Discover-NOW
Health Data Research Hub for Real World Evidence

Discover-NOW Citizens Advisory Group
Deliberation 2, Report

May, 2021

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Executive summary

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Introduction

The Discover-NOW Board made a commitment to establish a Citizens Advisory Group in line with recommendations made by the OneLondon Citizens' Summit for how the public should be involved in ongoing oversight and development of policy relating to the use of health and care data moving forward.

Ipsos MORI, working in partnership with Imperial College Health Partners, was commissioned to design and deliver two deliberations over the course of 2021. This report presents findings from the second of these deliberations, which focused on the distribution of a future surplus and potential alternative value exchange models.

Methodology

The deliberation consisted of two virtual workshops in April 2021, comprising c40 Londoners recruited to reflect the North West London population.

Each workshop lasted three hours and included a combination of informative expert presentations and moderated group discussions in which smaller groups of around six participants reviewed stimulus materials and deliberated their views, experiences and expectations.

Deliberation question: How should the value of Discover-NOW's health and care data for research be realised and distributed?

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Executive summary – surplus findings

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The first workshop began with a brief discussion about the value of health and care data research. Most participants' first association was **non-financial value** such as helping with decision-making and the accuracy of the data itself. To many participants, **financial value** was simply for sustaining the hub. Participants then considered four different ways in which a potential future surplus could be invested, none of which were mutually exclusive.

Option 1: investing back into the asset
Participants believed that investment in the Trusted Research Environment was justified in order to preserve data security, maintain accuracy, and improve the quality of the product to increase revenue. However, some participants expressed concern that too large of an investment could be wasted on unessential improvements.

Option 2: investing back into the NHS
Some participants believed that investing back into the NHS was 'fair' given that it had provided the data and initial investment, while others believed that the NHS receives sufficient funding from other sources. Participants generally agreed to keep the surplus within NW London but recognised the challenges of distributing this across over 400 organisations.

Option 3: investing into a research fund
Participants were broadly supportive of this option as they recognised the long-term investment of helping a research community that could bring about financial benefits to the hub at a later stage. They also stressed the importance of aligning the research fund to local needs, but also highlighted the risk of stretching the surplus too thinly to be of use to individual researchers.

Option 4: paying patients / local community groups directly
Almost all participants immediately discounted the idea of paying patients directly, due to technical infeasibility and the minimal amount per individual. However some participants did suggest using the surplus to support a small number of patients who are most in need. Many supported the option of distributing surplus to local community groups because of their in-depth knowledge of the area and the types of schemes that could benefit local people. One suggestion was for choosing charities was to use a mixed board of public and experts (akin to the one proposed in Deliberation 1).

Executive summary - Surplus expectations

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- Across the groups, the most and least preferred options did not always align. However in deciding how any future surplus should be distributed, three clear and consistent underlying principles emerged.

Greatest Impact

- Any future surplus should be allocated to the areas where there is potential for the greatest impact.

Robust, transparent process

- In deciding where any surplus should go (based on the principle of greatest impact), there must be a robust and transparent process, which involves the right people (including patients).

Address local issues

- In allocating future surplus, the driving factor for how the funds will be used should be the ability to address local issues.

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Executive summary – surplus expectations

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- Participants' preferences also varied depending on the size of the potential surplus. We presented two **nominal** surplus amounts of £1m (large) and £100k (small)

In situations where the surplus is large enough (i.e. a significant amount):

- There was support – across most groups - for at least some of this to be **reinvested back into the asset ***. This is the foundation upon which everything else is based on and it is important to maintain and improve the data storage, security and to ensure that the technology 'keeps up with the times'.
- There was also support for some of the surplus to go **back into the NHS**. The NHS invested in the asset initially, so should see some financial return. However groups recognised that this would likely be a 'drop in the ocean', and it will be difficult to decide where the money should go. Groups also recognised that using any surplus to invest in other areas (i.e. a research fund) will likely benefit the NHS in the long run anyway.

In situations where the surplus is smaller:

- There was unanimous support for this to be distributed to the areas that need it most, and where it will have the greatest impact on local people.
- Hence, across the groups, there was support for any small surplus to be distributed across the following:

A research fund, which was liked for its ability to tackle local issues (i.e. diabetes), with a focus on prevention while creating jobs and opportunities for early career researchers. Having a fund like this could save the NHS money in the long term too.

Community groups or charities (rather than directly to patients) or through public health initiatives focussed on prevention (i.e. free exercise classes) and keeping people well. Also important to give back to the most vulnerable.

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Executive summary – value exchange findings

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In workshop two, participants were introduced to five different value exchange models. Across all options, participants remarked upon their legal, commercial and technical complexity. With expert help, however, they provided rich insights.

Option 1: one-off payment
Many participants appreciated the legal and technical simplicity of the one-off payment model, provided that the current tiered pricing model was maintained to encourage less profitable research organisations. However, some participants believed not capturing any value from outputs was unfair to Discover-NOW.

Option 2: free/discounted products
Participants often criticised the lack of access charge in this option as opening Discover-NOW up to too much financial risk. Additionally, while some participants found the potential for the NHS in NW London to access free/discounted products, they expressed concerns about how this would work practically.

Option 3: royalty/profit share
Participants were split between those who believed that a royalty/profit share could provide Discover-NOW with a long-term investment, and those who thought that this option was too great a commercial risk. Additionally (as in option 2), most participants disliked the prospect of not charging for access.

Option 4: intellectual property/equity share
Like option 3, participants were split between those who saw IP / equity shares as an innovative long-term investment, and those who feared that the commercial nature of the model could lead to privatisation (participants were reassured that this was unlikely). Some participants also highlighted the administrative burden of registering patents and sitting on company boards.

Option 5: Multiple one-off fees linked to product milestones
Some participants appreciated this option's mitigation of risk through holding organisations to account at multiple stages rather than just at the start. However, some participants expressed concerns around the complexity of this model and the potential lack of incentive for researchers to hit milestones.

Near the end of the second workshop, participants discussed how Discover-NOW could best communicate the value of health and care data research. Participants commonly believed that they should address low awareness of the research with success stories disseminated through social media and posters/displays in health settings.

