

**Executive Group & Secretariat  
In-person meeting**

**Wednesday, 29 November 2023, 10:45 to 15:00**  
Franklin, 7<sup>th</sup> Floor, Wellcome Trust, Gibbs Building, 215 Euston Road, NW1 2BE

**Meeting notes - confirmed**

<p><b>Item 1.0</b></p>	<p><b>Attendees</b> Executive Group - Richard Ballerand, Samina Begum (Item 4.0 onwards), Dave Chuter (Vice Chair), Jo Gumbs, Sarah Markham (Item 4.0 onwards), John Marsh, David Snelson &amp; Ceri Steele.</p> <p>Secretariat - Chris Carrigan, Elizabeth Lloyd-Owen &amp; Alison Stone.</p> <p><b>Apologies</b> - Richard Stephens (Chair) &amp; Pete Wheatstone</p> <p>Dave, the meeting Chair, warmly welcomed all attendees. It was Ceri's first meeting and introductions were made. Meeting etiquette and housekeeping were noted.</p> <p>Thanks were noted for Health Data Research UK's support for use MY data in providing the meeting room and refreshments.</p>	<p>Dave Alison</p>
<p><b>Item 2.0</b></p>	<p><b>Where we are: use MY data's resources and status</b></p> <p><b>Intended outputs/possible products from this item</b></p> <ul style="list-style-type: none"> <li>• Paper on charitable status options, to present to Members, with timelines and recommended option (if agreed by Executive Group)</li> </ul> <p><b>To inform this discussion</b></p> <ul style="list-style-type: none"> <li>• Funding, expenditure &amp; financial forecast - paper &amp; update from Chris</li> <li>• Secretariat recruitment - update from Chris &amp; Alison</li> <li>• Charitable status options - paper &amp; update from Dave &amp; Jo</li> <li>• Logic Model session feedback - update from Chris</li> </ul> <p><b>Key points from discussions</b></p> <p><b>Funding</b></p> <ul style="list-style-type: none"> <li>• Chris is hopeful that the funding from NHS England (NHSE) will be processed soon and the route for the funds to reach use MY data will be confirmed (this is highly likely to be via a Health Innovation Network). It looks as though the paperwork will be completed by the end of December and the funding will be received by the end of January 2024. Chris has a call with NHSE later today (29 November) to finalise details and will report back. The intention is for the funding to be one year, followed by one further year.</li> <li>• If the route via the Health Innovation Network is successful, this could be a route for future funds that support engagement/involvement work with NHSE.</li> <li>• Chris's update was welcomed, with the comment that while this provides sufficient information for Executive Group purposes, if use MY data moves to a charitable status Trustees would need to have sight of the draft accounts.</li> </ul> <p><b>Recruitment</b></p> <ul style="list-style-type: none"> <li>• If the funding paperwork is in place by the end of December, it should then be possible to begin the administrator recruitment process in mid-January 2024.</li> </ul>	<p>Dave Chris Alison Jo</p>

