project was instead being led by a commercial organisation?** • How do you feel about not knowing in advance exactly what improvements this project might enable? *If needed: Data mining' is a way of analysing data from different sources, like databases and statistics, to find patterns which can help make predictions about disease, assess risks to patients and help doctors make clinical decisions. These kinds of insights aren't always expected, and having access to broader datasets can help analysts make more connections across social, community, and healthcare contexts. While there are benefits of data mining, there are also downsides /risks, such as difficulty of data cleaning, and inaccuracies in the findings (i.e., spurious findings). *Request 7 (Large US-based pharmaceutical company):* • **How do you feel about this request?** • Are there any factors that make you feel particularly strongly about this request? • **This example, as with request 5, involves a commercial organisation. How do you feel about these examples in comparison?** • How do you feel about this project being commercially driven? • **How would you feel if this project wasn't being part funded by a grant?** • How would you feel if less research had already been conducted in this area?
15:20		Facilitator to place a quadrant on the table with two axes (x axis = likelihood of approval; y axis = prioritisation). Facilitator to cover up the y axis labels (on prioritisation of requests) for the first part of the conversation (can use a flipchart page for this). Participants firstly asked to position the requests on the x axis (spectrum of most → least likely to approve) using cards on the table. Facilitator to take a picture of where case studies are placed on x axis. (15 mins) • **Where would you position these requests horizontally? Why?** • Does anyone disagree with any of these positions? Why? • *(If disagreement)*: how do we balance these views? Shall we put the example halfway between these two positions?

15:35

OneLondon CAG Deliberation 1: day 2

Sunday 11th July – 10am-4pm. DISCUSSION GUIDE

Time	Discussion structure	Questions and materials
9.30-10.00	**Arrival and registration**	**Participants arrive at etc venues Mary Ward House** • Participants arrive at the venue, are signed in and given name sticker to wear, with table number shown on it (there will be 12 tables of 8 participants). • They will be sat with different people to day 1 (but everyone on the new tables will have looked at the same requests on day 1)
10.00-10.10	**Introduction and scene setting** **Plenary**	**Ipsos Chair to welcome the room to the session:** Remind participants of the OneLondon/London Health Data Strategy Programme, Ipsos and ICHP. Re-anchor participants to the first deliberation question: *What criteria should the IIAGs use when deciding to permit direct access to deidentified data, including for non-member organisations?*
10:10-11:20	**Role playing a data access committee and the different perspectives** **Table discussion**	**Table discussion (70 mins)** Participants are asked to consider the perspectives of different members of the Independent Information Access Group (IIAG) (set out on cards on the table) as the group reviews 3 fictional data access request requests from non-members representing novel and future use cases: • Linking of NHS and crime data to tackle domestic abuse. • New drug treatment for patients with Motor Neurone Disease • Large US health tech company developing an AI algorithm to more accurately detect breast cancer. The cards on the table feature quotes representing the views of the following stakeholders: • Citizen rep • Citizen rep • Legal perspective • Data controller • Clinical researcher • Ethicist • NHS Clinician

		The cards are laid out on the table. Participants are given 10 minutes to review all the cards (10 mins). For each of the fictional data access requests, facilitators will prompt a group discussion (20 mins per request): • What do you think the reaction of the different personas would be to this request? (*NB: We are less interested in what participants think of the persona views, more what drives their views and if the persona views resonate*) • Which persona do you think would be most supportive and which persona would be most concerned? (*NB: We are less interested in what participants think of the persona views, more what drives their views and if the persona views resonate*) • (*Ask the following questions about the most concerned and most supportive personas):* can you sympathise with this position? What would need to change to reassure/put off this individual? • Can you think of any particular communities or types of people in London who might be more nervous about approving this request? IF YES: how do we ensure that their views are taken into account? • What info do you think the IIAG would need to know in order to make an informed decision about whether or not to grant access? Facilitators to note down the key themes that are emerging from the discussion. Specific prompts for each request: *Request 1 (Partnership between several London ICBs and a regional police force, supported by a UK-based AI company):* • **How do you feel about the linking of health and crime data?** Which of the personas do you think would feel most strongly about this? • **How do you feel about data being linked at a person level?** Which of the personas do you think would feel most strongly about this? (*NB: We are less interested in what participants think of the persona views, more what drives their views and if the persona views resonate*) • **How would you feel if this project sought to intervene around the link between heavy drinking and criminal activity?** Or if different data was being linked? *Request 2 (A UK medical research charity in partnership with a UK pharmaceutical):* • **How would you feel if this project directly benefitted a larger number of patients?** Do you think this would change the view of any of the IIAG personas? • **How do you feel about the fact London's dataset makes it especially suitable for this type of research?** Which of the personas do you think would feel most strongly about this? (*NB: We are less interested in what participants think of the persona views, more what drives their views and if the persona views resonate*) • How would you feel if data was only required for 6 months? Do you think this would change the view of any of the IIAG personas? • **How would you feel if the charity was leading this project independently without the pharmaceutical company? How about if it was being led independently by the pharmaceutical company?** • How would you feel if the charity had the necessary in-house expertise to conduct the analysis itself? Do you think this would change the view of any of the IIAG personas?