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Executive summary – value exchange expectations

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Every value exchange model should incorporate an upfront access fee

- Most groups (though not all) felt as though there should always be an access fee charged up front as part of the value exchange model
- However, this could be refunded if charged as part of value exchange models 2-5, if the product was successful.

The tiered pricing model must remain

- Most groups expressed the importance of ensuring that any value exchange model that Discover-NOW uses does not exclude smaller organisations. This can be achieved through the existing tiered pricing model and Discover-NOW should consider how models are implemented to ensure that this is honoured.

One size does not fit all and options are not mutually exclusive

- Across the groups, there was support for Discover-NOW utilising a range of value exchange models. Where certain models for particular arrangements are going to be too restrictive for Discover-NOW/the NHS, others might work better. Likewise a model might work for one commercial organisation, but not another
- Overall, the one-off payment, multiple one-off fees and royalty/profit share options were more favourable although this wasn't the case across all groups. These options felt more secure / less risky.

Discover-NOW/the NHS should enter into realistic arrangements

- There was more support for a share in royalties (option 3), as opposed to a share in equity (option 4), given this felt more tangible to the groups, easier to measure and less risky.

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1. Introduction and methodology

Introduction and methodology

Discover-NOW
Health Data Research Hub for Real World Evidence

Discover-NOW, the Health Data Research Hub for Real World Evidence, is committed to engaging patients and the public in a meaningful way throughout its work.

The Discover-NOW Board made a commitment to establish a Citizens Advisory Group in line with recommendations made by the OneLondon Citizens' Summit for how the public should be involved in ongoing oversight and development of policy relating to the use of health and care data moving forward.

Ipsos MORI, working in partnership with Imperial College Health Partners, was commissioned to design and deliver two deliberations over the course of 2021. This report presents findings from the second of these deliberations, which focused on the distribution of a potential future surplus and potential alternative value exchange models (see Figure 1 for the full deliberation question).

Methodology

The deliberation consisted of two virtual workshops in April 2021, comprising c40 people recruited to be reflective of the North West London population. Further details of those who took part can be found in the appendices.

Each workshop lasted three hours and included a combination of informative expert presentations and moderated group discussions in which smaller groups of around six participants reviewed stimulus materials and deliberated their views, experiences and expectations. Further detail about each workshop can be found on the next slide.

How should the value of Discover-NOW's health and care data for research be realised and distributed?

Figure 1: Deliberation question

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Introduction and methodology

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Workshop 1:

- An introductory presentation on the purpose of the second deliberation and how the recommendations from the first deliberation are being implemented.
- A presentation on the initial investment and ongoing costs of running the Discover-NOW hub
- A presentation on the potential for a future surplus and the different ways that this may be distributed
- A Q&A slot with experts to address emerging questions and concerns.
- Moderated discussion around the different surplus distribution options
- Moderated recommendation forming based on how participants believe a possible surplus should be distributed.

Workshop 2:

- A playback of some of the emerging themes from discussions during workshop 1.
- Moderated discussion to check that participants were happy with how the emerging recommendations were presented.
- A presentation on alternative value exchange models
- A Q&A with experts to address emerging questions.
- Moderated discussion around the different value exchange options
- Moderated recommendation forming based on how participants believe Discover-NOW should exchange value.
- Moderated discussion around how the value of health and care data research should be communicated to the North West London population.
- A presentation of the Citizens Advisory Groups' collective recommendations.

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Introduction and methodology

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How to read this report

During this report, the conventions of qualitative social science reporting are used:

- We indicate via "a minority" to reflect views which were mentioned infrequently and “most” or “commonly” when views are more frequently expressed. We use “some” to reflects views which were mentioned some of the time, or occasionally.
- However, we also indicate strength of feeling even when views are expressed by a minority, as this may also give useful insight into the range of feelings which exist within different groups of people.

We are reporting perceptions rather than facts; in the case of this project there are various misconceptions our participants expressed about questions of fact, for example low awareness of research and why different organisations would require access to health and care data. We have indicated where we are reporting perceptions of participants, and where we are offering analysis of the implications of these perceptions.

Stylistic conventions

We have used the convention of describing the word data in the singular rather than plural, plus the terminology around patient data recommended by Understanding Patient Data (e.g. describing data as de-personalised).

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2. Surplus distribution options - participant feedback and expectations

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Initial thoughts on the value of health and care data research

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- Before participants were introduced to the surplus distribution options, they were asked to briefly reflect on the value of health and care data more generally.

- Most participants' first association of value was **non-financial**, highlighting the 'greater good' of improving public health and care.

"My initial thought was it was just valuable to save lives and come up with new leading surgeries."

- Some participants made more specific associations with the data's non-financial value, as a means of **decision-making**, planning services, budgeting, and for addressing the problems associated with the COVID-19 pandemic .

"In this current climate, data has been really important to make the right decisions. If there was no data, it would have been hell. Data is helping us get through this terrible time."

- A few participants believed that the value of data for positive impact was highly dependent on its **quality and accuracy**.

"As long as the data is accurate and reliable, that is where the value is."

- When participants did talk about financial value, most saw this as an inevitable means to the ends of the non-financial benefits. However a few participants expressed concerns about the financial value skewing the types of health and care data research that takes place.

"I think sometimes things aren't necessarily always developed for the greater good but for the greater financial good of an individual company."

"I also think there's a huge imbalance of where the research goes. Research does great things for a lot of things, but there are also things left out."

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Initial questions and comments on the running of the assets and surplus distribution options

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The first workshop included two presentations: from Kavitha Saravanakumar (Associate Director of Business Intelligence, North West London Collaboration of CCGs and Technical Lead for Discover-NOW) , to inform participants about the initial investment and running costs of the Discover-NOW health data research hub; and from Amanda Lucas (Director of Information, Discover-NOW), to introduce the possibility of a future surplus, with different options of how this surplus could be distributed. Participants were encouraged to reflect on what they had heard, as well as to voice any concerns that they had at this stage and any questions (see Figure 2).

