3KQ

Putting Good into Practice Public Dialogue

Final evaluation report
November 2021

Putting Good into Practice public dialogue
Final evaluation report

Commissioning bodies: National Data Guardian (NDG), Understanding Patient Data (UPD), Sciencewise

Contractor: Hopkins Van Mil

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Contents

Executive summary

This report

The National Data Guardian (NDG) and Understanding Patient Data (UPD) in partnership with Sciencewise, funded by UK Research and Innovation (UKRI), commissioned a public dialogue to feed into the development of guidance on making public benefit assessments when using health and care data – the *Putting Good into Practice* (PGiP) public dialogue.

This is the final evaluation report for the project. It presents overall reflections on the project and its impacts, taking account of the Sciencewise Guiding Principles and Quality Framework. This report reflects on the context and delivery of the dialogue and the actual and potential impacts emerging from the process. It includes key learning and recommendations for future dialogue processes.

Key reflections

This was a well-conceived, timely dialogue process with significant potential for impact. The project team delivered a high quality dialogue process, leading to a comprehensive report to feed into the development of the NDG's guidance – the final product of this process.

The focus throughout the process was the development of practical, useable final guidance, built around the dialogue outputs and informed by the needs of the end users. As the NDG finalises its guidance, it will be important to keep a focus on practical guidance that both reflects the input of public participants and stands up in the face of the most challenging and potentially controversial decisions about data use.

There are a number of attributes that combined to contribute to the success of this project:

- **Topic**. An emerging / young topic with some controversies and uncertainties to be explored with members of the public, but without entrenched views among stakeholders.
- **Timing**. A project fulfilling a clear need at a time when this issue is rising up the agenda.
- **Output**. A clear gap in current guidance or policy, with end users who recognise the need for practical, credible guidance.
- **Decision-makers**. Commissioners are responsible for developing guidance or policy, have the power to effectively implement it, and the agility to flex the process as needed.
- **Motivation**. Key stakeholders and decision-makers *want* to genuinely reflect public perspectives in emerging guidance or policy, as well as recognising the *need* to reflect public perspectives from a trust and transparency perspective.

Impact of the shift to an online process

A significant feature of this dialogue process was the shift from the face-to-face process originally planned to an online format, in the context of the COVID-19 pandemic. Compared to the original planned face-to-face process, the online process presented benefits (e.g. physical accessibility) and challenges (e.g. enabling softer interactions). Impacts on other aspects such as participant focus and quality of interactions are harder to quantify, and there is scope for further exploration of how best to maximise the value of online working in dialogue processes. The shift online was overall resource-neutral and did not appear to impact the quality of final output.

Recommendations

Impacts

1. Sciencewise and other future dialogue commissioners should continue to proactively address the balance between "asking about what's important to us" and "hearing what's important to members of the public" when designing future dialogue processes.

2. NDG should bear in mind the success factors identified by project team, Oversight Group members and evaluators in the refinement of the final guidance.

3. Sciencewise should consider further evaluation of this process six months or a year after the launch of the guidance, to gauge the practical and longer term impacts of this process.

Project context

4. Sciencewise and other commissioning bodies should consider this process a strong example of clear identification of a policy home and potential for impact, to inform the development and selection of future dialogue projects.

5. Sciencewise and UKSBS should continue to work to make the bidding process as smooth and clear as possible for contractors and commissioning bodies in future.

Governance, management, communications, stakeholder involvement

6. Sciencewise should consider more active early encouragement of Oversight Group membership from diverse groups for future projects. This should include looking at options for payment and covering expenses, if these are potential barriers to participation.

7. Learning from this project, future project teams should consider how to maximise value from online working, including in relation to Oversight Group interactions and process development. This could include use of an online workspace or document sharing site to enable ongoing access to latest versions of key documents and materials for the project team and potentially also the Oversight Group. It could also include exploring options for online meeting functions within Oversight Group meetings (e.g. use of breakout groups and online workspaces).

8. Similar to this project, Sciencewise and other future commissioning bodies should consider mechanisms for actively involving policy makers / decision makers / other stakeholders likely to be at the "impact end" of the process in responding to emerging findings or other dialogue products.

9. Learning from this project, future project teams should consider how best to involve specialists in dialogue workshops balancing variety of format with consistency of content and e.g. avoiding Q&A in small groups.

Delivery

10. Future project teams should pay a similar level of attention to scope as this process, bearing in mind the need to potentially revisit scope based on where participants' conversations are going, and to be clear about which out of scope aspects are potentially useful and which are not.

11. Learning from this project, future project teams should consider experimenting with a variety of online format and tools, while bearing in mind the need to focus on participant experience and accessibility, and quality and consistency of outputs.

Participant experience

12. Learning from this project, future contractors and evaluators should consider how best to integrate evaluation survey/s into the workshop process to maximise response rate.

13. Similar to this project, future project teams should consider building in roundtables / pilots / other pre-dialogue activities to help refine the process design – focusing on developing an effective process that meets the dialogue aims and enhancing participant experience.

14. Similar to this project, Sciencewise and other future commissioning bodies should consider mechanisms for actively feeding back to public participants and involving them in the finalisation of any products.

1. Introduction

1.1. This report

This is the final evaluation report for the Putting Good into Practice (PGiP) public dialogue project – a public dialogue on making public benefit assessments when using health and care data. It presents overall reflections on the project and its impacts, taking account of the Sciencewise [Guiding Principles](#) and [Quality Framework](#).

Earlier evaluation reports were produced to capture learning and provide formative input project delivery. These internal reports included an initial baseline evaluation report reflecting on the context and initial delivery of the dialogue, and an interim evaluation report added reflections on the delivery of the dialogue and the potential for impact.

This final evaluation report includes key learning and recommendations from those two earlier reports, with the addition of further reflection on actual and potential impacts. It is written thematically, starting with impacts. The Sciencewise indicators covered by this report are listed in Appendix 1 – relevant sections of the report are cross-referenced from the appendix, rather than each indicator being covered in turn in the text of the report.

1.2. Evaluation principles

3KQ provided two key forms of evaluation input throughout the dialogue process:

- Ongoing input feeding back into the design and delivery of the process (formative input), provided to the project team at regular points – for example during or after dialogue events, or at the regular project management calls.

- Reports reflecting on the process to date, provided at key points during the dialogue through the baseline, interim and final evaluation reports (summative input).

To remain a trusted critical friend to all parties and to provide ongoing input that is useful and impactful, 3KQ adheres to a firm set of principles throughout all evaluation activities. These include:

- **Constructive:** focused on gaining understanding and learning rather than on criticism.

- **Proportionate**: allocating sufficient resources to provide sufficient depth of evaluation at each stage of the process.

- **Flexible:** adapting the evaluation process to match the evolving dialogue process and context.

- **Transparent:** ensuring clear communication of the evaluation process, objectives and findings with participants and stakeholders.

- **Useful:** communicating evaluation findings in jargon-free language, and in a form that is relevant and practical.

- **Independent:** producing findings that reflect the evidence and data rather than being directed or overly influenced by the views of any one party.

2. The dialogue project and evaluation process

2.1 The dialogue project

The National Data Guardian (NDG) and Understanding Patient Data (UPD) in partnership with Sciencewise, funded by UK Research and Innovation (UKRI), commissioned a public dialogue to feed into the development of guidance on making public benefit assessments when using health and care data. The final combined NDG, UPD and Sciencewise spend on the project was £244,940.50 plus VAT, including NDG and UPD staff time (not including Sciencewise or UKRI staff time).

The project was delivered by Hopkins Van Mil and evaluated by 3KQ. An Oversight Group comprised of stakeholders representing data providers and assessors, data users, academics, health and social care providers, and public interest provided oversight for the dialogue process. This included commenting on the process, stimulus materials and outputs.

The overall process included:

- Desk research in April 2020 to review 43 relevant documents, including reports of previous dialogue processes, academic papers, current data assessment guidance, and health and social care data use guidance.

- Follow up interviews with 15 stakeholders to inform process design.

- Four roundtable discussions in June 2020 to inform the dialogue design, each consisting of two one-hour workshops a few days apart, with those involved in existing Patient Public Involvement groups.

- Pilot workshops in September 2020 to test the draft process.

- Recruitment of 28 participants from in and around (50 mile radius) four locations in England – Great Yarmouth, Plymouth, Reading and Stockport.

- One webinar and four dialogue sessions, all online, for each dialogue location – in November and December 2020.

- Reflective tasks for participants in between workshops, using a version of Recollective tailored for the process – this enabled participants to upload and comment on visual stimulus materials and films, as well as to comment and share views and reflections based on what they had heard at the workshops.

- An additional workshop in May 2021 (not part of the dialogue process delivered by Hopkins Van Mil) designed to road test the emerging public benefit assessment guidance from NDG, in advance of the June workshop.

- A reconvened workshop in June 2021, bringing together a selection of public participants with data assessors and other specialists, to discuss the emerging public benefit assessment guidance from NDG.

See the final *Putting Good into Practice* dialogue report, produced by Hopkins Van Mil, for further detail on the dialogue process and findings.

2.2 Evaluation approach and objectives

3KQ's evaluation approach is grounded in the Sciencewise requirements and guidance for evaluating public dialogues, including the Sciencewise Quality Framework and the Sciencewise Guiding Principles.

The evaluation aims to provide an independent assessment of the impacts and quality of

process – including design, delivery, reporting and governance activities – with two objectives in mind:

- Gather and present objective and robust evidence of the nature and quality of the impacts, achievements and activities of the project.

- Identify lessons from the project to support the design and delivery of future public dialogue projects.

2.3 Evaluation evidence and data sources

	Baseline stage	Interim stage	Final stage
Verbal evidence	18 telephone or video calls with project team and Oversight Group members	14 telephone or video calls with project team and Oversight Group members	Discussion of forward process and impacts with project team at a final wash-up meeting
Written evidence	-	84 public participant survey responses following the end of workshop 1 and 77 following the end of workshop 4	Online survey responses from 15 public participants
Observations	Attendance at OG meeting 1	Attendance at OG meetings 2-4, the two pilot workshops, two out of four webinars and 12 out of 16 workshops	Attendance at OG meeting 5, and at the May 2021 road-testing workshop and June 2021 reconvened workshop
	Ongoing observations of process, communications and documentation, including attendance at most project team meetings		

3. Impacts

3.1. Purpose, context and potential for impact

3.1.1. Background, purpose and context

A roundtable with a number of relevant stakeholders in August 2019 explored the purpose of a potential dialogue on the topic of the benefits of data use. The outputs of this discussion, along with a series of discussions between the National Data Guardian (NDG), Understanding Patient Data (UPD) and Sciencewise, informed the development of this dialogue project.

The dialogue process began with a clear purpose: to enable NDG and UPD to understand how participants assess public benefit in the use of health and adult social care data for purposes beyond direct care. The ultimate focus was on developing a practical output that could inform NDG's second piece of statutory guidance – to assist organisations processing confidential or personal health and adult social care data for purposes other than individual care. This clarity of purpose and end goal set the dialogue process up to have a high potential for impact.

From the start of the process, there was a clear desire from the commissioning bodies and Oversight Group (OG) members to build on rather than repeat existing work and a sense that this project could fill an important gap in current understanding.

> *"There is so much existing work in this area I think it fits a niche and seems to have a good focus. So it's well positioned."*

> *"For me the key is that this work moves the debate on and looks at some of the emerging issues. There are a growing number of projects using this type of methodology and lots of previous reports, so we need to make sure we don't start from scratch."*

The emergence of the COVID-19 pandemic during the early stages of dialogue planning led to early discussions regarding its potential impact on process and content, but ultimately did not negatively impact the quality of the dialogue design and delivery, or hinder its potential for impact – see section 6 for more on this.

3.1.2. Potential for impact

During the baseline interviews, all project team and OG members interviewed said they thought the project has the potential to impact either their own work directly, or the wider policy and decision making landscape around patient data use.

> *"There are huge potential implications for how data is used and there could be significant long term impacts."*

Other areas of work or potential outcomes beyond helping to shape the NDG guidance interviewees said they hoped or expected could result from this project are listed in Appendix 2. These included influence on data use and handling more widely, contributing to more streamlined data flows and information governance, informing future processes of public involvement, communication or research, revealing injustices in data use, and informing future policy decisions on data-related issues.

Overall, interviewees tended to share the view that the guidance produced by NDG using the dialogue outputs has the potential to be impactful and long-lasting.

Gaining a deeper understanding of public values and trade-offs was seen as a key component to this final output. The main caveats were that the guidance had to be practical and usable, rather than a set of high-level principles.

> *"There is a bit of general weariness about guidance and principles, and about lack of consistency and practicality. If this is just another one of those, it won't be helpful.*

But if it's really practical and usable then I think it will be taken up."

3.2. Impacts identified to date

Impacts resulting from the dialogue process to date include the impact of the process on the people involved, and the impact of the dialogue outputs on the emerging guidance being developed by NDG. In both cases, there had clearly been positive impact.

3.2.1. Impact of the process on the people involved in the dialogue process

See section 7 for discussion of the impact on public participants. During the interim evaluation interviews, project team and OG members identified a number of ways in which involvement in the process would inform their own or wider work, including:

• Applying learning from this process to future online or hybrid engagement processes.

• Informing the focus of future dialogue projects.

• Informing future research and service design processes and priorities (e.g. highlighting the need for more research about social care).

• Confirming existing thinking and concerns around the use of data.

• The potential to use this process as a starting point for further / ongoing discussions with members of the public.

Observation of the OG meetings, dialogue workshops, May road-testing workshop and June reconvened workshop also suggest that the range of specialists involved in the process have found their involvement in the process (e.g. speaking with members of the public directly) and the outputs from the process (summarising participant views on the topics discussed) useful and in some cases illuminating. For example, commenting on the importance of feeding the dialogue outputs directly into the NDG guidance and noting the focus on aspects such as transparency.

3.2.2. Impact of the dialogue outputs on the emerging NDG guidance

There has been a clear focus through the whole dialogue process on ensuring outputs from the dialogue workshops fed directly into the NDG's guidance on public benefit assessments. The clear presentation of findings in the final dialogue report combined with targeted discussions in project team and OG meetings helped to ensure this happened.

Further discussion at the May road-testing workshop, and direct discussion of the draft guidance with a selection of public participants in the June workshop helped to ensure that dialogue outputs informed the draft guidance in a way that was both recognisable to dialogue participants and practicable from the perspective of data assessors. A simple presentation shared at the June workshop showed how key issues emerging from the dialogue process had fed directly into specific aspects of the draft guidance. These workshops were a key part of the process in terms of securing and maximising impact from the dialogue process.

3.2.3. Impact of the understanding of public dialogue processes and content

One further impact based on the evaluator's observation of the process overall, is that this dialogue project has provided useful insight into the challenges of discussing complex or abstract topics with members of the public, but also the valuable input and unexpected findings that can still emerge during those discussions.

The objectives of the dialogue process included testing understanding of what members of the public consider to be beneficial about the use of health and adult social care data for purposes beyond direct care and exploring how members of the public weigh benefit and disbenefit of the use of this data. Dialogue participants sometimes found it easier to talk

about the process of public benefit assessment rather than the specifics of what public benefit is or isn't or how to weigh this up. This resulted in some additional findings around issues such as governance and transparency that have fed directly into the draft guidance.

There are implications here for future dialogue processes in terms of balancing the desire to meet the objectives or answer the questions identified upfront with giving space for unexpected or wider discussions that might also prove to be impactful and valuable.

3.3. Maximising future impact

The ultimate impact resulting from the dialogue process will become apparent once the NDG's guidance has been finalised and launched. There is further road-testing and consultation planned in order to refine and finalise the guidance, so at this stage in the process it is not possible to reflect on this longer term impact or on many of the other avenues for potential impact identified by participants (see Appendix 2).

Interviewees at both the baseline and interim evaluation stages were clear that the ultimate impact of the dialogue would depend upon the production of guidance that successfully translates the dialogue report into a practical, usable and well-used document. The baseline evaluation highlighted a number of aspects that members of the project team and OG felt would help to make any final guidance useful and useable from their perspective. These are repeated in Appendix 3.

Based on process observation and interviews, other aspects to consider as the guidance is further refined and ultimately finalised are:

- Continued attention to the credibility of the final guidance, including transparently balancing the range of inputs and perspectives that have been sought to help shape the guidance.

- Ensuring unintended consequences and edge cases are fully accounted for in the final guidance, to enable data assessors to use the guidance confidently where decisions are potentially problematic or not clear cut.

- The practical useability of the guidance – i.e. enabling confident and transparent decision-making rather than becoming seen as a burdensome addition.

- The wider value and use of the guidance beyond use by those with a statutory duty to use it.

- How future-proof the guidance is to evolving and emerging data systems, technologies, legislation and potential data uses.

  "The timing will be really interesting. The guidance needs to be cognisant of the forthcoming government strategy. If that strategy proposes mandating data from social care providers there is the potential for conflict between government plans and what the guidance says. The NDG probably needs powers to compel as well. There's a feeling the landscape is quite fast changing and there will be social care reform. So keeping it practical and current in a fast moving landscape is a difficult thing to pull off, especially when you're translating it into statutory guidance."

- The successful communication and dissemination of the final guidance.

- The level of trust in the guidance from all relevant stakeholders (including data assessors / providers / users and the wider public).

- The degree to which the guidance is used equally and equally as effectively for health and care data cases.

Observations to date suggest that the guidance is emerging in good shape, with a strong

sense of credibility and commitment to maximising its effectiveness from those involved in its development to date. Several interviewees commented on the credibility of NDG and UPD as commissioners as being an important factor that should help to ensure acceptance of the guidance by key stakeholders.

> *"The fact that the NDG and UPD are behind this, given their historical action in this space, I think will mean it's well received."*

Recommendations

1. Sciencewise and other future dialogue commissioners should continue to proactively address the balance between "asking about what's important to us" and "hearing what's important to members of the public" when designing future dialogue processes.

2. NDG should bear in mind the success factors identified by project team, Oversight Group members and evaluators in the refinement of the final guidance.

3. Sciencewise should consider further evaluation of this process six months or a year after the launch of the guidance, to gauge the practical and longer term impacts of this process.

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4. Project context

4.1. Rationale and timing

The need for this project was identified by NDG following a public consultation process in early 2019 about the priorities NDG should pursue as its role moved into a statutory footing. One of the themes emerging from the feedback was a call for more dialogue on the benefits of using of health and care data, particularly for purposes beyond individual care. This sits alongside significant recent government investment in the life sciences sector, particularly with respect to data-driven innovation.

This dual public- / policy-led driver for engagement presents a clear rationale for dialogue. And given the investment in the sector is already happening, engagement sooner rather than later is likely to have a greater potential to influence policy decisions for the longer-term.

The stakeholder interviews undertaken by the contractor as part of the early scoping work confirmed the need for dialogue on this topic, particularly pointing out the need for clear, practical guidance to aid decision-making on data sharing and use. This was further supported by the baseline evaluation interviews.

> *"There is a definite need for this piece of work, and one thing that most interests me is the issue around adult social care and which services will access certain bits of data, and the level of comfort with different people accessing and using different data."*

The COVID-19 pandemic has provided additional context to be taken account of both in relation to process and content – read more on this in section 6 below.

4.2. Procurement process

The need to complete the procurement process before the end of the financial year gave a relatively tight window for contractors to submit bids. This was exacerbated by some issues with the procurement portal – including access issues and limited technical support. Other issues experienced with the portal on previous Sciencewise projects (e.g. errors with budget spreadsheets) had been resolved and were not an issue with this project.

From the commissioning perspective, some aspects of the bidding process – e.g. understanding which information from the bids would be provided when, and the practical workings of the funding process – could have been clearer.

Recommendations

4. Sciencewise and other commissioning bodies should consider this process a strong example of clear identification of a policy home and potential for impact, to inform the development and selection of future dialogue projects.

