

Putting good into practice: making public benefit assessments when using health and care data

Oversight Group draft terms of reference

Project background

The [National Data Guardian](#), [Understanding Patient Data](#) and [Sciencewise](#) are jointly funding a public dialogue to explore public benefit that justifies the use of health and care data. The dialogue process is being designed and managed by [Hopkins Van Mil](#), following a mini competition run by Sciencewise.

There is significant government activity and investment to advance the country's life sciences sector by providing improved access to health and care data to encourage data-driven research and innovation. The project partners share a view that the drive to progress research and innovation built on data generated by use of publicly funded health and social care services must be accompanied by meaningful public engagement.

Previous research has shown that the extent of public benefit is the key condition to people's acceptance of such data use. Assessments of public benefit or interest form part of a number of codes and frameworks used by a range of bodies to support decisions about whether data should be used for purposes beyond direct care.

Our review of previous public engagement exercises has identified some factors as influencing whether participants consider that a use of data has a benefit for the public. But we believe that there remain some gaps in our understanding of public attitudes. This project aims to address these in order to develop a more sophisticated way of assessing the extent to which a proposed data use could be said to be of sufficient public benefit to justify its use for a specific purpose. In dialogue workshops we intend to:

- Check we have a full understanding of the range of benefits and disbenefits as perceived by public
- 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
- Explore how far attitudes are similar or differ in regard to adult social care data

Our aim is to use this to develop guidance or advice that would help organisations to carry out public benefit assessments with greater confidence that this is in line with public values. This guidance or advice would be tested back with participants who had taken part in the original workshops.

Public dialogue workshops will take place in autumn 2020 at four locations in England: Reading, Stockport, Great Yarmouth and Plymouth. The intention is to run these as face-to-face sessions, but will use online engagement methods if Covid19 measures are

prolonged. A report will be published in spring 2021 summarising the findings of the initial workshops. This will be used by the National Data Guardian and Understanding Patient Data to develop public benefit guidance and a further dialogue workshop will be held that spring with a number of the original workshop attendees to test whether this meets their expectations.

Oversight group role and purpose

The role of the group is to oversee the dialogue process and materials, and to help ensure that:

- The dialogue material is:
 - Comprehensive
 - Balanced
 - Accessible to the lay audience
- The engagement process is:
 - Far reaching
 - Accessible
 - Targets all relevant stakeholder groups

In addition, members will be expected to:

- Bring diverse views and perspectives to the framing of the dialogue
- Bring intelligence from their own organisations, where applicable, to help shape the dialogue
- Disseminate and promote dialogue findings through their own networks
- Help select appropriate experts to inform the dialogue process, materials and speak at dialogue events, where appropriate and feasible

Members of the group are expected to comply with the Standards in Public Life¹ (also known as the “Nolan Principles”). The secretariat to the group will maintain a register of interests, which will be publicly available. The Chair should ascertain, at the beginning of each meeting, the existence of any conflicts of interest relating to matters on the agenda. These will be minuted accordingly.

Functions

It is expected that the Oversight Group will comment on the following:

- Background/stimulus materials
- Communications strategy
- Language and framing
- Questions asked during the dialogue
- Sampling and recruitment
- Outputs from the dialogue exercises (reports, videos etc)
- Policy guidance developed as a result of the first round of dialogue workshops

Responsibilities

The role of the Oversight Group is advisory. It is the responsibility of the National Data Guardian and Understanding Patient Data and the management group comprised of members of those organisations and Sciencewise to make decisions on the dialogue process, materials, resultant policy guidance and to disseminate the outcomes.

Membership

¹ <https://www.gov.uk/government/publications/the-7-principles-of-public-life>

Members of the group are not remunerated for their time, however reasonable expenses will be paid for attendance at meetings or events (eg observation of the dialogue workshops, speaking at events about the project).

A list of the membership of the group will be published and kept up to date on the NDG's web pages.

Name	Organisation
Amy Darlington	One London
Annemarie Naylor	Future Care Capital
Ben Moody	TechUK
Gary Cook	Office for Life Sciences
Ian Turner	Registered Nursing Home Association
Jacob Lant	Healthwatch
Prof James Wilson	National Data Guardian Panel
John Marsh	Use MY Data
Dr Indra Joshi	NHSx
Joseph Savirimuthu	Liverpool University
Kirsty Irvine	Independent Group Advising on Release of Data (IGARD)
Philippa Lynch	Local Government Association
Richard Ballerand	Use MY Data
Simon Madden	Department of Health and Social Care
Sophie Brannan	British Medical Association
Vicky Chico (Chair)	Health Research Authority

Also attending the oversight group will be the following members of the project management group:

Name	Organisation
Diane Beddoes	Sciencewise
Fionnuala Ratcliffe	Sciencewise
Helen Fisher	3KQ
Henrietta Hopkins	Hopkins Van Mil
Jenny Westaway	Office of the National Data Guardian
Natalie Banner	Understanding Patient Data
Dr Philippa Lang	UK Research and Innovation
Rhuari Bennett	3KQ
Simon Burall	Sciencewise
Suzannah Kinsella	Hopkins Van Mil

Secretariat

Secretariat support for the group will be provided by the Office of the National Data Guardian, which will work with other partners on the management group to ensure that papers and minutes are prepared. The ONDG will be responsible storing and, where relevant publishing documents and information related to the work of the oversight group. These will include membership, register of interests and minutes.

Communications

Open communication about the work that is taking place during and after the lifetime of the project will strengthen the impact of the project. The management group will be responsible for ensuring that this takes place; the support of members of the Oversight Group in this activity is welcome. Where members of the group wish to communicate publicly about the work, they should liaise with the Chair and secretariat, the latter will offer support and liaise with the management group.

Meetings

It is expected that there will be four meetings of the oversight group during the project lifetime, these will be held via video conferencing as long as the current Covid19 measures are in place.

May 2020

Review project scope, context and plans for preliminary roundtables, recruitment and workshop approach.

July 2020

Review early learning from research and scoping stage, discuss plans for workshops in light of pandemic restrictions.

Sept 2020

To review draft materials and process for the dialogue workshops.

Jan 2021

To review draft public dialogue report

May 2021

To review policy guidance produced as a result of the dialogue workshops