

Advisory Group & Secretariat meeting

Wednesday, 21 July 2021

14:00 to 16:00

Online meeting

Meeting notes - confirmed

Attendees - Advisory Group

Dave Chuter

Jo Gumbs

Richard Stephens

Attendees - Secretariat

Emily Boldison

Chris Carrigan

Alison Stone

Welcome, apologies and housekeeping

Richard

Richard welcomed attendees. Apologies were received from Richard Ballerand, Sarah Markham John Marsh, David Snelson and Pete Wheatstone.

The meeting etiquette was agreed as:

- Mute unless speaking
- Within the limitations of being online, do our best not to speak over each other
- Everyone has a turn to speak
- Put a hand up to speak
- Keep videos on unless have sound quality issue
- Don't use the chat function unless having technical probs etc.
- Be in the meeting and not multi-tasking.

Position Statements

Chris

Final review and next steps

Chris presented the statements for a final review. They have all been reordered, to provide a focus on the benefits in the headline 'blue box'.

- *Expectations of organisations which use our patient data*
All were happy with this version, no further changes needed.
- *Realising the benefits of a truly National Health Record*
A minor amendment is needed - under the 'implementation' section, a note needs to be added to ensure it is started by a set date.
- *Highlighting the benefits of using patient data*
A minor amendment is needed - as well as providing a link to information about 'The Five Safes' it would be best to list them out in full within the document.
- *Recognising the use of patient data*
A title change was agreed upon, to 'Acknowledging and raising awareness of patient data'.

All of the statements require a final proofread and formatting check, ahead of publication. Chris and Alison will do this; with the holiday period, a realistic date for this work to be completed by is the end of August.

All attendees agreed that it is now time to begin using the position statements. Once published, use MY data Members should be invited to use them, share them, comment on them. We need a feedback loop from Members, so that the Advisory Group and Secretariat know when and how the statements are used.

It may be that the statements generate questions, that need to come back to the Secretariat and Advisory Group.

It would be good to receive ideas from Members for future position statements. Chris and Alison will think about the best method to gather this information and the timeline.

Calls to Action: the next steps

Chris presented the position statement that created as a result of the call to action from our March 2021 webinar, Show me my data!

- *My access to my health records*

All were happy with this final version. We do need a mechanism to evaluate its use. One method for this would be to host a poll of Members, to evaluate who has access to their records.

Jo highlighted that sometimes access to records is not for the patient themselves, but for their dependents, e.g. children, relatives we care for. For the next Advisory Group meeting, it would be good to discuss how we evaluate the call to action, how we identify gaps and how quickly we need to review.

ADVICE GIVEN FOR DECISIONS TO BE TAKEN

- The position statements are ready for use, subject to the minor changes identified.
- They should be published as soon as possible and follow-up work undertaken with Members.
- *My access to my health records* is a priority, as it aligns with current public concerns around the use of patient data. This will be in the weekly update to our Membership on 29 July.
- Chris and Alison should determine the schedule for the position statements depending on Secretariat resources.

ACTIONS

- **Chris & Alison** - Will finalise the position statements ready for publication, by the end of August.
- **Chris & Alison** - Will define the publication schedule for the position statements.
- **Chris & Alison** - Will put processes in place to obtain feedback on the use of the position statements from Members and work out a timeline for this.
- **Alison** - Will ensure publication of *My access to my health records* by 29 July.
- **Alison** - Will bring the topic of the need to access records by those caring for the patient, to the next Advisory Group and Secretariat meeting.

Webinar outcomes & next steps

- **September 2020 - NHS COVID-19 Data Store, Access & Release Register**

We have now escalated this, as the Register is still not published. Richard, Dave, Chris and Alison have been working on a formal letter to NHS England and NHS Improvement (NHSE/I), seeking either the date of publication or the reasons why publication is being held back. Once we have sent the letter, which we are aiming to do today, 21 July, we will publish on our website and share the link in the weekly update.

Chris

<ul style="list-style-type: none"> • March 2021 - Our access to our health records This was covered under the position statements item. • June 2021 - GDPR follow-up actions with NHS Digital Following the pause of the General Practice Data for Planning and Research (GDPR), use MY data will follow-up formally with NHS Digital to seek information on the remaining actions. We will also ask for information about oversight groups. Richard, Dave, Chris and Alison are working on a formal letter to NHS Digital and hope to send today, 21 July. <p>Chris has been working on an update for the website, to bring all of the GDPR information together. This needs a tweak in the title - to state that the Government/NHS has committed or responded to use MY data's asks.</p> <p>Richard noted that the webinars have been successful as events in themselves but also in establishing use MY data as an independent voice for and of patients, and thanked Emily for her work on these and Chris and Alison for their support in helping to deliver them.</p> <p>ACTION</p> <ul style="list-style-type: none"> • Chris & Alison - Ensure the letters to NHSE/I and NHS Digital are sent on 21 July, published on our website and the information shared with our Membership. 	
<p>Membership update & work programme</p> <ul style="list-style-type: none"> • Update on Membership numbers & engagement Alison gave an overview of current Membership numbers, which are 190 Members and 140 Associate Members. The gap between Members and Associate Members has narrowed over recent months. It would be interesting to know from Associate Members their reasons for joining. <p>We should consider whether to have a Membership drive next year and, if so, would probably need to look at gaps that need to filled, rather than purely expanding numbers. It will probably be necessary to expand the Advisory Group for the same reason.</p> <ul style="list-style-type: none"> • Creating a realistic work programme to deliver our organisational aims Alison presented the programme for this year, highlighting that external engagement requests have increased significantly and part of this stems from organisations coming to us for advice as an independent voice for and of patients. <p>Alison gave an overview of items that have been removed from the work programme for this year, due to Secretariat resources. Richard suggested that a work programme for 2022 is needed and could include these items, pending discussion.</p> <p>Attendees felt that the work programme for 2021 is ambitious and we need to be mindful of what we choose to do, particularly in relation to adhoc engagement requests. Attendees advised Alison to share engagement requests as needed with the Advisory Group, for guidance on how best either to engage or sign-post on. There was agreement that the work programme should come back to the September meeting, for review.</p> <p>Attendees discussed the September webinar, which is pencilled in, with the topic to be defined. It is possible that the topic could be the GDPR, for which use MY data could host the webinar, open to patients and the public, and involve NHS Digital. One aspect of the webinar could be to include members of the public, who are worried about the use of data and hear their views as part of a balanced panel. Some of our Members have opted out and, if they were willing, it would be good to include them.</p>	<p>Alison</p>

<p>ACTIONS</p> <ul style="list-style-type: none"> • Chris - In the letter to NHS Digital about GDPR, add our offer to host a patient/public September webinar on the topic. • Emily - Take the planning of the September webinar forward. • Alison - Draw up the 2022 work programme and include items removed from 2021, ahead of discussion about re-including them. • Alison - Add a review of the work programme to the September Advisory Group & Secretariat meeting. 	
<p>Any other business</p> <p>There was no further business.</p>	Richard
<p>Date of next meeting</p> <p>Meeting dates for September onwards are to be selected via doodle polls, which will be sent out by 22 July. Future meetings will be for two hours.</p>	Richard