

**Advisory Group & Secretariat
Online meeting**

**Wednesday, 20 October 2021
13:00 - 15:00**

Meeting notes - confirmed

<p>Item 1.0</p>	<p>Attendees: Advisory Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Richard Ballerand, Jo Gumbs, Sarah Markham, John Marsh (joined towards the end), David Snelson, Pete Wheatstone. Secretariat - Chris Carrigan, Emily Connearn, Alison Stone.</p> <p>Apologies received from: no apologies.</p>	<p>Dave</p>
<p>Item 2.0</p>	<p>Updates</p> <p>a. use MY data's funding</p> <p>Funding for the Secretariat posts remains due to end in August 2022. Chris is building a funding proposal for use MY data into the business plans for DATA-CAN. The funding for DATA-CAN ends at the end of August 2022 and the future model for sustainability is being designed and costed, which includes support for the work of use MY data. The current plan is to support the three Secretariat posts at the existing level.</p> <p>Chris has written to NHS Digital to seek their support to fund, or part-fund, the work of use MY data beyond August 2022. He has also raised the issue of funding with Amanda White at Health Data Research UK, noting the potentially serious consequences of losing both use MY data and Understanding Patient Data in Autumn 2022, when there is such an emphasis on patient data.</p> <p>In response to a question about how much of the funding was being sought from DATA-CAN and what proportion of use MY data funding needs this would cover, Chris said that at the moment, this would be to cover the Secretariat posts. Funding for non-pay costs would need to be sought in addition. If the DATA-CAN funding proposal is approved, this would cover a sizable element of funding for use MY data.</p> <p>Alison asked if, with their work on DATA-CAN as well as use MY data, Chris and Emily would have the necessary time to spend on use MY data, going forward? Chris recognised that this was a challenge, particularly at the moment, but was confident that he and Emily would continue to work on use MY data under the funding proposal as part of their PPIE (Patient and Public Involvement and Engagement) roles.</p> <p>The outcome of the funding proposal will not be known until 2022. Chris will report back as plans progress.</p>	<p>Chris</p>

	<p>b. The future of Understanding Patient Data</p> <p>Chris was not aware of any further progress or news around the future of Understanding Patient Data (UPD), since the last meeting of the Advisory Group. UPD is due to close towards the end of 2022, when the Wellcome funding ends.</p> <p>Chris thought that there was at least one organisation looking at whether they could host UPD, but there had not been any news updates about the programme. Natalie Banner, the UPD lead, is leaving this month, which will be a significant loss of leadership. Chris was not aware of the organisation that had expressed interest but would report back if more information became available.</p> <p>c. Discussions with national organisations (NHS Digital, NHSX etc.)</p> <p>Chris noted that the NHS Digital team had ‘inherited’ a PPIE function when they took over the NHS DigiTrials Hub. NHS Digital is looking to ‘adopt’ the team and use it for wider PPIE work, including the General Practice Data for Planning and Research (GPDPR) programme.</p> <p>Alison reported that David and the Secretariat met with NHS Digital on Monday, 18 October, to discuss the invitation to use MY data to join the patient/public GPDPR Panel. This Advisory Group discussed this invitation in detail, later in the meeting (under Any Other Business).</p> <p>NHSX had just sent the details of their next public engagement session, which will take place on Thursday, 04 November and the Advisory Group noted that this would be an ideal opportunity to highlight our Call to Action around access to health records, as this topic will feature on the session’s agenda. Alison will follow-up with NHSX about the session and circulate details to the Advisory Group.</p> <p>d. Summary of actions</p> <p>Funding</p> <ul style="list-style-type: none"> • Chris - Continue to provide updates on funding to the Advisory Group at each Advisory Group and Secretariat meeting, or more urgently if there are significant developments. <p>National organisations</p> <ul style="list-style-type: none"> • Alison - Ensure that NHSX is aware of our Call to Action, My access to my health records, ahead of NHSX’s 04 November engagement session. Circulate details of the session to the Advisory Group. 	
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>b. Update on activities deferred due to resources</p> <p>The work programme has been revised with the following changes:</p> <ul style="list-style-type: none"> • Events information has been updated to show webinars with Sensyne Health in November 2021 and NHS Digital in February 2022 • The timeframe for Calls to Action following our events has been amended, to be within two weeks of events - for 2021 and 2022 • National Disease Registration Service patient data stories have been added for the remainder of 2021 and 2022 • use MY data becoming the ‘trusted patient voice’ has been added for early 2022 	Alison