5. Sciencewise and UKSBS should continue to work to make the bidding process as smooth and clear as possible for contractors and commissioning bodies in future.

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5. Governance, management, communications, stakeholder involvement

5.1. Project governance and structures

5.1.1. Overall governance and project team

There were two key groups involved in project design and delivery:

- The project team – lead representatives from the commissioners (NDG, UPD, Sciencewise), contractors (Hopkins Van Mil), and evaluators (3KQ).

- The Oversight Group (OG) – representing a range of organisations involved in the use of patient data and decisions about the use of patient data, as well as a lay perspective.

A wider group of specialists was also involved in providing content input to the dialogue workshops and, later, as participants in the May road-testing workshop and the June reconvened workshop.

The project team met fortnightly via video conference throughout the process to reflect on emerging issues or findings and discuss key decisions. This was supported by regular written project updates from Hopkins Van Mil. Observations and interviews suggest the project team structure and communication mechanisms worked well. The project team meetings have been crucial to keeping the project on track, with strong chairing and a good level of focus and efficiency. There was an open and relaxed communication style within the group throughout the process, facilitating discussions about sometimes challenging issues. The project team email chain remained active throughout the process with all parties being quick to respond to requests for input.

All interviewees who mentioned either the commissioning bodies or the contractors spoke positively about the organisations involved – particularly in relation to the credibility of the process, previous experience of working with them (including on other public engagement processes) and the ability of the process to deliver on its aims.

5.1.2. Oversight Group

The OG has met five times in total, with the original number of planned meetings being increased to enable discussion and input at key points in the process.

The initial OG membership was extended to include a member representing industry interests. Although the dialogue was focused on public-sector data, the increasing number of public / private partnerships for data use made this a relevant and useful addition, since this aspect is likely to arise during workshop discussions and will need to be taken account of in the final NDG guidance.

Beyond this addition, interviewees at the baseline evaluation stage tended to comment that they felt the group composition is about right and represents the relevant interests. A few did comment on the diversity of the group, however – saying for example that there were familiar faces on the group, or that there could be more diversity in terms of age and ethnicity in particular.

> *"The terms of reference look comprehensive, and it's clear what the role of the group is. The membership seems to be the right range and we should be able to bring a diverse range of views."*

Early comments from baseline evaluation interviews highlighted the need to ensure the group was being used for maximum value to the project, e.g. by encouraging check and challenge. The project team took account of this in the planning of future OG meetings, for example by asking specific questions of the group designed to elicit clear and constructive input.

OG members interviewed for the interim report all commented positively on their

involvement and the overall level of communication with them.

> *"We've got good information in advance and the meetings have been run well. We had a chance to speak and contribute to the chats and there was a collaborative atmosphere. It worked out better than I thought in the virtual space."*

One interviewee commented it might have been nice to have the opportunity for more in-depth discussion at some points and another that more ongoing contact between meetings might have been useful. Another, however, said that given their time constraints it was useful to have clear, focused points at which to input. It's also worth noting that, given these interviews were self-selecting, they likely do not include views from less engaged members of the OG.

The project team commented on how useful the OG's input had been overall, the quality of the chairing, the good range of perspectives included in the group and its generosity in terms of providing time and attending the public workshops (six OG members attended between one and four workshops each). There was also a feeling in some cases, however, that there was some getting back up to speed to do at the beginning of each OG, or that the project team had to push particular points forward – for example there was limited input in terms of the more challenging 'edge' cases for discussion at the dialogue workshops, which led to the project team developing the 'what if' questions in order to elicit some of the risks and challenges around public benefit decisions.

The point about getting up to speed is not unusual for OGs in public dialogue processes, although potentially more challenging with an online format, where the travel to the meeting, initial socialising and breaktime discussions do not happen, and therefore those potential spaces for 'reintegrating' into the process are absent. Consideration of asking even more direct questions regarding input (e.g. coming to the group with more fully formed case studies for input) or use of an online shared document space could also help for future processes.

The OG was on the large side for a project of this nature. This is understandable given the complexity of the topic and the need to include health and social care interests. While this presented the need for careful thought to be put into how best to engage the whole group both within meetings and remotely, the size and range of represented interests should aid the use and dissemination of the final guidance among relevant networks.

5.2 Project management and resourcing

The strength of the project team and effectiveness of its meetings ensured good overall oversight of the project management and delivery throughout the process. This enabled key decisions to be made quickly – for example the decision to shift to an online process in light of the COVID-19 pandemic.

The contractors fielded a team including two leads, both of whom sat on the project team, and utilised shared documents within the team to aid remote working. This ensured contingency for either person to take the lead where necessary, and secured version control for key project documents.

The projects management of the dialogue process by the contractor was strong, particularly in the context of adapting the process to new circumstances and shifting the whole process to an online format.

At times the process was fast moving – for example during the preparation of workshop materials and structure – and some project team members commented it was challenging to keep on top of the volume of paperwork and reading. Suggestions from interviewees that might help to meet this challenge included some more clarity over specific questions being asked of the group, including clarity over updates versus decision points, and the potential to

use a shared online workspace in future similar projects to enable team members to easily keep in touch with the latest versions of key documents.

Overall, the shift to the online format for this project was relatively budget-neutral, but did require clear and early project management decisions to reallocate resources. For example: resources originally allocated to venues and catering were used to ensure a dedicated tech support for each session and to set up the pre-dialogue tech support sessions for participants; design resources were reallocated from creating physical stimulus to re-designing stimulus for online use. In additional, an extra facilitator was required for each location to enable smaller groups of 6-7 online (slightly larger groups would have been used in a physical space) – savings made from team travel and subsistence we used to resource this.

5.3 End user involvement

The June reconvened workshop and the additional road-testing workshop held in May were crucial mechanisms for directly involving potential users of the NDG guidance in its development. Both of these workshops enabled the emerging guidance to be tested for practical use, informed by example scenarios, and both led to further refinement of the emerging guidance.

Earlier involvement of data assessors may have helped to gather a wider range of edge case and insights into emerging data applications where the balance of public and other benefits may be fine or as yet unclear.

5.4 Other stakeholder involvement in dialogue workshops

The inclusion of stakeholder interviews to inform the scoping showed a clear recognition of the complexity of the topic and range of potential impacts, and therefore the need to take account of as broad a range of views as possible in the process design. Similarly, the roundtables with members of the public informed the development of stimulus material and specific questions for the dialogue workshops. The participants for the roundtable workshops were members of existing Patient Public Involvement groups. The input from these participants largely confirmed the project team's thinking, as well as highlighting issues around inclusion and informing use of language (e.g. not to use the word 'disbenefit'), the project title and workshop timing.

A range of specialists provided introductions to specific topics (e.g. the social care sector) or case studies for the dialogue workshops themselves – either in person, via written input or by video. Observation and discussion suggest that the range of content and variety of mechanisms used was good, but that the specific content from in person presenters varied depending on the workshop location.

Members of the OG, project team, and other specialists attended each workshop – primarily as observers, but also in some cases to present on specific topics in place of one of the videos and then to answer relevant questions.

The level of engagement and contribution from OG members and other specialists contributing to the materials or attending workshops was viewed positively by project team interviewees.

Where specialists were present in small groups and were asked to answer questions or provide input, this was often useful for the small group, but from observation did tend to shape their emerging views or focus on the topics being discussed. The lack of cross-fertilisation between groups (e.g. being able to walk around the room and see other people's input, chat in breaks etc) heightens this risk in an online format. Use of the online space (Recollective) in between workshops enabled participants to reflect and build on workshop

discussions and allowed some of this cross-fertilisation to occur. Increasing the use of existing workshop elements such as use of plenary sessions to feed back key points and ensuring the prompting of alternative viewpoints could have enabled more of this cross-fertilisation.

For future online processes, further thought could be given to how to maximise the potential of online mechanisms for sharing content and specialist input with participants, while ensuring a highly consistent approach across different workshop locations as far as possible.

Recommendations

6. Sciencewise should consider more active early encouragement of Oversight Group membership from diverse groups for future projects. This should include looking at options for payment and covering expenses, if these are potential barriers to participation.

7. Learning from this project, future project teams should consider how to maximise value from online working, including in relation to Oversight Group interactions and process development. This could include use of an online workspace or document sharing site to enable ongoing access to latest versions of key documents and materials for the project team and potentially also the Oversight Group. It could also include exploring options for online meeting functions within Oversight Group meetings (e.g. use of breakout groups and online workspaces).

8. Similar to this project, Sciencewise and other future commissioning bodies should consider mechanisms for actively involving policy makers / decision makers / other stakeholders likely to be at the "impact end" of the process in responding to emerging findings or other dialogue products.

9. Learning from this project, future project teams should consider how best to involve specialists in dialogue workshops balancing variety of format with consistency of content and e.g. avoiding Q&A in small groups.

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6. Delivery

6.1. Scoping and framing

6.1.1. Planned scope and framing

Alongside the overall dialogue purpose (enable NDG and UPD to understand how participants assess public benefit in the use of health and adult social care data for purposes beyond direct care), the commissioners developed a set of objectives and questions for the dialogue. These were refined following the stakeholder interviews and roundtables, and a scope check was undertaken with the Oversight Group (OG) following the baseline evaluation report. The final set of objectives is shown below.

Objectives:

1. Test our existing understanding of what people consider to be beneficial about the use of health and adult social care data for purposes beyond individual care (e.g. research, innovation, planning)

2. Explore how people weight benefit and disbenefit of the use of data generated from publicly funded health and care, taking into account a number of factors such as:

a) The identity of those who benefit or are disadvantaged

b) The scale of any benefit and disbenefit

c) How close the benefit should be to the original purpose of the data collection

d) The likely prospect of the benefit or disbenefit

e) The impacts of the type of data used on public benefit assessments

3. Explore how far the attitudes vary on 1 and 2 when social care data is being used.

4. Ensure that the policy we develop following these dialogues reflects participants views in a further workshop after the main workshops.

These objectives and questions are linked clearly to the overarching purpose and informed both by earlier work leading up to the dialogue and initial discussions between NDG, UPD and Sciencewise.

The range of ground covered by stakeholder interviews emphasised the complexity of the topic, and the risk of the scope expanding either through design or during the workshops themselves (given the number of related issues members of the public could bring into conversations).

This complexity was further compounded by two things:

- The difference between the health and social care sectors, both in terms of structures and systems, and collection and use of data. Many interviewees (stakeholder interviewees and evaluation interviewees) commented that the social care sector is less mature when it comes to data use, as well as being very complex in terms of the range of structures and providers in place.

    "There's the issue of social care data having far less work done on it and not much existing literature. So there's new territory here where it might be useful to go a bit more broad brush. But with health data there is lots of existing work and literature, so we may look to ask more subtle questions not previously asked."

    "How do you get the information and understanding of social care when some people are outside of organisational frameworks, e.g. where they privately fund their own care?"

- The COVID-19 pandemic. The pandemic presented a very specific context for this project. It has also led to fundamental shifts in data use, systems, and legal powers,

which potentially impact the context of the questions being asked by the dialogue, as well as the content being discussed.

> *"Hopefully this process enables people to think bigger picture, but there's a risk this doesn't happen because we're in a public health emergency. I'm excited to see if it can be done and if it can get beyond the high level principles to something more tangible and concrete."*

> *"What's acceptable in terms of use of data is probably changing month by month at the moment."*

> *"I wonder if there's room to review the scope given the current context (e.g. national data stores, contact tracing, etc.), to check whether we're still focusing on the pertinent issues. Do we need a check point?"*

The issue of complexity is something the project team kept in mind as the process design and delivery continued, with the aim of maintaining focus on the desired output and not being distracted by the potential for broader conversations on related issues.

> *"It's a complicated topic and we need to ensure we don't spend all the dialogue talking about things that won't move us forward on the objectives. It will take careful design to stay focused."*

6.1.2. Participant direction of discussion

As the delivery of the dialogue workshops began, it became clear that participants frequently wanted to discuss topics outside of the direct scope of the dialogue. In some cases, interviewees commented certain topics (e.g. consent) were not so useful for contributing to the dialogue outputs. But in others, interviewees commented going outside of the original scope was actually useful for informing the development of the guidance, for example themes such as trust and transparency and comments about the process surrounding public benefit assessments.

> *"When participants go beyond the scope sometimes it's a light bulb moment and sometimes it's not helpful. It's hard for facilitators to shut things down that are obviously not useful and hear more about the stuff that is."*

> *"I think some of the interesting things that came out were out of scope, for example is the research useful, is the method good and so on."*

This links to the related point that participants often seemed to find it challenging to pin down a definition of what constitutes public benefit, even when asked specific questions around aspects such as identity of beneficiaries, scale of benefit, and so on. There could be a number of reasons for this, including:

- The need for more specific test cases to be given (e.g. "if you were the assessor in this situation, how would you decide if this is public benefit").

- Participants not feeling able to make judgements to that level of granularity.

- The possibility that the idea of public benefit is not felt by public participants to be as complex as it is for project team and OG members.

- The potential that the details of what the public benefit is are less important than the process of the assessment (e.g. is it based on sound data, what's the track record of the applicant, is the process transparent, and so on).

As a result, the opportunity to road-test the draft guidance with practical cases in the May and June workshops was important to ensure dialogue findings had been taken account of both in a way that aided public benefit assessment and that was satisfactory to public participants.

The shift of participant conversations around or away from the original scope of the dialogue

has on the whole been viewed as a useful thing by evaluation interviewees, but as discussed in section 4 above, this does highlight a common challenge of dialogue processes – enabling participants enough space to talk about what's important to them, while also bounding the conversations to ensure their input contributes to the aims and objectives of the dialogue. There isn't a single solution to striking this balance, and it is worth noting the difference between aspects that are definitely out of scope and not useful to informing the dialogue outputs, versus those that are unexpected topics which might turn out to be useful or interesting to the final outputs.

6.2. The context of Covid-19

The COVID-19 pandemic has been a significant context for this dialogue, both in terms of process and in early conversations about content.

Early in the process, the contractors developed two lines of contingency for the process, including one covering face to face meetings with social distancing in place, and one covering a fully online process. This enabled budgetary impacts to be kept at a minimum. In light of likely ongoing restrictions, the decision was made to deliver the process entirely online.

Digital exclusion was a point mentioned by a few interviewees and was taken account of in the planning of the workshops – see 5.3.2. below for more on this.

> *"I don't think we need to delay the engagement, as a lot of the world has got used to engaging online. There may be certain groups that this might exclude, or that are already at risk or being cautious about engaging online. And those specific views might be underrepresented, but we just need to make sure that's clear."*

In terms of content, the pandemic was taken account of in the development of the case studies – including some specific references to relevant data uses. There has been significant activity in the patient data space during the course of the pandemic, offering tangible scenarios and case studies that could be used as the basis for discussion.

> *"How will the answers to the questions we're asking be impacted by the pandemic – that's important to consider. Will it be a snapshot in time or have longevity? It's still a useful thing to do now as no one knows what things will look like in a few years, so it's still useful to do in a reflective way with an understanding and acceptance of that."*

> *"Context-wise it's really difficult to talk about data without talking about COVID. Also, it presents a series of really succinct case studies about what could be public benefit and where are the edges."*

During the workshops, participants were encouraged to look behind and ahead of the COVID-19 pandemic to inform their own responses, to test the degree to which their responses might be "of the moment" and e.g. influenced by more relaxed attitudes to data sharing during the pandemic. It is difficult to determine whether this final point was the case or not, and there was a mixed view among interim evaluation interviewees over the extent to which COVID-19 impacted discussions beyond providing an important context and some current case studies. As discussed below, one interviewee commented that acceptance of data use is a common finding in other similar research processes, so it may be that any additional impact from the COVID context was negligible.

It seems likely that context of the pandemic may have affected participants' general interest and familiarity with some of the language or backdrop to conversations – for example test and trace, data sharing, discussion of care homes – but that it was more of a framing for the dialogue rather than directly influencing people's core views and values. Indeed, there is some suggestion that other contextual issues, such as social media and misinformation, were more influential in informing participants' views.

"Probably people might have been a bit more interested and aware of what we're talking about unable to place it in real life. I don't think the risk of it playing out in terms of a moment in time and not being usable in the long term has really played out. I think attitudes may have shifted, but then they've probably shifted for the long term. And also the examples covered lots of things outside of covid. We need to bear it in mind, but it shouldn't detract from the validity of the results."

"People already felt quite anxious about data manipulation and COVID perhaps has not made a difference to that. Awareness of data use has maybe gone up, and awareness of internal sharing."

"Less [influential] than I thought actually, although it might have helped people to understand the use of data. But I didn't feel people automatically said it was fine to use all data due to the pandemic."

It is also worth noting that the workshops happened at a time when many would have adjusted to having COVID-19 as a backdrop to everyday life but just before the approval of various vaccines for use – had the timing been earlier or later, the newness of the situation or the significant developments in treatments and vaccines may have impacted conversations in different ways.

6.3. Workshop delivery

Overall observations and interviews suggest that the dialogue workshops were well designed and delivered, particularly given the shift to an online format and in the context of the range of considerations and pressures brought about by the pandemic.

"The project always took account of uncertainty and the online aspect never felt like a plan B or a fallback. It felt like it was well planned in. And as much thought was put into a successful deliberative campaign online as for a face to face process. And we're seeing the pay-off of that now because it was so well considered."

"I think we got an energy dip in the middle of the process that was Covid related, but it's remarkable the process was delivered with so little slippage."

6.3.1. Structure and design

The workshop structure and design were initially informed by a comprehensive piece of desktop research, including a stakeholder workshop, and later by a pilot process with a selection of public participants with a certain level of pre-existing background knowledge. These processes helped to inform both the scope of the workshops and the detail of the structure and materials used within them.

"I was really impressed with the desktop research and I haven't had much involvement in dialogue or deliberately projects but that felt really thorough and up front end preparation seemed really on top of things from the outset."

As discussed earlier, in hindsight, some more direct conversations with people on the frontline making data assessments would have added value to the scoping elements of the process such as identification of edge case and insights into emerging data applications. The involvement of data assessors and controllers in the May and June workshops was a vital part of involving these stakeholders directly in the development of practical outputs.

Each of the four groups of workshop participants attended an optional technical support drop-in session, an introductory webinar for an hour, and four workshops (three for two hours and one for three hours), with homework tasks in between workshops. The workshop sessions were held on Zoom and generally consisted of plenary sessions with information giving and sometimes Q&A sessions, interspersed with small group discussion sessions. In each discussion session, a facilitator asked participants questions based on what they had

seen or heard, or building on earlier discussions, taking notes of key points and sometimes asking the group to prioritise.

The consistent format across workshops likely has pros and cons in terms of participation and data collection. On the plus side, it enables participants to know what to expect and ensures a level of consistency of data collection. The potential drawbacks are that it risks feeling slightly extractive and repetitive, especially where the questions being asked use similar language or focus on principles rather than specifics (noting there was a mix of high level and example-based questions for these workshops).

There is a balance to strike here. Given the shorter amount of time spent with participants compared to equivalent face to face dialogue processes it is perhaps natural that the process necessarily feels a little more extractive. And given this is one of the first Sciencewise-funded public dialogue processes to move fully online, it's also perhaps natural to focus on achieving useful outputs rather than experimenting with format too much. In future online processes, and as online tools and platforms evolve (and perhaps become more familiar to people) it is worth considering more variety in the style of questions and type of activity used across the process. This also needs to be balanced with accessibility considerations around digital literacy.

6.3.2. Recruitment, inclusion and accessibility, online format

For the dialogue workshops themselves, the contractor used a recruitment specialist to recruit participants for four locations, selecting for a range of characteristics. These included gender, age, ethnicity, disabilities, life stage, working status / type, social grade, urban / rural. Social care users and carers were included on the original list of criteria, and following OG feedback it was decided to oversample for this group, to ensure the complexity of this sector is more fully represented within discussions.