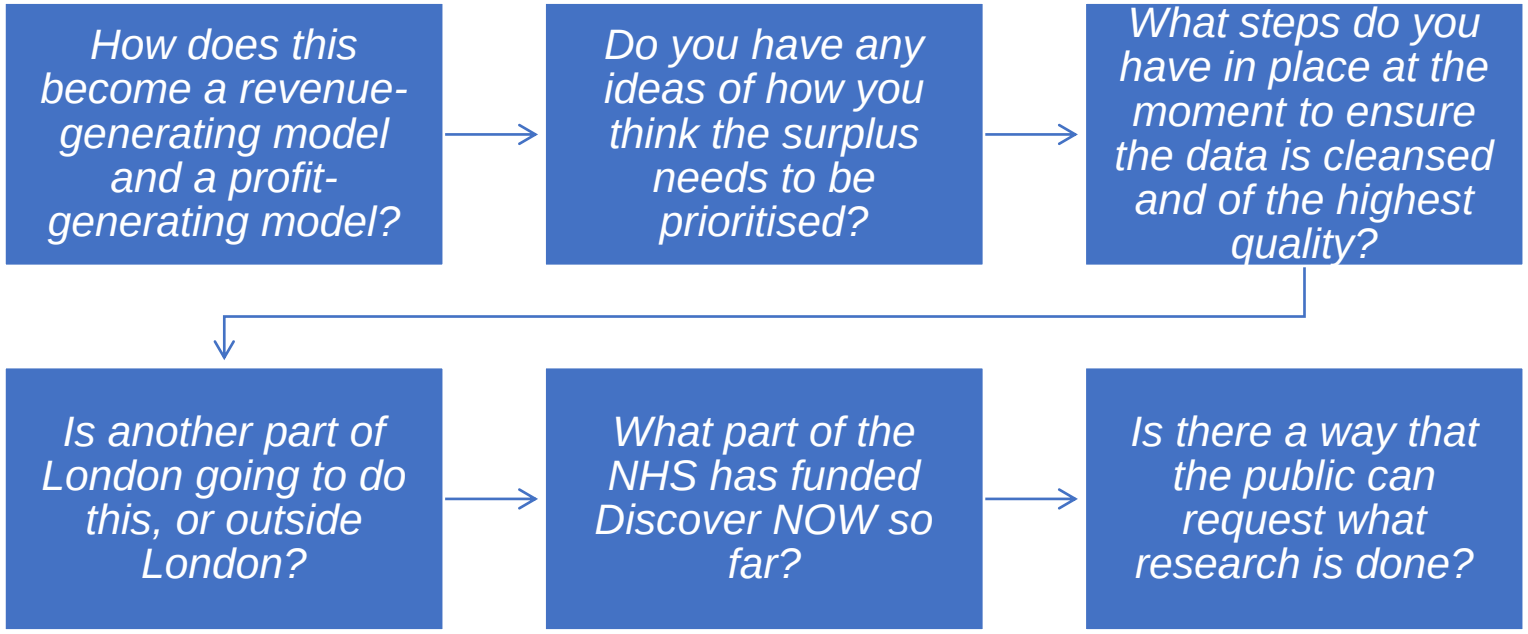

Figure 2: A selection of participant questions

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Surplus distribution options – 1 & 2

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The tables below outline the trade-offs presented and discussed with participants. We presented participants with two **nominal** surplus amounts of £1m (large) and £100k (small)

Surplus distribution option	✓	✗
Option 1: Back into the data infrastructure and improving the data quality	• Investment in platform support, data quality, data richness and scale, technical tooling and software to improve usability of the platform. • Enables platform to develop capabilities and a development fund to fulfil user requirements of the platform. • Develop future value of the platform for future research opportunities.	• May reach a point whereby the platform does not require additional investment and development. • May reach a point where the platform development and growth is unable to generate new income and value for the NHS.
Option 2: Back into the NHS (local or wider)	• NHS providers of care receive revenues from the value exchange which can be fed directly into front line care. • Compelling link from the data providers who capture the data to financial benefit of health and care research. • Potential to link research revenues to NHS providers on the condition that they improve the data quality to help with research.	• Challenge to determine equitable distribution of any surplus to the NHS. Would this be to NWL NHS or wider London region or beyond? • In NWL alone there are over 400 NHS care providers (hospitals and GP practices) so how we would decide where it goes? Potentially use per patient of population calculation? • Anticipated surplus to be shared will be low in proportion to other NHS income sources • Administration overhead of income distribution to multiple NHS organisations.

Surplus distribution options – 3 & 4

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The tables below outline the trade-offs presented and discussed with participants. We presented participants with two **nominal** surplus amounts of £1m (large) and £100k (small)

Surplus distribution option	✓	✗
Option 3: Research fund (based on local needs or to support early career research)	• Research funds are highly competitive and difficult to secure in particular by early career researchers which this would help to address • Focus research income on addressing real world problems in NWL, driven by local communities • Opportunity for research to make a real difference to the people of NWL by connecting researchers to the NHS and real world problems.	• Assessment criteria and procedures would need to be established to oversee the research fund • There would be a cost involved with administering and managing a group to govern access to research funds for the duration of the TRE. • Cost of management, and distribution of funds.
Option 4: Back to public and patients directly / through local community or charity body	• Link is established between patients / the community and research promoting transparency of health care data use. • (direct) patients financially benefit from use of their health and care data for research. • (community) community or charity bodies financially benefit from use of their members/beneficiaries' health and care data for research.	• (direct) technology to trace the source data to the patient may exist but not known in UK healthcare, would be costly to implement and technically difficult (since patient identifiers are removed). • (direct) potential funds for an individual are likely to be very low, unless perhaps for a rare disease. • (community) administrative burden of choosing local community or charity groups and distributing revenue to them.

Attitudes to Option 1: investing back into the asset

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- Participants commonly highlighted the importance of investing into the asset from the point of view of **security** and **accuracy**. For security, they recognised the severe risks of failing to maintain up-to-date security infrastructure.

"It needs to be really secure. That's important, so that not anyone can access it."

- Accuracy was important to participants as they believed that this would maintain or increase the data's value and subsequently ensure a greater surplus overall.

"If you have the means to produce accurate data, it's going to be required. It's going to have a value, and people will pay more and more for accurate data. That's how you have a continuous flow of money."

- However, some participants' support of this option was more cautious. They recognised the importance of investing into the asset for accuracy and security to a point, but expressed concerns about money being used inefficiently beyond what is needed.