		Request 3 (Large US health tech company developing an AI algorithm): • **How do you feel about algorithms reviewing mammograms alongside radiologists?** Which of the personas do you think would feel most strongly about this? • **How do you feel about the commercial incentives of the company?** Which of the personas do you think would feel most strongly about this? (*NB: We are less interested in what participants think of the persona views, more what drives their views and if the persona views resonate*) • How would you feel if the company could curate the data itself, rather than this falling on the NHS SDE team? Do you think this would change the view of any of the IIAG personas? • **How would you feel if this request focused on a non-life-threatening disease area?** Do you think this would change the view of any of the IIAG personas? • **How would you feel if this was a UK-based health tech company?**
11:20-11:35	**BREAK**	*Facilitators to arrange flipchart pages in way that makes it possible for participants to review them in following discussion.* *Facilitators to remind participants that they must be back for a prompt start at 11.35*
11.35-12:10 - 11:55	**Prioritising requests & identifying and exploring common themes** **Plenary then table discussion**	**Table discussion (35 mins)** Participants asked to assume that the three data access requests are accepted. Participants reminded why projects will need to be prioritised for access. Group discussion (20 mins): • Which, of these three data access requests, would you regard as the highest priority project? Why? • Which is the lowest priority project? Why? • What are the most important things that should be taken into account when deciding which projects to prioritise? If necessary, prompt: type of organisation? Type of data? Purpose/outcome of research? Duration of access? Burden on NHS analysts? • Are the personas likely to have different views on which project should be prioritised? • What are the most important things that should be taken into account when deciding which projects to prioritise? Participants then asked to consider key themes from all their discussions so far and to identify some common themes (15 mins): • What were some of the key points that came up when we were discussing how likely we were to approve access requests? • What were some of the key points that came up when we were discussing how eligible projects should be prioritised? Facilitators to prompt based on notes from the discussion on the provided facilitator notetaking templates) if necessary – *i.e., is the purpose of the research an important consideration? How so?*

		Facilitator to note down any questions for Q&A in the afternoon.
12:10-13:00	**LUNCH**	**50 mins** *Facilitators to remind participants that they must be back for a prompt start at 13.00.*
13:00 – 13:35	**Introduction to charging for direct access for non-members** **Plenary then table discussion**	**Amanda Lucas' presentation (15 mins):** • Explain the costs of maintaining an SDE – and that these fall to the NHS. • Summarise previous engagement/public expectations e.g., that access should be charged, and this should be tiered. • Explain that members won't be charged and why. • Explain that there are various ways that London could establish the tiers (i.e., by headcount, turnover, type of project, something else) + the trade-offs here. • Explain that there are circumstances where the research team is interdisciplinary (NHS + Pharma) which means tiers won't necessarily be straightforward to assign. • Introduce second Q for deliberation: *What criteria should drive decisions about charging, and what are the principles that underpin more complex interdisciplinary partnerships?* **Table discussion (20 mins)** • **What do you think to what you have just heard?** • **Anything unclear or confusing? Anything surprising or exciting?** • **What are your thoughts on how decisions about charging should be made?** *Facilitator to note down Qs the table want to clarify with specialists.*
13:35 – 13:50	**Q&A with specialists** **Plenary**	**Plenary Q&A (15 mins)** Option for questions to be asked in plenary to allow for any misperceptions to be corrected, and to provide clarity on charging options.
13:50 – 14:30	**Working through tiered charging criteria** **Table discussion**	**Table discussion (40 mins)** Participants asked to revisit 3 requests from day 1 (plus 1 new one) to compare, contrast and consider how they should be charged relative to each other. The first request in each set (cohort) is unlikely to be "approved" by participants earlier in the workshops but we have kept it here in case this is not the case. The group will be split again into two cohorts. **Cohort A:**

- **1**: Insurance company to explore correlation between air quality and other predictors in the development of respiratory diseases
- **2**: An Artificial Intelligence (AI) algorithm to detect signs of stroke on a brain scan
- **3**: Early identification of adolescent mental health problems
- **4**: Small Swedish medical devices company wanting to conduct a feasibility study for a chronic back pain device
- **8.** Tech company testing an algorithm designed to detect rare diseases