Despite the shift to an online process, it was decided to keep the four dialogue groups focused around four geographical locations, with some expansion of the recruitment radius. 28 participants were recruited for each set of workshops, in line with the agreed recruitment criteria and specification.

Observation suggests the decision to stick with specific locations helped to provide a sense of identity and shared experience to the groups, which feels implicitly valuable in the context of an online process. This appeared to be reflected in the nature of interaction between participants, for example during the settling in period at the beginning of workshops. It's also possible that the wider context (lockdown / isolation) added to the general sense of positivity at engaging in the process.

It's clear that the online process enabled some people with mobility or health issues to participate who might not have found it easy to attend face to face events. Technical / technological accessibility did not present a major issue – again this was possibly lessened by the context, since many will presumably have become more familiar with connecting online or digitally in the months leading up to the workshops. See participant experience below for more on participant feedback regarding the technology.

The fact that participants could attend workshops from the comfort of their own homes may have had a range of effects. While, as discussed above, this increases accessibility for some participants, it may also impact upon focus, although to what degree is unclear – overall, participants appeared to remain engaged and committed to the process and, as with any dialogue process there are a range of factors other than setting that contribute to participants' ability to stay engaged (for example, the topic being discussed, facilitation style, and process design). And while it may have enabled participants to feel more comfortable and perhaps freer in their contributions, much of the "glue" that happens in face to face meetings is not present in online meetings. This includes the discussions that happen in breaks, the ability to occupy the same space and react to each other's contributions and body language, ask questions as an aside, and see other groups' work directly.

It's uncertain to what extent this lack of "glue" has impacted the participant experience and dialogue outputs. It may be that the impact on experience was minimal given participants came into the process expecting to participate online and in some cases possibly with limited experience of face to face workshop settings. The main point of difference is likely to be in individual participant journeys and evolution of views, given the limited exposure to other participants, facilitators and specialists other than in structured sessions. However, this may not have impacted the quality or the range of the data collected for the purposes of analysis.

6.3.3. Materials

A range of materials were developed for use in and alongside the workshops, including background information for use on a shared online space accessible by all participants (Recollective), videos and case studies for use within the workshops (in some cases speakers attended to provide input in place of the videos), in-workshop surveys using Mentimeter, and paper packs sent to all participants so they could read and reflect back on relevant material throughout the process.

Observation, participant feedback and interviews suggest the range of materials provided was good and enabled participants with different learning styles to pick up information in different ways. There was a lot of information to digest, making the recap of case studies in small groups and the provision of supporting packs essential parts of the process. See below for further comments about the case studies and videos.

6.3.4. Facilitation and discussions

Each location had a consistent team of facilitators, and each small group stayed with the same facilitator throughout the process. This enabled a good level of familiarity and rapport to be built throughout the process, and several interviewees and participants commented on the amount of sharing of personal stories that happened, and the level of comfort with contributing to conversations (although in some cases participants felt time was a constraint in this regard).

Reflection and feedback sessions at the end of each workshop enabled the facilitation team and evaluator to check in and discuss what had gone well or could be reflected on further for future workshops, enabling the team to adapt and improve processes where necessary.

The case studies and videos tended to focus on potential uses for data and were therefore by their nature "positive" about data use. The contractor flagged the need to include edge cases and emerging data applications early in the process, but these proved challenging to pin down. Although specialist speakers in the workshops presented some examples, there was otherwise limited input in the form of specific examples of edge cases or dilemmas (see comments above on this), and instead the case studies included a series of "what if" questions to encourage participants to think about challenges and red lines. This was a particular focus for the facilitation team following the first round of workshops, particularly for small groups where there were limited risks or challenges being discussed (although other groups were different in this regard).

One interviewee commented that general acceptance of data use is a common finding in other similar research processes, but it will still be important to test this through the June workshop, for example by presenting some potential ethical dilemmas or edge cases to consider using the draft guidance (see section 5 for more on this).

> *"Participants didn't necessarily seem that interested in the level of depth in terms of criteria for public benefit, more that there was someone overseeing and considering it. I'm not surprised by much of the discussion around concerns and questions, but once the discussion evolved it seemed to be really strong positivity for using data, which is reflected in lot of similar research."*

> *"I think it's going well overall. What I think is crucial is what comes out in the report. I*

was a bit concerned that the process wasn't always getting at what we needed it to get at, but I saw a few discussions and some were great and got where we wanted to."

"It's been a very tricky topic and a nebulous thing to pin down. I think the findings will go wider in terms of the interpretation of public benefits, including things like the process, the quality of who's involved and so on."

"I think there was an expectation on our part that we'd really get into the nature of public benefit in quite a philosophical way and maybe that was unrealistic. We've heard a sensible message which is that it's hard to provide one definition for one definitive framework for deciding what is public benefit, but more the secondary characteristics that might be there to be able to say it is public benefit, for example there is transparency around the process."

6.4. Data capture, analysis and reporting

All workshops were recorded, including the small group sessions. The chat from each workshop and comments made in the online space provided additional input in participants' own words. Alongside visible notes taken by facilitators in some sessions, all recordings were transcribed and used for analysis, providing a comprehensive set of verbatim notes to feed into the analysis process.

Although the nature and flow of the online sessions are likely to have impacted discussions in ways discussed above, this comprehensive data capture is more robust than what sometimes happens in face to face workshops, where the recording is used as a backup and the facilitator notes provide the main source of analysis material. The facilitator notes in this case instead provided a sense of key points and prioritisation.

NVivo was used as the analysis programme, with all input coded by topic or theme, before being translated into the dialogue report. Although this is not a statistically representative research project, this type of structured analysis is essential for providing a robust foundation to the report and for highlighting common and diverse areas of discussion or opinion.

The report itself has been through two rounds of review with the project team and one (in between) with the OG, supported by a presentation and discussion of key findings with the OG.

"Public participants pointed out benefit will be limited if the data aren't accurate. And also where people can find out about the outcomes of data sharing: it can't be buried away. The outcomes, good or bad, need to be somewhere visible. I think the findings will be helpful to the conversations around public benefit. The one thing that surprised me is that people seemed quite accepting of the shot in the dark research. It's interesting people were happy with that."

"Aside from a distinction between data that can't identify individuals and data that can I felt it was good. It was a bit of misunderstanding about that anonymised point but no feeling of anything else being underexplored."

"The critical thing will be that the report conveys whether there are any clear messages or consistency coming out in terms of public benefit. I think the early analysis suggests things that to some extent already exist, for example clear processes, criteria around companies and so on."

"I think we observed during the workshops the greater ambition around public benefits. for example a greater ambition around exploratory research and freedom of movements around data use, and changing objectives. There was a sense that the benefit doesn't have to be the original aim if there is public benefit, and that it's not in

The report has been positively received by the project team and OG members, with a range of comments taken on board in the redrafting, and with the focus on providing a foundation for the NDG to draft the guidance for data assessors on evaluating public benefit.

6.5. May and June workshops

As discussed in sections 3 and 5 above, the reconvened workshop in June (part of the original dialogue plan) and the May road testing workshop convened by NDG (added to the process later on) were significantly positive additions to the core dialogue workshop process. Workshop planning took account of earlier input from project team and OG member evaluation interviews, including providing scenarios to road test the guidance against, checking back with public participants that they recognise the guidance is in line with what they said, ensuring really good interaction between the participants and specialists and enabling public participants to talk about their experience of the process.

Recommendations

10. Future project teams should pay a similar level of attention to scope as this process, bearing in mind the need to potentially revisit scope based on where participants' conversations are going, and to be clear about which out of scope aspects are potentially useful and which are not.

11. Learning from this project, future project teams should consider experimenting with a variety of online format and tools, while bearing in mind the need to focus on participant experience and accessibility, and quality and consistency of outputs.

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7. Participant experience

7.1. Participant understanding, expectations and satisfaction

Workshop participants were asked to complete two online evaluation surveys as part of their participation in the dialogue – one at the end of the first workshop, and one at the end of the fourth and final workshop.

7.1.1. Evaluation survey participation

Out of 28 participants in each location (112), a total of 84 completed the first survey and 77 completed the second. This is not as high a percentage as would be expected in a face to face workshop, which is perhaps to be expected given participants were given the link to the survey and asked to complete it at the end of the relevant workshops rather than filling it out "in the room" as would be the case in a face to face process.

A total of 64 participants from across the four locations provided contact details to enable follow up evaluation input, suggesting a high level of engagement and enthusiasm for continuing to contribute to the process. A follow-up survey was sent to these participants after the June reconvened workshop, asking for final reflections on the process and impacts on them. A total of 15 respondents completed the survey, spread fairly evenly across the four locations.

For future processes consideration could be given to making the evaluation survey/s essentially a compulsory part of participation (for example by tying to release of the incentives in the same way as workshop attendance), to building in time within the online workshop format for participants to complete the survey/s while still in attendance rather than in their own time, or perhaps to linking to the evaluation questions from an online homework space such as Recollective. The first and third of these options have the potential to blur the boundaries between the process delivery and the evaluation, while the second has time implications for what are necessarily much shorter sessions than equivalent face to face workshops. All options, however, may have a positive impact on completion rate.

7.1.2. Clarity of purpose

By the end of the first workshop, all participants completing the evaluation survey said they were fairly or very clear about the purpose of the workshops.

How clear is the purpose of these workshops to you? (End of workshop 1)		
Response	Participants	Percentage
Very clear	48	57%
Fairly clear	36	43%
Not particularly clear	0	-
Not at all clear	0	-

7.1.3. Technology

All but one of the participants reported that the technology worked fairly or very well for them in both evaluation surveys. This is significant, since the ability to use and interact with the technology in an online meeting is essential to being able to participate. Clear advance and in-meeting instructions, an optional pre-workshop tech briefing, and having someone on hand to deal with tech issues during each meeting all likely contributed to this positive response.

Things participants said worked well about the tech included the ease of logging on, switching between sessions, variety of media used, use of Menti, use of breakout rooms, use of screen sharing, the support provided, and overall smooth running using Zoom.

Things participants said didn't work so well about the tech included occasional video glitches, lag or screen freezing, internet issues, and trouble with audio or cameras.

How well did the technology work from your perspective? (End of workshop 1)		
Response	Participants	Percentage
Very well	61	73%
Fairly well	22	26%
Not particularly well	1	1%
Not at all well	0	-

How well did the technology work from your perspective? (End of workshop 4)		
Response	Participants	Percentage
Very well	62	79%
Fairly well	15	19%
Not particularly well	0	-
Not at all well	1	1%

7.1.4. Experience in the workshops

As the table below shows, participants reported consistently positive responses to questions about ability to contribute, time for discussion, ease of interaction, facilitation, and level of support and respect. Any specific reflections or comments from participants potentially requiring action were shared with the facilitation team either at the end of each workshop or alongside circulation of survey responses.

This positive feedback is echoed by general comments from participants about the workshops, which reflect high overall levels of engagement and enjoyment.

There was also an overall positive response to the statement "I am clear about how my views could make a difference (e.g. to policy or future decisions)". This potentially indicates a high level of expectation that the outputs of the dialogue will make a difference, emphasising the importance of feeding back to participants what happened with their input and how it helped to shape the NDG's guidance.

Statement	Strongly agree	Tend to agree	Tend to disagree	Strongly disagree	Don't know
a. I felt able to contribute my views today.	**W1:** 67 (80%)	15 (18%)	1 (1%)	1 (1%)	-
	W4: 68 (88%)	9 (12%)	-	-	-
b. There was enough time for me to discuss the things that mattered to me.	**W1:** 41 (50%)	35 (43%)	5 (6%)	1 (1%)	-
	W4: 47 (60%)	29 (37%)	2 (3%)	-	-
c. I felt able to interact easily with others in the meeting.	**W1:** 48 (57%)	31 (37%)	4 (5%)	-	1 (1%)
	W4: 55 (71%)	22 (28%)	-	1 (1%)	-
d. The facilitators made it easy for me to participate	**W1:** 71 (85%)	12 (14%)	-	-	1 (1%)
	W4: 71 (91%)	6 (8%)	-	1 (1%)	-

e. I felt supported and respected.	**W1:** 70 (84%)	12 (14%)	-	-	1 (1%)
	W4: 68 (87%)	10 (13%)	-	-	-
f. I am clear about how my views could make a difference (e.g. to future policy or decisions).	**W1:** N/A	N/A	N/A	N/A	N/A
	W4: 56 (72%)	20 (26%)	1 (1%)	-	1 (1%)

W1 = end of workshop 1 survey; W4 = end of workshop 4 survey

7.1.5. What worked and what didn't

Participants were asked what had worked particularly well about the workshops or what they would change for next time, in both workshop surveys and later in the follow up survey.

The use of break out rooms was the most commonly mentioned aspect that participants thought worked well, for example because it enabled them to express themselves more comfortably and have their voices heard. Other things participants said worked well included the facilitation, the Menti poll, the diversity and different views in the group, clarity of explanation, timekeeping, and the overall format or structure.

Respondents to the follow up survey, when asked what went well, focused on learning about the topic, engaging in interesting discussions, having the opportunity to contribute and hear others' views, and meeting new people. These responses tended to focus more on the bigger-picture impact-focused aspects of the workshops, rather than specific elements of the process, which is perhaps to be expected given the timing of the evaluation surveys.

Many survey respondents said they wouldn't have changed anything. Others mentioned specific things including timing (e.g. more time for group discussion so everyone got more chance to speak, rather than information giving), shorter workshops (perhaps with an additional session), more clarity about use of the chat, more sharing of what other groups said, more presentation of negative views about data sharing, and less repetition of discussion content.

Respondents to the follow up survey, when asked what went less well, often had no comment. Where they did comment, the focus was on the sessions feeling long for online, technical issues, wanting smaller sub groups, or feeling that some people either talked a lot or didn't take the process seriously.

Overall, the feedback from participants was very positive. In an online format it is more challenging for facilitators to 'read the room' to gauge individual levels of engagement and comfort, and also harder to adapt or change the format of the process midway through in response to what's happening in the room. This emphasises the need to build in that flexibility and adaptability in advance where possible, although this will always be within the constraints of the range of online platforms used for a workshop and the need to balance delivery options with ease of use.

7.2 Participant influence and responsiveness

Although not participants in the full dialogue process, attendees at the early roundtable and pilot sessions provided important public-focused influence over the final process design. This process of testing was particularly important given the complexity of the topic and the shift to the online workshop format.

During the workshops themselves, the process for taking away overarching content or context questions and responding to these on the online participant platform (Recollective) was a good way of demonstrating responsiveness to participant information needs, and having a member of staff dedicated to technical support in each of the workshops provided

in-the-moment responsiveness.

Respondents to the follow up survey were asked for their thoughts about the additional reconvened workshop in June, if they attended this. Those who attended commented that it was good to see how their input had fed into the guidance and to hear from and interact with people who would be using the guidance. Indeed, the June workshop was a good way to feed back to those participants who were invited to attend and share how their input was impacting the emerging guidance. For future similar workshops, thought could be given to how to keep other public participants feeling involved too, for example the option to live stream a workshop and enable viewers to share comments while not actively participating in discussions.

7.3 Impacts on public participants

As part of the end of workshop 4 evaluation survey, participants were asked what had changed for them as a result of taking part in the workshops. Of the 75 participants who answered this question, the majority reported learning or increased knowledge as the main change. This included knowledge about health and social care data sharing and use, the organisations involved and their roles, safeguarding and data protection, risks and benefits of data sharing and use, and public dialogue processes.

Some participants reported a change in view or perspective, for example feeling more positively or thinking differently about data sharing, changing perspective on anonymised data, having an increased interest in the topic for the future, being more aware of how they use services on the internet, or welcoming hearing things from other people's perspectives.

> *"I was a bit daunted to start with as the subject matter was quite abstract but I have learnt so much, not just from my own perspective but how the use of data can be a power of good for all if used ethically and correctly."*

> *"It's given me an insight into the problems and dilemmas thrown up when people have to make these decisions on data usage."*

> *"I now have a better understanding of how difficult it is for data assessors to do their job well, and the implications if they don't."*

> *"It's not a topic I'd ever considered before in detail but what it demonstrated to me was the level of insight and knowledge could be bought to the subject by a very diverse group of people, all making interesting and valid points on a very difficult subject."*

Respondents to the follow up survey were asked what had changed for them as a result of taking part in the workshops. Participants pointed towards increased learning or understanding of the topic of data and data use as well as health and social care, appreciation of others' views on the topic, or a change of perspective (e.g. becoming more supportive of data sharing). One person said the workshops inspired them to apply their newfound knowledge and has had a direct impact on their future – they have since become a member of the research committee for the charity that supports their rare disease and have been offered 12 months' professional mentoring with the aim to set up a patient registry.

Follow up survey respondents were also asked two questions about their confidence in their views making a difference and their willingness to take part in similar processes. Their responses are show below.

Statement	Strongly agree	Tend to agree	Tend to disagree	Strongly disagree	Don't know
a. I am confident my views will make a difference (e.g. to future policy or decisions).	3 (20%)	9 (60%)	2 (13%)	-	1 (7%)
b. Based on my experience with this process, I would take part in similar workshops in the future	13 (87%)	2 (13%)	-	-	-

Recommendations

12. Learning from this project, future contractors and evaluators should consider how best to integrate evaluation survey/s into the workshop process to maximise response rate.

13. Similar to this project, future project teams should consider building in roundtables / pilots / other pre-dialogue activities to help refine the process design – focusing on developing an effective process that meets the dialogue aims and enhancing participant experience.

14. Similar to this project, Sciencewise and other future commissioning bodies should consider mechanisms for actively feeding back to public participants and involving them in the finalisation of any products.

8. Final reflections and summary of recommendations

This was a well-conceived and timely dialogue process with a significant potential for impact. In spite of the practical and personal challenges of the pandemic, a high quality dialogue process has been delivered, leading to the delivery of a comprehensive report to feed into the development of the NDG's guidance – the final product of this process. There are a number of delivery aspects surrounding the online format to consider further for future processes.

The project team stayed focused throughout on developing practical, useable final guidance, built around the dialogue outputs and informed by the needs of the end users. As the NDG finalises its guidance, it will be important to keep a focus on practical guidance that both reflects the input of public participants and stands up in the face of the most challenging and potentially controversial decisions about data use.

Shifting to an online format – key reflections

- There is scope for further creative exploration of how best to maximise the value of online working in dialogue processes, including use of shared workspaces for project teams and Oversight Groups, and examining the potential of new features available in meeting platforms as and when these emerge – noting that the quality of dialogue and outputs should always remain at the heart of the process.

- The online process enabled some people with mobility or health issues to participate who might not have found it easy to attend face to face events. Technical / technological accessibility did not present a major issue – again this was possibly lessened by the context, since many will presumably have become more familiar with connecting online or digitally in the months leading up to the workshops

- It was difficult to gauge the extent to which participating remotely from home impacted participant focus compared to attendance in a dedicated meeting space. Overall, participants appeared to remain engaged and committed to the process and, as with any dialogue process there are a range of factors other than setting that contribute to participants' ability to stay engaged (for example, the topic being discussed, facilitation style, and process design).

- While participating from home may have enabled participants to feel more comfortable and perhaps freer in their contributions, much of the "glue" that happens in face to face meetings is not present in online meetings. This includes the discussions that happen in breaks, the ability to occupy the same space and react to each other's contributions and body language, ask questions as an aside, and see other groups' work directly. The extent to which this lack of "glue" impacts the participant experience and dialogue outputs is uncertain. It may be that the impact on experience is minimal where participants come into the process expecting to participate online and in some cases possibly with limited experience of face to face workshop settings. The main point of difference is likely to be in individual participant journeys and evolution of views, given the limited exposure to other participants, facilitators and specialists other than in structured sessions. However, this may not negatively impact the quality or the range of the data collected for the purposes of analysis.