"It's not necessary to keep ploughing money into it. You might build things that are too advanced. You might be using the money for the sake of it."

- A few participants were confused about how much maintenance was needed beyond the £2.5 million provided to the hub, and what any additional investment would add beyond these essential running costs.

"Of course, it needs to be upgraded and improved and its capabilities expanded. But doesn't that come into the £2.5 million as maintenance in a year? Doesn't the maintenance of the platform include developments and improvements to it as well?"

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Attitudes to Option 2: investing back into the NHS

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- Participant opinion on this option was more divided. The most common reason in support of investing back into the NHS was that this **was 'fair' given that it had provided the data – as well as financial investment** - in the first place.

"I think that's a good idea because they started the data initially."

- However both those who supported and opposed investing back into the NHS agreed that **distribution would be complex.** Most participants agreed that, if any surplus were to be reinvested, it should be to NHS NW London to keep things 'simple' and 'fair'.

"I think if all the different research organisations stick to their area, it keeps it simpler."

- Only a few participants thought that surplus should be distributed to the NHS 'nationally', but other participants challenged them on the practicality of this. One specific suggestion (linking back to Deliberation 1) was to share surplus out across other hubs that have combined data with Discover-NOW.

- Despite the consensus on keeping the surplus within NW London, participants expressed concern about the large number of NHS organisations, the admin costs and the risk of distributing amounts that are too small to be useful.

- As a solution to this, some participants suggested focusing the surplus on those NHS organisations in most need, and a few participants specifically suggested giving this responsibility to the CCGs who already have strategic oversight. However, some participants thought that a targeted approach such as this could exacerbate inequalities.

"Do you just split everything between the 400, and maybe some areas might have more issues and you give them more? I don't know how you would do it fairly."

- A few participants were opposed to the NHS receiving any of the surplus as they did not believe it would have an impact or they felt the NHS receives enough funding from elsewhere. As highlighted in later slides, this opinion varied for participants depending on the size of the potential surplus.

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Attitudes to Option 3: investing into a research fund

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- Participants were broadly supportive of this option as they recognised the **long-term investment of helping a research community** that could bring about financial and other benefits to the hub at a later stage.

"This is an investment into the future that could come back to the NHS…it almost goes full circle."

- They underlined **the importance of aligning research to local needs**. They were particularly supportive of addressing important health and care issues which may be overlooked as a result of the commercial logic of organisations that work with the hub.

"There's always going to be something where it's a small part of the community, and they're left out in the cold, and the funds aren't given to them."

- However, participants also expressed concerns around there being enough surplus to be impactful, and that this might vary between different types of research projects.

"I think this would need a lot of surplus to get this, and then it does depend on what kind of research they're researching."

- Some participants were also supportive of investing in early career researchers, recognising the difficulty of accessing funding.

"I'm still in university and I see some people really struggling with so many great ideas that they can't fund from their pockets, it's really hard to get funding."

- Some suggestions to make the fund more locally specific were to focus on diverse researchers based in NW London, or to combine the early career and local research funds.

"I think both , because I think stuff the community might propose might already be in research...There are a lot of people that have got ideas, and researchers could work with them to develop those ideas."

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Attitudes to Option 4: paying patients / local community groups directly

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- The majority of participants supported the option of distributing surplus to locally-based community groups or charities (rather than patients directly) because they have **in-depth knowledge of the area** and the types of schemes that could benefit local people (e.g. preventative schemes around addiction, weight loss etc.)

"[Charities] will be able to divide it up and put it where needs must, better than where individuals will."

- Some participants also highlighted the **lack of data protection** issues when paying community groups rather than patients directly.

"For them to pay me, they have to know my name. But, if it's not coming directly to me, and it goes into a community centre, everyone can use it."

- However, participants did highlight the **difficulty of choosing** which charities or communities groups would be most deserving of the surplus.

"But how do they go about choosing which community or charity is entitled to the surplus?"

- Sharing surplus with patients directly was quickly rejected outright by most participants on the grounds of **technical infeasibility** and the minimal amount that would go to each person.

"Would it make a difference to one patient getting 20p?"

- However, some participants did see potential benefits from a system that focuses on a **smaller number of patients with the greatest needs**. A few participants explained in more detail how they imagined this would work, with a mixed decision-making board akin to the one proposed in Deliberation 1.

"I think there would have to be a spokesperson from each thing…a person from the NHS, a person from the community. They can talk on their behalf. It would be balanced."

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Surplus distribution – expectations

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- Across the groups, the most and least preferred options did not always align. However in deciding how any future surplus should be distributed, three clear and consistent underlying principles emerged.

Greatest Impact

- Any future surplus should be allocated to the areas where there is potential for the greatest impact.

Robust, transparent process

- In deciding where any surplus should go (based on the principle of greatest impact), there must be a robust and transparent process, which involves the right people (including patients).

Address local issues

- In allocating future surplus, the driving factor for how the funds will be used should be the ability to address local issues.

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Surplus distribution – expectations

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We also presented participants with two **nominal** surplus amounts of £1m (large) and £100k (small) which helped test whether participant expectations varied depending on the size of the surplus.

In situations where the surplus is large enough, (i.e. a significant amount):

- There was support – across most groups - for at least some of this to always be **reinvested back into the asset ***. This is the foundation upon which everything else is based on and it is important to maintain and improve the data storage, security and to ensure that the technology 'keeps up with the times'.
- There was also support for some of the surplus to go **back into the NHS**. The NHS invested in the asset initially, so should see some financial return. However groups recognised that this would likely be a 'drop in the ocean', and it will be difficult to decide where the money should go. Groups also recognised that using any surplus to invest in other areas (i.e. a research fund) will likely benefit the NHS in the long run anyway.

In situations where the surplus is smaller:

- There was unanimous support for this to always be distributed to the areas that need it most, and where it will have the greatest impact on local people.
- Hence, across the groups, there was support for any small surplus to be distributed across the following:

A research fund, which was liked for its ability to tackle local issues (i.e. diabetes), with a focus on prevention while creating jobs and opportunities for early career researchers. Having a fund like this could save the NHS money in the long term too.