Cohort B:

- **1**: Insurance company to explore correlation between air quality and other predictors in the development of respiratory diseases
- **5.** Private consultancy working with an NHS Integrated Care Board to identify people at risk of hypertension
- **6.** Large datasets used to detect patterns which can help plan and allocate resource
- **7**: Pharmaceutical company examining outcomes of patients treated with anti-Covid-19 medication
- **9**: A charity doing a strategic review of its services

Participants recall the key features of each request. Participants asked to place the requests on a spectrum (set out on the table) of how much they should be charged (3 options on spectrum: (i) high cost (ii) medium cost (iii) low cost.

Participants to ask the following prompts for each request and to move requests up/down the spectrum as appropriate (approx. 20 mins per request – 2 of these pre-break):

FACILITATOR: The list of prompts beneath each request below are to be used if the discussion dries up, and/or people struggle to verbalise their reasoning for charging decisions for each request. Spontaneous discussion is important to collect, and you should take care not to lead the witness.

*Request 1 (*Insurance company to explore correlation between air quality and other predictors in the development of respiratory diseases):

- **Where do you think this should fall on the spectrum? Do you all agree this should be placed in this part of the spectrum? Is there any disagreement?**
- Would your view change if this was a UK based insurance company? If yes, why? If no, why?
- Would your view change if it was a local authority wanting access to deidentified data to plan services and interventions? If yes, why? If no, why?
- Would your view change if it was a charity? If yes, why? If no, why?
- Would your view change if the project required less assistance of NHS staff? If yes, why? If no, why?
- *(Facilitator to ask participants to remind themselves of the 'factors' mentioned on slide 18.)* **When you consider and weigh-up these different factors, how do you feel about where this example is positioned on the spectrum? (***Facilitator to probe on trade-offs i.e., ensuring the NHS is getting a fair deal vs supporting research opportunities and recognising NHS bargaining power varies).*

		• **Is there anything else about this request you think should be a factor in determining how much is charged? Is there any more information you would like to know?** *Request 2 (*An Artificial Intelligence (AI) algorithm to detect signs of stroke on a brain scans)*:* • **Where do you think this should fall on the spectrum? Do you all agree this should be placed in this part of the spectrum? Is there any disagreement?** • Would your view change if this was a smaller company in the UK? If yes, why? If no, why? • Would your view change if the company were based outside of the UK? If yes, why? If no, why? • Would your view change if the company was not working with an NHS clinician? If yes, why? If no, why? • Would your view change if the NHS clinician were being funded by a UK university? • Would your view change if the company were seeking a smaller sample of data? If yes, why? If no, why? • Would your view change if the potential impact of the project was smaller? If yes, why? If no, why? • Would your view change if the project delivered impacts sooner? If yes, why? If no, why? • Would your view change if the project required less assistance of NHS staff? If yes, why? If no, why? • Would your view change if it did not mean other projects would have to wait while this project takes place? If yes, why? If no, why? • *(Facilitator to ask participants to remind themselves of the 'factors' mentioned on slide 18.)* **When you consider and weigh-up these different factors, how do you feel about where this example is positioned on the spectrum? (***Facilitator to probe on trade-offs i.e., ensuring the NHS is getting a fair deal vs supporting research opportunities and recognising NHS bargaining power varies).* • **Is there anything else about this request you think should be a factor in determining how much is charged? Is there any more information you would like to know?** *Request 3 (*Early identification of adolescent mental health problems)*:* • **Where do you think this should fall on the spectrum? Do you all agree this should be placed in this part of the spectrum? Is there any disagreement?** • Would your view change if this was a university seeking access? If yes, why? If no, why? • Would your view change if it were a charity seeking access? If yes, why? If no, why? • Would your view change if it were a private company seeking access? If yes, why? If no, why? • Would your view change if there was not a request to link health and education data? If yes, why? If no, why? • Would your view change if they were requiring access for a shorter period? If yes, why? If no, why? • Would your view change if the project required less assistance of NHS staff? If yes, why? If no, why? • Would your view change if the project focused on shorter term benefits, rather than longer term ones? If yes, why? If no, why? • *(Facilitator to ask participants to remind themselves of the 'factors' mentioned on slide 18.)* **When you consider and weigh-up these different factors, how do you feel about where this example is positioned on the spectrum? (***Facilitator to probe on trade-offs i.e., ensuring the NHS is getting a fair deal vs supporting research opportunities and recognising NHS bargaining power varies).*

