

Advisory Group & Secretariat meeting

Wednesday, 24 February 2021
15:00 to 16:00
Online meeting

Meeting notes - confirmed

Attendees - Advisory Group

Richard Ballerand
Dave Chuter
Jo Gumbs
John Marsh
David Snelson
Richard Stephens
Pete Wheatstone

Attendees - Secretariat

Emily Boldison
Chris Carrigan
Alison Stone

Welcome, housekeeping and apologies

Alison welcomed attendees, thanking them for their time and highlighting how great it was to bring the new Advisory Group together. Apologies were received from Sarah Markham.

Attendees confirmed they were happy for the meeting to be recorded, both for those who could not attend and as an aide to the note taking. Attendees were assured that the meeting would finish on time, even if the agenda ran behind.

Meeting etiquette was agreed as:

- Be on mute unless speaking
- Raise a hand to speak
- Try not to speak over each other
- Everyone needs a turn to speak
- Keep videos on where possible
- Only use the chat function to flag a tech problem, or if you need to leave the meeting
- Be present in the meeting, rather than multi-tasking.

Introductions

Chris highlighted that John, Richard S and Pete, as Members of the previous Advisory Group, with the experience/knowledge that brings, would be happy to assist members of the new Group with any questions they may have.

A quick round of Advisory Group and Secretariat introductions took place.

Ways of working

- **Communication methods**

The Ways of Working document, created by the Advisory Group and Secretariat, defines four categories of communications between the Secretariat and the Advisory Group. These were created to make the best use of the Advisory Group's time, by providing clarity on the purpose of Secretariat emails. As much as possible the Secretariat will use these categories and give adequate response times. If a response time is limited, the Secretariat will explain the reason for this.

The Ways of Working document is a fluid document, which will continue to evolve and input/feedback is welcome.

- **Having different perspectives and common aims**

It's essential that the Secretariat receives a range of perspectives from the Advisory Group, to assist in taking forward the work of use MY data. This was one of the key reasons for expanding the Group. Different perspectives bring the need for discussions and keeping common aims in mind.

- **The Advisory Group's time**

Prior to advertising for Members of the Advisory Group, the Secretariat estimated that the time commitment was approximately two hours per week (excluding meetings). The Secretariat is very aware that Members are working as volunteers and asked to be informed if Members find the time commitment required is more than they thought it would be.

The Advisory Group operates in a flexible way. While it is helpful if Members can attend meetings regularly, there is not an expectation that all Members can attend all meetings. If Members need to drop out of Advisory Group work for a period of time, the Secretariat would just need to be informed (to stop the Secretariat from seeking input where it cannot be given).

- **The Secretariat's resources**

The Secretariat's working hours combined are the equivalent of approximately one full time role. The Secretariat have separate roles but work very much at a team and meet weekly (Tuesday afternoons). A brief overview of their hours and working week:

- Alison is contracted for 24 hours per week and usually splits this over five days
- Chris is contracted for 10 hours per week and usually splits this over five days
- Emily is contracted for 01 day per week and has a variable working pattern, due to working for four teams in total.

- **A Chair of the Advisory Group**

Up to now, Chris and Alison have co-chaired Advisory Group meetings. They have previously sought a Chair from within the Group, but there were no takers for the role. They would be happy for a Member of the new Advisory Group to Chair. From questions asked and answers given at the interviews, most applicants thought that it would be appropriate/positive for the Group to be patient-led.

- **Claiming honoraria / funding / legal status**

Applications for honoraria should be made to Chris and Emily. Payments come via our current funder, the Leeds Institute for Data Analytics (LIDA), based at the University of Leeds. There are tax implications around claiming honoraria and Emily will forward documentation about this. Emily will set claimants up on the system. Chris confirmed that funding will be available for honoraria on an ongoing basis.

Current funding provision for use MY data is via LIDA but this will move to the Leeds Institute for Medical Research from April 2021 and funds are due to be supplemented by NHS Digital and DATA-CAN (The

Health Data Research Hub for Cancer). Once this funding is in place, we will update the funding section of our website.

use MY data is not a charity and does not have a legal status. This has not hindered the organisation so far, although it could be limiting for future work/funding. The previous Advisory Group carried out evaluation work to assess whether we should change our legal status. It is useful to have this as a reference, although at this time, it is perhaps best to have an outwards focus on the work programme and strategy, rather than an inwards focus on structure and process.

DECISIONS

- The Advisory Group will begin to consider whether it would like to elect a Chair, once it has received supporting information from the Secretariat.
- The Advisory Group's immediate focus should be on use MY data's strategy and work programme.

ACTIONS

- **Chris & Alison** - Provide a broad outline of the responsibilities of a Chair of the Advisory Group, along with the Secretariat's expectations of the role.
- **Emily** - Forward information about claiming honoraria and tax implications.
- **Alison** - Circulate the evaluation work on use MY data's legal status.
- **Chris & Alison** - Ensure use MY data's strategy and work programme are a focus of Advisory Group work.

Reflecting the diversity of our Members on the Advisory Group - What we will need to do, to address the gaps - an initial think about next steps

Chris gave a brief overview of the results of our 2020 Members' Census, highlighting where the expansion of the Group had filled gaps in the representation of use MY data's Members and where gaps remain.

We have been successful in convening an Advisory Group which covers a wider range of health conditions. However, we have significant gaps in ethnicity diversity, gender balance, age range and UK representation.

Ways to address the gaps were discussed with the suggestions of:

- Finding out why a wider range of applications were not forthcoming
- Working to expand use MY data's Members first, so that there is a larger pool to draw from
- Looking outside of use MY data for people interested in joining the Advisory Group
- Actively targeting Members who would fill the gaps.

DECISION

- Further recruitment is needed, to ensure the Advisory Group reflects the diversity of use MY data Members.

ACTION

- **Alison** - Circulate details of the actions identified to expand use MY data's Members, as a result of the 2020 Members' Census.

Any Other Business

use MY data Webinar, 03 March

Emily thanked the Advisory Group for their input and suggestions for the polls that will run during the webinar, which she is working through. Emily asked for the Advisory Group's help in promoting the webinar to their contacts/networks.

ACTION

- **Advisory Group** - Help to promote the 03 March webinar as widely as possible.

Date of next meeting & goodbyes

Meetings will take place online on the following dates:

- Wednesday, 24 March, 15:00 to 16:00
- Wednesday, 21 April, 15:00 to 16:00
- Wednesday, 19 May, 15:00 to 16:00
- Wednesday, 23 June, 15:00 to 16:00.

For meetings beyond June, Alison proposed that we have an online meeting in July, we do not meet in August and we plan an in-person meeting in September.

A well-received suggestion for meetings was to take a blended approach, perhaps meeting together twice a year, with online meetings in between.

Several Advisory Group Members highlighted the value of meeting in-person sooner rather than later and asked if this could take place in July. A vote was taken, to ascertain from attendees whether they would be happy to meet in-person, in July. Some Members were happy to do so, while others felt it was too soon in terms of health considerations.

DECISION

- Set a date for a July Advisory Group meeting, exploring whether it is possible for this to be in-person.

ACTION

- **Alison** to explore options for the July meeting, including liaising with Sarah to obtain her views, and feedback to the Advisory Group.

Alison brought the meeting to a close, thanking attendees for their time and contributions.