

Advisory Group & Secretariat meeting

Wednesday, 19 May 2021

15:00 to 16:00

Online meeting

Meeting notes - confirmed

Attendees - Advisory Group

Richard Ballerand
Dave Chuter
Jo Gumbs
Sarah Markham
John Marsh
David Snelson
Richard Stephens

Attendees - Secretariat

Emily Boldison
Chris Carrigan
Alison Stone

Welcome, housekeeping and apologies

Alison welcomed attendees, thanking them for their time. The meeting etiquette was agreed upon and attendees were reminded of the process to claim an honorarium, should they wish to (via an email request to Chris and Emily after the meeting).

Apologies were received from Pete Wheatstone.

Position Statements - for feedback, discussion & next steps

Chris gave an overview of the work on the position statements, thanking those who have worked on them for their time. There have been volunteers for each position statement and good progress has been made. There are some areas to finish off in terms of content and then formatting and adding general information about use MY data. The challenge will be in consistency and quality control.

The sign-off process and next steps were discussed, with the following agreed:

- Add the position statements to the Advisory Group's shared drive, for review and comments - it will be best to keep comments to any major changes needed, rather than an abundance of minor changes.
- The statements will be added to the shared drive as they are become ready, with the Advisory Group notified of each new upload and given a week to review and comment.
- We will aim for the full, final set to be ready by mid-June.
- Once we have this full and final set, we will set the launch date and the manner/method of the launch.
- Publishing all of the statements together would probably have the most impact. However should events on a particular topic dictate a faster pace, we might respond by publishing some in advance (being mindful of the need to ensure that this may dilute the impact of the statements).
- If events have not necessitated an earlier release, we will aim to launch the statements as one set, in September.
- Alison will arrange for an accompanying set of graphics to be used to promote the position statements.

DECISION

- Add the position statements to the Advisory Group's shared drive for review and comment, with the aim of this work being done and the statements finalised by mid-June.
- Once we have the final set, we will determine the launch timings and method/manner.

ACTIONS

- **Position statement volunteers** to send their 'final' versions to Chris for upload to the Advisory Group's shared drive.
- **Chris** to upload position statements to the shared drive and inform the Advisory Group as each one is uploaded.
- **Advisory Group Members** to review the statements and provide feedback within the agreed timescale of one week.
- **Alison** will arrange a set of graphics to accompany the position statements.

Call to action from the March webinar - for discussion & deciding next steps

Our March webinar produced the Call to Action - **Compose a resource for patients informing them how to access their patient data and how to overcome any barriers in accessing them.**

John had produced a document to help take this work forward and for which he would welcome the Advisory Group's review. The paper was circulated just ahead of the meeting and, while there had not been time for an in-depth review, initial comments were positive. The paper will be added to the Advisory Group's shared drive, for review and feedback with one week's turn around. We will then use it to lobby for change.

David raised the topic of the COVID-19 vaccine, the NHS App and GP records, noting that the NHS App now includes details of your vaccination status. He thought this would stimulate more people to access their GP as a result of downloading the app for travel purposes.

[Post meeting note: The NHSX Webinar on the 20 May confirmed that there had been a sudden increase in patients downloading the App and requesting access to GP records.]

The name of the paper **Make sure patients know how to access their health records and overcome any barriers to that access** is different to the name of the initial Call to Action. This reflects that use MY data cannot create the resource itself. Rather, it needs to work on behalf of its Members, to ask the relevant organisations to create the resource. The essential aspect is that we follow-up on the action and demonstrate that we are doing this, to our Members.

It would be good to mention the Call to Action at the start of our next webinar (Tuesday, 25 May) to demonstrate that we are a movement that takes action and works to act and influence on behalf of Members. It is also important that each webinar/workshop has an outcome for change.

DECISION

- Ensure that each of our workshops/webinars has an identified call to action/outcome for change.
- Ensure that we demonstrate to our Members that use MY data is a movement that takes action on their behalf.

