

## Putting good into practice –oversight group meeting minutes



06.05.2020



10:00-12:00



Virtual Zoom Meeting

### Meeting attendees

Oversight group members	In attendance	Apologies
Amy Darlington	Fionnuala Ratcliffe	Sophie Brannan
Annemarie Naylor	Helen Fisher	
Gary Cook (left 10:57)	Henrietta Hopkins	
Ian Turner	Jenny Westaway	
Jacob Lant	Karen Swift	
Prof James Wilson	Natalie Banner	
John Marsh	Suzannah Kinsella	
Kirsty Irvine	Diane Beddoes	
Philippa Lynch		
Richard Ballerand		
Simon Madden (joined at 10:40)		
Vicky Chico (Chair)		
Joseph Savirimuthu		
Dr Indra Joshi		

Item	Agenda item
1	<p><b>Welcome, introductions, declarations of interest</b></p> <p>The chair welcomed everyone to the first oversight group meeting and members introduced themselves on Zoom.</p> <p>The chair asked members to submit their declaration of interests forms to the Office of the National Data Guardian <a href="mailto:NDGoffice@nhs.net">NDGoffice@nhs.net</a> if they haven't already done so.</p> <p>Kirsty Irvine, Chair of the Independent Group Advising on the Release of Data (IGARD) stated she had a strong professional interest in this work. There were no other declarations of interest for items on the agenda.</p>
2	<p><b>Project background and purpose</b></p> <p>Jenny Westaway explained that the National Data Guardian (NDG) held a workshop in February 2019 about the priorities that the NDG should be pursuing as the role of the NDG moves to a statutory footing</p> <p>During the consultation the NDG received several suggestions for themes that the NDG should explore including a recurrent call for more dialogue about the benefits of the use of health and care data, in particular where it is being used for purposes other than individual care.</p> <p>The background work to developing a proposal to Sciencewise identified some factors that emerged as influencing whether the public consider that a use of data has a benefit for the public and also some gaps. The project proposes to address these, which are in summary:</p> <ul style="list-style-type: none"> <li>• Check we have a full understanding of the range of benefits and disbenefits as perceived by public</li> </ul>

	<ul style="list-style-type: none"> <li>• Explore when public benefits are considered sufficient to justify the use of health and care data, particularly where there are trade-offs to be made</li> <li>• Explore how far attitudes are similar or differ in regard to social care data</li> </ul> <p>Following the workshops, the aim is to use this to develop NDG guidance that would help organisations to carry out public benefit assessments with greater confidence and that this is in line with public values.</p> <p>Natalie Banner from Understanding Patient Data (UPD) added that there is already a great deal of guidance/frameworks out there and which may contribute to a risk averse culture where the default answer to whether data should be used is no. The hope is that the project can create something practical which will help people on the ground.</p>
3	<p><b>Sciencewise and public dialogue</b></p> <p>Fionnuala Ratcliffe described the role of Sciencewise and how it provides assistance to policymakers to carry out public dialogue to inform their decision-making on science and technology issues. The Sciencewise programme is led and funded by UK Research and Innovation (UKRI). Fionnuala went on to outline that all Sciencewise public dialogues should adhere to guiding principles including that there is a clear aim and that the outcomes feed into public policy. She explained that all projects are independently assessed. Further information is available on the Sciencewise <a href="#">website</a>.</p>
3	<p><b>Oversight group operation</b></p> <p>The chair discussed the role and requirements of the oversight group (OS), the terms of reference, declarations of interest and planned meetings. The project has a clear purpose, to have more dialogue with the public about the benefits of the use of health and care data, in particular where it is being used for purposes other than individual care. The Oversight group is advisory and will be required to feed into process and materials. There are 4 meetings planned and contingency plans in the context of the current pandemic.</p> <p>The question was raised as to whether there should be an additional meeting of the group around July to look at the outputs from the initial roundtables and consider the effect of the pandemic and the restrictions on the way that the full workshops should run. It was agreed that the project team would consider this.</p> <p><b>2020.05.06/3:1:</b> The project team to consider having an additional update meeting in July.</p>
4	<p><b>Project plan overview</b></p> <p>Henrietta Hopkins and Suzannah Kinsella from Hopkins Van Mil presented the project overview slides for OS group. Key stages, timings, logistics and the number of planned workshops were discussed.</p> <p>Henrietta also covered contingency planning for COVID-19 and how the workshops would be designed appropriately. She explained that the team was considering a few options and that it would be important to ensure that, even if restrictions had been lifted, if some people felt too vulnerable to attend in person they could be supported to take part.</p> <p>Members discussed that the attitudes to sharing data from and with social care do appear to vary. And that there is a lack of understanding about the range of social care and the opinions of those receiving social care. It was discussed that the project needed to help workshop participants understand the breadth of social care.</p> <p>The question was also raised about why the project is looking at ‘publicly funded health and social care services’ and what were the implications for social care given the preponderance of independent provider orgs and self-funders (and the data they generate)? Jenny explained that the NDG’s powers to issue guidance apply to publicly funded health and social care services and that this includes private or third sector</p>

