

**Advisory Group & Secretariat  
Online meeting**

**Wednesday, 08 June  
11:00 to 12:30**

**Meeting notes - confirmed**

<p>Item 1.0</p>	<p><b>Attendees:</b> Advisory Group - Richard Stephens (Chair), Richard Ballerand, Pete Wheatstone. Secretariat - Chris Carrigan, Emily Connearn, Alison Stone.</p> <p><b>Apologies received from:</b> Dave Chuter (Vice Chair), John Marsh, David Snelson.</p> <p><b>Non-attendees:</b> Jo Gumbs, Sarah Markham.</p>	<p>Richard</p>
<p>Item 2.0</p>	<p><b>Updates</b></p> <p><b>a. use MY data's funding</b></p> <p>The Secretariat's funding ends on 31 August 2022 and members of the Secretariat are now going through the HR process regarding termination of their contracts, in case the funding is not renewed.</p> <p>Chris provided an overview of funding possibilities.</p> <p><b>NHS Digital</b> We are awaiting a decision from NHS Digital about continuing funding for use MY data (which covers around 60% of Secretariat roles). While this is not yet confirmed, NHS Digital is in the process of drafting the approval documentation.</p> <p>We have requested additional funding to expand the Secretariat's time and are waiting to see if this has been granted.</p> <p><b>NHS England</b> At the invitation of NHS England's (NHSE) NHS Transformation Directorate, the Secretariat submitted a proposal for funding in late February. In early June we were advised that the Business Case approval process has taken a little longer than expected and that NHSE is hoping to resolve this within the next month.</p> <p><b>Health Data Research UK</b> We are waiting to see if Health Data Research UK is able to provide resources to support our work, possibly in the form of one day a week, on communications.</p> <p><b>Commercial companies</b> Two commercial companies are interested in providing funding to use MY data, in the form of putting money into a communal pot. Chris is to send a pitch document to each company, by the end of this week.</p>	<p>Chris &amp; Alison</p>

	<p><b>b. Discussions with national organisations</b></p> <p>Alison gave a brief update on recent discussions with national organisations.</p> <p><b>The Association of the British Pharmaceutical Industry</b>  The Association of the British Pharmaceutical Industry (ABPI) approached use MY data to discuss the possibility of engagement work and this is in the process of being set up, following discussions with the Advisory Group and receipt of a draft Terms of Reference. The nature of the work will be for the Advisory Group to be an independent ideas testbed for the ABPI, providing confidential feedback. We have suggested a provisional start date of 01 July 2022.</p> <p><b>Health Data Research UK</b>  Health Data Research UK had previously asked if use MY data would consider a role as a central library of resources for patient data information. This is on hold for now, as another national body is also considering producing a library. Further information is awaited from HDR UK.</p> <p><b>NHS England</b>  NHS England (NHSE) has invited use MY data to join a new steering group - Citizen Access Senior Responsible Officer (SRO) Steering Group. The invitation follows our previous work on patient access to patient records, with NHSX and now NHSE. Exploratory work is underway prior to us joining the group, including awaiting the Terms of Reference.</p> <p><b>c. Summary of advice</b></p> <ul style="list-style-type: none"> <li>· If we are entering into arrangements with commercial companies, transparency is key for both parties and it will be essential to declare any arrangements.</li> <li>· It is important that when entering into discussions and arrangements with external organisations on behalf of use MY data, the Secretariat follows a defined set of standards (e.g. emphasising our independence, highlighting the need for transparency, asking about reimbursement).</li> <li>· A broad range of funding contributors would bring more balance.</li> <li>· We need a contingency plan in case funds are not forthcoming.</li> <li>· Sense About Science has multiple funders and could be a useful model for us.</li> <li>· Multiple funders could lead us to becoming a constituted independent charity and, in turn, this could make it easier for organisations to provide funding.</li> </ul>	
<p>Item 3.0</p>	<p><b>How does use MY data further develop its work as the trusted patient voice on the use of patient data?</b></p> <p><b>a. Updated plan from the Secretariat, which includes Advisory Group expansion plan, for Advisory Group consideration</b></p> <p>Alison presented the updated plan for the Advisory Group’s consideration. Acknowledging the merits of the document and that it has helped to evolve thinking, the consensus was that it read more as a manifesto than a defined plan, and a reworked and more structured document would be useful (or an alternative document using extracted information to create a defined plan). Ideally this will be ready for the September Advisory Group meeting.</p> <p>Ahead of revising the document, Alison requested clarification from the Advisory Group on what they would like to see in the next version. Members will provide advice on how best to revise this.</p> <p>The timing of expanding the Advisory Group was discussed. We need to expand the number of use MY data Members, alongside the next stages of the Trusted</p>	<p>Alison</p>