	<ul style="list-style-type: none"> Securing funding for use MY data beyond August 2022, has been added to early 2022 Advisory Group expansion has been moved to 2022, due to resources. <p>Chris highlighted that he is only able to do one hour per day on use MY data work at present and there is significant drain on Secretariat resources. He hopes that he will be able to return to his normal level of work for use MY data, in November.</p> <p>With Secretariat resource pressures, it would be good to bring this back to Advisory Group, to ascertain which work needs to be dropped. Alison said it is quite hard to do this, when we do not know fully the time demands of the Secretariat going forward. The Secretariat will meet in early November and will review resources, ahead of bringing this to the November Advisory Group and Secretariat meeting.</p> <p>The Advisory Group reiterated their previous advice on priorities. This is that all internal work should be postponed, and external work should be the focus, to underpin/expand our voice as the trusted patient voice on patient data. National NHS issues data issues take priority over regional issues at present.</p> <p>The Advisory Group acknowledged that resources are problematic, which is stressful for the Secretariat at present. Funding for a communications person, even if part time, would be extremely useful.</p> <p>c. Summary of actions</p> <ul style="list-style-type: none"> Secretariat - Review resources in early November, ahead of bringing this back to the November meeting. 	
Item 4.0	<p>Guest - Amanda White, Health Data Research UK</p> <p>Dave welcomed Amanda White from Health Data Research (HDR UK) to the meeting. Amanda provided an update on the plans for HDR-UK.</p> <p>HDR UK are in the process of developing their next 5-year strategy for 2023-2028. As part of this development work, they are presenting their thoughts to other groups and seeking their input. Amanda noted that she had a meeting with Alison and Chris earlier in the month, and they had suggested that she come to speak directly with the Advisory Group.</p> <p>The HDR UK Mission is to unite the UK’s health data and support scientific discovery. Their vision is for 20 years, for large scale analytics to benefit the public and health. Their initial funding was 5 years, so they are now in the process of reviewing the progress made and the impact they have had and preparing the case for the next 5 years to the funder, to seek funding.</p> <p>The role of HDR UK is to convene different organisations in order to achieve best results. They have a strong commitment to patient and public benefits and transparency. The first 5 years have really been to establish the Institute. In the next 5 years they want to scale this up, demonstrating better uses of data and the impact of data research, building the community further.</p> <p>Amanda described the way that data collected through the Zoe symptom study app during the COVID-19 pandemic was collated and was made available through the HDR UK Gateway. She also described the publications which had been produced and the impact of these on Government policy and practice for COVID-19.</p>	Amanda White

The plan for the next 5 years has 4 key blocks:

- Demonstrator programs - around six to show how data can 'power up' health research
- Infrastructure Services - building on the Gateway and the Health Data Research Alliance, citizen involvement is one element of the proposed infrastructure services
- Regions - building partnerships across the UK to share knowledge
- One Institute - providing leadership, communications and services.

Amanda described their plans for citizen involvement. Their first 5 years had focused on citizen involvement, working closely with patients and public through the public advisory board and other groups. Future plans would involve scaling this much further to engage with 100,000 members of the public by 2028. They intend to create a more federated approach with partners, so that they can really scale that up and get large groups of people involved. They want to work with partners, including Health Data Research Alliance members and also to build capacity to support researchers in access to PPIE skills.

Amanda invited attendees to a HDR UK event on the strategy, on 03 November.