organisations that are contracted to deliver these. But organisations providing entirely privately funded care would be obliged to have due regard to the guidance. This is why the project has this scope BUT those organisations could find it useful and it was agreed that it should not exclude them.

### **Scoping programme**

At the moment the project team are currently completing desktop research. Some oversight group members said that it could be useful to share to ensure that there are no gaps. The project team said they would have a look at sharing this.

Stakeholder interviews are currently taking place and the feedback from that exercise will help shape the design of the roundtables and workshops. Initial roundtables will be run with knowledgeable patients and service users to give the project team additional ideas with the design of the workshops. Jacob from Healthwatch offered help with recruiting for these roundtables.

A design planning workshop will be held in late June to help decide on the design. HVM will engage with stakeholders throughout the project so they can check the outcomes are going to help those who need to use the guidance.

### **Workshop plans**

HVM explained proposals for the locations of the roundtables and workshops. The aim is to ensure they get a good spread of attendees from different types of location.

HVM also outlined their recruitment approach; they have a recruitment specification which aims to recruit a balanced sample, but it will not be nationally representative; that would not be possible in samples of this size. There will be oversampling for adult social care users and carers of adults in receipt of social care. There was a discussion of the adult social care needs that would be represented. Just those with physical needs? Or also learning disabilities, dementia, others? The project team outlined the rationale for the initial scope, which focused on those with physical needs, who make up the biggest group of social care users. The thinking was that it would not be possible, even with oversampling, to include all types of social care user. However, it was agreed that it should be reconsidered to see what else we could do to ensure we are including as wide a range of perspectives as possible and to ensure that we have a clear rationale for the recruitment specification.

It was confirmed that the workshops are intended to be with people who do not necessarily have prior knowledge of the subject. The recruitment process will have some questions to assess attitudes to data use, but these will not be used to screen participants, simply to inform us about what range of opinions we have in the room at the workshops. There was some discussion about how to address the fact that attitudes to data sharing may have been affected by COVID-19, maybe to make people more favourable to data sharing, but that these attitudes may not persist. It was agreed that the project needed to take this into account but also that it was challenging to do this.

The attendance incentives were outlined and explained to be in line with good practice in order to minimise financial barriers to participation. If attendees need personal assistants to attend, this will be facilitated.

A question was raised about whether the guidance that will be developed following the workshops will be framed as recommendations flowing from public views - rather than those of commissioners, providers, researchers, innovators? It was explained that this was not the intention. The guidance would be developed following the initial workshops - but then there would be consultation with other stakeholders to make sure it was usable and helpful practically. This would be via a further workshop bringing together some of the public participants with system stakeholders. And via other forms of consultation, e.g. open public written consultation.

	<p><b>2020.05.06/4:1:</b> The project team to reconsider recruitment spec what else we could be done to include as wide a range of social care perspectives as possible and to ensure that a clear rationale.</p> <p><b>2020.05.06/4:3:</b> The project team to consider if the desktop research overview can be shared for the oversight group to identify any gaps.</p>
5	<p><b>Project evaluation plans</b></p> <p>Helen Fisher, independent assessor from 3KQ, outlined the process for evaluating the effectiveness and learning from this engagement project. Helen will join project team and oversight group meetings. 3KQ will be in touch with some members of the oversight group as part of this process.</p>
6	<p><b>AOB</b></p> <p>The chair reiterated the points raised during the meeting and asked OS group members to submit their declaration of interests (DoI) forms and any comments on the terms of reference (ToR) as soon as possible.</p>