## Charitable status

- Dave & Jo's charitable status paper presented several options, before concluding with the recommendation that use MY data becomes a Charitable Incorporated Organisation (CIO). This option was generally supported by the Executive Group, with some key concerns and points discussed in-depth.
- The Executive Group and Secretariat both emphasised that being Member-led is what makes use MY data different and trustworthy. It is essential that this model is retained, no matter which type of status use MY data may move to.
- The Secretariat needs time to process how they would work within a CIO framework. They strongly felt that they should not have leadership roles, as this would distort the essential need for use MY data to remain patient-led.
- Ahead of being sent for Members' consideration, the paper should be amended to include the option of use MY data not having a charitable status.
- The paper does not mention any impacts on the Executive Group's future role and the decision-making process if the Executive Group were to continue. This needs to be agreed and documented prior to any final decision - it is essential that all have a fully documented understanding of the implications of such a significant decision.
- Trustees for a CIO were discussed - who these should be, how many and how they should be selected. The Executive Group picking Trustees would not sit well within our Member-led organisation. A Trustee would need to be a Member - patients must be part of the Trustee Board, to keep it grounded.
- If they are willing, current Executive Group Members could become Trustees, to get the ball rolling. The Trustee role brings a certain amount of responsibility. Not all current Executive Group Members may wish to become a Trustee. If so, it may still be possible to have a role within use MY data.
- Trustees would be invited to attend Executive Group & Secretariat meetings, in order to aid understanding of discussions and decisions and therefore arrive at mutually agreeable decisions whenever possible.
- Trustees are not paid for their time - it is a governance role. Clarity is needed as to whether Trustees can be paid honoraria (which is available for some aspects of the Executive Group's work, reflecting how hands-on the Group is).
- Should Members of use MY data (who are not on the Executive) be invited to be Trustees? There is merit in this - in terms of broadening the spread of the Executive Group (particularly UK representation and ethnic diversity). On balance, it was felt best to move forward without going through the process of an Executive Group membership recruitment drive and to look at broadening representation on the Executive Group, once a charitable status is in place.
- If the Executive Group were to be Trustees, the term of serving in this role would need to be set. Ideally, roles would be on a rolling-term basis to ensure stability. A one-year term is would not give enough time to settle in/achieve much, with a two-year or three-year term being more useful.
- A strong Trustee board needs different skill sets. Would Associate Members be eligible to be Trustees? They are already potentially working as ambassadors for use MY data. On balance, becoming Trustees would divert from the patient-led aspect of use MY data. We have Members who have skills that can help as Trustees (i.e., Members are not 'just' patients, relatives, carers - they have wide-ranging careers, knowledge and skills).
- The next step is to put the options to the Members, with the Executive Group's recommendation, to seek Members' views. It will be essential to review all responses and ascertain the will of Members (rather than look at a percentage of votes for a certain option).
- Chris is in contact with a professional who works in this area and could help with the process of obtaining a charitable status, for a minimum cost.
- Alongside this work, it's important to capture the current skillsets of Executive Group Members and the Secretariat team - these need to be written down.
- Formal documents such as Articles of Association should be kept fairly loose, so that they can be adapted, as necessary.

