

Advisory Group & Secretariat meeting

Wednesday, 21 April 2021

15:00 to 16:00

Online meeting

Meeting notes - confirmed

Attendees - Advisory Group

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

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 David Snelson and Pete Wheatstone (happily Pete was able to join during the Chair section).

Engagement work - for information & discussion

• NHS COVID-19 Data store

Chris provided a progress report on his work with NHSX to date.

At our September 2020 webinar with NHSX **The COVID-19 exit strategy - what next for patient data?** delegates requested more transparency around the uses of the NHS COVID-19 Data Store, which was built by NHSX and NHS England & NHS Improvement (NHSE/I) as a key resource in the response to the pandemic. Responsibility for the Data Store is with NHSE/I.

The NHSE/I website already included information on what was actually in the NHS COVID-19 Data Store [here](#) and we learned that they had an ambition to publish the list of releases, but the timelines had not yet been worked out.

We wrote to NHSX (our original contact for the webinar) in October 2020, highlighting the need for transparency and offering to bring the patient voice to assist in the scoping, development and publication of a register. We also informed our webinar delegates and our Membership that we had written to NHSX about this.

During December 2020 and January 2021, we worked with key members of NHSE/I, who had taken over responsibility for the Data Store, to help scope and co-design the format of the release register. In late January, the first outline draft versions of a register of data releases were shared with us, with the commitment that a corresponding draft data access register would be available to see in February. At that point NHSE/I's plan said that they intended to publish both of these documents in the Spring. We updated our Membership to this effect in the weekly update.

Since that point Chris has had regular 30-minute catch-ups with them. We set these up on the basis that it would keep things focused, realising that not everyone would be able to make every meeting. Recently some meetings have been cancelled (one was to attend a workshop about release registers, which was flagged to them) and progress has slowed. We have also been in communication with both the National Data Guardian's Office and Health Data Research UK's central team about this work.

The latest update from NHSE/I in April 2021 said "We're still in the process of developing the fields data release register. We've been working with the developers of the Data Platform, to ensure we're capturing the right information and to make it easier to download a report as we move into BAU [business as usual]. We're aiming to have completed this process in the next few weeks."

Chris is due to meet the NHSE/I team on Thursday, 22 April and will update the Advisory Group members after that. If no significant progress has been made use MY data will formally write to NHSE/I, highlighting the need for clear actions and timelines, and requesting a formal response. We would publish our letter and any response from NHSX on our website, for transparency.

DECISION

- Chris will liaise with NHSE/I on Thursday, 22 April to obtain a progress report on the NHS COVID-19 Data Store. If progress has not been made, use MY data will write to NHSE/I to highlight the need for clear actions and timelines and will request a formal response.

ACTION

- **Chris** to liaise with NHSE/I on 22 April about the NHS COVID-19 Data Store and feedback to the Advisory Group. If progress has not been made, Chris will organise a letter from use MY data to NHSE/I.
- **May webinar**
Emily provided an update on plans so far and sought Advisory Group input for the next webinar. This will take place on Tuesday, 25 May from 10:00 to 11:30.

After sifting through the list of preferred topics from the Advisory Group and taking into account the short timeframe for organising and speaker contacts, Emily proposed the topic for is **A researcher's journey to patient data** which will have a UK focus. The aim of the webinar will be to look at the steps which a researcher needs to take.

Following feedback that there are several different journeys to patient data researchers, Emily clarified that the webinar will focus on the use of routinely collected healthcare data, often called Real World Data (RWE). This data is collected routinely throughout the care of a patient and is collected with the prime purpose of looking after the patient. However, it also has significant opportunities to be used for research. The patient will not normally have been asked about this (they will not have been asked to consent), so a researcher has to jump through lots of hoops and satisfy several legal and policy safeguards, to be able to access this data.

Our webinar will explore these steps, to highlight:

- What are the steps, from application through data access to completed research?
- Where are the frustrations of a researcher in the complexity of data access?
- Where does the patient voice fit into this data access landscape?

- Where is patient input lacking?
- How much more involved they could be, and how. And would this make a difference?
- Are there different experiences or examples from across the UK?

Potential speakers are:

- Alex Bailey at the Medical Research Council (MRC), as he has written a toolkit to help researchers navigate the data access steps.
- Elizabeth Lemmon, researcher based in Scotland.

Emily and Chris have calls booked with Alex and Elizabeth, the week commencing 26 April.

Emily asked whether any Members of the Advisory Group would want to be on the panel, or whether they wanted to suggest someone from outside the Advisory Group. After discussion, Richard Ballerand offered to be on the panel, as he has had relevant experience in this area. Other Members with direct experience of being involved in trials which use RWE could also be approached.