ACTION

- **Chris** will add the Call to Action paper to the Advisory Group's shared drive.
- **Advisory Group** to review and comment on the paper within one week.
- **Chris** to highlight the Call to Action work from the March webinar, at the start of the 25 May webinar.
- **Chris & Emily** to ensure there is a Call to Action from the 25 May webinar (and all future ones).

Any other business

NHS Digital and patient involvement strategy

John highlighted that, despite its significance in the patient data world, NHS Digital does not seem to have a patient involvement policy.

DECISION

- Contact NHS Digital to formally ask about their patient involvement policy and offer use MY data's assistance, as an independent patient group. This letter will be co-signed by Richard and Dave, as Advisory Group Chair and Vice Chair, and Chris and Alison on behalf of the Secretariat.

ACTION

- **Chris, Alison, Richard and Dave** will liaise to produce a letter to send to NHS Digital, enquiring about their patient involvement policy and offering use MY data's assistance.
- **Chris and Alison** will produce an initial draft of the letter.

NHS Digital's General Practice Data for Planning and Research data collection

Alison asked for the Advisory Group's thoughts on hosting a webinar with NHS Digital and other stakeholders, on the topic of the incoming NHS Digital's General Practice Data for Planning and Research (GPDPR) data collection. This would enable Members to engage direct with questions.

There has not been sufficient communication to the public/patients about the upcoming changes to the collection of primary care data and so there is a risk of a backlash and subsequent loss of trust in using patient data.

There was agreement that it would be good to host the webinar and that this needs to happen within the next few weeks, to be relevant. We need to ensure that speakers taking part are those who are in a position to change the culture within their organisations.

Chris is working on a position statement about the GPDPR, to share with use MY data Members. Once he has the initial draft, he will share this with Advisory Group volunteers for their input into the next stage.

DECISION

- use MY data will press ahead with trying to arrange a webinar on NHS Digital's General Practice Data for Planning and Research (GPDPR) data collection.

ACTION

- **Chris** to liaise with NHS Digital to confirm we would like to host a webinar on the topic and we wish to invite their CEO to speak.
- **Chris & Emily** will take the webinar forward.
- **Chris** to send the position statement draft to Advisory Group volunteers, for their input.

Data training drop-in sessions

Chris highlighted two upcoming topics for the Friday training sessions. These are NHSX and the AI Laboratory on 11 June and Dr Janet Valentine of the Clinical Practice Research Datalink (CPRD) on 25 June.

NHSX webinar

Chris has written to NHSX to ask if they wish to take part in a use MY data webinar, focussed on their upcoming data strategy for health and social care.

Precision Medicine Forum - Patient Week

Alison outlined details of an invitation to use MY data, to be a partner of the Patient Week, which will be at the end of September 2021. We would have the opportunity to be part of the programme, exhibit and network, in return for promotional work. The event is free for patients, relatives and carers to attend.

DECISION

- The Advisory Group agreed that use MY data should be a partner for the September 2021 Patient Week event.

ACTION

- **Alison** to circulate the Patient Week brochure to the Advisory Group and to confirm our participation with the organiser.

Digital Leaders - Award nomination - UK focus

Chris reported that use MY data has been nominated in the Trust, Ethics & Privacy category of the Digital Leader Impact Awards. We are now in the final of this category, with two other organisations. The next stage is to give a short presentation on Tuesday, 25 May. However, the timing is a direct clash with our webinar. We can submit a short video presentation instead. Chris asked if there were any volunteers for this, if not he will try to prepare a video by himself. There were no volunteers amongst the meeting attendees but agreement to ask any Advisory Group Members not present at the meeting.

ACTION

- **Chris** will contact Pete Wheatstone to ask if he would like to volunteer to make a video to promote use MY data for the Impact Awards.

Date of next meeting & goodbyes

Meetings will take place online on the following dates:

- Wednesday, 30 June, 15:00 to 16:00
- Wednesday, 21 July, 15:00 to 16:00
- September - If COVID-19 circumstances permit we will meet in-person, with the option to join online

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