Community groups or charities (rather than directly to patients) or through public health initiatives focussed on prevention (i.e. free exercise classes) and keeping people well. Also important to give back to the most vulnerable.

* There were also participants who felt that the asset was already well funded (£2.5million for annual maintenance), so were keen to see any surplus distributed elsewhere (i.e. where it could have the greatest impact). There were also some participants who felt as though some surplus should always go back into the asset even if the surplus was smaller, though this was a minority view.

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3. Value exchange models - participant feedback and expectations

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Initial questions and comments on value exchange models

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The second workshop included a presentation by Saira Ghafur from the institute of Global Health Innovation to introduce alternative value exchange models, as adapted from the report she co-authored (link). Participants were encouraged to reflect on what they had heard, as well as to voice any concerns that they had at this stage and any questions (see Figure 3).

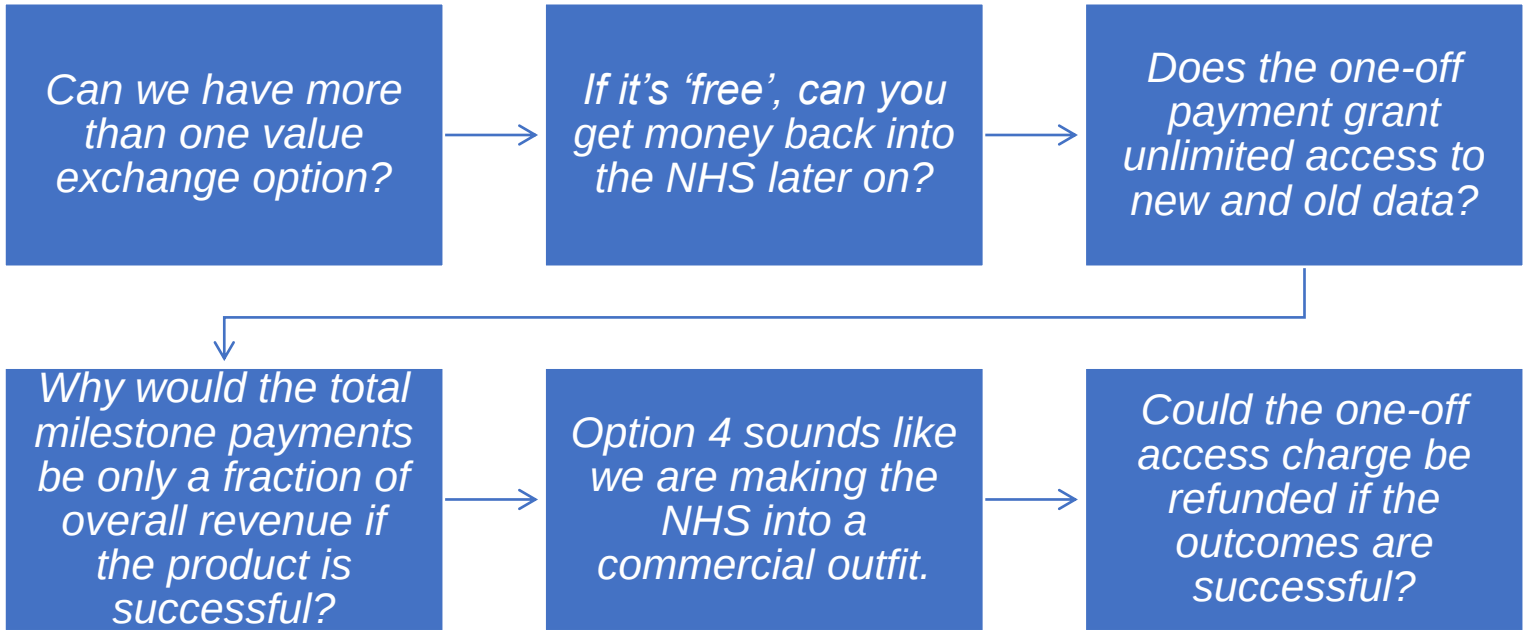

Figure 3: A selection of participant questions and concerns

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Value exchange models – 1 & 2

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The tables below outline the trade-offs presented and discussed with participants:

Surplus distribution option	✓	✗
Option 1: One-off payment NHS receives a one-off payment in exchange for access to the data (and if there is an output, the NHS would have to pay for it).	• Quick and certain access to money for the NHS • Up-front payment mitigates the risk no useful product will be developed. • Potential to license same datasets for same uses to multiple organisations or individuals to maximise revenue.	• Depending on the pricing models for access and any derived products, this could limit the value for the NHS • Depending on the fee, this may create a financial barrier to initial access to data, potentially penalising smaller companies.
Option 2: Free / discounted products The product developed using an NHS dataset is provided to the contributing NHS organisation/s for free or at a discount (for a defined or unlimited period of time). The product might also be offered to the rest of the NHS at a discount.	• NHS as a whole or an individual organisation (i.e. a particular hospital) gets access to cutting-edge products at no or reduced cost.	• No additional value specifically captured from product revenues. • Risk that no useful product is developed. • Potential delay to revenue generation for the NHS. • If product is discounted/free only for one organisation, other NHS organisations will still have to pay for it. • Free products would need to be reviewed to ensure no breach of regulatory compliance obligations by industry.

Value exchange models - 3

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The tables below outline the trade-offs presented and discussed with participants:

Surplus distribution option	✓	✗
Option 3: Royalty / profit share The NHS receives a royalty/portion of profits from products developed using its data.	• Potential long term source of income for the NHS. • Likely to generate the most income for the NHS. • (for profit share) NHS receives income every year that the company is profitable (irrespective of whether a specific profitable product is created).	• NHS would still have to pay for tools developed using its data. • Potential delay to revenue generation for the NHS. • Risk that no revenue-generating product is developed / small and medium-sized enterprises may not be profitable for some time • Industry may require exclusivity in respect of the data limiting the NHS's ability to deal in the data with third parties. • Share will likely require significant negotiation and legal expense to agree contract terms. • Historically industry has been less likely to accept this model as hard to attribute value to the role of data in a complex product development process.

