

**Advisory Group & Secretariat
Online meeting**

**Wednesday, 23 March 2022
11:00 - 13:00**

Meeting notes - confirmed

<p>Item 1.0</p>	<p>Attendees: Advisory Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Richard Ballerand, Sarah Markham, John Marsh, David Snelson, Pete Wheatstone. Secretariat - Chris Carrigan, Emily Connearn, Alison Stone.</p> <p>Non-attendees: Jo Gumbs. Apologies received from: no apologies.</p>	<p>Richard</p>
<p>Item 2.0</p>	<p>Updates</p> <p>a. use MY data's funding</p> <p>NHS Digital Chris has had recent discussions with NHS Digital about funding for use MY data. We have agreed to supply a short breakdown of our work over the last year, with an outline of our unique role, as evidence to support a transparent funding decision.</p> <p>Our current funding from NHS Digital covers about 60% of the overall Secretariat costs. Chris has asked NHS Digital about the possibility of increasing the grant to allow us to increase our capacity and therefore our work. He has informed NHS Digital of the conversations that we are having with other potential funders.</p> <p>NHS England At the invitation of NHS England's NHS Transformation Directorate, the Secretariat has submitted a proposal for funding and feedback is awaited.</p> <p>Health Data Research UK At the invitation of Health Data Research UK (HDR UK), the Secretariat has submitted a brief proposal for funding and feedback is awaited.</p> <p>b. The future of Understanding Patient Data Chris has requested a meeting with Understanding Patient Data (UPD), to discuss plans for how existing resources will be managed, once UPD ends. A meeting date is awaited, and this is likely to be May at the earliest.</p> <p>c. Discussions with national organisations</p> <p>The Association of the British Pharmaceutical Industry The Association of the British Pharmaceutical Industry (ABPI) has approached use MY data to discuss the possibility of engagement work. Chris and Alison met with the ABPI on 10 March and, following subsequent liaison with the Advisory Group, have submitted follow-up information to the ABPI. We are awaiting feedback on this. The Advisory Group emphasised the need to make the relationship clear; something along the lines of an independent think-tank or ideas</p>	<p>Chris & Alison</p>

	<p>testbed, but not to be confused with the ABPI’s existing patient (group) relationships or advisory bodies.</p> <p>Health Data Research UK An objective for a newly formed sector-wide partnership that HDR UK is jointly leading with Administrative Data Research UK (ADR UK) and the Office for National Statistics (ONS) is to explore ways in which to have a central location for existing resources that cover the access and use of data for research such as explainers/descriptors and reports of public attitudes/perceptions.</p> <p>As part of the scoping work, HDR UK has asked for our consideration of use MY data having a role as a central library of resources for patient data information. The Advisory Group felt that, in principle, this sounded positive but that much further information is required. Any participation in a role of this nature would require additional resources and funding for that resource. The Advisory Group also emphasised the need to make the relationship clear; hosting a library should not imply that use MY data supports or endorses any views or policies expressed in the documents, papers or other materials.</p> <p>d. Summary of actions</p> <p>Funding</p> <ul style="list-style-type: none"> · Chris - Bring funding updates to the June meeting. · Chris & Alison - Keep the Advisory Group informed about any developments with the potential NHS England and Health Data Research UK funding. <p>The future of Understanding Patient Data</p> <ul style="list-style-type: none"> · Chris - Keep the Advisory Group informed about discussions with Understanding Patient Data. <p>The Association of the British Pharmaceutical Industry</p> <ul style="list-style-type: none"> · Alison & Chris - Keep the Advisory Group informed about discussions with the Association of the British Pharmaceutical Industry. 	
Item 3.0	<p>Work programme</p> <p>a. Update on the work programme Alison gave a brief overview, highlighting three key points.</p> <ul style="list-style-type: none"> · National Disease Registration Service (NDRS) patient data stories Alison has asked the NDRS if they still plan to publish case studies on patient data this year and, if so, whether they would like us to collaborate on them. If not, we will remove the data stories from our work programme. · Call to action for our Wednesday, 30 March webinar We have a two-week turnaround time for any calls to action that are an outcome of our events and, for our upcoming webinar, the call to action deadline will be Wednesday, 13 April. · NHS England and Improvement case study Last year, NHS England and Improvement (NHSE/I) asked use MY data to participate in a case study to showcase “the importance of the work we [NHSE/I] is doing in data and analytics, specifically looking at how the use of data has been crucial to our COVID-19 response”. Filming for this took place in February this year (for which David was filmed) and we are now awaiting the follow-up steps from NHSE/I. <p>b. Educational sessions & webinars Emily updated the Advisory Group on the first educational session for Members</p>	Emily & Alison