It was suggested and agreed, that Paul Affleck from the University of Leeds would be a good panellist, as he has extensive experience of Ethics Committees, has had direct involvement in negotiating the data access path for Bowel Cancer Intelligence UK and is also a member of the Independent Group Advising on the Release of Data (IGARD).

Emily asked if any Advisory Group Members would like to chair the webinar, or possibly co-chair. Either way, it would be good to separate out the technical side of hosting from the chairing and ensure this is established as a standard way of running our webinars.

It is important to ensure that there are outcomes from the webinar. Our last webinar had an identified call to action which we have publicised but, as an organisation, have not yet taken forward.

DECISIONS

- Ensure the webinar has a real-world evidence focus.
- Speakers: invite Paul Affleck to be a speaker and confirm a patient speaker.
- Decide upon the chair and tech support.
- Ensure the webinar has a call to action.

ACTIONS

- **Emily** will update the webinar content, issue further speaker invitations (Paul Affleck and patient speaker) and confirm the Chair.
- **Emily** will ensure the webinar identifies a call to action.

• **Feedback mechanisms for Members who formally represent use MY data with external organisations**

Alison sought Advisory Group input on the most useful ways for our representatives to feedback on their engagement activities. There are three areas of engagement:

- Formal - where a Member represents use MY data
- Informal - where a Member has a representative role, perhaps found through use MY data, but is not formally representing use MY data
- Secretariat engagement.

There were different perspectives from the Advisory Group on the best methods of feedback, with the strong feeling that it is essential is to provide feedback to use MY data's Members, rather than only to the Advisory Group.

Acknowledging that the form of feedback depends on the nature of the feedback, suggestions were:

- Using a template email and asking for any Members engagement to be included
- Having a website section for feedback
- Using the weekly update to provide feedback.

ACTIONS

- **The Secretariat** will provide an engagement update on a monthly basis.
- **Alison** will reflect on the Advisory Group's suggestions to decide the best way forward for the feedback.

Advisory Group Chair - for decision and next steps

- **Role outline & Secretariat expectations / Next steps**

The Secretariat presented the latest version of the role description / Secretariat expectations document, which had been updated with Advisory Group input.

Term of office: following consideration of suggestions which ranged from one to three years, this was agreed as two years.

Vice Chair: it was agreed that a vice chair is needed, to provide support and back-up to the Chair and to provide cover in the Chair's absence, including chairing meetings. This should also be a two-year term.

There was acknowledgement that, as this is new territory, we do need a flexible approach. The key requirement is to ensure transparency.

Advisory Group Members will nominate each other and can nominate themselves. The Secretariat will not be part of the voting process but will coordinate the process on behalf of the Group.

DECISIONS

- The Advisory Group will have a Chair and Vice chair and each will have a two-year term of office.
- The Secretariat will coordinate the voting process, for which Advisory Group Members will nominate each other (and possibly themselves). The voting process will not begin until all Members are available for voting.

ACTIONS

- **Alison** will update the role outline to reflect the confirmed term of office and the role of Vice Chair.
- **Alison** will coordinate the voting process.
- **Advisory Group Members** will vote to elect a Chair and Vice Chair.

Any other business

- **Guidelines for identifying as a Member of use MY data**

Richard B asked about the protocol/policy for identifying oneself as a Member or Advisory Group Member of use MY data, when attending external meetings. Alison said that while there is no policy, she believes there is guidance within the Information and Guidance document for Members and will check this.

This led on to the Advisory Group highlighting the value of use MY data Members having the resources necessary to promote the movement. Alison agreed and has previously circulated resources to Members, however the resources have recently been updated, plus we have new Members. It is timely to circulate updated resources to Members, highlighting the value of promoting use MY data as widely as possible.

ACTIONS

- **Alison** to locate information that will help Advisory Group Members who are representing use MY data and to update the Advisory Group.
- **Alison** will circulate updated resources to use MY data's Members, to use in external engagement to promote use MY data.
- **Show me my data! webinar - 03 March 2021**
John requested the webinar's call to action is brought to the May Advisory Group & Secretariat meeting.

ACTION

- **Alison** will add the March webinar's call to action to the May meeting agenda.
- **June Advisory Group & Secretariat meeting**
The meeting date was set for Wednesday, 23 June. However this is now the date for Health Data Research UK's (HDR UK) annual conference. A quick show of hands from Members indicated that most would like to attend the HDR UK event and it would therefore be best to rearrange our meeting.

ACTION

- **Alison** will find an alternative date for our June Advisory Group & Secretariat meeting.

Date of next meeting & goodbyes

Meetings will take place online on the following dates:

- Wednesday, 19 May, 15:00 to 16:00
- June - Meeting date to be rearranged
- 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.