Value exchange models - 4

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The tables below outline the trade-offs presented and discussed with participants:

Surplus distribution option	✓	✗
Option 4: Intellectual property / equity share The NHS owns some of the intellectual property generated in the project which uses its data and/or a share of the equity of the company developing solutions from the data.	• Intellectual property (IP) ownership for the NHS and potential to control over how IP is used • Ownership interest in company developing product and potential to have a say in its activities.	• IP ownership does not itself generate revenue. • Potential delay to revenue generation for the NHS. • Difficult and costly to manage and will tie NHS into a relationship with the company creating an administrative burden for the NHS. • Difficult to decide what a fair share of the equity for the NHS would be • Likely to require significant negotiation and legal expense to agree contract terms • Unappealing to companies: NHS involvement might complicate decision making and hinder company progress. • Historically industry has been less likely to accept this model as hard to attribute value to the role of data in a complex product development process.

Value exchange models - 5

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The tables below outline the trade-offs presented and discussed with participants:

Surplus distribution option	✓	✗
Option 5: Multiple one-off fees linked to product milestones NHS receives multiple one-off payments triggered by the licensee achieving certain regulatory and product milestones (e.g., start of clinical trial, regulatory approval, in each case of a product relying on the relevant data).	• Likely increased revenue vs one-off payment. • Less complex to administer vs other models. • More likely to be accepted by industry as payments linked to success – less risky for industry • Could reduce the "financial barrier" for smaller companies as larger payments are made when/if a product is successful.	• If product is unsuccessful NHS may only receive small sum. • Audit may be required to verify if milestones have been met. • Total milestone payments may only be a fraction of overall revenues if product is highly successful.

Attitudes to Option 1: one-off payment

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NHS receives a one-off payment in exchange for access to the data (and if there is an output, the NHS would have to pay for it).

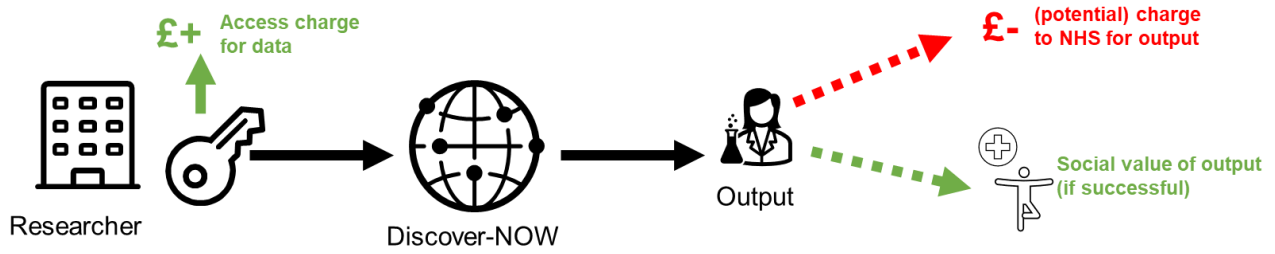
- Many participants **appreciated the legal and technical simplicity** of the one-off payment model for both Discover-NOW and the researchers who use the data.

"It's a one stop shop. You get what you want to do with it, you do it, and get paid for it."

- As a caveat to this support, they stressed the **importance of maintaining a tiered pricing system** to avoid pricing out smaller organisations (reaffirming Discover-NOW's current practice and the recommendations from the OneLondon Citizens' Summit deliberation*).

"The smaller companies might have a genius coming up with something innovative. If they can't do the research because of the up-front cost, the benefit to the NHS is lost as well."

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



- However, some participants believed that **this option was giving away too much value too easily**. They thought that it was unfair that the NHS would not have any discount or financial value returned later on in exchange for the data it provided.

"As the big provider of the data that they've been collating over years, surely they should get discounts or a stake in the profits."

- A few participants also challenged the one-off payment model as being unable to capture the potential future success of the outputs.

"How can you be certain that you've charged enough? Who gets to make that decision?"

Attitudes to Option 2: free / discounted products

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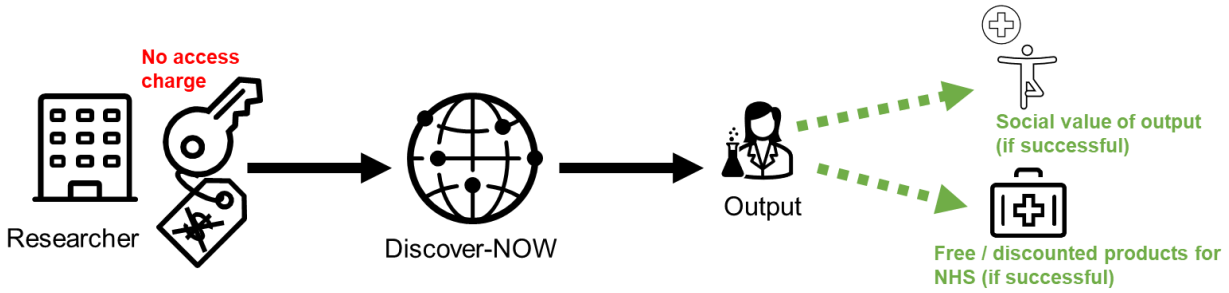
The product developed using an NHS dataset is provided to the contributing NHS organisation/s for free or at a discount (for a defined or unlimited period of time). The product might also be offered to the rest of the NHS at a discount.

- Participants' most common first reaction **was concern regarding the absence of an up-front access charge**. Reflecting on what they had heard in the presentation about Discover-NOW's running costs, they stressed the importance of keeping 'money in the bank'.

"I disagree with having a totally free service for access to the data…Nothing is totally free, as they say. It's in the commercial world. It's dog eat dog."

- However, some participants did see potential benefits in offering a discounted access charge, **to give innovative but less profitable businesses a chance to access health and care data.**

- For a few participants, **charging something** (even a nominal amount) was **important to dissuade spurious projects**. Participants were reminded that Discover-NOW's controls should guard against this, yet they believed that a small charge would encourage higher quality submissions with a greater chance of successful outputs.



- While most participants saw social benefits in the possibility of free or discounted products for the NHS, some expressed **concerns about how this would work practically**. These concerns included how certain regions of the NHS would get discounts while other areas would not, the risk of poor negotiation by Discover-NOW/the NHS, and the perception that free or discounted products would be of lesser quality.