	<p>Patient Voice work and, in view of this, Advisory Group Members felt it would be best to begin the expansion recruitment after our September meeting. Alison highlighted that a use MY data Member has proactively expressed interest in joining the Group.</p> <p><b>b. Summary of advice</b></p> <ul style="list-style-type: none"> <li>• Either revise or produce an alternative Trusted Patient Voice document, to create a more structured plan, ready for the September meeting.</li> <li>• Advisory Group expansion should take place after the September meeting and the next stage of the Trusted Patient Voice work.</li> <li>• Invite the use MY data Member who is keen to join the Advisory Group to do so and align this with the September meeting. (If the Member feels keen to join sooner, recognising there will be less Advisory Group support at this stage, this can be considered too.) Update the Advisory Group as a whole about the potential new Member.</li> </ul>	
<p>Item 4.0</p>	<p><b>Webinars &amp; educational sessions</b></p> <p><b>a. Webinar updates June to December 2022 - for Advisory Group consideration</b>  Emily confirmed that the webinar originally pencilled in for June ‘Does the NHS sell my data?’ will now go ahead in September. A range of speakers are confirmed with one or two more to be signed up, including the chair. Involving a commercial company was discussed, with agreement that this would be a good perspective to bring. Emily flagged her difficulty in ensuring the panel is balanced in terms of gender.</p> <p>Emily sought advice on whether to try and schedule a July webinar, having previously called for topics from the Advisory Group. The consensus was not to have a webinar in July, but instead to concentrate on the planning for the September webinar.</p> <p>A quick discussion took place about whether we could make better use of our webinars to recruit new Members, as we usually have delegates who are patients or members of the public but who are not use MY data Members. There was agreement that we should proactively promote the benefits of joining use MY data within our webinars, highlighting the additional benefits that Members receive through their membership.</p> <p><b>b. Educational sessions - update on the programme</b>  Emily gave an overview of the next stages of the programme:</p> <ul style="list-style-type: none"> <li>• June session - This will run on 17 June and will examine why it takes so long for researchers to access the data they need for research</li> <li>• July session - There will be a session, with the date and topic to be decided</li> <li>• August - No session this month, due to holidays.</li> </ul> <p>The sessions are a benefit of being a Member of use MY data and we could do more to promote this aspect.</p> <p><b>c. Summary of advice</b></p> <ul style="list-style-type: none"> <li>• September webinar - Invite a commercial company to speak and bring a perspective of a ‘buyer’ of the data.</li> <li>• July webinar - Do not hold a webinar in July, instead concentrate on planning for the September webinar.</li> <li>• To aid recruitment of new Members, use our webinars to better effect and promote the educational sessions as a benefit of joining.</li> </ul>	<p>Emily</p>