		• **Is there anything else about this request you think should be a factor in determining how much is charged? Is there any more information you would like to know?** *Request 4 (*Small Swedish medical devices company wanting to conduct a feasibility study for a chronic back pain device: • **Where do you think this should fall on the spectrum? Do you all agree this should be placed in this part of the spectrum? Is there any disagreement?** • Would your view change if the company was based in the UK? If yes, why? If no, why? • Would your view change if this was being funded by the university? If yes, why? If no, why? • Would your view change if the company was not working with the university? If yes, why? If no, why? • Would your view change if the company was larger? If yes, why? If no, why? • Would your view change if the request focused on a condition that affects fewer people? If yes, why? If no, why? • Would your view change if the team were committed to running the trial in London? If yes, why? If no, why? • Would your view change if the company required less support from the NGHS to conduct the research? If yes, why? If no, why? • *(Facilitator to ask participants to remind themselves of the 'factors' mentioned on slide 18.)* **When you consider and weigh-up these different factors, how do you feel about where this example is positioned on the spectrum? (***Facilitator to probe on trade-offs i.e., ensuring the NHS is getting a fair deal vs supporting research opportunities and recognising NHS bargaining power varies).* • **Is there anything else about this request you think should be a factor in determining how much is charged? Is there any more information you would like to know?** *Request 8 (*Tech company testing an algorithm designed to detect rare diseases)*:* • **Where do you think this should fall on the spectrum? Do you all agree this should be placed in this part of the spectrum? Is there any disagreement?** • Would your view change if it was a university seeking access? If yes, why? If no, why? • Would your view change if it were a charity seeking access? If yes, why? If no, why? • Would your view change if the company was smaller? If yes, why? If no, why? • Would your view change if the request focused on a more common disease which affects more people? If yes, why? If no, why? • *(Facilitator to ask participants to remind themselves of the 'factors' mentioned on slide 18.)* **When you consider and weigh-up these different factors, how do you feel about where this example is positioned on the spectrum? (***Facilitator to probe on trade-offs i.e., ensuring the NHS is getting a fair deal vs supporting research opportunities and recognising NHS bargaining power varies).* • **Is there anything else about this request you think should be a factor in determining how much is charged? Is there any more information you would like to know?** *Request 5 (*Private consultancy working with an NHS Integrated Care Board to identify people at risk of hypertension)*:*

		• **Where do you think this should fall on the spectrum? Do you all agree this should be placed in this part of the spectrum? Is there any disagreement?** • Would your view change if the company was smaller? If yes, why? If no, why? • Would your view change if the company were not being commissioned by an NHS ICB? If yes, why? If no, why? • Would your view change if the private consultancy were funding NHS researchers to deliver this work? If yes, why? If no, why? • Would your view change if it were a non-London ICB (and therefore not a member)? If yes, why? If no, why? • Would your view change if the request focused on a rare disease area? If yes, why? If no, why? • Would your view change if the data access period was longer than 6 months? If yes, why? If no, why? • *(Facilitator to ask participants to remind themselves of the 'factors' mentioned on slide 18.)* **When you consider and weigh-up these different factors, how do you feel about where this example is positioned on the spectrum? (***Facilitator to probe on trade-offs i.e., ensuring the NHS is getting a fair deal vs supporting research opportunities and recognising NHS bargaining power varies).* • **Is there anything else about this request you think should be a factor in determining how much is charged? Is there any more information you would like to know?** *Request 6 (*Large datasets used to detect patterns which can help plan and allocate resource): • **Where do you think this should fall on the spectrum? Do you all agree this should be placed in this part of the spectrum? Is there any disagreement?** • Would your view change if it were just the charity leading this project? Or instead of a charity it was a commercial organisation? If yes, why? If no, why? • Would your view change if the NHS Trusts were not London based? If yes, why? If no, why? • Would your view change if the accessor were based outside the UK? If yes, why? If no, why? • Would your view change if a smaller dataset were required? If yes, why? If no, why? • Would your view change if they were not proposing to link health data with other datasets? If yes, why? If no, why? • Would your view change if it required less time of NHS data analysts? If yes, why? If no, why? • Would your view change if the project were more directly focused on addressing a life-threatening condition? If yes, why? If no, why? • *(Facilitator to ask participants to remind themselves of the 'factors' mentioned on slide 18.)* **When you consider and weigh-up these different factors, how do you feel about where this example is positioned on the spectrum? (***Facilitator to probe on trade-offs i.e., ensuring the NHS is getting a fair deal vs supporting research opportunities and recognising NHS bargaining power varies).* • **Is there anything else about this request you think should be a factor in determining how much is charged? Is there any more information you would like to know?** *Request 7 (*Pharmaceutical company examining outcomes of patients treated with anti-Covid-19 medication):