	<p><b>Summary of actions, deadlines and responsible person(s)</b></p> <ul style="list-style-type: none"> <li>• <b>Chris</b> - To contact the charitable status project manager and engage him to create a project plan and guidance on the details of becoming a CIO. This will have a deadline of Wednesday, 31 January.</li> <li>• <b>Dave &amp; Jo</b> - To finalise the charitable status options paper, with the amendments and additions as recorded in the discussion, including the Executive Group’s recommended option.</li> <li>• <b>Alison</b> - Circulate the paper to Members and set deadlines for the next steps.</li> <li>• <b>Executive Group &amp; Secretariat</b> - To write up their individual skill-sets.</li> </ul>	
<p><b>Item 3.0</b></p>	<p><b>Where we are heading: use MY data’s internal work</b></p> <p><b>Intended output/possible product from this item</b></p> <ul style="list-style-type: none"> <li>• Decision about format and timing of Members’ census</li> <li>• Decision about timing for Executive Group expansion/refresh</li> </ul> <p><b>To inform this discussion</b></p> <ul style="list-style-type: none"> <li>• Draft census for review - paper &amp; update from the Secretariat</li> <li>• Framework for use MY data’s governance - paper &amp; update from Alison</li> </ul> <p><b>Key points from discussions</b></p> <p>Draft census for review</p> <ul style="list-style-type: none"> <li>• Following Alison’s outline of the proposed questions for a Members’ Census in 2024 (with one set of questions on demographics and one on involvement) the Executive Group fed back that, ahead of proceeding with the census, it is essential to ensure there is certainty about the purpose of hosting the census.</li> <li>• Demographics - important to ask the same questions as asked in the previous census, plus new questions - since that will provide a more informed context for the new questions that we wish to ask. Looking at some of the proposed questions: <ul style="list-style-type: none"> <li>- ‘Which country are you in?’ (do you live in) - could we ask something more granular such as outer portion of postcode or county?</li> <li>- ‘Health condition or disease area’ - this is a bit simplistic as it assumes just one rather than any comorbidities and, as a significant proportion of Members appear to be carers and possible patients, based on the previous census, whose condition are we referring to?</li> <li>- ‘Is there a particular aspect of use MY data’s work that you would like to be involved in?’ - Interesting point whether ‘involved’ suggests a degree of commitment or at least expectation of commitment from members. Would ‘interested in’ be a little more palatable to members?</li> </ul> </li> <li>• Use of the results - this begs the question ‘what are the specific objectives of the census?’ which we ought to know before working out the phrasing of the questions and the required format of the answers.</li> <li>• Can use MY data be described as a public group, with patients at the heart of it? Rather than describing ourselves purely as a patient movement, as this could possibly imply that fit members of the public are excluded. Perhaps actively leaning towards the public, as well as patients, would increase our impact and range - a patient organisation, but public facing? Using the term ‘people’ could work instead, either way good communications is key.</li> <li>• Elizabeth is working on refreshing the website and the new version could make clear that all are welcome to engage with use MY data - patients and public - providing they are in agreement with the vision, mission and aims.</li> </ul> <p><b>Summary of actions, deadlines and responsible person(s)</b></p> <ul style="list-style-type: none"> <li>• <b>Alison</b> - Refresh the census document, taking on board all views. This includes defining the specific objectives of the census and how the results will be used. Share the refreshed document with the Executive Group, for sign-off, ahead of hosting the Census in 2024.</li> </ul>	<p>Dave Elizabeth Alison Chris</p>

	<ul style="list-style-type: none"> <li>• <b>Alison</b> - Proposed census timelines to be set.</li> <li>• <b>Elizabeth</b> - Incorporate wording around engaging with patients and the public, into the new version of the website.</li> </ul> <p><b>Framework for governance</b></p> <ul style="list-style-type: none"> <li>• use MY data’s current governance framework document had two key aspects - ‘How use MY data is led’ &amp; ‘Governance of use MY data in relation to Legal Status’.</li> <li>• How use MY data is led - this included details of the terms of service for the Executive Group, with the terms of eight Members due to end in February 2024. The Executive Group expressed concern about a potential lack of continuity and discussed the best way to ensure continuity. Clearly, rolling terms of Membership of the Executive Group are needed. This work needs to be aligned with the charitable status/Trustee work.</li> <li>• The Executive Group asked Alison to contact Executive Group Members individually, to ascertain if: <ul style="list-style-type: none"> <li>- they wish to stand down when their term ends or extend the term (on a basis to be determined)</li> <li>- they would be interested in becoming a Trustee if/when a charitable status is obtained.</li> </ul> </li> <li>• The document could be a little more specific, irrespective of whether or not the Executive Group’s roles are changing.</li> <li>• Governance of use MY data in relation to Legal Status - part of this states “The Directors have chosen to delegate the management of use MY data to use MY data’s Executive Group”. This is a rather ambiguous statement that does not clarify whether it is a temporary or permanent arrangement (though presumably the latter). It also suggests a delegation of all aspects of the management, which was queried. The Executive Group requested a refreshed sight of the Articles of Association.</li> </ul> <p><b>Summary of actions, deadlines and responsible person(s)</b></p> <ul style="list-style-type: none"> <li>• <b>Alison</b> - Contact Executive Group Members individually, to ascertain their views on becoming a Trustee and whether or not they wish to remain on the Group when their term ends.</li> <li>• <b>Chris</b> - Circulate the current Articles of Association to the Executive Group.</li> </ul>	
<p><b>Item 4.0</b></p>	<p><b>Where we are heading: use MY data’s external work</b></p> <p><b>Intended outputs/possible products from this item</b></p> <ul style="list-style-type: none"> <li>• Decision on use MY data joining the Research Advisory Group</li> <li>• Outline of use MY data’s events programme for 2024</li> <li>• Draft engagement plan for all UK nations</li> </ul> <p><b>To inform this discussion</b></p> <ul style="list-style-type: none"> <li>• Research Advisory Group - paper &amp; update from David Snelson</li> <li>• Discussions with national organisations - update from Chris &amp; Alison</li> <li>• Connections in N Ireland, Scotland &amp; Wales - update from Elizabeth</li> <li>• Draft events programme 2024 - paper &amp; update from Elizabeth &amp; Chris</li> </ul> <p><b>Logic model session with Cancer Research UK</b></p> <p>Ahead of the discussions, Chris gave a brief overview of the Logic Model session, hosted by Cancer Research UK for use MY data on Thursday, 23 November. This was offered as part of our funding/partnership working arrangement. From use MY data, several Executive Group Members and the Secretariat attended. It was good to have someone external to use MY data facilitating and helping us in this area, and the time given by Cancer Research UK staff in the Research Data Strategy team was acknowledged and appreciated. Chris will circulate his overview notes to the Executive Group.</p>	<p>Dave David Elizabeth Chris Alison</p>