"Five years…I don't know who negotiated that contract, but it doesn't seem very equitable for the benefit of the NHS."

"There's also the risk you might get second-grade products given away for free. It's getting something from the pound-shop versus the chemist."

Attitudes to Option 3: royalty / profit share

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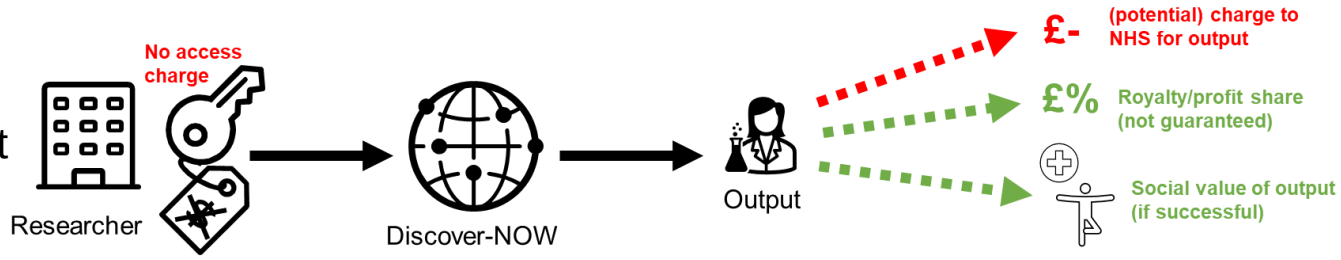
The NHS receives a royalty/portion of profits from products developed using its data.

- As above (option 2), participants generally disliked the prospect of not charging any access fees. Otherwise, **participants were split** between those who believed that a royalty/profit share could provide Discover-NOW with a long-term investment, and those who thought that this option was too great a commercial risk.

- A few participants believed that **by being patient, rather than charging too much money up-front**, Discover-NOW could end up with a larger surplus in the long-run.

"Royalties might seem very little, but over a long period of time it could be a lot of money."

- However, **some participants felt uncomfortable with the 'commercial' nature of this model**, due to a perceived cultural clash between public institutions and commercial businesses, and/or a lack of risk appetite for investing into longer-term contractual arrangements with non-NHS bodies.



- Participants highlighted numerous other concerns with this option: the risk of outputs not making a substantial profit, or this profit being delayed; the possibility of large global companies not being transparent about their profits; and the confusion or conflict of interest with the NHS as seller and customer.

"There are no regulations that [multinationals] have to declare profits from individual products. They declare one global income for tax. They won't disclose it themselves."

"I think it's a bit odd because if the NHS are one of the biggest customers for the product, how are you getting a royalty or profit share off yourself."

Attitudes to Option 4: intellectual property / equity share

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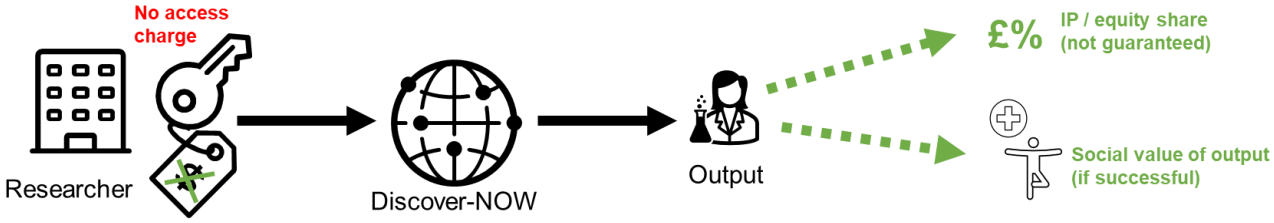
The NHS owns some of the intellectual property generated in the project which uses its data and/or a share of the equity of the company developing solutions from the data.

- Participant views on this model were similar to those on Option 3, with a split between participants who saw IP / equity shares as an innovative long-term investment, and those who feared that the model was too commercial for a public sector organisation. Although participants expressed unanimous support for the NHS as an institution, a few believed that **an IP/equity share model was needed to allow the organisation to be more financially sustainable.**

"I don't want [the NHS] being privatised but it needs to evolve with the times and I feel this could be that middle ground."

- However, some feared that the commercial nature of the model could **lead to privatisation** (though participants were reassured that this was unlikely) and were concerned by the risk of **little to no return**.

"It says shares aren't guaranteed, so it's also quite risky. If it doesn't make it, then nobody will get money."



- As with Option 3**, participants commonly challenged the feasibility of this option** due to the potential administrative and legal burdens of equity and intellectual property.

"The process for filing patents is really, really complicated…It would create an administrative burden that would need oversight and resources."

- Finally, some participants were unsure whether commercial companies and Discover-NOW/the NHS would be able to work together effectively, given their different objectives.

"The company will want to do their own thing. If the product does well for five years, then they want to do something else, but the NHS doesn't want them to, then there's a problem."

Attitudes to Option 5: Multiple one-off fees linked to product milestones

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NHS receives multiple one-off payments triggered by the licensee achieving certain regulatory and product milestones (e.g., start of clinical trial, regulatory approval, in each case of a product relying on the relevant data).

- On the one hand, some participants appreciated this **option's mitigation of risk through holding organisations to account a multiple stages** rather than just at the start.

"It also gives the NHS or data provider a progress report as well as the product is developed. It keeps them aware of how they're doing."

- A few participants also thought that, by spreading the access charges across multiple stages, this **could enable access for less profitable research organisations.**

- However, those who supported this option often added the caveat that this **would need rigorous auditing procedures**.

"I like the idea of getting a return at different stages, but there will need to be some kind of audit or someone carrying out an inspection…[otherwise] things may not be disclosed fully."

- Some participants also expressed the **concern that researchers may either be dissuaded or actively avoid hitting milestones** in order to avoid further payments.

"You create an opportunity for them to pay the initial payment but never meet the milestone."

- On the other hand, some participants **rejected the option outright as too complex and would add risk of administrative burden** onto Discover-NOW.

"The life of a product is limited, and it's too complex, it just really would not work."

Value exchange – conditions and considerations

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- Across the groups, participants were able to recognise the benefits to Discover-NOW/the NHS, and to researchers, for all the different value exchange models discussed. There was not a consensus for one model over any of the others, however as groups discussed the models, a set of conditions and considerations were voiced concerning any future contractual arrangements.