		• **Where do you think this should fall on the spectrum? Do you all agree this should be placed in this part of the spectrum? Is there any disagreement?** • Would your view change if there was no grant funding behind this research? If yes, why? If no, why? • Would your view change if the pharma company were based in the UK? If yes, why? If no, why? • Would your view change if the company were smaller? If yes, why? If no, why? • Would your view change if the pharma company was working with the NHS? If yes, why? If no, why? • Would your view change if the accessor were not seeking to make profit out of the project? If yes, why? If no, why? • Would your view change if the project was focusing on a different condition? If yes, why? If no, why? • *(Facilitator to ask participants to remind themselves of the 'factors' mentioned on slide 18.)* **When you consider and weigh-up these different factors, how do you feel about where this example is positioned on the spectrum? (***Facilitator to probe on trade-offs i.e., ensuring the NHS is getting a fair deal vs supporting research opportunities and recognising NHS bargaining power varies).* • **Is there anything else about this request you think should be a factor in determining how much is charged? Is there any more information you would like to know?** *Request 9 (*A charity doing a strategic review of its services)*:* • **Where do you think this should fall on the spectrum? Do you all agree this should be placed in this part of the spectrum? Is there any disagreement?** • Would your view change if it was a university seeking access? Or a commercial organisation? If yes, why? If no, why? • Would your view change if the charity was larger? If yes, why? If no, why? • Would your view change if the charity wasn't London based? If yes, why? If no, why? • Would your view change if the project was focused on a more common condition, impacting more people? If yes, why? If no, why? • *(Facilitator to ask participants to remind themselves of the 'factors' mentioned on slide 18.)* **When you consider and weigh-up these different factors, how do you feel about where this example is positioned on the spectrum? (***Facilitator to probe on trade-offs i.e., ensuring the NHS is getting a fair deal vs supporting research opportunities and recognising NHS bargaining power varies).* • **Is there anything else about this request you think should be a factor in determining how much is charged? Is there any more information you would like to know?**
14:30-14:45	**BREAK**	**15 mins** *Facilitators to remind participants that they must be back for a prompt start at 14.45*
14:45-15:55	**Working through tiered charging criteria (contd)**	**Table discussion (70 mins)** Continuation of discussion before break, covering final 2 requests (40 mins)

15:25 15:40		Facilitator to remind participants of the second part of the question posed earlier: *what are the principles that underpin more complex interdisciplinary partnerships?* Prompt questions (15 minutes): • Where a commercial company partners with an (i) NHS organisation or (ii) a university, how should payment be determined? • Where a UK-based company is partnering with a company based outside the UK how should payment be determined? • If members of the SDE are funded by organisations that are not members, what should be the commercial arrangements? • How should universities that are financially benefitting from research be charged compared to grant-funded research agencies that are not benefitting financially from the research? Facilitator to remind participants of the prioritisation exercise they were asked to do earlier (i.e., to decide what should determine which project can access data as a priority). Facilitator to explain the view that organisations paying higher amounts for data access may not want to wait for it and to ask participants whether and how payment should be a factor in questions of prioritisation. Facilitator to ask (15 mins): • To what extent, if at all, should organisations paying more money for data get prioritised access? • How should payment be balanced with the other factors we discussed earlier (i.e., public benefit and the credentials of the accessor) in making decisions about prioritisation?
15:55 – 16:00	**Thanks and close**	**Chair to close the day (5 mins) covering:** • An overview of the objectives of today and what we have covered. • A 'sneak preview' of the final day • A reminder to arrive promptly at 9:30am on the morning of July 1st.

OneLondon CAG Deliberation 1: day 3

Saturday 1st July – 10am-4pm. DISCUSSION GUIDE

Prompts in bold text are priority to ask.

Time	Discussion structure	Questions and materials
9.15-10.00	**Arrival and registration**	**Participants arrive at etc venues Mary Ward House**