### Research Advisory Group

- Following an invitation from NHS England to use MY data to join the Research Advisory Group (RAG), David attended the 13 November planning meeting, in a scoping capacity. David's report for the Executive Group and update at the meeting, emphasised that this was a very senior meeting. The meeting chair invited David to speak on a number of occasions and it was clear that patient representation was welcome on the Group. It seems that use MY data will be the only patient voice on the Group.
- There is a potential stumbling block around transparency, as the meetings will not be fully minuted, to ensure they are a safe space to present and discuss problems and find solutions. However, there will be outputs from each meeting, which the organisers are keen for use MY data to disseminate as widely as possible. The outputs from the 13 November planning meeting are awaited.
- **[Post-meeting note: the outputs from the 13 November planning meeting were produced on 19 December and are published on use MY data's website.]**
- As a minimum for use MY data, in line with our [Standards for engagement with external bodies](#), we need to publicise that we are involved in discussions, even if we cannot reveal the content of those discussions.
- There was unanimous agreement that use MY data should join the Research Advisory Group. Alongside joining, we must actively work to avoid any potential transparency problems/issues, by continuing our due diligence work and always working within our guiding principles and standards.
- The Executive Group asked Alison to inform NHS England of the decision for use MY data to join the Research Advisory Group and, as part of this, to send use MY data's Standards for engagement and to enquire about the outputs for the 13 November meeting (which David will need to review).
- David is unable to attend the next meeting and there was consensus that a small pool should be formed, to represent use MY data at the meetings. Due to the seniority of the Research Advisory Group and the knowledge required, at present the pool should be drawn from within the Executive Group, rather than also including Members outside of the Executive.
- Prior to each meeting, a pre-meeting brief will take place, with use MY data's attendee, the Secretariat and the previous attendee (if their diary permits).

### Discussions with national organisations

- Alison gave an overview of recent discussions and will circulate this summary to the Executive Group.
- There was a quick discussion about the possibility of use MY data working with NHS England on GP data for research, the Federated Data Platform and the public engagement work for the Data Saves Lives strategy. Following stepping down from the Patient and Public Engagement and Communications Advisory Group Panel (PPECAP), the Secretariat has written to NHS England twice, seeking ways in which use MY data can connect with the three workstreams. At present, there does not seem to be a way in which this work would be possible.

### Connections in Northern Ireland, Scotland & Wales

- Elizabeth is initially working on seeking stronger connections with Members and Associate Members in Scotland. At present, despite a call out to the Membership, there is not sufficient material to fill a newsletter with a Scottish focus. Elizabeth is actively seeking materials via other sources.
- A Membership recruitment drive in the devolved nations is needed. Perhaps via contacting different charities for help and via asking our Members and Associate Members in those nations, to help with recruitment.