- There are many balances to strike in online processes (as with face to face processes), including the level of extractive versus exploratory discussion given the shorter time available, the degree to which new technologies are experimented with to maximise positive participant experience without sacrificing quality, and the continued need to take account of accessibility and digital literacy – including who might be excluded or included by the use of online processes. These questions should be borne in mind throughout the design and deliver of future online and hybrid processes.

- As discussed in section 5.2, the shift to the online format for this project was relatively budget-neutral – i.e. not significantly cheaper or more expensive than the planned face-to-face process. To deliver a process as close as possible to the original plan, with similar levels of quality and participant experience, the contractor reallocated resources to ensure elements central to online delivery were in place – for example redesigning resources for online use, resourcing an extra facilitator for each workshop and providing tech support. The shift to an online process could have led to a lower overall cost, potentially at the expense of some desired outputs and participant experience, or a greater cost, with use of additional elements such as more facilitators, online tools and resources. The experience of this project suggests, however, that similar costs should be considered for 'equivalent' online and offline processes in terms of process, participant experience and outputs.

Compiled recommendations

Impacts

1. Sciencewise and other future dialogue commissioners should continue to proactively address the balance between "asking about what's important to us" and "hearing what's important to members of the public" when designing future dialogue processes.

2. NDG should bear in mind the success factors identified by project team, Oversight Group members and evaluators in the refinement of the final guidance.

3. Sciencewise should consider further evaluation of this process six months or a year after the launch of the guidance, to gauge the practical and longer term impacts of this process.

Project context

4. Sciencewise and other commissioning bodies should consider this process a strong example of clear identification of a policy home and potential for impact, to inform the development and selection of future dialogue projects.

5. Sciencewise and UKSBS should continue to work to make the bidding process as smooth and clear as possible for contractors and commissioning bodies in future.

Governance, management, communications, stakeholder involvement

6. Sciencewise should consider more active early encouragement of Oversight Group membership from diverse groups for future projects. This should include looking at options for payment and covering expenses, if these are potential barriers to participation.

7. Learning from this project, future project teams should consider how to maximise value from online working, including in relation to Oversight Group interactions and process development. This could include use of an online workspace or document sharing site to enable ongoing access to latest versions of key documents and materials for the project team and potentially also the Oversight Group. It could also include exploring options for online meeting functions within Oversight Group meetings (e.g. use of breakout groups and online workspaces).

8. Similar to this project, Sciencewise and other future commissioning bodies should consider mechanisms for actively involving policy makers / decision makers / other stakeholders likely to be at the "impact end" of the process in responding to emerging findings or other dialogue products.

9. Learning from this project, future project teams should consider how best to involve specialists in dialogue workshops balancing variety of format with consistency of content and e.g. avoiding Q&A in small groups.

Delivery

10. Future project teams should pay a similar level of attention to scope as this process, bearing in mind the need to potentially revisit scope based on where participants' conversations are going, and to be clear about which out of scope aspects are potentially useful and which are not.

11. Learning from this project, future project teams should consider experimenting with a variety of online format and tools, while bearing in mind the need to focus on participant experience and accessibility, and quality and consistency of outputs.

Participant experience

12. Learning from this project, future contractors and evaluators should consider how best to integrate evaluation survey/s into the workshop process to maximise response rate.

13. Similar to this project, future project teams should consider building in roundtables / pilots / other pre-dialogue activities to help refine the process design – focusing on developing an effective process that meets the dialogue aims and enhancing participant experience.

14. Similar to this project, Sciencewise and other future commissioning bodies should consider mechanisms for actively feeding back to public participants and involving them in the finalisation of any products.

Appendices

Appendix 1: Sciencewise indicators covered by this report

Relevant indicators are listed below, cross-referenced to relevant report sections, with those labelled N/A not covered by or not relevant to this report. Note, some indicators were covered in more depth by the baseline and interim reports, with relevant reflections fed back to the project team at those points in the process. <mark>TO UPDATE</mark>

1. CONTEXT		
Theme	**Quality indicator**	**Section of report**
1.1. RATIONALE AND PURPOSE	Evidence that the rationale for using public dialogue (rather than any other engagement / research methods) was clear, including how the dialogue results were expected to be used alongside other inputs to decision making	4.1.
	Evidence that the purpose was clear and agreed among relevant stakeholders, and that different motivations and expectations among those involved were articulated and understood	4.1., 6.1.
	Evidence that the stated objectives identified what the dialogue was expected to achieve (not just what it would do)	6.1.
	Evidence that the purpose and objectives were framed in a way that ensured that the dialogue would meet the required quality standards, including informing specific decisions	6.1.
	Rationale for the outputs, outcomes and impacts sought from the dialogue, including their extent and limits, and how they were expected to be achieved	6.1., 6.3.
	Evidence of plans for how, where, when and by whom the results of the dialogue were expected to be used in informing decisions	4.1., 5.3., 6.1.
	Evidence that any internal objectives were made explicit and shared (e.g. organisational and individual capacity building)	N/A
	Evidence that the stated purpose and objectives were expressed in language that could be used without amendment with public participants and all other stakeholders involved, so that a clear and shared understanding could be developed	5.4.
1.2. TIMING AND CONTEXT	Discussion of how the objectives were appropriate in the particular context and circumstances of the dialogue	4.1.
	Rationale for the use of public dialogue at the specific time it was done	4.1.
	Evidence that the issues being discussed were understood in relation to existing knowledge about	3.1., 4.1.

	public and political concerns on the main and related topics and concerns (e.g. review of existing public views on the topic, desk research, literature review, discussions with an Oversight Group and/or other key stakeholders)	
	Evidence that consideration had been given to related current initiatives on the topic, especially those involving public participants (e.g. links with formal online / written consultations)	3.1., 4.1.
	Evidence identifying any key external factors that could have influenced the tone and results of the dialogue (e.g. significant media coverage of the topic)	3.1.,4.1.
	Evidence that the dialogue was timed to feed into the relevant decisions as early as possible in the decision process, at a point at which the decision could be influenced by the dialogue results and the relevant decisions had not already been taken	3.1.
1.3. POTENTIAL FOR IMPACT	Evidence of clarity and openness about exactly what could be informed and influenced by the dialogue, and what could not	3.1.
	Evidence that there was potential for change, that decision makers were willing to be influenced	3.1.
	Evidence that dialogue discussions were not unduly restricted by what could or could not inform future decisions, and that participants could raise the issues that they felt were important	3.1., 6.1.
	Rationale for the approach to working with decision makers (e.g. to build understanding during the project, gain buy-in to the process and dialogue results; and/or build capacity for working with public dialogue)	5.1., 5.3., 5.4.
	Evidence that sufficiently senior decision makers were involved throughout the process to provide organisational support to the process and results in principle and practice, and that they were prepared, willing and able to use the dialogue results to inform their decisions	5.1., 5.2., 5.3., 5.4.
	Evidence that the appropriate decision makers were sufficiently involved in the framing, design and delivery of the dialogue to understand the nature of the process and be confident that the results could be used in decision making (e.g. attended at least one dialogue event in person; and were aware of the timing, form and purpose of the dialogue results so these could be used in decision making)	5.1., 5.2., 5.3., 5.4.
1.4. RESOURCES	Rationale for the budget and timescale allocated to the dialogue, and the particular skills needed for design, delivery, specialist input, analysis and reporting, and	5.2.

		clarity on the impacts any scarcity of resources had on the quality of the outputs.	
		Rationale for the design of the dialogue and any associated activities to meet the agreed objectives, given the time, skills and funding available (e.g. resource implications of any associated activities such as surveys to increase numbers of participants and provide triangulation of results)	5.2., 6.1.
1.5. GOVERNANCE AND MANAGEMENT		Rationale for the role and membership of an oversight group for the design and delivery of the project, with rationale for the inclusion (or not) of any external stakeholders to provide expertise on overall framing, process and content, design and delivery (e.g. the involvement of funders, decision makers, scientists and other specialists and other stakeholders).	5.1., 5.2.
		Evidence of effective engagement of any oversight group (e.g. members attend meetings provide feedback in other ways)	5.1.
		Evidence of effective input by any oversight group (e.g. influenced materials, design, identified or acted as specialists to be involved in work with public participants)	5.1.
		Evidence of clear roles and responsibilities being agreed and implemented, including how changes to the project design were discussed and accommodated.	5.1., 5.2.
		Evidence of clarity of ownership and ultimate responsibility for ensuring the project met its objectives, including sufficient allocation of time for this.	5.1., 5.2.
		Evidence of wider stakeholder engagement (or not) to help widen buy-in to the process and results (e.g. Early in the dialogue to input to framing of the topic and questions to be addressed; and/or at the end of the dialogue to discuss how the dialogue results can be taken forward)	5.3., 5.4.
		Evidence of clarity of decision making within the project organisation and management to ensure that the objectives were met, including clarity of roles and responsibilities for decisions and actions (e.g. Between commissioning bodies, contractors, advisers and evaluators on issues such as avoiding bias and building relationships with participants during and after the dialogue)	5.1., 5.2.
		Evidence of an appropriate and efficient internal management team for the day-to-day organising of the project	5.1., 5.2.
2. SCOPE			
2.1. MEETING ASPIRATIONS		Rationale for how the dialogue project overall was designed to identify and address the aspirations and	3.1., 4.1., 6.1.

	concerns of those involved (e.g. dialogue events; governance)	
	Rationale for the dialogue design and methods in relation to the objectives, budget and timescale (e.g. decisions about numbers and locations of events, one-off or reconvened events, length of time for events, numbers of participants at each event)	6.1.
	Rationale for any changes to the dialogue design during the process to meet participants' interests	6.1., 6.2., 6.3.
2.2. DIALOGUE SCOPE	Rationale for the main topics and issues to be covered by the dialogue, and what was included and excluded	3.1., 6.1.
	Evidence of how the main topics and issues to be covered by the dialogue were identified and agreed (e.g. through an oversight group, desk research, wider stakeholder engagement)	3.1., 6.1.
	Evidence of how public participants were able to suggest additional topics (or not), and to comment on and discuss any issues that went beyond any initially agreed topics during the dialogue process	6.1.
	Rationale for and framing of the main questions that the dialogue addressed	6.1.
	Evidence of how the main questions to be addressed by the dialogue were identified and agreed (e.g. through an oversight group, desk research, wider stakeholder engagement)	6.1., 6.3.
	Evidence of how public participants were able to suggest additional questions (or not), and to comment on and discuss issues that went beyond any initially agreed questions during the dialogue process	6.1.
2.3. PARTICIPANT INFLUENCE	Rationale for the extent to which public participants could influence the design, process and outputs of the dialogue	6.1., 7.2.
	Evidence that the nature of the expected relationship (including limits) had been explained clearly and agreed with public participants	Observed in workshops
2.4. RECRUITMENT APPROACH	Rationale for the overall approach to involving particular members of the public to meet the objectives (e.g. recruitment to reach participants who had no previous knowledge or interest in the topic, or an invitation process to reach interested and knowledgeable participants)	6.3.
	Rationale for selection of participants to provide a credible diversity and mix of participants and the basis for inclusions and exclusions (e.g. 'illustrative' demographic mix; 'broadly' representative of the relevant population; credibility with decision makers)	6.3.

	Rationale for the number of public participants to be involved in the dialogue.	6.3.
	Evidence of and rationale for the approach taken to recruitment and sampling, and how the specification for recruitment was agreed and implemented	6.3.
	Rationale for the use of a range of methods to increase participation beyond the numbers attending deliberative workshops (e.g. digital approaches to reach larger numbers)	N/A
	Rationale for and evidence of the approach to ensuring that a diverse range of views was included in the design and delivery of the dialogue (e.g. the role of external stakeholders in the process to reduce bias, ensure broad framing, include less often heard voices and values, and cover the breadth of interests around the topic)	5.1., 5.3., 5.4.
	Evidence of how openness, transparency and participation (and confidentiality where appropriate) were achieved throughout the project	5.1., 6.5.
3. DELIVERY		
3.1. ETHICS	Rationale for approach to ethics in relation to the ethical challenges of the project including any frameworks used and evidence of reflexivity	6.3.
	Evidence of approaches to anonymity, consent procedures, management and confidentiality of data	Observed during planning
	Discussion of measures to avoid potential harm or difficulty for participants, and to protect participants	6.3.
3.2. PROCESS DESIGN	Rationale for and evidence of how the overall approach to the design of the deliberative workshops meets the agreed dialogue objectives (fit for purpose)	6.1., 6.3.
	Rationale for the choice of methods used in the dialogue project overall, and extent to which data from different (including non-deliberative) methods were triangulated to strengthen robustness of results (e.g. a mix of deliberative workshops, open public meetings, opinion polls, formal written and online consultations, other digital engagement)	6.1., 6.3
	Evidence that the methods were appropriate to enable open, creative and productive discussions at deliberative workshops including sufficient time for participants to receive relevant and useful new information, discuss and think about implications (ideally with a break between events) and come to conclusions	6.1., 6.3
	Discussion of limitations of the workshop design and the implications of these limitations for the dialogue results; clear presentation of the limitations in dialogue reports	Observed in planning and

		dialogue report
3.3. WORKSHOP SPREAD	Rationale for number and location of workshops with public participants in order to meet the dialogue objectives	6.3.
3.4. DELIVERY PERSONNEL	Rationale for use and role of external contractors in detailed design and delivery, or use of internal personnel only	N/A (required by Sciencewise for this project)
	Evidence of the appropriate engagement of stakeholders, including through an oversight group, in decisions about the appointment or procurement of the personnel required	5.1.
	Evidence of the appropriate planning and methods to recruit internal staff or procure external contractors (e.g. clear timetable built into project timings; developing a specification for the project and an invitation to tender (ITT); open and fair recruitment or procurement processes; clarity about who will assess tenders and make decisions about appointment; clarity about contractual and financial arrangements)	4.2.
3.5. FACILITATION	Evidence (including from participants) that all the participants were able to have their say and that all those who wanted to give their views were encouraged and supported to do so	6.3., 7.1., observed in workshops
	Evidence that no single person or view was allowed to dominate and that diversity of views, multiple perspectives and alternative positions were supported in the discussions	6.3., 7.1., observed in workshops
	Evidence of attention to disagreements, questions, outliers and exceptions during discussions	6.3., 7.1., observed in workshops
	Evidence that the discussions were well structured, open, focused on the key issues, and that all the key issues were covered	6.3., 7.1., observed in workshops
	Evidence of attention to details of logistics, timing etc	6.3., 7.1., observed in workshops
	Exploration of contributors' terms, concepts and meanings, and discussion of explicit and implicit explanations of meanings	6.3., 7.1., observed in workshops
	Unpacking and portrayal of nuance / subtlety / intricacy	6.3., observed in workshops
	Detection of underlying factors / influences	6.3., observed in workshops

	Identification and discussion of patterns of association / conceptual linkages within data	6.3., observed in workshops
	Identification and discussion of illuminating observations	6.3., observed in workshops
3.6. ONGOING LEARNING	Evidence of wash-up sessions after each event to immediately identify what worked well and less well, and what needed to be retained or changed in subsequent events	Observed in workshops
	Evidence that event feedback forms were analysed promptly (usually by evaluators), lessons learned and applied for subsequent events	7.1. and ongoing formative evaluation input
	Evidence of other formative evaluation input provided throughout to aid continued improvement, without evaluators straying into co-design	7.1. and ongoing formative evaluation input
3.7. FOCUS ON OBJECTIVE	Clear statement of project purpose and objectives, agreed with relevant stakeholders and shared with public participants; evidence of reasons for any changes in objectives	6.1., observed in workshops
	Explanation of limitations of project in achieving the objectives and how these affect the interpretation of results (e.g. because of gaps in sample coverage; missed or unresolved areas of discussion; time and resource constraints)	6.3.
3.8. DECISION-MAKER AND SPECIALIST INVOLVEMENT	Rationale for the role of decision makers attending dialogue events and evidence that they were sufficiently briefed and supported (e.g. the extent to which they were 'observers', or were 'participants' in the discussions – 'dialogue' implies greater involvement than observation; provision of explicit briefing for the role agreed)	5.1., 5.4.
	Rationale for the role of specialists in the dialogue events (e.g. to provide information to support the discussion, or as participants in the discussion; 'dialogue' implies more than information provision)	5.1., 5.4.
	Rationale for the number, choice, use, diversity of perspectives, knowledge and skills of specialists involved in providing scientific and technical information support to the participants in dialogue events (e.g. including sceptics / devil's advocates; those with very different views on the topics)	5.1., 5.4.
	Evidence that specialists invited to provide information to dialogue events were adequately briefed and	5.4.

	supported, to enable them to provide appropriate information at the right time and in the right way	
3.9. INCLUSION	Rationale for whether and how special efforts were needed and made to ensure the inclusion of specific groups (e.g. those most affected by the topic; or that might be 'hard to reach' through normal recruitment approaches)	6.3.
3.10. RECRUITMENT DELIVERY	Detailed profile of the achieved sample (i.e. final numbers and types of participants involved), the extent to which the recruitment specification and target samples were met and the extent to which this was appropriate to the objectives of the project	6.3., dialogue report
	Description of extent to which the participants reflected the wider population (however defined) in terms of gender, age and ethnicity balance (as a minimum)	6.3., dialogue report
	Description of any other demographic, attitudinal or behavioural factors that were particularly important in relation to the topic	6.3., dialogue report
	Discussion of the implications for project findings and conclusions of any missing coverage in participants	6.3.
	Discussion of methods of sampling and recruitment and how these might have affected participation / coverage; evidence of efforts to reduce barriers to participation (e.g. physical access, translation etc)	6.3.
	Discussion of the credibility of the process given the balance between time and budget and numbers of participants, locations, length of discussions etc	6.3.
	Evidence of the credibility of the actual sample with those expected to use the final dialogue results	Observation of OG and interviews
	Evidence of level of retention of participants throughout the process (e.g. numbers dropping out and when)	Observation of workshops, dialogue report
3.11. MEDIA	Rationale for use (or non-use) of conventional and digital media to reach the wider population	N/A
	Evidence of appropriate and effective use of conventional and digital media to reach the wider population, if relevant	N/A
3.12. FAIRNESS AND RESPECT	Rationale for the approach to the roles of different internal and external stakeholders in designing the form and content of the dialogue, to ensure the process was fair and had no in-built bias	5.1., 5.3.
	Evidence of how a sufficient number and diversity of perspectives was brought into the planning and delivery	5.1., 5.3.

	of the dialogue to give robustness and credibility to the process	
	Rationale for managing the split of responsibilities between facilitators - whose role is to manage and protect the integrity of the process, on behalf of participants, and specialists - whose role is to provide technical information on the content of the topic	5.1.
	Evidence of how the objectives of the dialogue, and the extent and limits to the potential impacts of the dialogue, were shared with participants	Observed in workshops
	Evidence (including from participants) of how respect for participants was demonstrated in the dialogue events (e.g. treated with care, openness, encouragement, offered opportunities for meaningful contribution, input acknowledged and valued etc)	7.1., observed in workshops
	Evidence (including from participants) of honest and full communications with the public participants throughout the process (e.g. about the extent of and limits to the expected influence of the results of the dialogue; how the results will be used; how they will continue to be kept informed)	7.1., observed in workshops
	Evidence from participants of satisfaction with the process, and willingness to be involved again	7.1., 7.3., observed in workshops
3.13. INFORMATION	Rationale for the overall approach to drafting, finalising and using materials to introduce relevant and useful new information to participants to support discussion	6.3.
	Rationale for the methods used to introduce new information (e.g. the use of written material, input in person from specialists on particular topics, videos etc)	6.3.
	Evidence of the approach to ensuring that participants were provided with information and views from a range of perspectives (e.g. involvement of oversight group and/or wider stakeholder engagement in the drafting of materials)	5.3., 5.4., 6.3.
	Evidence of encouragement for participants to use information from other sources (where appropriate) to enable participants to extend their knowledge if they wished	6.3.
	Rationale for the roles taken in presenting information to ensure neutrality and independence (e.g. those presenting content information being independent from the commissioning / policy body; and independent from facilitators, who are responsible for process not content)	5.4., 6.3.
3.14. TIME FOR DELIBERATION	Evidence of and rationale for approach to ensuring there was sufficient time and support for participants to engage in deliberative discussions so that they could become informed about the topics, reflect on their own	6.3., 7.1.