In response to a question about the number of people involved in PPIE, Amanda had put a number of data custodian and researchers, so felt that they should also put an ambitious number for patient engagement, which was 100,000 by 2028. She noted that their statistics showed 25,000 people had already been engaged in some way or another with HDR UK, but she wanted to break that figure down into co-production, leadership involvement and engagement. They were yet to get into this level of detail.

Advisory Group feedback:

- Although feeding into this via another role, the described plans were good.
- Is there equal buy-in from different parts of the UK? Amanda said that there was, with their core funders coming from each of the four nations. She noted that this was part of what made HDR UK unique, focusing beyond the one-nation approach.
- For the figure of 25,000 people (which is high), what has their involvement and engagement actually been? Amanda replied that these figures were measured monthly and presented at the Executive Committee and the Board. The data comes from the different HDR UK teams, surveys, workshops and the work of the national science centres and the HDR UK Hubs. She did accept that this was not an exact science as things may be measured in different ways e.g. one Hub had reported 10,000 as that was the number of survey responses that they had had. Chris reflected from his DATA-CAN work that counting and submitting numbers was indeed a challenge. The Advisory Group highlighted that there were already standard definitions on engagement and involvement. Including 10,000 because they had responded to a survey was 'stretching it'.

Chris asked Amanda for her thoughts on use MY data, which does not have a natural fit with more traditional organisations. Amanda said that she had always felt that use MY data is an important group for HDR UK to work with and she saw the opportunity for a more formal partnership going forward, but that had not yet been defined. HDR UK has been having similar discussions with UPD. Amanda reflected that because we have such a strong community of patients and carers with an interest in patient data, this is seen as a really important asset. Amanda invited people to raise this at the 03 November event, for which Alison will circulate the details.

Dave thanked Amanda for her time.