Item 5.0	<p><b>Format and content of September meeting for the Advisory Group &amp; Secretariat</b></p> <p><b>a. September, half-day, London (date TBC): discuss meeting format and content</b> Alison sought clarification on whether the September meeting should be face to face only, or should be a hybrid meeting. Chris confirmed that we will seek to find a venue through an organisation we have connections with and that there are funds to cover Advisory Group travel and time.</p> <p><b>b. Summary of advice</b></p> <ul style="list-style-type: none"> <li>· The September meeting will work best as a face to face one. However, if people are unable to attend in person, the Secretariat will endeavour to make the best possible arrangements for them to join in and be accommodated on the agenda.</li> <li>· Set the date for the September meeting as soon as possible.</li> </ul>	Richard & Alison
Item 6.0	<p><b>Any other business</b></p> <p><b>a. Expert Data Adviser role</b> Chris confirmed that after August he intends to stop his DATA-CAN work and focus solely on use MY data. He will self-fund this work.</p> <p><b>b. Declarations of interest forms</b> Clarity was sought about the declarations of interest forms for Advisory Group Members, with regard to which information to include. The Secretariat advised that it is best to declare the information that each Member feels is relevant to their role.</p>	Richard

Record of actions arising from the meeting		
Action	Responsible for	Date to complete by
NHS Digital & funding - Seek clarification of the next steps of the process and the timelines.	Chris	10.06.22
HDR UK and funding - Follow-up with HDR UK on their offer of potential resources and funding.	Chris	10.06.22
Commercial companies & funding - Send a pitch to each company	Chris	10.06.22
Engagement with Association of the British Pharmaceutical Industry - Send Pete the Secretariat's engagement proposal document.	Alison	17.06.22
<p><b>Engagement with external organisations -</b> Use the established principles, values and position statements of use MY data to codify our standards for engagement with external organisations. Circulate in time for comment and bring to the September meeting, as part of the foundation for discussions.</p> <p>Ensure the Secretariat is using the defined set of standards when entering into discussions and arrangements with external organisations, on behalf of use MY data.</p>	<p>Chris</p> <p>Alison</p>	<p>30.06.22</p> <p>30.06.22</p>
Trusted Patient Voice - Advisory Group Members to review the document & provide Alison with advice on how best to either revise it or create a part 2.	Pete Richard B Richard S	10.07.22

<b>Advisory Group expansion</b> - Hold back on the recruitment for this until after the September meeting and the next stage of the Trusted Patient Voice work.	<b>Alison</b>	<b>Pending</b>
<b>Advisory Group expansion</b> - Update the Advisory Group with regard to the use MY data Member who wishes to join. Contact the use MY data Member who has expressed interest in joining the Advisory Group and invite her to do so, to do so and align this with the September meeting.	<b>Alison</b>	<b>24.06.22</b>
<b>September webinar</b> - Finalise the speakers and chair.	<b>Emily</b>	<b>01.07.22</b>
<b>September webinar</b> - Invite the commercial company to speak.	<b>Chris</b>	<b>10.06.22</b>
<b>Promoting the benefits of joining use MY data</b> - Use our webinars to promote the benefits of joining, to the patient/public delegates who are not (yet) Members.	<b>Emily</b>	<b>Ongoing</b>
<b>Promoting the benefits of joining use MY data</b> - Add our educational sessions as a benefit to our promotional materials for potential Members.  Create a comprehensive comparison table detailing the benefits of use MY data membership vs non-membership, including priority access to webinars, for inclusion in the Trusted Patient Voice engagement pack. [Post-meeting follow-up suggestion from Pete]	<b>Emily</b> - website <b>Alison</b> - emails  <b>Alison</b>	<b>24.06.22</b>  <b>Pending</b>
<b>September meeting</b> - Update the Advisory Group on the format and set a date as soon as possible.	<b>Alison</b>	<b>24.06.22</b>

<b>Suggestions for future meetings</b>	
September	<p>Items</p> <ul style="list-style-type: none"> <li>• Trusted Patient Voice strategy work</li> <li>• Expansion of use MY data</li> <li>• Expansion of the Advisory Group</li> </ul> <p>Standing items</p> <ul style="list-style-type: none"> <li>• Update on funding</li> <li>• Update on discussions with national organisations</li> </ul>