Do not allow exclusive data access	Invest in developing commercial skills	Consider a range of - and not solely financial - benefits	A fair and consistent charging model
• Discover-NOW should not enter into commercial arrangements which include exclusivity of data access.	• Discover-NOW/the NHS should consider investing in developing commercial skills to reduce the administrative and legal burden.	• Discover-NOW must consider a combination of social, economic and financial benefits when deciding which value exchange models to progress with.	• Discover-NOW must always charge for access and maintain a tiered pricing model.

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Value exchange – expectations

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Every value exchange model should incorporate an upfront access fee

- Most groups (though not all) felt as though there should always be an access fee charged up front as part of the value exchange model
- However, this could be refunded if charged as part of value exchange models 2-5, if the product was successful.

The tiered pricing model must remain

- Most groups expressed the importance of ensuring that any value exchange model that Discover-NOW uses does not exclude smaller organisations. This can be achieved through the existing tiered pricing model and Discover-NOW should consider how models are implemented to ensure that this is honoured.

One size does not fit all and options are not mutually exclusive

- Across the groups, there was support for Discover-NOW utilising a range of value exchange models. Where certain models for particular arrangements are going to be too restrictive for Discover-NOW/the NHS, others might work better. Likewise a model might work for one commercial organisation, but not another
- Overall, the one-off payment, multiple one-off fees and royalty/profit share options were more favourable although this wasn't the case across all groups. These options felt more secure / less risky.

Discover-NOW/the NHS should enter into realistic arrangements

- There was more support for a share in royalties (option 3), as opposed to a share in equity (option 4), given this felt more tangible to the groups, easier to measure and less risky.

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4. Communicating the value of health and care data research

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Communication discussion

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Before the final plenary session of the second workshop, participants briefly discussed how Discover-NOW should communicate the value of health and care data research to the population of North West London and wider audiences.

Before they took part in the Discover-NOW Citizen Advisory Group, most participants had **low awareness** of the deliberation topic, and had not even considered how their health and care data might be used for research. However, since they had taken part in the two deliberations, they recognised the potential benefits of raising awareness of this amongst the wider public.

"If I were marketing for Discover-Now, I'd stress the money that's been raised and the projects that have benefited from that money in the local area…It can get people engaged and on board, because everyone wants to see the community thrive, and getting vulnerable people the help they need."

In terms of **what** should be communicated, participants thought that successful outcomes would be most appealing to a wider audience rather than the process of how the researchers or Discover-NOW got to that point.

"I think most people would trust the researchers and the legal side of it how it is done, they would be more interested in the outcome than in the long process which led to the outcome."

Participants had a wider variety of suggestions on **how** the value of health and care data research should be communicated. Some suggested TV, radio, and public transport adverts, but other participants pushed back with the argument that these would be too expensive. There was greater consensus around using targeted local social media, and leaflets or digital displays in health settings such as GP waiting rooms. Participants' emphasis was on ensuring the whole community was reached.

"Different demographics access information in different ways. Youngsters look at social media, Facebook and Twitter. The older demographic may get it from the local paper. You want the reach to be as far as possible."

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Appendices

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Citizens Advisory Groups' steering group

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To ensure that the deliberation process, content and direction is authentic and balanced Discover-NOW have set up a virtual CAG steering group to underpin this work in an advisory critical friend capacity. This group consists of the following individuals:

Name	Organisation	Role
Alice Dowden	Health Data Research UK	Public Engagement and Involvement Officer
Avi Mehra	IBM	Associate Partner
Barrie Newton	Public	Lay member
John Norton	Public	Lay member
Kavitha Saravanakumar	North West London Collaboration of Clinical Commissioning Groups	Associate Director of Business Intelligence
Sanjay Gautama	Imperial College Healthcare NHS Trust	Caldicott Guardian, Chief Clinical Information Officer and Consultant Anaesthetist
Taj Sallamuddin	Information Governance Services/ Imperial College Health Partners	Data Protection and Information Lawyer. Data Protection Officer for ICHP
Tom Binstead	Telstra Health - Dr Foster	Director of Strategy and Analytics

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Citizens Advisory Groups' characteristics

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The Citizens Advisory Group was recruited to reflect the diversity of North West London, including gender, age, housing tenure and socio-economic status - as demonstrated below.

38* participants took part in this second deliberation.

Gender

Female	23
Male	15

Age

17-24	2
25-29	4
30-44	13
45-64	13
65-74	4
75+	2

Socio-economic category

AB	10
C1	10
C2	11
DE	7

Housing Tenure

Owner-occupier	17
Social renter	5
Private renter	13
'Live with parents'	3

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* Not all participants attended both workshops

Citizens Advisory Groups' characteristics

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38* participants took part in this second deliberation.

Country of birth

UK	26
Outside UK	12

Ethnicity

White British	9
White Other	6
Asian/Asian British	8
Black/Black British	9
Mixed/Other	6

Health service user

Light	16
Medium	13
Heavy	9

London Borough

Brent	2
Ealing	5
Hammersmith & Fulham	3
Harrow	5
Hillingdon	6
Hounslow	7
Kensington & Chelsea	4
Westminster	6

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* Not all participants attended both workshops

Experts who supported the deliberation

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The Discover-NOW Citizen Advisory Group deliberative workshops were supported by a group of experts in health data research, public engagement and data law. The experts helped present and explain some of the key issues for discussion. After, they moved between groups, listening and helping moderators to answer questions.

Workshop 1, Wednesday 21st April

- John Norton, Discover-NOW Citizen Partner
- Amy Darlington, Executive Director, ICHP/Discover-NOW
- Kavitha Saravanakumar, Associate Director of Business Intelligence, North West London Collaboration of CCGs and Technical Lead for Discover-NOW
- Amanda Lucas, Information Director, ICHP/Discover-NOW

Workshop 2, Saturday 24th April

- Saira Ghafur, Digital Health Lead, Institute of Global Health Innovation
- Amy Darlington, Executive Director, ICHP/Discover-NOW
- Amanda Lucas, Information Advisor, ICHP/Discover-NOW

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