<p>Item 5.0</p>	<p>use MY data webinar</p> <p>a. Update and discussion on our next webinar, with Sensyne Health</p> <p>Following use MY data’s development of a webinar plan, Dave, Pete, Chris, Emily and Alison met with Sensyne earlier today, 20 October, to discuss next steps.</p> <p>The pencilled-in date for the webinar is Wednesday, 24 November. Sensyne are open to our views and keen to work with us. The theme will be how commercial organisations use our data, demystifying this and focussing on the Sensyne model.</p> <p>We emphasised the need for openness and transparency and advised Sensyne that it is best to tackle difficult questions head on, such as if they are asked about the Sensyne model of operating.</p> <p>We said that we need the date and title confirmed by early November, to give us time to publicise the webinar. The panel will include a clinician from one of the NHS Trusts that Sensyne has an agreement with and a patient from one of the Trusts. We also agreed that we should have a member of the use MY data Advisory Group on the panel, and Dave has volunteered for this role.</p> <p>The Advisory Group asked whether a clinician would be the right person, or whether we might be better with a manager, non-Executive member or other Trust person. On balance, given the emphasis on clinical benefit, a clinician was seen as probably the best option, at a consultant (strategic) level or above.</p> <p>The Advisory Group discussed whether there was enough of a voice of challenge on the panel, in order to achieve balance (so that the event is not seen as a commercial company’s sales-pitch). Overall, they felt that the challenge should come directly from the delegates’ questions, and this will be enabled by the way that questions would be voted-up by the delegates themselves.</p> <p>The need to have a representative panel in terms of ethnic diversity and gender was discussed. It was noted that Sensyne would bring at least one female voice.</p> <p>Chris suggested that the webinar was an opportunity to develop a practical set of standards of transparency, to be used by commercial organisations who use our data.</p> <p>Sensyne is already working with the NHS, they are a commercial organisation, and it is our data that they are using. It is important that we move ahead and find a model for how we work with these entities. The Advisory Group agreed that we need to keep the focus on working practically with organisations who already have our data, highlighting the benefits to patients that arise from this.</p> <p>Chris asked the Advisory Group if they would be happy for him to chair the webinar or would prefer another chair. The consensus was that Chris should chair.</p> <p>use MY data has been invited to join Sensyne’s new Patient Advisory Council (PAC) and two Advisory Group Members will be participating. Part of this role will involve reviewing the draft Terms of Reference for the PAC.</p> <p>b. Summary of actions</p> <ul style="list-style-type: none"> • Emily - Will speak with Sensyne Health to finalise the date and title for the webinar and will circulate these details by Friday, 29 October. • Alison - Will plan our communications for the webinar, which will need to begin the week commencing 01 November. 	<p>Emily</p>
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<p>Item 6.0</p>	<p>Guest - Maisie McKenzie, National Data Guardian's panel</p> <p>Maisie McKenzie, use MY data Member and patient representative, gave an update on her role a patient/public involvement lead on the National Data Guardian's (NDG) panel and the work that she was doing in this area.</p> <p>Maisie came to the role via the NDG approaching use MY data and asking them to publicise the role to Members. The NDG team undertook the actual selection from those that applied.</p> <p>Maisie has been in the role for about a year now. At the moment Maisie is the only patient/public lead on the panel, though the plan is to increase this number to two. The meetings are attended by Panel Members and guests in attendance.</p> <p>Maisie frequently references her responses in line with the principles of use MY data, including openness and transparency around the use of patient data.</p> <p>Maisie has seen a continued rich and open dialogue within the established and dynamic Panel meetings in relation to two areas in particular:</p> <ul style="list-style-type: none"> · The importance of the patient and the public voice - recognising the importance of someone with lived experience · Data use and data sharing to improve patient outcomes through research and innovation, and openly discussing and supporting the use of data for secondary uses. <p>Dave thanked Maisie for her time.</p>	<p>Maisie McKenzie</p>
<p>Item 7.0</p>	<p>Any other business</p> <p>a. General Practice Data for Planning and Research (GDPR) Picking up the conversation from the 'Discussions with national organisations' section, the Advisory Group discussed the invitation to use MY data to join NHS Digital's patient/public GDPR panel. The panel meets fortnightly for 1.5 hours. This is a significant time commitment. The consensus was that we should ask NHS Digital if we can have a rotating pool of two or three members to represent use MY data on the panel. Three Members put their names forward.</p> <p>The Advisory Group agreed that this type of involvement should be front and centre of what use MY data does; bringing patient perspectives to organisations and helping them to make improvements from 'inside the tent'.</p> <p>In terms of our discussions with NHS Digital about the GDPR we have been transparent, publishing everything on the website, openly. If we are accepted onto the panel, we should be clear that we expect publication about the panel, according to our principles of transparency.</p> <p>b. Speaking invitations Pete has received an invitation, via another role, to speak at a National Cancer Research Institute event on 25 November, with the topic 'Is big data the answer?' Pete cannot attend and asked if other Advisory Group Members were interested in the opportunity. Two Members were and gave their names to Pete.</p> <p>c. BIVDA (British In Vitro Diagnostics Association) Jo had a meeting with BIVDA, who have just been awarded a substantial NHS contract about innovating to reduce cancer mortality. However, there was no PPIE structure in place in their plans. Jo has been invited to a meeting about this on 23 November and asked if Chris would accompany her, from a PPI angle, to explain how use MY data does this.</p>	<p>Dave</p>

	<p>d. Summary of actions</p> <ul style="list-style-type: none"> • Alison - Will confirm our place with NHS Digital on the GDPR patient/public panel and ask if they will accept a rotating team rather than an individual. • Jo - Will follow up with Chris about attending a meeting with BIVDA on 23 November. 	
Item 8.0	<p>Date of next meetings</p> <ul style="list-style-type: none"> • Tuesday, 30 November from 13:00 to 15:00 • 2022 meetings - frequency & format to be decided 	Dave

Suggestions for future meetings	
November	<ul style="list-style-type: none"> • Review of Position Statements - are they still fit for purpose(s), has anybody used or queried them, do they still represent our position. • Secretariat resources review. <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.)
Date TBC, 2022	<ul style="list-style-type: none"> • How does use MY data become more proactive in its work to become the trusted patient voice? <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.)