

**Advisory Group & Secretariat
Online meeting**

**Wednesday, 19 January 2022
13:00 - 15:00**

Meeting notes - confirmed

Item 1.0	<p>Attendees: Advisory Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Richard Ballerand, Jo Gumbs, Sarah Markham, John Marsh, David Snelson, Pete Wheatstone. Secretariat - Chris Carrigan, Emily Connearn, Alison Stone.</p> <p>Apologies received from: no apologies.</p>	Richard
Item 2.0	<p>Updates</p> <p>a. use MY data's funding</p> <p>There has not been a huge amount of change since our last meeting. Chris has spoken with a range of organisations, including NHS Digital, NHSX and Health Data Research UK to see if they would contribute funding. There are a few irons in the fire but nothing definitive at this stage.</p> <p>Chris and Alison are funded until the end of August 2022. Emily is funded until the end of March 2023.</p> <p>b. The future of Understanding Patient Data</p> <p>Understanding Patient Data (UPD) has recently published an update, giving an overview of projects for 2022 and a reminder that this is the last year of Wellcome funding. In the Spring UPD will focus on finding new homes for their key resources.</p> <p>Chris will contact UPD to discuss their plans for how the existing resources will be managed in future, and whether there is any scope for funding work through use MY data.</p> <p>c. Discussions with national organisations (NHS Digital, NHSX etc.)</p> <p>NHS Digital & the General Practice Data for Planning & Research (GPDPR) We have written again to NHS Digital (on 18 January) to follow-up our 30 November letter. The purpose of our letters is to seek publication of information about the GPDPR and the oversight groups.</p> <p>Our position on the GP Data Patient and Public Engagement and Communications Advisory Panel is increasingly difficult, without information about the Panel being in the public domain. We are part of an oversight group that does not officially exist and for which we cannot share information with our Membership.</p> <p>How will we make a decision about remaining on the panel? This is a finely</p>	Chris

	<p>balanced situation, as we do want to be involved. If we do have to leave, we would hope that this would not be irrevocable and that we would have the possibility of returning, when our concerns about transparency have been met.</p> <p>At the Panel meetings we have attended, we have emphasised the importance of the GDPR Programme Board understanding the need for public confidence. We do not know who is on the Programme Board, to be able to make contact with them and discuss our concerns.</p> <p>The next Panel meeting is on Thursday, 20 January and we will be attending. Hopefully, more clarity will be provided at this meeting. Dave Chuter, the Advisory Group Member who will attend, will ask who is on the Programme Board.</p> <p>The Advisory Group discussed the merits of contacting local MPs about the issue. Perhaps if not now, then at the point when we feel we must leave the Panel.</p> <p>We will wait a reasonable amount of time for NHS Digital to respond to our letter before deciding upon our next steps. This was agreed as 14 calendar days (10 working days).</p> <p>Some Secretariat and Advisory Group Members are attending the next NHSX engagement session on Thursday, 20 January and this could be a good forum in which to raise the point about the lack of transparency.</p> <p>d. Summary of actions</p> <p>Funding</p> <ul style="list-style-type: none"> • Chris - Will continue to seek core funding for use MY data, from August 2022 to March 2023. • Chris - Will seek additional funding to support additional work. • Chris - Will seek funding beyond March 2023. <p>The future of Understanding Patient Data</p> <ul style="list-style-type: none"> • Chris - Will speak with Understanding Patient Data by 28 February, to discuss the closedown process for the organisation and see if there are any resources that might be useful for use MY data and whether any residual funding is available to support use MY data's work. <p>NHS Digital and GDPR</p> <ul style="list-style-type: none"> • Dave - Will attend the 20 January Panel meeting and request information about the Programme Board. He will report back on this and the outcomes of the meeting to the Advisory Group and Secretariat. • Chris - Will raise the issue of transparency around the GPPDR at the NHSX engagement session on Thursday, 20 January. • Alison - Will monitor whether we receive a response from NHS Digital to our letters and will update the Advisory Group accordingly. 	
Item 3.0	<p>Work programme</p> <p>a. Update on the revised deliverable work programme, following suggestions from the Advisory Group at the September meeting</p> <p>Alison had circulated the 2022 work programme prior to the meeting for review. Several areas of the Work Programme were covered elsewhere in the meeting.</p> <p>A key point was about capacity within the Secretariat for flexibility within the work programme, should ad-hoc issues or new priorities arise. Alison has more scope for this at present. There is less flexibility for Chris and Emily, with both their workloads moving between peaks and troughs, and balancing use MY data</p>	Alison