	and others' views, discuss and explore issues in depth with other participants and come to considered conclusions (e.g. proportionally more time for discussion compared to time taken receiving information; time away from the discussions to reflect on and discuss the issues with others between dialogue events; reconvening events after a break of some days)	
	Evidence of and rationale for approach to ensuring that the discussions were long enough to allow those involved to probe the issues in sufficient depth to enable underlying key values, concerns and aspirations to be articulated, shared and understood collectively, and thus inform conclusions	6.3., 7.1.
3.15. RECORDING AND DATA COLLECTION	Rationale for the approach taken to recording and collecting data from the discussions and conclusions from the dialogue from the deliberative discussions at dialogue events	6.4.
	Rationale for the approach to ensuring there were sufficient resources to fully capture the depth, detail and nuances of the public discussions to provide credible results (e.g. note takers in addition to facilitators; audio recording; additional facilitators / note takers working across several small groups to pick up wider points; participant feedback on draft results; conventions for taking notes e.g. to distinguish verbatim recordings from note takers' commentary / analysis)	5.2., 6.4.
	Discussion of how the methods or context may have influenced data collected (e.g. timing, location, venue)	6.4.
	Demonstration of how error or bias may have arisen in data collection / reporting and how that was addressed (or not)	6.4.
3.16. CAPTURING UNCERTAINTY	Rationale for seeking to define and identify agreement among participants on a particular point and/or to map out the range of views (e.g. degrees of agreement found e.g. everyone agrees; participants can 'live with' an outcome; prepared to accept; not acceptable and needs more work to make progress; not acceptable and would provoke vetos on any attempt to progress)	Observed in workshops, dialogue report
	Evidence of openness about where there was a lack of agreement and there remained plurality of views and how the rationales and implications of diverging views were recorded and reported so that reasons for disagreement were covered as fully as collective statements	Observed in workshops, dialogue report
	Rationale for and evidence of choice of methods for identifying where there was and was not agreement in practice (e.g. electronic polling in the room, sticky dots on propositions put forward)	Observed in workshops, dialogue report

3.17. PARTICIPATN INVOLVEMENT IN REPORTING	Description of and rationale for approach to gaining public participant input to the final results of the dialogue, or not (e.g. results developed collaboratively with participants or data collected and results reported by others)	6.5.
	Evidence of how participants were involved in validating the results, and had the ability to challenge specific conclusions and overall results, or not	6.5.
3.18. ANALYSIS	Rationale for approach to analysis of data, and evidence of effective analysis	6.4.
3.19. REPORTING	Evidence of clear links between reporting, the aims and objectives of the dialogue and the key questions that were to be addressed	6.4., dialogue report
	Provides a narrative / story / clearly constructed thematic account and has structure and signposting that usefully guides readers through the commentary	6.4., dialogue report
	Provides clear links between dialogue objectives, methods, data collected, analysed and reported	6.4., dialogue report
	Provides accessible information for intended target audiences in lay language so that readers can make their own judgements about the status of the data and legitimacy of the findings	6.4., dialogue report
	Provides a short stand-alone Executive Summary, with key messages highlighted and summarised and conclusions focused around the aims and objectives of the dialogue	6.4., dialogue report
3.20. CLARITY OF AUDIT TRAIL	Discussion of how explanations / theories / conclusions were derived - and how they relate to interpretations and content of original data; whether alternative explanations were explored; discussion of extent to which conclusions were developed with participants in the course of dialogue events or subsequently	6.4., dialogue report
	Clear differentiation between original data, analytical commentary and recommendations	6.4., dialogue report
	Clear links between analytic commentary and presentations of original data with appropriate use of quotes, photographs and other methods for demonstrating links between evidence and conclusions	6.4., dialogue report
	Discussion of how / why particular interpretation / significance is assigned to specific aspects of data - with illustrative extracts of original data where appropriate	6.4., dialogue report
	Display of conflicting views and how they lie outside the main propositions / theories / hypotheses / conclusions; or how those conclusions were revised to include them	6.4., dialogue report

	Description of data sources, historical and social / organisational context, locations or settings (e.g. specific contextual factors that potentially affect the quality and nature of the dialogue process and results; use of data management methods that preserve context e.g. separation of reporting of findings from different categories of participants - such as public participants and stakeholders; explanation of origins of references)	6.2., 6.4., dialogue report	
	Participants' perspectives / observations placed in personal context (e.g. annotated with details of participant characteristics, such as location of event attended, or age etc - if relevant e.g. from specific events aimed at young people)	6.3., observation of workshops, dialogue report	
3.21. WIDER IMPLICATIONS	Discussion of what can and cannot be generalised to the wider population from which the sample is drawn, evidence to support any claims for wider inference and clarity on limits to drawing wider inference	Dialogue report	
	Discussion of the weight that can be given to the results as 'evidence', compared to other sources (i.e. evidence from dialogue is different from but can be of equal value to evidence from other evidence traditions such as natural sciences Detailed description of the contexts in which the project was conducted to allow applicability to other contexts to be assessed	Dialogue report	
	Evidence of honesty about the limitations of the results, and any caveats readers / users should take into account in interpreting dialogue results	Dialogue report	
4. IMPACT			
4.1. ACHIEVING PURPOSE	Evidence that the dialogue achieved its original purpose and agreed objectives; evidence of reasons for any changes in objectives	Whole report	
	Explanation of limitations of project in meeting the original aims and objectives and how these limitations affect the interpretation of dialogue results (e.g. because of gaps in sample coverage; missed or unresolved areas of discussion; time constraints)	Whole report	
	Explanation of the extent to which the project met the original expectations of those responsible for the dialogue, of any failures to meet these expectations and of the implications of the differences between expectations and actual outcomes	Whole report	
4.2. IMPACTS ON DECISION MAKING	Evidence of how, when, where and by whom the dialogue results had been used in achieving any specific changes to policy decisions or priorities (e.g. priorities for action changed; new policy ideas developed; existing policy ideas dropped)	3.2.	

	Evidence of how, when, where and by whom the results have been used to improve policy making (e.g. better risk management; addressing logjams from conventional stakeholder engagement; policy quicker, easier and cheaper to implement)	3.2.
	Description and discussion of the extent to which the project led to organisational change, collaboration, networking, broader participation and co-operation in relation to public engagement in policy (e.g. improved relationships with stakeholders, cross-departmental collaborations)	3.2.
	Evidence of plans to maximise the use of the dialogue results in the longer term, to continue to influence policy, decisions and practice	3.2., 3.3.
	Evidence of plans for tracking, checking and reporting longer term and wider impacts of the dialogue	3.2., 3.3.
	Results clearly linked to the purposes of the project, and the initiative or policy to which the results were directed	Dialogue report
	Results / conclusions were supported by data / evidence, with clarity about how the conclusions were arrived at	Dialogue report
	Results / conclusions 'made sense' / had a coherent logic	Dialogue report
	Results presented or conceptualised in ways that offered new insights / alternative ways of thinking (where appropriate)	Dialogue report
	Evidence that decision makers trusted the process and products of the dialogue sufficiently to be willing to use the results in decision making	3.2., 3.3.
4.3. UNEXPECTED IMPACTS	Description and analysis of the extent to which the project achieved any unexpected impacts, and the value of those to the body running the dialogue, participants and other stakeholders	3.2., 3.3., 7.3.
4.4. SHARING AND DISSEMINATION	Description of and rationale for approach to sharing the final reports and information about the impacts of the dialogue with those involved	3.2., 6.4., 6.5., observation
	Evidence of how final reports were published and shared with all those involved in the commissioning, design and delivery of the dialogue (e.g. public participants, members of oversight groups, specialists providing input to events, other stakeholders)	3.2., 6.4., 6.5., observation
	Evidence of follow-up communications with all participants to share information about how the results of the dialogue were disseminated and used in policy and decision making	3.2., 6.5., 7.2.

	Evidence of how, where and when the dialogue results were disseminated to those best placed to act on and learn from them	3.2., 6.5.
	Evidence of wider dissemination of dialogue results to other interested parties (e.g. conference speeches, journal articles, blogs, etc)	3.2., 6.5., observation of workshops
	Evidence that decision makers trusted the process and products of the dialogue sufficiently to be willing to disseminate the results to their networks	6.5., observation of workshops
4.5. DEMONSTRATING IMPACTS	Clear and transparent reporting mechanisms to demonstrate how the public participants' conclusions were taken into account in future plans and if not, why not	6.5., 7.2.
4.6. SHIFTS IN KNOWLEDGE AND UNDERSTANDING	Credible / clear discussion of how the dialogue results have contributed new insights and increased knowledge and understanding (e.g. influence on the knowledge, understanding attitudes and capacity of the public, policy makers and others on the topics and on the potential for public dialogue in informing policy and decision making in future)	3.2., 3.3., dialogue report
	Evidence of changes to participants' knowledge and thinking about the topic	7.1., 7.3.
	Evidence of change to participants' views on public engagement, and their willingness to engage more in future	7.1., 7.3.
4.7. COLLABORATION AND ENGAGEMENT	Evidence of increased collaboration, networking, broader participation and co-operation in relation to public engagement in science and technology	3.2.

Appendix 2: List of potential impact areas

Beyond informing the development of the NDG guidance on public benefit assessments, project team and Oversight Group members identified the following as areas of potential impact resulting from this project:

- Setting the precedent and direction for future guidance and decision making around use of public data (e.g. based on dialogue and taking account of public values).

- Enabling confidence in data use, with decision based on the potential for benefit weighed up against potential risks, rather than just the avoidance of risk (e.g. due to concern about breaching current regulations).

    "I hope it leads to more consistent and confident decision making about how and when data is used and hopefully more clarity for the public about how decisions are made."

- Facilitating the desire to streamline information governance within the NHS and the move towards shared health and care records / joining up health and social care records.

    "There is other work happening alongside this that this could feed into. One big thing is the idea of shared health and care records, so that information is flowing across different organisations – with the shared aim of better outcomes."

- Developing legal rules and values around data use, and how these are communicated with the general public, and with particular groups (e.g. over 60s, people who are illiterate, etc.).

- Revealing injustices in data use (e.g. for under-represented groups).

- Informing future policy decisions on AI, surveillance, data tracking platforms and apps.

- Enabling the social care sector to be better prepared for a potential second wave of COVID-19.

- Helping to resolve issues with data flow that might impede individual care.

- Influencing the development of the data platform in development by the Office for Statistics Regelation and Office for National Statistics.

- Understanding where members of the public are on the privacy vs usefulness spectrum when it comes to use of their data – including in the context of the current pandemic.

- Informing cross-sectoral guidance on data and technology currently in development.

- Identifying research gaps for future engagement projects.

- Understanding the motivations and expectations behind people sharing data.

- Avoiding previous erosions of public trust (e.g. with reference to care.data) being repeated.

- Defining public benefit, to enable a common understanding and a more consistent weighing up of risks and benefits by those making decisions on data use.

    "One thing that would be really useful is if we're able to distil a little more what we actually mean by public benefit and public interest. People are being asked to make these sorts of decisions about risks and benefits all the time but often do them intuitively. So it will be useful to have a more empirical understanding."

- Identifying areas for future public dialogue, or informing future dialogue projects already being planned.

- Providing learning for future dialogue processes, including online processes.

- Providing a template for public involvement in other policy areas.

- Informing the ongoing / future work of specific organisations such as NHSX and NHSX Data Research Hubs, NHS Digital, all NHS organisations using data (and especially those partnering with industry to do so), Centre for Data Ethics, the Health Research Authority and its Confidentiality Advisory Group, Office for Life Sciences, IGARD, Health Data Research UK, Ada Lovelace Institute. (Note, this list is not exhaustive.)

Appendix 3: Thoughts on final NDG guidance

Aspects members of the project team and Oversight Group felt would help to make the final NDG guidance useful and useable:

- Clarity over the specific gap this work is filling (not repeating, but building on other work).

- Inclusion of health and social care equally.

- Recognition of the need for greater links between health and social care, but also the difference between the two sectors, particularly with respect to nature of provision and collection / use of data.

- Something that looks beyond the gaps in social care data to bring is considerations of sensitivity and potential uses and benefits (e.g. in relation to mental health data).

- Detail on the why as well as the what – e.g. why do people feel a certain way, what are the nuances and trade-offs they are taking into account?

   "It needs a degree of specificity that informs policy, and reasoning that backs up the guidance with detail – why do people feel that way?"

- Consideration of how to present the outputs to different audiences (e.g. decision makers, data users, members of the public).

- Guidance to ensure there isn't avoidance of data use (e.g. for fear of breaking regulations), as well as to avoid poor data use.

- Consideration of commercial interplay and the types of considerations needed when these organisations are involved in the use of public data.

   "Something that looks at balancing public benefit of commercial use with risks and concerns."

- Inclusion of practical measures that are easy to implement and easy to know where they are not implemented (e.g. to help track application of guidance).

   "The amount of regulation around data sharing can be used as an excuse not to use data at all, so how do we use the guidance to ensure that's not happening?"

- Inclusion of clear definitions.

- Consideration of the decision making processes around data use – e.g. what specific questions are those making decisions asking and how does the guidance help to answer these?

- Use of scenarios and case studies, including sharing the types of scenarios members of the public considered as part of the dialogue process.

- An understanding of public views in relation to clinical trials – e.g. are there specific barriers around data and privacy preventing participation?

Interviewees for this interim report provided further input on expectations or considerations, including the following:

- Acknowledge who controls the data and what are the existing legal obligations on them.

- Focus on what we can do rather than what we can't do – make it enabling.

- Consider local service design as well as big research, and how to enable access for intelligence not just use.

   "Ensure the guidance is not just research focused but is also about using data to better inform outcomes and service delivery at all levels, especially locally"

- Include the factors that would be helpful to consider when looking at applicants and what factors to have regard to when assessing public benefit. And if possible include a sense of scale, i.e. does it have to be proportionate in terms of the money made by private companies, what is sufficient benefit, is it UK only, does it have to be health or can it be for policy research, etc.

  "One of the key aspects is trying to do something really practical. If we're making decisions about public benefit these are the things you need to take account of and these are the things that can tip the balance one way or another."

- Consider ethical issues – e.g. how to stop certain people doing certain things.

- Be really clear what kind of data is being discussed – e.g. does it make a difference if it's social care data, or if it's identifiable?

  "It would be a shame if the guidance said health and social care data was the same given forthcoming government activity in this area."

- Ensure the guidance is accessible to lay members of panels.

- Ensure there is clarity and consistency of language.

- Be clear who the guidance is for / who can use it, e.g. CPRD, NHS England, NHS Digital, who else?

Appendix 4: Public participant workshop survey results

End of workshop 1 survey

Q1 Which workshop have you just participated in?

Answered: 84   Skipped: 0

Q2 How clear is the purpose of these workshops to you?

Answered: 84   Skipped: 0

Q3 How well did the technology work from your perspective?