### Draft events programme 2024

- The potential UK Biobank webinar is now likely to be in January.
- Two suggestions for sessions:

	<ul style="list-style-type: none"> <li>- A Flatiron Health project that involves patients, collects NHS data from NHS Trusts, cleans the data and returns it to the Trust to improve care. Could this be a topic to look at, in the Summer, by which time there may be some tangible results and outcomes?</li> <li>- Could we perhaps offer an online Dragons Den session (perhaps jointly with Cancer Research Advocates Forum) for the Leeds CDT (Centre for Doctoral Training) in AI for Diagnosis and Health Care, as both a PPI and an Educational opportunity?</li> <li>• The events programme needs to reference that use MY data is providing a speaker and a Member presence for Cancer Research UK's Research Data Conference, in February.</li> <li>• Science fairs/festivals at Universities - a lot of patients/members of the public attend these and it could be good for use MY data to attend these, across the UK. This could help with diversity - reaching different communities and organisations.</li> <li>• Metal pin badges for use MY data - these would be a visible way to help to promote use MY data.</li> <li>• Education session - consider inviting Professor Cathie Sudlow to report on the review she has led into Unifying health data across the UK. We could also ask Cathie for information on patient data activities in Scotland.</li> <li>• Webinar topic - invite Palantir and NHS England to speak together about the Federated Data Platform and invite SAIL Databank, in Wales, to take part.</li> <li>• Webinar topic - Chris has been in touch with a researcher in Oxford, who leads a team that works within a Trusted Research Environment. The researcher described the benefits and the difficulties of working in this way and this could be a good webinar topic.</li> <li>• In-person patient data event in June - a sponsor would be needed, to enable this event to take place.</li> </ul> <p><b>Summary of actions, deadlines and responsible person(s)</b></p> <ul style="list-style-type: none"> <li>• <b>Chris</b> - Circulate the Logic Model session summary to the Executive Group.</li> <li>• <b>Alison</b> - Research Advisory Group - feedback to NHS England on the decision to join the Group, sending use MY data's criteria for external engagement and ask about the 13 November meeting notes.</li> <li>• <b>Alison</b> - Research Advisory Group - set up a pool of attendees and arrange pre-meeting briefings for our attendees.</li> <li>• <b>Alison</b> - Discussions with national organisations - circulate a summary of discussions to the Executive Group.</li> <li>• <b>Elizabeth</b> - Events programme 2024 - update this with Executive Group feedback, ready for circulation to Members in the new year.</li> <li>• <b>Chris</b> - Invite Professor Cathie Sudlow to take part in an Education Session for Members, to report on the review she has led into Unifying health data across the UK. In tandem with this, ask Cathie for information on patient data activities in Scotland.</li> <li>• <b>Alison</b> - Investigate use MY data's attendance at science fairs/festivals at Universities, across the UK.</li> </ul>	
Item 5.0	<p><b>Any Other Business</b></p> <p><b>Palantir</b> Follow-up is awaited from Palantir, on their actions from our 02 November meeting. As outlined in the update sent to use MY data's Membership, the actions were for Palantir to:</p> <ol style="list-style-type: none"> <li>1. Share their case studies, which describe the work carried out during the pandemic - we said we would look at these from a 'patient readability' perspective</li> <li>2. Consider taking part in a Members' Education Session and whether the timing of this could be prior to the FDP tender process concluding - the focus could be on the way that Palantir Foundry software was used during the pandemic</li> </ol>	Richard S