	<p>work with work with other organisations. Chris will be reducing his hours working on DATA-CAN to three days a week from April 2022.</p> <p>Alison gave a brief overview of key points in the work programme and asked for any comments or questions.</p> <p>Following up on our Call to Action ‘My access to my health records’ and our work with NHSX on the programme to accelerate patient access to health records, we now need to check what is happening (following the programme’s pause). It was agreed that we will raise this at the NHSX engagement session on Thursday, 20 January.</p> <p>b. Update on activities deferred due to resources This was not discussed.</p> <p>c. Summary of actions</p> <ul style="list-style-type: none"> · Alison - Will ask for an update on timelines for the programme to accelerate patient access to health records, at the NHSX engagement session on Thursday, 20 January. 	
<p>Item 4.0</p>	<p>use MY data webinars</p> <p>a. Update and discussion on our webinar series with NHS Digital</p> <p>Emily updated the Advisory Group on plans for our webinar series with NHS Digital.</p> <p>Chris and Emily have been meeting regularly with NHS Digital about the proposed GDPR webinars. Potential dates are 02 March and 09 March and the content would be on the opt-outs and the Trusted Research Environment.</p> <p>However, we have confirmed in writing to NHS Digital that it would be difficult for us to go ahead with the webinars, without information about the GDPR being published. Unless NHS Digital is able to confirm publication very soon, it will not be realistic for us to hold the webinars in March. It seems sensible to push them back to June 2022.</p> <p>We will need to update NHS Digital within the next 14 days, if we feel we cannot go ahead. This very much depends on any response to our letter(s) to the CEO of NHS Digital.</p> <p>b. Webinar programme for the rest of 2022</p> <p>Emily presented the idea of hosting a webinar about use MY data - an update forum with information about how and why to become involved, with Advisory Group Members speaking about the pieces of work they do. Patients talking to patients and promoting use MY data as a movement, so that Members can see how other Members are involved. It would be good for Alison to do a spot, as the person behind the weekly newsletter.</p> <p>This was generally well received, with the consensus to go ahead.</p> <p>Emily raised the idea of hosting patient data awareness events for our Members and the public. These could build on the informal drop-in sessions that Chris hosts for DATA-CAN, the NCRI Consumer Forum and the Advisory Group. This could also attract new people, hopefully equipping them with more knowledge and leading them to becoming active Members.</p>	<p>Emily</p>

We might consider hosting a poll during our Members' webinar, to see what topics for the awareness sessions would appeal.

One idea for the sessions is data inequalities, for which Chris could use existing materials from one of the drop-in sessions.

A further option could be to repeat a drop-in session on how data is created as part of the care system, and what the data looks like. One suggestion as a tangent to that, was to look at how patients can get incorrect data corrected. On the topic related to our Call to Action 'My access to my health records', one issue people might find and not be aware of, is how people might interpret their data (which could be unnecessarily alarming).

Anyone who has been through the practical aspects of seeing their record, and then the difficulties in trying to get errors corrected, could form a very useful patient advocate case study on our website (in a slightly different way to the existing case studies). Any experience gained in this area (of getting your records corrected) could also eventually be a resource on our website. We need to provide solutions as well as highlighting the problems.

It might be possible to do the inequalities session for February as a taster, as much of the content is written already. Chris's intention was to host the session soon and to be the sole speaker, rather than having a panel. It would be badged as a taster session for Members, to gain their views as to whether the format is useful or not.

c. Summary of actions

- **Emily** - To liaise with NHS Digital about the GDPR webinars and decide whether they will go ahead or be deferred (possibly to June 2022).
- **Emily** - To explore the possibility of a use MY data Members' focussed webinar, in March 2022.
- **Emily & Chris** - To explore the possibility of a use MY data Members' patient data awareness webinar, in February 2022.
- **Emily** - To map out themes for the rest of 2022.

Item 5.0

Review of our position statements

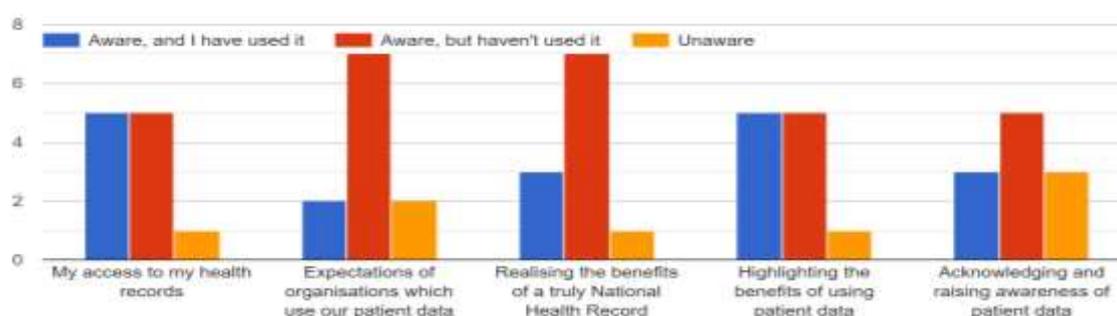
Chris & Alison

a. Are they still fit for purpose, have they been used, do they still represent our position? - Results from the evaluation

Chris presented the results of our evaluation, for which we asked our Members to complete a short survey. However, only 11 Members did this and so it is a very small sample.

The survey results:

Which of our Position Statements are you unaware of, aware of, or have used?