Answered: 84   Skipped: 0
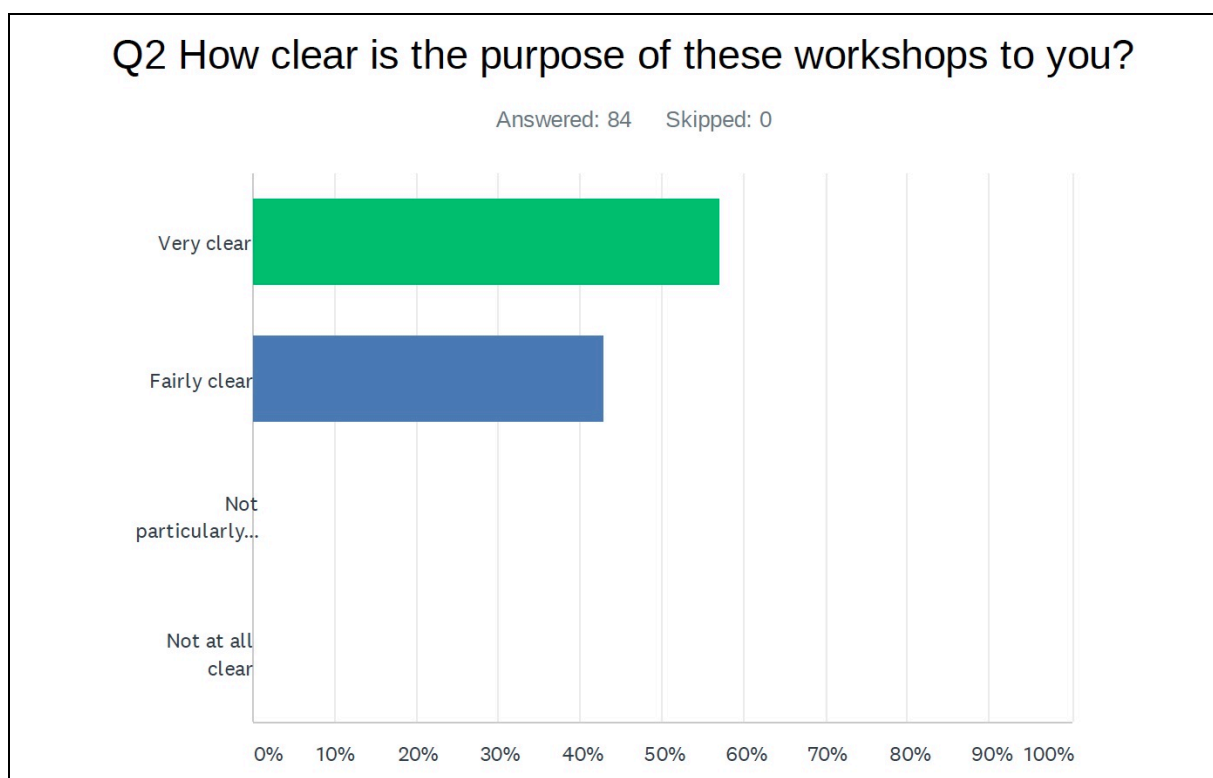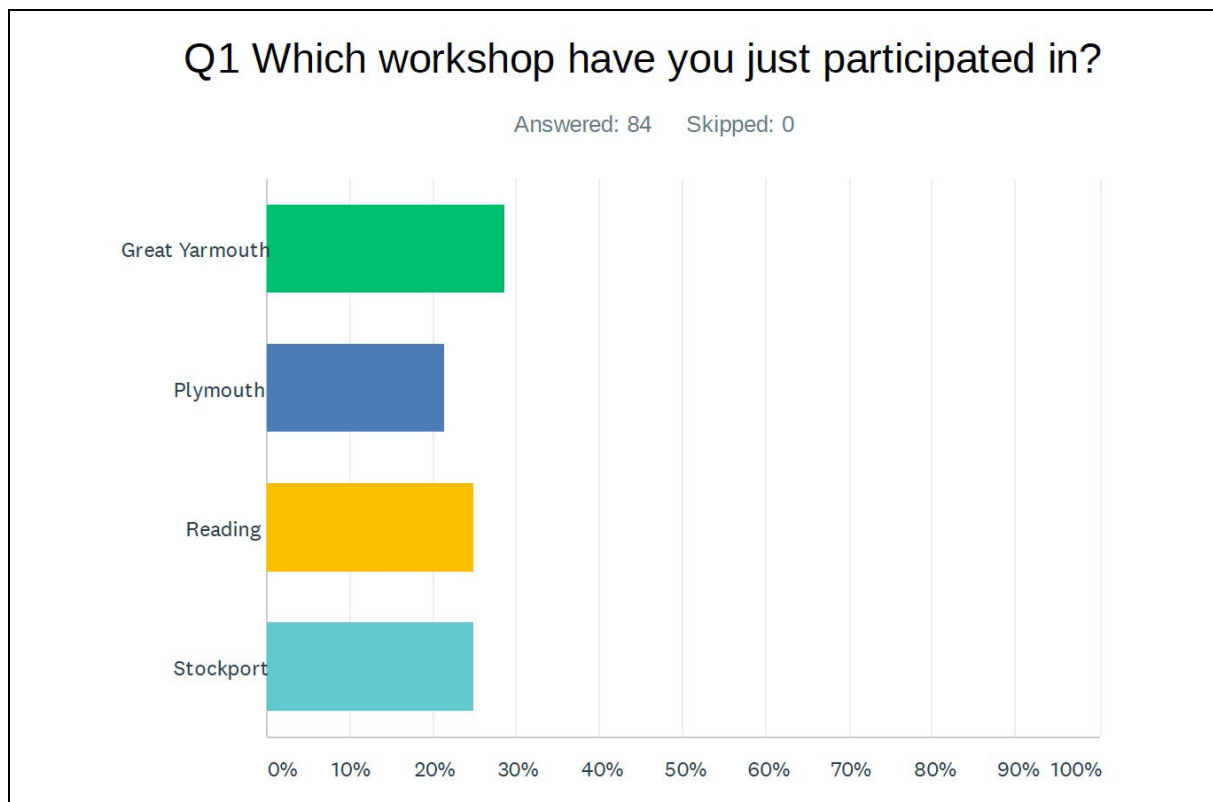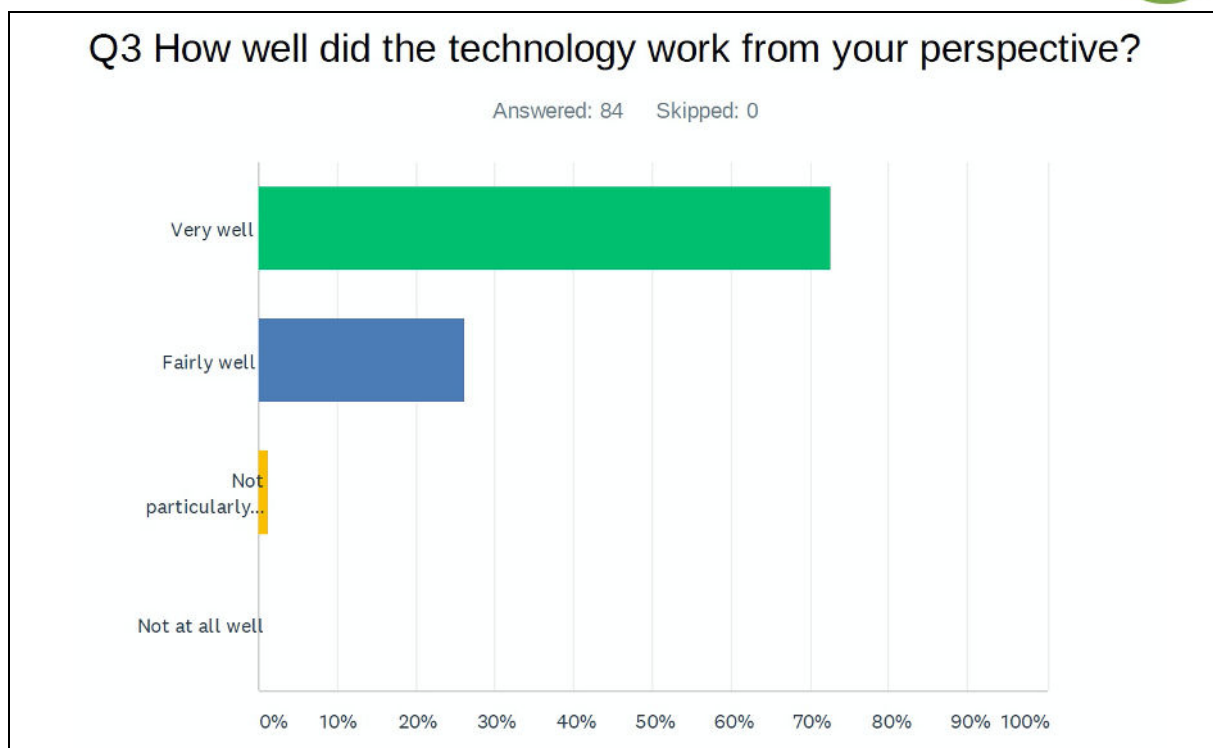
Q4 Tell us more about your answer to question 3: what worked or didn't work about the technology?

It was seamless, switching in between sessions.
Clarity of videos and presenters, very well introduced and managed throughout.
Not sure how to chat during shared screen video - but generally pretty impressed (I'm not very used to Zoom).
Zoom is a great tool.
The breakout rooms were really useful in allowing me to voice my personal opinion. I had no problems using the technology at all. However, I do wish the breakout rooms were slightly longer in terms of the amount of time we had.
Problems with internet!
My zoom just crashed at the start and I had to reboot my laptop and rejoin. The breakout rooms on zoom were good
Zoom is efficient and very well balanced.
Standard Zoom issues.
Sometimes didn't hear the speaker.
Easy to use and help with the technology.
Lost sound once when returning to the main group, but I sorted it.
The breakout rooms were great, smaller groups made discussion easier and flowed naturally as if it was in person
Screen sharing working very well, audio sometimes bad.

Could see dialogue, was helpful.
Zoom is easy to access and works well on my computer.
Breakout rooms very efficient.
Variety of media.
Everything worked very well including zoom and how breakout rooms and big sessions were arranged.
The menti tech is great! I think Zoom is the main issue for me, my internet occasionally dropping out makes it difficult for me to keep up with what's going on. Partly my problem obviously :(
I use zoom quite a bit for university purposes so navigating through was quite easy.
It all seemed seamless. No probs in sight or sound. Moving in and out of breakout rooms was smoothly done.
Videos are a little laggy but audio on them works fine.
I could clearly hear everyone with only a few minor glitches which is pretty impressive for such a large group!
Very easy to participate & very well facilitated.
All good.
Everything worked extremely well.
It was easy to chat in the group and could see and hear everyone.
Good video and audio - great meeting method.
The videos were a bit laggy, so that could be improved, but everything else was golden.
Nice and easy to use, helpful to have the information in the pack to advise on how to use it.
Splitting the zooms worked effortlessly (nice and smooth).
Zoom works well. Chat function is too hard to participate with on a tablet.
Ease of use.
Videos occasionally glitched.
No problems.
My camera was dark and some people were a little quiet. Apart from that it was fine.
I especially liked how we went off into smaller groups.
As I am severely deaf (I use blue tooth enabled hearings aids) it would be great if you could use subs on all videos, I notice you did on some but not all. Sometimes it's hard to keep up/focused when hard to hear and/or trying to read bullet points etc at same time. Thanks!
It all worked very well.
Mostly good, just a little delay on some videos.
Problem with mic at my end... so having to use a mobile and PC at the same time, to be able to interact.

All the tech I have at home with great broadband speed makes sure there are no interruptions.
All seemed to work well.
I was really impressed at how well so many people can access the workshop at any one time online.
Everything was fine.
I have struggled when using Zoom for work or sports club purposes so it's nice to see it working well with people who know how to best utilise its functionality.
Couldn't get my camera to work - Jemima offered to help but unfortunately I'd already done her suggestions but I was able to join in as had sound and chat option.
All moderators seemed to know what they were doing, everything ran smoothly and time spent in break out groups compared to in the main room was balanced nicely.
It all worked fine.
It is very well organised and runs smoothly. I just need to master flicking between Menti and Zoom!
Sometimes connection was slow but think that was just wifi connection also some mics were quiet.
With zoom there are always going to be issues with microphones.
It worked well.
The technology worked very well.
A little lag at times but mostly very smooth.
Was clear, could see the screen when other people were sharing their screen. Was very impressed by switching from the small groups to the big group.
Nothing from the host side. I had mild issues with my internet connection.
Everything worked as it should've done.
Slight lag on the zoom call at times.
No issues.
I think the use of Zoom and the breakout rooms are useful to hear the overall information in the large room and share my opinion and also have my opinion heard in a smaller group.
Screen froze.
The ability to see and hear others.
Some audio disappeared.
Have had no issues.
All worked fine. Breakout groups effective and the timer before returning to main session is helpful.
Very well organised and flowed no tech issues.
Zoom worked well was easy to hear what everyone was saying.
No issues with zoom and the breakout rooms, and video sharing.

Everything good.
All worked very well. Love Menti.
It all worked seamlessly.
Wasn't heard on two occasions.
All went smoothly. Transition to breakout rooms all very smooth.
All worked well.

Q5 Please select the answer that reflects your response to each question

Statement	Strongly agree	Tend to agree	Tend to disagree	Strongly disagree	Don't know	TOTAL
a. I felt able to contribute my views today.	67 (80%)	15 (18%)	1 (1%)	1 (1%)	-	84
b. There was enough time for me to discuss the things that mattered to me.	41 (50%)	35 (43%)	5 (6%)	1 (1%)	-	82
c. I felt able to interact easily with others in the meeting.	48 (57%)	31 (37%)	4 (5%)	-	1 (1%)	84
d. The facilitators made it easy for me to participate	71 (85%)	12 (14%)	-	-	1 (1%)	84
e. I felt supported and respected.	70 (84%)	12 (14%)	-	-	1 (1%)	83

Q6 Tell us your thoughts about today

What worked particularly well?

The break out sessions.
Going into smaller groups allowed the 'personal touch' which in our small group had all contributing.
Break out room - high level of participation.
The menti poll.
The use of the breakout rooms.
Small group discussions.
Breakout rooms.
Use of timekeeping and efficient discussions to enable thought provoking answers and clarity on public benefit data.
Discussions.

The clarity of explanations.
Plan and structure for the session.
Better understanding of the topics.
Very well hosted.
Breakout rooms.
Small group discussions - gave people a chance to contribute.
Breakout groups.
The groups allowed everyone to get their voice heard.
Smaller chat groups.
Breakout rooms.
Fascinating.
Smaller groups and larger groups very well co-ordinated.
The general feel of the group is very friendly and relaxed, and makes discussing these issues enjoyable! Big shouts out to the hosts and the other people in the group! Technically I also thought the Zoom mini rooms were pretty cool.
The individual groups.
Breakout rooms.
Group discussion.
The facilitators.
Everything.
Everything.
Small group discussions.
Working in smaller groups to discuss.
Interaction.
Smaller group chats - easier and less overfacing.
The breakout rooms are great.
The small groups gave people more of a chance to voice their opinions, a large group may have made it more difficult.
Splitting the groups - having [names].
Timings and group discussion.
Breakout rooms.
Breakout rooms.
Time keeping.
The group dynamic.
I felt that I was given the space and time and opportunity to speak.

The facilitators were really good, especially [facilitator name] - she kept everything on point and corralled us back when we went off topic (i.e. individual topics as opposed to social care).
The small focus group.
The group discussions.
Zoom, group participation, Menti.
How each person involved was patient with each other when answering a question.
Good interaction with the group and the facilitator.
It was very interesting hearing different thoughts and answers.
The smaller groups makes it easier to discuss matters.
I enjoyed the smaller groups.
Very helpful hearing from [names] found them very informative.
The breakout rooms.
Being given a talk.
The moderator was great at helping people flesh out their points, asking the right questions to help them extend on their points, as well as making sure everyone had a chance to contribute.
Small groups.
Breaking off into the smaller groups.
I liked the pace.
Everybody listened and was respectful.
Technology I felt was the best.
Providing us with the background knowledge that we may need to discuss the matter in a better and more informed way.
All of it.
Being able to share our thoughts and views in smaller groups.
The breakout sessions. Easier forum to give opinions/share ideas.
The whole workshop worked well.
I liked the smaller groups as it made it more comfortable and easy to contribute.
Very well put together.
The breakout rooms to allow me to say my thoughts.
Everything apart from it freezing.
The time management.
Timing of the meeting.
Shared a lot of info and like minded people my concerns are others.
Break out groups.
Hearing other ideas.

The smaller group sessions.
Break out rooms.
Group chat was much better.
Technology.
The format was excellent and well balanced.
Group discussion.
Information shared well.
Breakout rooms.
The break out sessions.
Going into smaller groups allowed the 'personal touch' which in our small group had all contributing.

What would you change for next time?

Nothing!
Nothing at this time.
Bit confused when to chat and when to save questions for later.
Nothing.
I would allow the breakout rooms to stay open for slightly longer.
Nothing.
Having to join 15 mins before the actual session starts makes it really long, just sitting for 15 minutes isn't great, 5 minutes would be better.
Less times on video watching and more on active discussions.
More time to discuss and bounce ideas off each other.
Too much time spent on education; not enough time on discussion and participant input, which is the purpose of the workshops after all.
Perhaps a bit more time in the group sessions for discussion.
Nothing.
One of the videos had no subtitles.
Two breaks, long session after a full day out at work.. as I only finished work with 5 mins to spare before the session.
More presentations.
Slower talk from the speakers crunching heavy information.
More focus group time.
N/A
N/A.
Nothing as of now.
Nothing I can think of.

Involve people a little more.
Unsure.
If we have a question to answer after watching a video, it would be good to know the question first so we can begin to form our answer whilst watching and remember the important points.
Nothing.
Nothing, all good.
Nothing I can think of.
More time for questions.
Nothing
Nothing.
I would maybe have a rotation of people talking in breakout rooms, sometimes it's hard to get in a word when there's a select few that are very talkative.
More time in the groups, some people got cut off trying to get through what they were saying.
Longer times in smaller groups.
Timings - could be shorter.
Nothing.
Nothing.
A little more group talk time.
Feel a little more comfortable and confident about voicing my thoughts.
I need to work out how to adapt my screen view - having all the participants in view whilst trying to listen is really distracting!
Sometimes was a bit rushed.
Nothing....it's working well.
Doing Zoom and Menti, together has been a struggle.. due to having to use two devices at the same time for Zoom.
N/A
Nothing, all went smoothly.
Answering more questions.
Nothing.
Nothing.
Tea for wine! Just joking. All good.
Break too long.
Reading aloud what is in the pack.
Have some sort of method of recording your points/opinions in break out groups that you didn't get a chance to share, like submitting a word doc or form that can add additional notes.

Nothing.
I would be really interested in knowing whether our ideas were similar to those in other groups - maybe the facilitators could give a brief summary of thoughts and comments?
I'll have to think about that more.
Nothing.
I would like a little longer to talk next time to chat and not feel I am to be hurried along.
Maybe even more time to discuss in small groups, especially to allow less confident people to psych up to answer more. Furthermore, although Calibri isn't a terrible font, a font such as Arial is easier to read and more dyslexia friendly.
Nothing.
Leave more time to share more points and expand our views.
Nothing.
Nothing.
Nothing.
Provide more interactive content throughout rather than videos.
I was happy with it.
Some participants are clearly not interested and bring the group down in smaller groups.
The questions asked in breakout are quite woolly so sends people off in too many directions for the amount of time given.
Nothing.
More time.
Nothing.
More group chat.
Some of the participants.
I think in discussion sometimes the purpose/outcome is lost. may be good to keep hammering this home.
Don't know.
Wouldn't.

Q7 Is there anything else you would like to say about this meeting or your experience of being involved with this process so far?

Found it very interesting and valued that 'my thoughts count' Everyday is a school day and I am picking up very interesting information on important matters in addition (hopefully) to assisting with improvement of future health and social care data gathering methods and security processes.
Pretty tightly run, good support.
Very interesting subject; I'm looking forward to the next workshop!
On a whole, the workshop process is working really well!

No.
I'm finding it interesting.
Thank you for allowing us to be a part of it. I would love to focus more into this in the future, so anyway to collaborate further would be helpful for more participants on joining the cause.
Found it hard initially to get my head around exactly what the subject of the discussions was but now have a good idea.
Very interesting so far.
No.
Very enlightening.
Enjoyed it.
None.
So far it's been really interesting and fun to be a part of!
Very interesting the information I am learning about.
It was actually enjoyable.
No.
It's really interesting to hear everyone's perspectives. Thank you.
I am enjoying the process and finding the discussions extremely interesting & worthwhile!
No, all good.
Very pleased to be part of the process to inform positive change.
It's really interesting and a great thing to get involved in.
It seems a little diffused - talking about older peoples social care as a salient point for a hot second, then it was never brought up again in detail.
I am having a great experience so far! It's very insightful and I feel very lucky to be part of such an interesting study.
It has been really insightful and interesting for me to take part in.
Better than I expected!
Very interesting.
I am enjoying the process. I was a little unsure after the first meeting as I didn't see where I would "fit" or if I had the correct skills to make a positive contribution but I feel much more comfortable now.
I've already learned a huge amount and I am keen to see how the workshops evolve now we are all getting more of a handle on the subject.
All good so far.
I'm enjoying it so far, and am pleased with the knowledge that our views, and input could shape new data protection guidelines.
Really good, and good experience, as being in social isolation has helped.
I think it well really well and my group were lovely people to speak to.

Enjoying it.
No.
The facilitators are professional and friendly, I think this helps people relax and think more clearly.
Looking forward to the next workshop.
I feel grateful to be involved in such a worthy research project. Thank you.
Really enjoyed it, nice to have so many views and experiences included.
Works much better than I expected, really impressed with the way the workshops are turning out.
Enjoyed it very much, very interesting!
It has been really enjoyable and it's good to be able to explore a topic that normally I wouldn't feel I had the knowledge to discuss i.e. 'data'.
I enjoyed it. Thanks!
Enjoying it.
This meeting was a lot easier than the introduction, even though it was longer, the ability to participate more and have more mental stimulation made it more accessible to me with ADHD, whereas I struggled to sort of stay focused and motivated in the webinar. I thoroughly enjoyed the discussion groups and almost wish we had a little longer, maybe 15 minutes for each set of questions.
I have found it very interesting and I have enjoyed listening to other people's views and opinions. I wish there were more younger people as they may be more likely to share my view points and trust technology and data sharing a little more.
I appreciate the opportunity to give my opinion and discuss the topics, especially during this Covid period. Highly relevant.
I really enjoyed it. My first workshop and I feel I have learnt so much about a topic that is actually rather important.
I'm really enjoying it so far and I'm finding it very interesting.
Very happy with it so far.
I'm enjoying the experience.
Great.
Hosted very well.
Very positive.
Is there any way to ensure no stutter on the videos during sharing?
Everything great so far.
Really good - though I do think that some of the participants should have a drug test before joining!
Not sure yet.
Not at this point.

End of workshop 4 survey

Q1 Which workshop have you just participated in?

Answered: 77   Skipped: 1

Q2 How well did the technology work from your perspective?