	<p>3. Consider having a patient and public voices on their Board  4. Consider having a patient on the engineering products Panel.</p> <p>The Executive Group would like Alison to contact Palantir about these actions, particularly the education session, as we are about to publish our 2024 programme and need to know whether to include this session, or not.</p> <p><b>NHS England, the Federated Data Platform (FDP) &amp; the opt-out effect</b>  An Executive Group Member had asked NHS England for a copy of the specification for the Federated Data Platform. They have responded that a redacted version of the contract will be published by 20 December.</p> <p>The NHS data dashboard shows that approximately 20,000 additional people have opted-out (via a National Data Opt-out - NDOO) - since the announcement of Palantir as the supplier of the FDP. This is alarming, as this type of opt-out will not affect how data is used within the FDP but will affect patient data being used for research and planning.</p> <p><b>Hampshire &amp; Isle of Wight (IoW) Integrated Care Board Digital Assembly</b>  An Executive Group Member highlighted two systems, doing similar things, in the same local area - these are the Federated Data Platform (FDP) and CHIE (Care &amp; Health Information Exchange). CHIE is a secure system which shares health and social care information from GP surgeries, hospitals, community and mental health, social services and others. It is to be hoped that a sensible rationalisation will take place, once the FDP is up and running.</p> <p><b>Executive Group training session</b>  The Secretariat would like to host an in-person training session for the Executive Group, on patient data topics. This is being planned for the New Year and the Secretariat will involve the Executive Group (particularly newest Members) to help design the session.</p> <p>The Executive Group felt that the opportunity should be widened to include Members. A limit on numbers will need to be set, to ensure the session works well. Once the first session has taken place, the Secretariat and Executive Group can assess its success (or otherwise!) and determine future frequency.</p> <p>Possible topics for the session: the basics of patient data, primary care and secondary data, how data is joined up or not, data opt-outs - these will all have a UK focus.</p> <p><b>Summary of actions, deadlines and responsible person(s)</b></p> <ul style="list-style-type: none"> <li>• <b>Alison</b> - Contact Palantir to ask about their follow-up actions from the 02 November meeting, particularly the potential education session.</li> <li>• <b>Secretariat</b> - Take forward the new year in-person patient data training day, for Executive Group &amp; Members.</li> </ul>	
<p>Item 6.0</p>	<p><b>Dates for next meetings</b></p> <p>Confirmed dates for the first part of 2024 are:</p> <ul style="list-style-type: none"> <li>• Monday, 22 January, 10:30 to 12:00 - online</li> <li>• Monday, 18 March, 10:45 to 15:00 - in-person (London)</li> <li>• Wednesday, 24 April. 10:00 to 11:00 - online</li> <li>• Wednesday, 22 May, 10:30 to 12:00 - online.</li> </ul> <p>A meeting date for February is also being sought (one hour, online). Dates for the second half of 2024 are to be set.</p>	<p>Richard S</p>

Suggestions for future meetings	
Mon, 22 Jan 10:30 to 12:00 Online	<p>Key items</p> <ul style="list-style-type: none"> <li>Confirmation of the schedule of proposed activities/events for 2024 (where known)</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>
Feb - tbc one hour, online	<p>Key item</p>
Mon, 18 March 10:45 to 15:00 in-person	<p>Key items</p> <p>Standing items</p> <ul style="list-style-type: none"> <li>Update on funding</li> <li>Update on discussions with national organisations</li> </ul>
Weds 24 April 10:00 to 11:00 one hour, online	<p>Key item</p>
Weds, 22 May 10:30 to 12:00 online	<p>Key items</p> <p>Standing items</p> <ul style="list-style-type: none"> <li>Update on funding</li> <li>Update on discussions with national organisations</li> </ul>
July - date tbc in-person	<p>Key items</p> <p>Standing items</p> <ul style="list-style-type: none"> <li>Update on funding</li> <li>Update on discussions with national organisations</li> </ul>
September - date tbc online	<p>Key items</p> <p>Standing items</p> <ul style="list-style-type: none"> <li>Update on funding</li> <li>Update on discussions with national organisations</li> </ul>
November - date tbc In-person	<p>Key items</p> <p>Standing items</p> <ul style="list-style-type: none"> <li>Update on funding</li> <li>Update on discussions with national organisations</li> </ul>