	<p>Some of the respondents provided additional information as free text, which highlighted the opportunity for more active communications on the Position Statements, or to use them more actively in conversations.</p> <p>The Position Statements are fit for purpose; however we need to find ways to publicise them and use them more. This could include webinars - both our proposed Member focussed ones and our public webinars. Ideally, we should be looking for opportunities to weave the Position Statements into all our webinars.</p> <p>Survey responses showed that some Members are unaware of the Patient Data Citation. This was surprising, as it such as fundamental part of our work and is emphasised in the joining information that all new Members and Associate Members receive. The lack of awareness seems to highlight a communications issue.</p> <p>Chris noted that the Position Statements had been used several times as parts of our responses to national consultations.</p> <p>As so few Members completed the survey, there may be benefit in taking items of this nature out of the weekly update to our Membership. Instead, we could consider sending specific standalone emails to seek the input of Members to use MY data's work. We could then follow-up in the newsletter with a reminder. Alison is willing to try this, though is hesitant about sending too many emails to our Membership and overloading inboxes.</p> <p>b. Expectations of organisations which use our patient data - updated version</p> <p>This Position Statement has been updated, following an Advisory Group Member's suggestion that it could specifically include the need for patients to be included in all parts of any organisation which uses patient data.</p> <p>The Advisory Group agreed the change and requested an additional part to the Statement. This is to add that if patients are on patient data committees, then part of the transparency should be for Terms of Reference and meeting notes/minutes to be published. Once the Statement has been amended to reflect this, the Advisory Group will be happy for the Secretariat to go ahead, publish and promote.</p> <p>c. Summary of actions</p> <ul style="list-style-type: none"> · Alison - To amend the communications process with Members, for the occasions when we need to seek their input for specific items/topics. · Chris & Alison - To amend the 'Expectations of organisations which use our Patient data' Position Statement, then publish and promote it. 	
<p>Item 6.0</p>	<p>How does use MY data move further towards delivering its strategic aim to become the trusted patient voice?</p> <p>a. Secretariat overview/update on work in this area, to date</p> <p>b. Identify ways to encourage the pro-active involvement of more Members</p> <p>Alison had circulated an overview of this prior to the meeting, for information. This detailed many different ways in which use MY data has become a trusted patient voice, with a wide range of organisations.</p> <p>Discussion took place on how we might develop this further and how Members might drive this, supported by the Secretariat.</p>	<p>Richard & Alison</p>

	<p>Key suggestions:</p> <ul style="list-style-type: none"> - NHS Trusts - at a local level (as we already engage at a national level) - Charities including health charities - Off the back of other events i.e. attending patient forums - people talking to other people - Does use MY data have any links for patient advocacy with the organisations that Public Health England moved into - the UK Health Security Agency (UKHSA) or the Office for Health Improvement and Disparities? - Our profile will be raised if we achieve the transparency we are seeking with NHS Digital, around the GDPR - The ZOE COVID study, which is starting to morph into data gathering - Northern Ireland, Scotland and Wales; we need a push to engage with our Members in those nations - Seeking formal links with the Association of the British Pharmaceutical Industry (ABPI) and the Association of Medical Research Charities (AMRC) - NHS England. <p>We could consider having a supporters' page on our website, for organisations which agree with our principles etc. However, it would not be possible to police this and we would need to make clear that a supporter's logo does not mean an endorsement by use MY data.</p> <p>We could consider creating and publishing a 'story' on all of our work on the GDPR, as an example of how we operate and work within the principles, created by Members.</p> <p>c. Summary of actions</p> <ul style="list-style-type: none"> · All - To reflect on the suggestions to take the 'trusted patient voice' work forward and the contacts it would be useful for us to make, and identify priority tasks when we meet in March. · Secretariat - Develop an outline plan of suggestions for the 'trusted patient voice' work. Send to the Advisory Group as an aid for their action, ahead of the March meeting. · Alison - To consider if there is a story in our work on the GDPR and, if so, to find the best way to take this forward. · Alison - Bring this topic back to our March meeting. 	
Item 7.0	<p>Any other business</p> <p>There was no further business.</p>	Richard
Item 8.0	<p>Date of next meetings</p> <ul style="list-style-type: none"> · Wednesday, 23 March, 11:00 to 13:00 - online, via Zoom · June & September - Dates to be decided & we will meet in person if possible 	Richard

Suggestions for future meetings	
March	<ul style="list-style-type: none"> ▪ Secretariat resources review ▪ How does use MY data move further towards delivering its strategic aim to become the trusted patient voice? - Part II <p>Standing items:</p> <ul style="list-style-type: none"> ▪ Update on funding ▪ Update on the future of Understanding Patient Data ▪ Update on discussions with national organisations (NHS Digital, NHSX etc.)
June	<p>Standing items:</p> <ul style="list-style-type: none"> ▪ Update on funding ▪ Update on the future of Understanding Patient Data ▪ Update on discussions with national organisations (NHS Digital, NHSX etc.)
September	<p>Standing items:</p> <ul style="list-style-type: none"> ▪ Update on funding ▪ Update on the future of Understanding Patient Data ▪ Update on discussions with national organisations (NHS Digital, NHSX etc.)