	<p>and on our webinar programme.</p> <ul style="list-style-type: none"> • Educational session - Data to measure inequalities, Thursday, 03 March This first (test) event went well and delegates have given positive feedback, including on the content of the session and the interactivity. The recording of the session has now been edited and added to the website, as a resource. <p>Emily is planning to host one educational session per month. The next will be on Friday, 22 April, with the topic to be confirmed. The Advisory Group suggested that future feedback to delegates could include a question on how delegates will use the information they have learned.</p> <ul style="list-style-type: none"> • Webinar - use MY data, using our voice..., Wednesday, 30 March Emily gave an overview of the content and format. The Advisory Group requested more clarity for the talk titles and gave advice on the running order of the talks. The webinar will feature polls and Emily sought the Advisory Group's input into the content of these. • Webinar - June (date and topic to be confirmed) Emily proposed that the next webinar (pencilled in for June) could examine the topic 'Does the NHS sell our data?' This in the early stages of development and Emily will work up a brief for the Advisory Group. <p>Emily asked the Advisory Group for their suggestions for topics for our webinars beyond June.</p> <p>c. Summary of actions</p> <p>Educational sessions and webinars</p> <ul style="list-style-type: none"> • Emily - For our educational sessions, add a question into the feedback survey to ask how delegates will use what they have learned. • Emily - For our 30 March webinar, provide more clarity for the talk titles and rework the running order. • Richard B, Richard S & Emily - Work together to finalise the wording for the 30 March webinar polls. • Emily - Work up a brief for the Advisory Group for our June webinar, 'Does the NHS sell our data' (working title). • Advisory Group - Send suggestions for future webinar topics to Emily. 	
<p>Item 4.0</p>	<p>How does use MY data further develop its work as the trusted patient voice on the use of patient data?</p> <p>a. To consider the Secretariat's outline plan and to advise on priorities within it The Advisory Group provided feedback on the Secretariat's outline plan and highlighted that the obvious gap in the plan is to make connections with patient and the public. Following discussion, the decision was taken to target patients and, ideally, to start with patients who are already interested in research. Our work needs to be across the four nations.</p> <p>Suggestions for making connections with patient groups:</p> <ul style="list-style-type: none"> • Clinical Research Networks of the National Institute for Health Research • Charities - that support research and patient support charities • The Patients Association • Data Saves Lives (the EU organisation). <p>Resources for Members are required. A webinar would be useful, to provide tools and information on how our Members can engage and with the purpose of patients coming along to speak with us.</p>	<p>All</p>