(45 mins)		• Participants arrive at the venue and are sent to the rooms they will be working in for the morning session. There will be floor maps at registration desks to show people where to go. • Facilitators will be prepped to address each room.
10.00-10.10 **(10 mins)**	**Introduction and scene setting** **(Groups of 12/13)** **Plenary.**	**Four facilitators to welcome the groups to their room to open the session and explain the purpose of the day** (to develop recommendations that will be shared with OneLondon in the afternoon) Remind participants of the deliberation questions on access criteria and pricing. Providing a high-level overview of the 3-day process (including a visual flowchart of the day). Also covering ground-rules and housekeeping – i.e., breaks, toilets, lunch area and fire alarm. Remind participants about consent forms they were given at sign-in – point out the boxes where these should be left on exit.
10:10 – 10:15 **(5 mins)**	**Facilitator introducing topic and activity to groups of 12/13**	**Facilitator introduction to topic** and the recommendation-forming process. Explaining that we have collated the views on the topic from the previous two days of deliberation (these are the 'recommendation sets' on posters and handouts)
10:15-10:35 **(20 mins)**	**Revisiting previous deliberation in groups of 12/13**	**The facilitator will present** the set of recommendations and the key trade-offs from the stimulus pack**.** Facilitator will explain to participants that there are more detailed quotes which represent competing perspectives on the recommendations and that they may want to refer to these through the day as they are working on the recommendations.
10:35 – 11:35 **(60 mins)**	**Draft recommendation forming in groups of 12/13**	Group tasked with reviewing, developing and refining draft recommendations on their topic with support of a facilitator (60 mins). Participants told their task is to build upon and develop the recommendations that have come out of days 1&2. They can refine recommendations, add new recommendations or remove recommendations based on their deliberation. Facilitator to share screen with the set of recommendations and lead participants through the draft recommendations and the 'unresolved questions' (set out on max 4 slides) and to document proposed changes to the recommendation live on screen (as comments on the slides and/or using red text so the changes are easy to see), or add additional recommendations on new slides, based on suggestions from participants. Each group of 12/13 asked to review the set of recommendations as a whole. Prompt questions (10 mins): • Which of these recommendations do you think is the most important? • Do you think any of these recommendations clash or contradict one another? Is there anything we could change to make the recommendations more aligned? *(If changes are proposed then facilitator should follow the process outlined below).*

		Facilitator then asks participants which individual recommendations they would like to adapt or refine, and whether there is anything additional they would like to add. **40 MINS IN TOTAL FOR GOING OVER THE RECOMMENDATIONS AND COMING UP WITH CHANGES/ADDITIONS** **For each proposed change, ask:** • What do people think about this change/addition? • Can people see any drawbacks to this change/addition? • Would people be happy to adopt this change for now? *(If several people agree the change is positive, then facilitator should live edit the recommendation on screen, either by leaving a comment or in red writing)* If the group do not spontaneously come up with any changes when presented with the full set, it may help to ask participants to **focus on a particular recommendation** and to review the stimulus material on that recommendation. Prompt questions: • **How do you feel about this expectation? To what extent does it chime with conversations you have had? Are you in agreement with it?** • *(If majority say they <u>do not</u> agree):* Is there anything that could be changed to make you support this recommendation (it might help to look over the perspectives provided on the stimulus slide)? ○ *(If majority say 'no'):* Shall we remove it from the list of recommendations? *(If yes):* facilitator deletes the recommendation from the list (to enable easier comparison with the other group). • *(If majority say they <u>do</u> agree):* Are there any changes we could make to improve this recommendation or make it more clear? Is there anything we could change to respond to the 'against' quote on the handout? • **Are there any situations where this recommendation would not apply or where it should be applied differently?** There are also some **specific prompts for some of the recommendations** you may want to ask. These are intended to help participants add detail or weight up aspects of the draft recommendations. These are listed below using the numerical system in the handout packs. Access/prioritisation recommendations: • (Public benefit rec): Which is more important to you, the breadth of the benefit (how many people are benefited) or the depth of the impact (how much people are impacted)? Which are most important of the other elements listed here? Should any of this be reflected in the recommendation? • (Health inequalities rec): Is there any detail we could add to define what we mean by 'harm'? Should this be included in the recommendation? • (Benefits in London/UK rec): Should projects that only bring benefits elsewhere in the UK be prioritised the same as projects that bring benefits to Londoners? Should this be reflected in the recommendation? • (Additional checks/balances rec): What do you think might be some effective checks and balances to ensure responsible use of data when accessors are requiring longer term access or more sensitive data?

Pricing recommendations:

- (Org type rec): Do you have a view on whether (when all else is equal) charities should be charged more or less than universities? Should this be reflected in the recommendation? Are all profit-making companies charged the same?
- (UK/non-UK rec): How do you feel about charging non-UK companies more for access?
- (Money saving potential rec): How do you feel about discounting projects that aim to save the NHS money? How do you feel when you read the 'against' statement on the slide?
- (Bargaining power rec): How do you feel about the NHS applying a commercially driven approach to determining pricing?
- (Value exchange rec): In what circumstances should other value exchange models be considered and who should decide this? Should this impact the up-front cost and if so, how?