Answered: 78   Skipped: 0
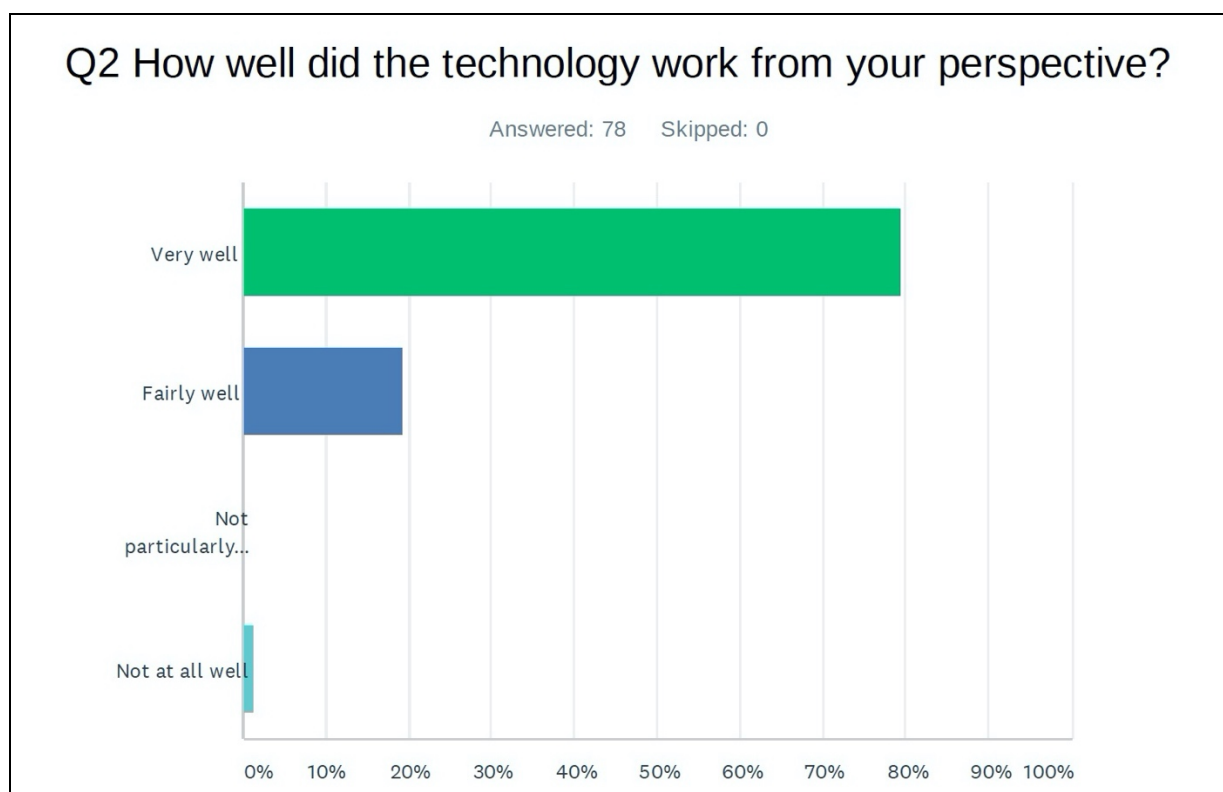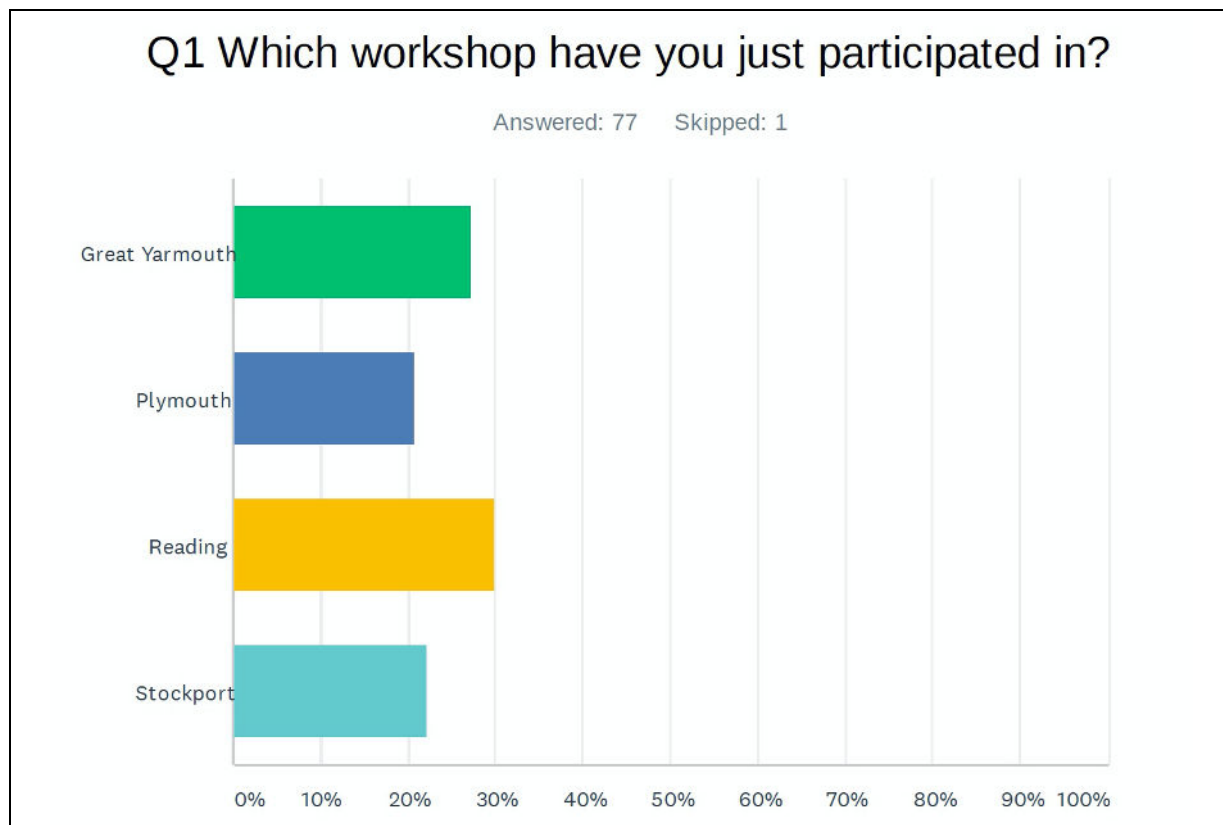
Q3 Tell us more about your answer to question 2: what worked or didn't work about the technology?

Would be nicer in an actual face to face setting but obv not possible at the mo.
Quality video & audio. Share screen function worked without any glitches.
I like how seamless it all was with moving into breakout rooms and polls.
I had problems with my internet speed so had to turn video off quite often.
My connection etc was excellent but when the facilitator was sharing her screen I was unable to see the rest of my group (only 2 of them max) which meant I couldn't see who was talking, and we had a tendency to talk over each other. However that could have been my fault, as I'm not as family with Zoom as some others, plus I was using an iPad Pro.
It was easy to log on and follow all the information.
Zoom and breakout rooms worked well.
Menti, website and Zoom all worked well.
Sometimes when leaving smaller groups zoom would kick me from the call rather than put me back in the bigger group.
Zoom excellent.
Problems at my end rather than yours as despite best efforts I couldn't get sound on laptop - from me to you - to work. Ended up having to use laptop and mobile.
IT let our small group facilitator down at the last session, otherwise it was good.
Able to watch on tv which was fab.
The format of breakout groups worked well.
I got thrown out of Zoom twice when transferring to a breakout group.
The breakout rooms worked really well in allowing me to share my opinion.
Mostly very well although in the very last session our small group facilitator did, through no fault of her own, lose the ability to share screen.
The zoom sessions were very smooth, breakout rooms were great.
Everything worked as planned.
Zoom work very well, screen sharing.
Zoom worked, can't think of anything that didn't.
All good.
Breakout rooms were successful
Problems with connection. Had to close down video to continue. Think this was more a Zoom problem.
Sound and vision were fine. The break out rooms worked well.
It was more glitchy tonight but on the whole it's been great. Grace was a real star at sorting all the tech issues.

The technology worked really well. The breakout rooms were well managed and gave everyone the opportunity to speak and being able to ask questions to the speaker was fantastic.
It all ran very smoothly!
Was easy to join and have your voice heard.
There were no issues, it was smooth and well managed.
It was all good, only a little laggy on the videos.
Video and sound worked well.
All worked well
Everything worked perfectly.
Chat function hard on a tablet. Zoom worked well.
Was easy to use.
All worked well.
It all went smoothly.
The zoom groups worked really well, especially the screen sharing.
Everything worked fine, and people were given help when necessary, no problems.
Couldn't get my microphone to work, tech came up with using both mobile and pc, to participate, although having menti as well was bit difficult... would be better if menti were integrated into zoom.
I had no problems with the technology, it all worked well for me.
Zoom and Menti worked very well, only issues were from people's personal setups.
Had no issues with my broadband, so makes any connections easy.
Technology was great, Jemima was excellent at bringing people back in, didn't have any issues except with my own wifi.
It was better once I got the hang of changing the gallery so I didn't get distracted by people morphing into strange backgrounds etc!
There was no issues with tech.
Everything worked.
Nothing to do with the team....just that the internet issues can be annoying but I know no one can do anything about that.
Some chat room malfunction.
The use of zoom was very useful: The breakout rooms made separate zoom discussions very easy. The only issues I had was with my own internet connection.
Worked very well in everyone having their say and chances to break away to discus in a smaller group.
Connecting to the chat and being able to see and hear everyone very clearly was great.
I think it was my technology that was the issue except for the day I got thrown out of the group accidentally.
It all worked as intended and there was no drop in video or sound.

Everything worked fine.
Everything worked fine.
It all ran very smoothly and I was impressed by the technical support that was available if we needed it.
All good.
My connection was lost sometimes but that was from my point.
Mild lagging at times but otherwise very smooth.
It all worked from what I could see.
Everything worked on the most part.
It all worked perfectly.
Loved menti - very used to Zoom and it worked well.
Good to have warning the breakout sessions were ending and going back to main room however once the 60 sec countdown begins you can no longer control mic of video.
Was easy to use and respond in the smaller groups.
Worked perfectly.
No issues since last survey.
I had no problems at all.
Bit laggy at times.
Really good engaging and smooth.
All worked well.

Q4 Please select the answer that reflects your response to each question

Statement	Strongly agree	Tend to agree	Tend to disagree	Strongly disagree	Don't know	TOTAL
a. I felt able to contribute my views today.	68 (88%)	9 (12%)	-	-	-	77
b. There was enough time for me to discuss the things that mattered to me.	47 (60%)	29 (37%)	2 (3%)	-	-	78
c. I felt able to interact easily with others in the meeting.	55 (71%)	22 (28%)	-	1 (1%)	-	78
d. The facilitators made it easy for me to participate	71 (91%)	6 (8%)	-	1 (1%)	-	78
e. I felt supported and respected.	68 (87%)	10 (13%)	-	-	-	78
f. I am clear about how my views could make a	56 (72%)	20	1 (1%)	-	1 (1%)	78

difference (e.g. to future policy or decisions).		(26%)				

Q5 Tell us your thoughts the workshops overall

What worked particularly well?

Lots of varied debate.
Fairly good range of diversity within the group.
Discussions.
Good interaction in [facilitator name] meetings.
Small groups with the same people.
Good explanation of the questions being asked.
Overall structure.
Group discussions, very well moderated by [facilitator name].
The smaller groups allowed everyone to give their opinion.
Follow up tasks to consolidate thoughts.
Technology worked well, stages worked well once into the workshops, and the range of views given suggests that most, if not all, were able to contribute.
Well structured, supported by SME in each case. Whole event well managed with consistent communication reminders.
Structure.
The format, the structure, the presenters; our group host did a great job at extracting answers from us.
Workshops were very professionally run and enjoyable.
The breakout rooms.
Smoothness of the facilitation of the sessions.
It was good to have the large group presentations and some discussion and then work in the smaller groups to go into more detail of the issues.
The facilitators were able to handle pressing questions and concerns easily and highly knowledgeable.
Small group discussions.
Breakout groups.
Groups well organised.
Breakout rooms.
The whole way the workshops were constructed made for easy understanding of the required outcome.
The use of zoom probably got people involved who might not have been able to get to a physical location.
The facilitators and [name]. The booklet with space for notes. The emails and text reminders!

Breakout rooms.
The break out sessions.
Having smaller groups to discuss in.
Having small group discussions.
Pleasant experience, not awkward and easily accessible.
Small group chats.
Interaction and data from experts.
Speaking in smaller groups.
Group chats.
The break out groups.
Breakout rooms.
Breakout rooms.
The facilitators tried to involve everyone, and there were clear timing in place which were closely adhered to, so it was well structured.
The small groups were a good way to share ideas without having to compete for space to speak.
The smaller groups worked better for me. A chance to hear and be heard.
Developing the understanding of the process was well paced.
I think the breakout rooms were really good.
Smaller groups.
How so diverse backgrounds we all were, but came together for one cause.
When everyone had their microphone on it made it particularly easy for people to come in rather than waiting for the facilitator to bring you in.
I've not participated in such a large Zoom group before but it seemed to work really well both technically and through the skills of the facilitators.
Small groups.
The different views on the topic.
I loved using break out rooms so that we could have mini discussions that we could share with the larger group of participants.
Good rapport with facilitators and other people taking part in research.
The case studies invoked thoughtful discussion, it gave a framework to the conversation and allowed/made it easier for people to give their opinions.
The fact the hosts would pick on people who hadn't said much in case they felt to shy but didn't push it.
Our discussions are very informative.
The smaller discussion groups.
The breakout rooms and the in depth discussions in them.
The facilitators are fantastic. It's been a brilliant experience.

Everything.
The dividing up into small groups and then the ability to pool and share our ideas.
The breakout small group chats worked well.
Individual groups perfect size.
Well presented and explained.
The breakout groups made it easier to discuss the issues raised without everyone clashing at once.
It was an excellent mix of expert speakers, presentations and opportunities to discuss and contribute.
The facilitators.
Breakout groups to focus on key points.
Using zoom.
I enjoyed the small group talks.
Everything.
Break out rooms and return to big room to discuss main points.
Everything worked perfectly.
Small groups.
Moving between rooms.
The small group discussions worked particularly well.
Group dynamics and group facilitation.
Lots of varied debate.

What would you have changed?

Face to face discussion groups.
Less time repeating the homework study and more time interacting with each other.
More time in discussions.
Nothing.
I felt the guest speakers all had a vested interest in us finding that the sharing if our data was a good thing. Perhaps there should have been at least one person who disagreed with that view. I also felt the language used my some of the speakers was very emotive and somewhat manipulative.
Some more information before the workshop started to better understand the topic.
Perhaps having more case studies.
Not sure there was a proper roadmap, we seemed to meander and revisit things.
The timing of the meetings meant having dinner at an awkward time.
Nothing.

Maybe getting into the project quicker, perhaps from workshop 1. Perhaps as well a reminder when we might have strayed off brief as to the purpose of the exercise.
Not much, perhaps a change of personnel in small groups for each session but I can understand why it would be beneficial to remain together.
More sessions.
Educational material could have been gone through more succinctly to allow more time for group discussion.
The workshops didn't always finish on time.
Have live speakers rather than the pre-recorded videos.
Perhaps would have varied the people in small group sessions rather than with the same people every time but can see the benefit of same groups.
The three hour workshop felt too long, I think 2 hours should be max, I'd rather do slightly more sessions and keep time down.
More time in groups.
More voting.
N/a.
None.
N/A.
Perhaps longer time in individual groups. Felt a bit hurried towards the end of the given time group.
Perhaps changed the composition of the breakout groups for different sessions?
Maybe a bit more time as we were always very rushed to finish in our small groups.
Nothing.
Given slightly longer to breakout sessions.
More time for discussion.
Nothing.
Rewatching videos we had already seen or reviewing other documents for the sake of writing "read" seems superfluous.
Nothing.
Nothing.
Nothing.
Length of 3 hour session.
Nothing.
Shorter time.
Nothing.
I think the three hour session was too long; I'd have preferred to have an additional session of two hours or less.
Nothing.

Nothing. I think the balance was just right.
To work together on a flow chart as a team...
Maybe a little more prompting to involve quieter group members.
Slightly more time.
Nothing, has been an excellent Zoom chat.
Maybe a little more time in the breakout groups so that people can go back to certain points rather than moving on from each point and not revisiting it.
Nothing really.
Nothing.
You could use a system where we all record responses or ideas individually from home and send in to you so that you can get everyone's ideas that way too.
Less case studies, more talk time.
I don't think I'd change anything. The presentation given were short, concise and got the point across. Not too much detail, which meant people could really delve into discussion and voice their opinions.
Not much.
I still think that more time is needed to talk about things. Also think the facilitator maybe needs to reword sentences better for people who don't quite understand a question due to health reasons.
I would have trusted people to have read over the salient points from the meeting before rather than reading them and the pamphlet pages aloud at the start of each workshop.
I would have allowed people with technical issues to contribute via thumbs up and thumbs down to still contribute.
Nothing.
Nothing.
Nothing. It was a wonderful experience - thank you to all involved in putting it together.
All good.
Slightly improved access for dyslexia i.e. friendly fonts and background colours.
Perhaps change the groups around - different perspectives.
Nothing, the facilitators ensured everyone was able to contribute.
No idea.
Intelligence tests for participants.
Some of questions could have been written better as hard to understand some of them.
Nothing.
Perhaps slightly more time for the small talks.
Nothing.
Nothing.
Nothing.

Nothing.
Nothing.

Q6 What's changed for you as a result of taking part in these workshops? (For example: learning, a change in view, something you'll do differently, or anything else.)

Learnt a lot of thing re health data sharing I didn't know.
Question more my public & private GPS to see what they are doing with my data. Research NHS Digital and extensively.
A lot more aware of my data and how it's used in the health system.
More knowledge about how & where Data is used.
I was interested to learn that I'm able to opt out of sharing my data.
How much of our health and social data is collected and the type of things it is used for.
Interesting to see what is happening with data currently.
Admiration for the scale of what NHS digital and the NDG do.
My idea of what health data is used for and how easy it is to access.
Learnt a great deal about data and it's usage.
Not sure my views changed. I did wonder how much the 4groups would be able to help the core purpose given that we had very little knowledge of how the organisations currently come to a view on public benefit. I thought it entirely possible that our points would already be undertaken by the organisations. But I could be wrong and there were some thoughts of ours put by NDG rep at the end that she suggested were 'new' areas for her team.
More consideration as to the level of work that could go into any data research and a feeling of reassurance that NHS and Social Care data is protected now and for the future. Learned a huge amount in a short period of time.
Awareness raised.
An educational experience that adds to my general understanding of how the world works and makes me a wiser person in a small way.
Feel I know more about data use etc.
I gained a lot of knowledge regarding data use.
Understanding of the vast amount of data research purposes there may be in the world let alone UK and the potential benefits from it.
I've been really interested to hear about all the different organisations involved in this and it's made me think about future job roles in this field quite a bit that I hadn't considered.
Learning more about the impact of data and the various organisations involved in keeping data regulated, safe and understood. A lot of appreciation for the work the NDG do.
A greater appreciation for how much thought goes into how data is shared.
I know a bit about data protection now.

Got an idea how public dialogue will look like.
Learnt more about how our data is used and the safeguarding available.
It stimulated the little grey cells:)
Using Zoom. Knowing more about how data is used in health and social care.
I recently watched The Social Dilemma and had quite a negative view of sharing data at the forefront of my mind from that. I now view data sharing much more positively and it's been really interesting to learn all about why people request data, what happens, and to hear everyone's differing views on the topics that were brought up.
Being able to see things from other peoples views has been really interesting and helped me to see things from other angles.
I shall think very differently about how data is gathered and used in future.
I feel educated on benefits and risks of data sharing as well as more confident to say how I feel.
I have learnt a lot about how data is used and how it is not all linked.
I have a vested interest in data and public benefit and an increased understanding.
I never thought before how complex the process of data sharing could be.
Just enhanced awareness.
My knowledge of my data usage and how public data can really impact research on a broader scale.
Better understanding of data use and application process.
Increased my knowledge base.
The way I consider how my data is used when I go to the doctors.
A new knowledge/awareness.
It's given me an insight into the problems and dilemmas thrown up when people have to make these decisions on data usage.
My understanding of the vetting process for researchers has increased considerably.
I will take more interest in these topics in future, not switch off because I think I don't understand them. I felt I contributed, and am quite proud of that.
Learning about this area of work, different views of data handling, consider more about data permissions…
I now have a better understanding of how difficult it is for data assessors to do their job well, and the implications if they don't.
Got a greater perspective of other members of the publics points of view.
My understanding of what our data would be used for and the possible benefits to it all.
Being more aware about my data, how it is accessed and who I am letting use it (when I get the choice).
I was a bit daunted to start with as the subject matter was quite abstract but I have learnt so much, not just from my own perspective but how the use of data can be a power of good for all if used ethically and correctly.
Become more aware of data sharing.