	<p>Suggestions for making connections with NHS Trusts:</p> <ul style="list-style-type: none"> • The route would be via the communications department, the CEO, the Chair of the Trust, the local governor. Trusts have been through two years of digital patient involvement and this could be a key time for engagement. <p>Suggestions for prioritising contact with other organisations:</p> <ul style="list-style-type: none"> • ZOE COVID study - It would be good to have a relationship with the team, to understand any challenges that they have, or potentially will have, which we could help with. And in the same way, raise their awareness of what we do, and our profile. • Office for Health Improvement and Disparities - As a minimum we should raise our profile with the organisation and, as well as seeking a meeting, perhaps we could seek inclusion in their internal communications e.g. newsletters. <p>We need to establish our ‘pitch’ for all of the organisations and groups we approach - to highlight what they would gain from engagement with us and to demonstrate how we would add value. As a test case, Dave offered to make contact with his NHS Trust, to highlight the work of use MY data and outline the value we could add to the Trust.</p> <p>A revised, agreed prioritised list is needed. It would be helpful to include the organisations we are working with at present, the organisations we wish to work with (and why), and also a list of ‘pending organisations’ (subject to further funding).</p> <p>We would need to have additional funds and resources up and running, to take much of this this work forward. We hope to have updates on funding by the time we meet in June, which would tie in with reviewing the priority list.</p> <p>b. Summary of actions</p> <ul style="list-style-type: none"> • Alison & Chris - Create the prioritised list for use MY data’s development work and present this at the June Advisory Group & Secretariat meeting. • Dave - Make contact with his NHS Trust, as a test case, to highlight the work of use MY data and the value we could add to the Trust. 	
Item 5.0	<p>Any other business</p> <p>a. Declarations of Interest</p> <p>The Advisory Group discussed whether it is necessary and/or useful for them to declare details of interests arising from their work with other groups and/or organisations. Within the nature of Members’ work, there are unlikely to be actual conflicts of interest, but there may be perceived potential conflicts, as outlined in the Nolan Principles¹. Moreover, it could be helpful for Members to have knowledge of others’ areas of interest (whether working for or working with organisations). The idea was supported by all, with the degree of detail required to be determined.</p> <p>The Advisory Group has a page on our website, with a short biography for each Member. Advisory Group Members will check this information and advise of any changes needed. The Secretariat will then use this information as the basis to create a ‘declarations of interest’ document, to be circulated with papers prior to each meeting (at which point, Members will advise of any updates to their information). This information would also be useful for the Secretariat, in engagement work with other organisations.</p>	Richard

¹ The Seven Principles of Public Life (the Nolan Principles)
<https://www.gov.uk/government/publications/the-7-principles-of-public-life/the-7-principles-of-public-life--2>

	<p>b. Summary of actions</p> <ul style="list-style-type: none"> • Chris - Circulate the website link for the Advisory Group's page, by 23.03.22. • Advisory Group Members - Inform Chris of any required changes to their profile information. • Secretariat - Create an Advisory Group 'declarations of interest' document, for circulation prior to each meeting. 	
Item 6.0	<p>Date of next meetings</p> <p>The Advisory Group briefly discussed meeting formats for the rest of this year, whether it would be possible to meet in person and, if so, which location would work.</p> <p>a. June meeting This will be online, for two hours, with the date to be set.</p> <p>September meeting This will be in-person (subject to any future COVID-19 restrictions) and the location chosen for this meeting was London. It will have a hybrid option, to accommodate anyone unable to attend in person.</p> <p>Recognising that this will mean a lengthy journey for some Members, the meeting will be of sufficient duration to make the travel worth-while and is likely to be a workshop format. By June, we might be in a better position to plan out future activity for use MY data, if funding proposals have come to fruition.</p> <p>b. Summary of actions</p> <ul style="list-style-type: none"> • Alison - Circulate date options for an online meeting in June. • Chris & Alison - Circulate date options for an in-person meeting in September and investigate venues. • Alison - Add determining the content for September's meeting, to the agenda for our June meeting. 	Richard

Suggestions for future meetings	
June	<p>Items</p> <ul style="list-style-type: none"> • Trusted Patient Voice strategy work - Secretariat presentation on priorities • Content for our September meeting <p>Standing items</p> <ul style="list-style-type: none"> • Update on funding • Update on the future of Understanding Patient Data (if still not known) • Update on discussions with national organisations
September	<p>Standing items</p> <ul style="list-style-type: none"> • Update on funding • Update on the future of Understanding Patient Data (if still not known) • Update on discussions with national organisations