Wherever the group gets to after maximum 50 mins (at 11:25), you must move onto the unresolved Qs. If conversation on the recommendations dries up before moving straight on to the 'unresolved questions'.

10 MINS FOR UNRESOLVED QUESTIONS (5 mins for each access criteria Qs/10 mins for the pricing Q)
For the 'unresolved questions' in the stimulus materials, the facilitator should explain that these were areas where there was debate and disagreement in days 1 & 2, but that this was clearly an important area for participants. Our goal is to develop a recommendation on this topic, which could either be one of the options set out in the slide, a combination of both, or a completely new recommendation. Additional prompts for the 'unresolved questions:

- **Which of these perspectives do you find most convincing?**
- **How can we land on a position that we can all live with?**
- Is there any way we could find an approach that is acceptable to both perspectives? Can we combine the two options somehow?
- Is there any additional information we might need to develop a recommendation on this issue?

There are also some **tailored prompts for the different 'unresolved questions'** you may want to ask:

Access/prioritisation questions:

- (Opt out Q): Does the question about whether or not to apply the opt out impact how comfortable you are about the other recommendations in the list? Would you like there to be further engagement on the application of the opt out?
- (Non-members prioritising Q): How do you feel about prioritising organisations that pay for access?

Pricing question:

		• (Turnover or profit): How do you feel charging according to profit would work in practice? Is the profit/turnover of the organisation more or less important than the type of organisation (i.e., should a small startup be charged more or less than a very large university?) Facilitators to tell participants where to go after the break.
11:35 – 11:50 (15 mins)	**Break**	
11:50 – 12:30 (40 mins)	**Compiling recommendations in groups of 25**	Facilitators to welcome participants back. Explains that the screen is displaying the two edited sets of draft recommendations (set out on max 4 slides) side-by-side. In this session the objective is to go through the recommendations to decide which changes to adopt and to end up with a single set of recommendations for the group of 25. **TIMINGS FOR RECOMMENDATIONS (30 MINS)** Facilitator goes through the draft recommendation slides side-by-side on the screen and pauses where there are suggested changes on one/both of the recommendation sets. Where there are suggested changes, facilitator to ask participants to make a collective judgement on the suggested changes via a show of hands. For each proposed change ask: • **What do people think about this suggested change? Are there any benefits/drawbacks?** • Does this contradict any of the other recommendations or any of the changes suggested by the other group? • (Where are changes suggested) Raise your hand if you agree with this change? *(if majority raise hand, the amendment is adopted)* Check reasoning if there is strong (even if not majority) disagreement so this can be captured. **TIMINGS FOR UNRESOLVED QUESTIONS (10 MINS)** Facilitator should finish by focusing on the 'unresolved questions' and trying to find the preferred way forward on this. Access/prioritisation criteria unresolved Qs: • What are your views on the application of the national data opt out in London? • *(Facilitator to briefly summarise the positions 'for' and 'against' the opt-out):* Raise your hands if you are 'for/against' the opt out. (*If there is clear consensus then this position should be added to the foot of the recommendation list)*

		• *(If there is a divide in the group):* It seems like there is no clear consensus on this position. We won't have time to fully address this issue, and the arguments for and against today, so is there need for further engagement on the application of the data opt-out in London? • *Should projects from non-members be prioritised as they bring in revenue to the SDE/NHS?* ○ *(Facilitators from both groups to briefly summarise the discussions from groups of 12/13. If the groups came up with a similar position, then this position should be added to the foot of the recommendation list).* ○ *(If there are differences between the group of 12/13 positions):* Is there any way we could combine these positions, or develop a new recommendation, to get an outcome we could all live with? *(Facilitator to live edit on screen and, as far as possible, to establish a negotiated position that people seem broadly happy with)* Pricing unresolved Qs: • Should charging be based on an organisation's turnover or the forecasted/real profits it makes from the project? ○ *(Facilitators from both groups to briefly summarise the discussions from groups of 12/13. If the groups came up with a similar position, then this position should be added to the foot of the recommendation list).* ○ *(If there are differences between the group of 12/13 positions):* Is there any way we could combine these positions, or develop a new recommendation, to get an outcome we could all live with? *(Facilitator to live edit on screen and, as far as possible, to establish a negotiated position that people seem broadly happy with)* Facilitator to tell participants where to go after lunch.
12:30 – 13:15 (45 mins)	**Lunch**	
13:15-13:45 (30 mins)	**Vote in group of 50**	Facilitator to welcome groups of 50 back from lunch. To explain that we have all been working on recommendations all morning and that there are now two sets of recommendations. We will be spending the time as a group of 50 to consolidate a single set of recommendations for the topic. Facilitators to briefly present the two lists of recommendations and then to explain how they derived from that a group of a/b or yes/no options.