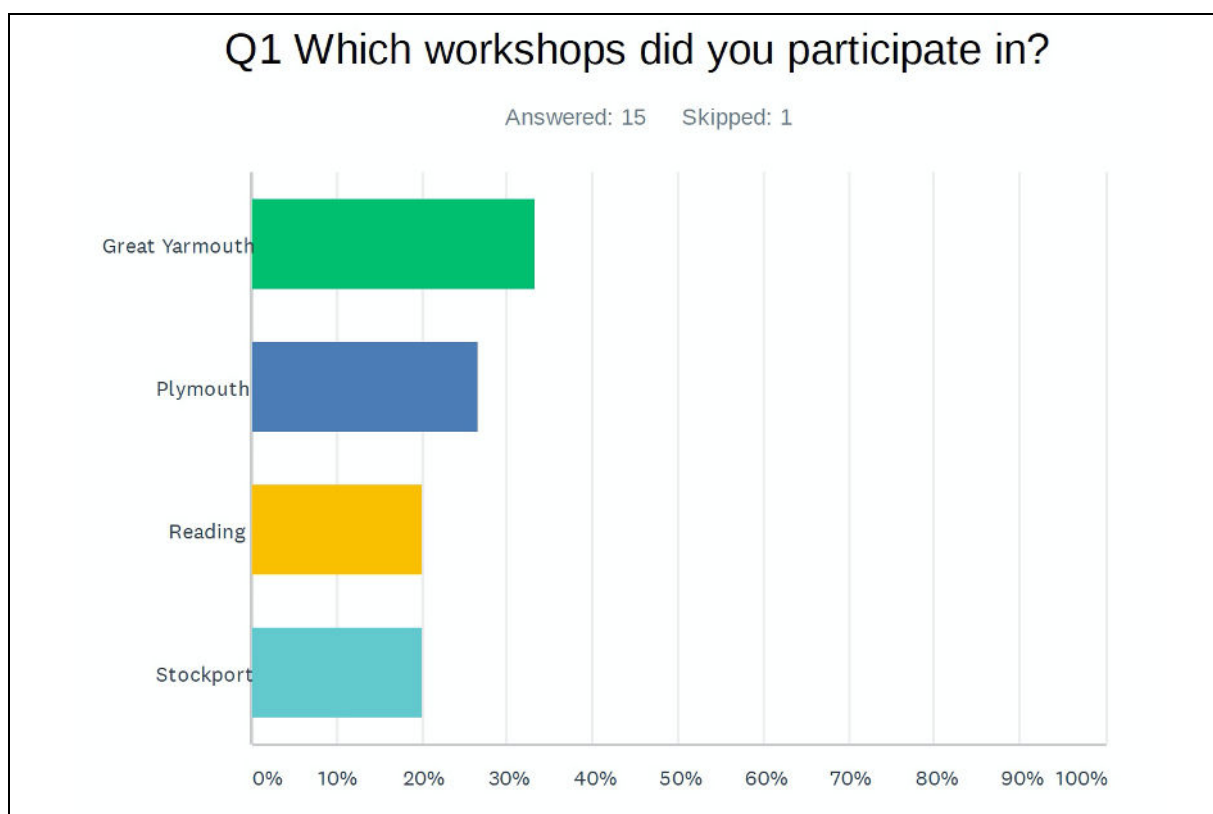| |
|---|
| Learning something new. |
| Even more respect for the job that the NHS do with data handling- you do an amazing job! |
| More information about things I hadn't thought of. |
| It made me aware of what goes on behind the scenes with regards to combatting health issues/pandemics. It also gave me a renewed awareness of consent. |
| I feel I have more knowledge into what happens with data and what is considered and made to feel like public opinion really does count as why would this group have happened. |
| I am more aware of how I use services on the internet and also reading thoroughly reading through documents very carefully and taking my time to do so. |
| It's been really interesting to see the broad agreement across so many people. |
| I have learnt a lot about accessing data for health and social care. |
| I have literally changed my whole perspective on public benefit. I would certainly do more to help, in regards to surveys or giving my opinion to try help or change an issue for the greater good. |
| Learning more about what happens to our data. |
| I will be much more mindful of how data that I consider to be irrelevant can actually be used for something much more substantial and meaningful. |
| I feel more confident at Zooming now! Great experience to be able to have meeting with face to face contact and hold discussions. |
| Learning that people of all walks of life can think critically and discuss important matters and learn from said discussions. |
| I have learned a lot and thought about concepts that I hadn't thought much about previously. |
| I've learnt a lot about the sharing of information. |
| It's not a topic I'd ever considered before in detail but what it demonstrated to me was the level of insight and knowledge could be bought to the subject by a very diverse group of people, all making interesting and valid points on a very difficult subject. |
| Completely 180 on my views regarding anonymised data. |
| More awareness of the need to share medical data. |
| A better understanding of data requests and how our data could be used. |
| Enjoyment in discussions with others and confidence to air my views. |
| Knowledge of date and greater understanding of our NHS and government authorities. |
| Greater awareness on the attention given to public benefit assessment and the nature of due diligence that is given to each data assessment. |
| It has made me think more about my personal data. |
| I know much more about data usage than I ever did before. |
| Wow it has been massively enlightening I found the information clear and informative. |
| Clearer knowledge regarding public data use. |
| More informed about health and social care data and implications. |

Q7 Is there anything else you would like to say about this meeting or your experience of being involved with this process?

Very good experience was a pleasure to take part in.
On the final day when we had more time to discuss our views, I held my hand for 10mins twice. I felt ignored as the facilitator did give me the "floor" to speak whilst other spoke 3 times.
All facilitators were fantastic and lovely people!
Thoroughly enjoyed being involved in this project...will miss chatting with my "colleagues".
The workshops had a tendency to be a little repetitive.
I enjoyed meeting everyone and hearing the different points of view.
I wasn't clear on how our input was really going to change things and had a feeling that we were perhaps going through a process, ticking boxes to demonstrate public consultation. I also wonder whether the participants were a true enough cross section of society - everyone seemed well educated and obviously computer literate (which I guess is inevitable).
Enjoyed it very much... interesting topic
Enjoyed it. Purpose became clearer as we went along, workshops worked pretty well, there were similar as well as opposite views expressed and I hope all felt they got a fair crack of the whip. I did.
Enjoyed all of the sessions which were well managed and interesting. Time spent on each was just right to maintain enthusiasm and gather a decent portion of feedback.
It was a pleasure participating, though I didn't find the homework review tasks particularly useful to my retention of information.
Nothing.
N/A.
Extremely enlightening for me and a privilege to be involved in something I knew very little about even although we probably only scratched the skin of this controversial topic.
I didn't really know what to expect until I received my pack. A little more info from the 'take part in research' company would have been good. But anyway, I was pleasantly surprised at how engaging and interesting it was and I enjoyed taking part.
It's been a fun process and I wish discussions about this we're more widely open for younger audiences.
I've learnt a lot.
No.
N/A.
It was very enjoyably and informative about the process and organisation involved in the control valuable datasets.
It was actually enjoyable.
Thank you. I've learned a lot and it's been a really positive experience.

I have found the process really interesting. It's not something I have done before but I have really enjoyed being part of it.
Everyone made us feel very welcome and valued.
I'd love to do it again.
Looking forward to seeing the outcome and joining in May.
It was a pleasure.
I really enjoyed it.
Very enjoyable all round.
The whole process we extremely interesting and educational.
Thank you. It was a very positive and interesting experience.
No. It was excellent.
No.
I enjoyed it more than I expected.
I really enjoyed it, hopefully my small contribution will help as part of the overall group effort.
I really enjoyed being part of this experience and thank you for giving me the chance to take part.
How professional and friendly all the facilitators and speakers were, they put everybody at ease, so they could just be themselves.
I've not worked for over two years, due to Mental/Physical health, and was quite daunted by it at first, as not interacted with people for a long time, although it raised my current limitations, of my mental health, was surprised that I was able to get through all the sessions, aided by it being a safe space.
I have really enjoyed being part of this research group, I feel really pleased that my contributions in this study, could help to shape future guidance in how the data assessors work.
Speakers were excellent, really appreciated having them +their case studies.
Everyone concerned has been fantastic and my group facilitator [name] kept us all on track when we were off in another direction. Pay rise for her I say haha.
I think it took a while for people to realise that we were looking at uses of data for public benefit not personal care. I also think it would be helpful to get some preliminary information before the first session, as some of the questions asked were later answered by the key speakers for example regarding how the NDG process applicants. If known before this might have allowed more time to be spent on issues surrounding public benefit rather than being in the dark about how the data was currently being handled.
It was a great opportunity to be part of something this big that can help influence a positive but very powerful outcome. Superb learning curve too!
Very interesting and I be learned a lot from it.
No.
The approach to speak to the public about things that impact the public is a great one and would love to see more of this with other issues in the future.

It was a pleasure.
I thoroughly enjoyed it. Not only speaking to people from different areas/backgrounds, but people with different opinions, which forced me to be more considerate and appreciative of other points of view.
I have really enjoyed it and would love to be kept updated and happy to help further if I can.
I've really enjoyed participating and being able to hear other views (or my own expressed better and more succinctly!)
I enjoyed it and would be happy to take part in future studies :).
I was very nervous to begin with. The facilitators and other people in the group were all really friendly and just a fantastic bunch of people. I will actually miss doing these workshops.
Really enjoyed it.
Just a big thank you - it feels good to have been involved in such a project and hopefully we'll see the impact of this in the future.
I have found it very interesting and thought provoking.
It has been an absolute pleasure and truly fascinating. Thank you for the opportunity to experience this but also to have a say in something so important.
Thank you for including me!
I enjoyed the experience. It was intellectually stimulating and in ways made me explore and re-assess some of my own understandings.
Thoroughly enjoyed.
Thank you for the opportunity.
No, thank you.
Greatly enjoyed it.
N/a.
Just that I had a great time doing this and I am open to doing more.
I thoroughly enjoyed it.
No.
Thank you for allowing me to take part - it has been a pleasure and incredibly informative and insightful.

Q1 Which workshops did you participate in?

Answered: 15   Skipped: 1

Workshop	
Great Yarmouth	(~33%)
Plymouth	(~27%)
Reading	(~20%)
Stockport	(~20%)

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

Q2 What was the best thing about taking part in the workshops?

Discussions were stimulating.
Interesting talks and discussions with other people with other views.
Learning about the process of sharing, storing, and using data.
The opportunity to be able to contribute and see things taking shape.
Having the chance to give my views on the topic.
Understanding the reason why data is used and hearing other people's point of views.
Enlightening information discussed which I'd never really understood or thought about how it may be used.
Learning so much about data collection, and how it's used for the benefit of the public.
Learning about the complexity of the NHS data systems.
Learning a lot of new information and exploring people's views.
Being able to have my voice heard.
Listening to others views.
Gleaning information and insight into health and social care issues.
Sharing thoughts and views.
Meeting new people in my area, and learning about how it all works.

Q3 What didn't work so well?

Sessions felt very long online.
Sometimes the link didn't hold up, but that's rural connections!
N/a.
There is nothing that I can point to.
Nothing, it all worked just fine.
Always a challenge on zoom - sadly some people didn't take it seriously.
Can't think of anything that bothered or annoyed me through any session.
Sometimes the audio feedback was intrusive, maybe mute everyone unless they are specifically speaking about something.
Not much at all, maybe some times people talked a lot but that wasn't anyone's fault.
N/A.
Nothing
I feel the sub groups could have been smaller.
Everything went well.
Nothing really.

Q4 What's changed for you as a result of taking part in the workshops? E.g. a change in attitude or perspective, learning, something you'll do differently, or something else?

I've changed my perspective on the use of patient data and it increased my knowledge.
N/a.
I've since become a member of the research committee of the charity that supports my rare disease and have been offered 12 months' professional mentoring with the aim to set up a patient registry! So, the workshops inspired me to do something proactive with the knowledge I'd learnt. A big thank you to the team for the opportunity not only to help shape the future of the report but also to help shape my future!
It was certainly a learning exercise but it was useful in being able to apply knowledge that I already had to something that was challenging.
I understand the topic much more.
Much more supportive of data sharing and have tried to explain to people why they shouldn't be opting out.
I don't believe I have changed anything I do although it has helped me understand the very difficult decision making processes currently being made by the government based on a short period of data gathering.
Learning how many times one set of data can be used, for different purposes! Not always for its original intention!

Made me aware that my data is valuable.
Understand the NHS data share and telling my friends this info.
I have understood more about how data is used and the necessity of the public opinion behind the data usage.
Appreciation of others views on the topic.
A wider appreciation of health and social care and planning issues.
Gained more knowledge, understanding and different perspectives.
Learning side.

Q5 Please select the answer that reflects your response to each question

Statement	Strongly agree	Tend to agree	Tend to disagree	Strongly disagree	Don't know	TOTAL
I am confident my views will make a difference (e.g. to future policy or decisions).	3 (20%)	9 (60%)	2 (13%)	-	1 (7%)	15
Based on my experience with this process, I would take part in similar workshops in the future.	13 (87%)	2 (13%)	-	-	-	15

Q6 If you took part in the additional workshop, please tell us what you thought about it. E.g. what was good or not so good about it?

It felt really good to be part of the follow-up and to see how the report had progressed, and more importantly how our initial views had shaped the outcome.
I didn't take part.
It was great to follow and see what had happened, listening to the views of others and the explanations from the experts. Overall a very interesting experience and thoroughly enjoyed participating.
N/a.
It was really good to see how much our input was used in the final draft, it made me feel that we were responsible for helping to shape that.
It was great to hear and interact with people who are going to be using the guidance.
Didn't take part.
There was a lot to take in at one go; perhaps two shorter sessions may have been better.

Q7 Is there anything else you'd like to say about your experience of being involved in these workshops?

It was a great opportunity and the whole team, the speakers, and the participants made it a valuable, pleasant and professional experience. I really enjoyed being a part of it I hope we helped make a difference.
The facilitation was excellent.
Keep up the good work!!
I thought the workshop was very well structured and each of the personalities conducting the event ensured all had the opportunity to be involved.
It's been really good to see all the other participants and see how similar our views actually were. I really enjoyed myself so much.
N/A.
It was good to have a say.
I've really enjoyed being part of this, and hopefully my input will make a small contribution to improved health and social care in the future.
Thank you for the opportunity to take part.
No.

Appendix 5: Evaluation interview questions

Baseline interviews

Oversight Group members

1. Could you tell me a little bit about your role and particular area of interest?

2. What kind of experience have you had with public dialogue before?

3. What's your impression of the PGiP public dialogue so far? (Follow up with anything they think is particularly good about it, and what they think are the key challenges, if not covered.)

4. How do you see the current global context (coronavirus) influencing the dialogue in terms of a) process (including accessibility / inclusion) and b) content.

5. How did you find the first OG meeting? (Anything that particularly worked about it for you? Anything you would change? Anyone else who should have been in the room?)

6. What potential do you see for the dialogue outputs informing a) your future work; b) future policy more generally?

7. Are there any particular policy developments or decisions coming up that you can see the dialogue being of relevance to?

8. What's your level of expectation for involvement in the dialogue process? (Feed in to process / materials, meetings, attending dialogue events, etc)

9. What would make the dialogue outputs credible (or not credible) from your point of view?

10. Is there anything specific you'd like to see included in the final guidance in order to make it particularly useful or usable from your perspective?

11. Is there any literature or other materials it would be useful for us to look at to inform the context for the dialogue evaluation (e.g. previous work to engage the public; previous policy work)?

12. Is there anything else you'd like to say about the dialogue or your involvement in it at this point?

Project team

1. Confirm role and previous experience with public dialogue.

2. How are you feeling about the PGiP dialogue so far?

    a. What's working well from your point of view?

    b. What, if anything, do you have concerns about at this stage?

    (Prompt to discuss specific aspects if not covered: procurement, governance, design process, communications and decision making, OG, looking ahead to workshops, reporting, follow up workshop, dissemination / launch, anything else…)

3. How do you see the current global context (coronavirus) influencing the dialogue in terms of a) process (including accessibility / inclusion) and b) content.

4. What potential do you see for the dialogue outputs informing a) your future work; b) future policy more generally?

5. Are there any particular policy developments or decisions coming up that you can see the dialogue being of relevance to?

6. Based on your impressions and conversations with decision makers so far, what (in your opinion) is the potential for the dialogue to have a tangible impact?

7. What would make the dialogue outputs credible (or not credible) from your point of view?

8. What do you see as the key challenges for the dialogue? And what are you most excited about?

9. Is there anything else you'd like to say about the dialogue or your involvement in it at this point?

Interim interviews

Oversight Group members

1. What's your overall impression of how the process is going so far?

2. How have you been finding your involvement in the project so far? (What's working about it for you? Anything you would change? How have you found communications / being kept in touch?)

3. Tell me some more about your involvement in the workshops:

    a. Confirm how many attended

    b. Were you clear about your role / did you feel sufficiently briefed?

    c. What did you think about the workshop/s? What worked well / what would you have changed?

    d. What did you think about the range of participants (demographics / views / life experience)?

    e. What did you think about the balance of materials presented?

    f. What did you think about the range of conversations, e.g. the issues covered / mix of benefits and challenges discussed?

4. Is there anything you feel was underexplored or not sufficiently covered that you'd like to see picked up in the final workshop in May? / Are there any issues you'd like to see explored further in the final workshop in May?

5. Did you see any evidence of the Covid pandemic influencing the dialogue discussions?

6. Are there any issues in particular you'd expect to see covered in the final guidance based on what you've heard, and in order to make it particularly useful or usable from your perspective?

7. What potential do you see for the dialogue outputs informing a) your future work; b) future policy more generally?

8. Is there anything else you'd like to say about the dialogue or your involvement in it at this point? (Follow up with anything they think is going well / any challenges)

Project team

1. It would be great to start with some high level thoughts on how it's going so far before we dive into to the detail.

2. What (else) has worked well from your perspective?

3. What (else) have the main challenges been or what would you change for next time?

4. Regarding the workshops specifically, it would be great to hear your thoughts on the

online format versus face to face – again, what was challenging and what worked well or better? [role of observers, participant input and balance]

5. [For workshop observers]

   a. Were you clear about your role / did you feel sufficiently briefed?

   b. What did you think about the range of participants (demographics / views / life experience)?

   c. What did you think about the balance of materials presented?

   d. What did you think about the range of conversations, e.g. the issues covered / mix of benefits and challenges discussed?

6. How have you been finding the OG and specialist input and involvement during the workshop delivery phase?

7. How have you been finding the Project Team meetings in terms of regularity and usefulness?

8. How's the analysis and reporting process coming along? And confirm analysis mechanism / platform? (NVivo?) [Others] Expectations of reports?

9. Thinking ahead to the final workshop, do you have any thoughts on design or scope at the moment – e.g. is there anything you think it might be useful to explore in more depth or any particular process elements you're considering (or would like to see considered)?

10. What kind of contact is planned with participants between know and the May workshop? [and pick up how participants for may are being selected, as well as how results / outputs are being fed back to participants]

11. Did you see any evidence of the Covid pandemic influencing the dialogue discussions?

12. What are the key messages you picked up from the workshop discussions? Anything surprising or new?

13. What potential do you see for the dialogue outputs informing a) your future work; b) future policy more generally?

14. Any feedback for me as evaluator?

15. Is there anything else you'd like to say about the dialogue at this point?