		Facilitator to give an opportunity to ask any clarification questions about the vote. Facilitator will make clear this is just to seek clarification and that further changes cannot be made prior to the vote (but there will be a chance to make further changes after the vote). Amy, Michelle and moderators distributed between groups to support voting process. Specialists stationed in each group to support with clarifications. Facilitators to administer a show of hands vote on each of the a/b or yes/no options. Options are adopted through a simple majority. One facilitator will be assigned to create slide(s) with the final set of recommendations for their topic (this will involve copying and pasting the adopted recommendations into a new document). Facilitators to ask for a volunteer of someone to present the recommendations to the plenary. Facilitator to ask participants to return to the main room.
13:45 – 13:55 (10 mins)	**Participants return to Mary Ward Hall**	
13:55 – 14:35 (40 mins)	**Feedback in plenary (100)**	Plenary Q&A/feedback session where participants are able to ask questions to clarify the sets of recommendations for both topics, and to suggest changes or things to consider for both sets of recommendations. Participants encouraged to be as clear as possible with their suggested change/piece of feedback and to make clear which part of the set of expectations it is referring to. Participants asked to make suggestions either by raising their hand and sharing out loud or by writing and holding up a post-it note (for a facilitator to collect off them). There will be one flipchart for post-it feedback on access/prioritisation and another for post-it feedback on pricing. Facilitators will be assigned to collect post-its from participants who hold them up and take them to the relevant flipchart. Facilitators will also be stationed at flipcharts to cluster post-its according to which recommendation they relate to. **<u>20 mins per topic - including time for presenting the recommendations (5 mins) and time for feedback 15 mins)</u>** There will be one facilitator at each flipchart to take detailed notes on all the suggested changes, new ideas or considerations for each topic – they will need to make clear which recommendation each piece of feedback relates to, using the recommendation numbers. This will be on a shared doc (all facilitators to have access to this shared doc). Michelle to finish by telling people to return to the same group of 50 as this morning (in the same place)

14:35 – 14:50 (15 mins)	**Break**	
14:50 – 15:20 (30 mins)	**Responding to feedback in groups of 50**	Facilitators to share the page of notes from plenary session on the tv screen and to display the flipchart sheet from the plenary session Facilitators to explain that this is a final opportunity to make changes to the recommendations and that the purpose of this session is to respond to the feedback made in the plenary. Facilitator to explain that we may not be able to respond to every piece of feedback and we may not be able to discuss everything in depth (due to time) but that we will do as much as we can and capture everything in the final report. Participants reminded that a lot of work has gone into these recommendations and that, given trade-offs, no recommendations can be ideal for everyone. Facilitator to go through the feedback on the screen/flipchart (30 mins). For each piece of feedback ask the following questions (if necessary) and then to invite a very quick vote (by show of hands) on each proposed change. One facilitator to be live editing the recommendations on a laptop. • **Is there any straightforward change/addition we could make to respond to this feedback?** *(Push participants to propose the change as clearly as possible – i.e., add 'x' here or change the working of 'y' to 'z')* • How do people feel about this potential change? Are there any drawbacks? Are there any ways of negating these drawbacks? • *If changes aren't accepted ensure we capture the reasoning why* One facilitator to live edit the recommendations on a laptop (in a shared doc), making changes as necessary based on the outcome of the votes. Facilitator to tell participants to return to the main room after the break. Michelle to access the revised recommendations via live doc.
15:20 – 15:30 (10 mins)	**Moving back to Mary Wall Hall**	
15:30 – 15.45	**Presentation and ratification of recommendations**	Facilitators from each group of 50 briefly present back the final set of recommendations (5 mins for each topic – 10 mins)

(15 mins)		(5 mins for two votes) Participants asked to use Ipsos voting software to show their level of support for each set of recommendations. Participants told where they should leave post-its if they want to register any dissenting views.
15.45 – 15.55 (10 mins)	**Thank you from panel**	OneLondon panellists thank participants for their efforts over the three days and their recommendations. *Facilitators to go around room to collect voting devices)*
15.55-16.00 (5 mins)	**Goodbye**	Ipsos Chair thanks participants once again, reminds them about payment and reminds them that they are THE London SDE CAG, cannot be replaced and that they will be contacted in the future about other important engagements. Remind participants to hand in their voting device before leaving if it hasn't already been collected.

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About Imperial College Heath Partners

ICHP is a partnership organisation bringing together NHS providers of healthcare services, the Integrated Care Board and universities across North West London to drive improved population health through innovation and collaboration.

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