

**Executive Group & Secretariat - Online meeting**

**Wednesday, 25 September 2024  
12:00 to 13:30**

**Meeting notes - confirmed**

<p>Item 1.0</p>	<p><b>Welcome, apologies &amp; housekeeping</b></p> <p>The Chair welcomed attendees and the meeting etiquette was agreed.</p> <p>A warm welcome was extended to Marta Delfino. Marta is a new Associate Member of use MY data, attending as a shadow participant, to help understand how things are run. Marta is a data scientist at the William Harvey Research Institute and is interested in understanding more about a bigger data scope and learning from use MY data.</p> <p><b>Attendees</b></p> <ul style="list-style-type: none"> <li>• Executive Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Yvonne Adebole, Jo Gumbs, John Marsh &amp; Ceri Steele</li> <li>• Secretariat - Chris Carrigan &amp; Alison Stone</li> <li>• Associate Member - Marta Delfino</li> </ul> <p><b>Apologies</b></p> <ul style="list-style-type: none"> <li>• Richard Ballerand, Samina Begum, David Snelson &amp; Elizabeth Lloyd-Owen</li> </ul>
<p>Item 2.0</p>	<p><b>Where we are heading: use MY data’s internal work</b></p> <p>Intended output from this item:</p> <ul style="list-style-type: none"> <li>• Plans for election of Executive Group Chairs</li> <li>• Programme for patient data training for Members (in tandem with decision on Education Session programme).</li> </ul> <p><b>Funding &amp; recruitment</b></p> <p>Alison reported the good news that, following interviews on 18 September, an Administrator has been recruited. This is a two-year role, made possible by our Cancer Research UK funding. The tentative start date is Wednesday, 09 October (following completion of paperwork/references). Alison will lead on the induction process, which will temporarily reduce the Secretariat’s capacity.</p> <p>The administrator will have three main areas of work:</p> <ul style="list-style-type: none"> <li>• Managing and supporting Executive Group &amp; Secretariat meetings and associated work</li> <li>• Supporting finance work</li> <li>• Administrative work associated with use MY data having a charitable status.</li> </ul> <p><b>CIO application</b></p> <p>use MY data’s application to become a Charitable Incorporated Organisation (CIO) was submitted to the Charity Commission on 30 August and we hope to have a decision in November. Richard S sent this information (and the Constitution) direct to Members, in his Chair’s briefing of 03 September.</p> <p>Dave has led on the process for use MY data. As part of this Dave is collecting signatures of those who will be Trustees, for submission to the Charity Commission. Two signatures are still to be collected and Dave will follow-up with the relevant Executive Group Members.</p>

### **Chairing roles of the Executive Group**

The current terms of the Chair and Vice Chair are due to end on 23 November. Alison sought the Executive Group's views on whether to run an election process for new chairs, or whether, with our charitable status pending, the current terms should be extended until we have the Charity Commission's response and switch to a Trustee model, with a Chair of the Trustees.

Alison recapped the timeline of the terms of the Chair and Vice Chair roles, to date:

- original two-year term from 24 May 2021 to 23 May 2023
- extension of twelve months from 24 May 2023 to 23 May 2024
- extension of a further six months from 24 May 2024 to 23 November 2024.

Decision:

- The Executive Group voted on whether, or not, the terms of Chair & Vice Chair, should be extended, pending the Charity Commission's decision about our application (which we hope will be in November). The result was a unanimous decision to roll the terms over.

### **Patient data training session**

Chris ran a test in-person session on Wednesday, 11 September, for a small number of people:

- Yvonne Adebole & Ceri Steele, Executive Group Members
- Alison Stone & Elizabeth Lloyd-Owen, Secretariat Members
- Matt Howard-Murray, Public Involvement Lead (Research Data Strategy), Cancer Research UK
- Tara Dowd, Patient and Public Involvement and Engagement Officer, Health Data Research UK.

Health Data Research UK (HDR UK) provided a room for the training. Thanks were given to Tara for arranging this and to HDR UK for the provision of the room.

The session was run as a 'test bed' of the contents of the training module, ahead of training Members. This session followed the attempt to host the first of a series of in-person training for Members, which was due to be on Monday, 24 June, in London. There was not enough interest for the session to go ahead - which may reflect the date/time/location rather than a lack of interest in the training. It's important that the Members who did express interest have the opportunity to attend a session.

Ceri, Yvonne and Chris reflected on the training. Ceri & Yvonne felt it was helpful and useful, helping to bridge the gap with terms that are heard in the health data world. However, the content was too much for one day, with too many details to absorb.

Chris is reviewing how it could be packaged differently and potentially hosted differently - online rather than in-person. There is a crossover with our Education Sessions and perhaps this is a good time to rethink how we use those slots - to make them more structured and focussed on training. However, the Education Sessions do bring a strand of external engagement to use MY data, which would be lost if the Sessions are repurposed.

There is interest from external organisations in the training (and in use MY data hosting this).

The content and format of the training, combining or not with the Education Sessions was discussed.

Decisions:

- The training programme will switch to online modules
- Chris, Ceri and Yvonne will scope out the next steps of the training programme.

Summary of actions, deadlines and responsible person(s)

- **Dave** - For the trustee aspect of our charitable status submission - collect the remaining Executive Group signatures, for submission the Charity Commission
- **Chris** - Liaise with Ceri & Yvonne for the next steps of the training programme for Members

<p>Item 3.0</p>	<p><b>Where we are heading: use MY data's external work</b></p> <p>Intended outputs from this item:</p> <ul style="list-style-type: none"> <li>· Fundraising strategy for NPaDD</li> <li>· Steer for the Secretariat on engagement for September to December</li> </ul> <p><b>Funding pitch/plans for NPaDD</b></p> <p>Funding pitch</p> <ul style="list-style-type: none"> <li>· The Secretariat has updated the fundraising pitch document for NPaDD, although this is still at a draft stage. Chris &amp; Alison have been meeting with organisations who are potentially interested in supporting/funding. They have also had scoping meetings with organisations who are interested in being part of the programme.</li> <li>· There is a difference between sponsorship and support, and this will be taken into account when liaising with organisations who may wish to be involved.</li> </ul> <p>Conference Committee</p> <ul style="list-style-type: none"> <li>· The Conference Committee is now confirmed. There was a fantastic response from Members interested in the places, with interest outweighing available places by four to one. All of those who could not be given a place are interested in being involved/helping at a future point in the NPaDD's planning/development (as are Members of the Executive Group not on the Committee).</li> <li>· The first Committee meeting is scheduled for Monday, 07 October.</li> </ul> <p>Programme</p> <ul style="list-style-type: none"> <li>· Three key speakers are confirmed, with two further responses awaited and two invitations pending. The Committee will now take the lead on developing the programme.</li> <li>· Prior to the conference, Chris is thinking of hosting a series of online sessions, on topics related to the programme. The aim is to prepare Members on patient data topics and/or for those who are interested, but unable to attend the conference.</li> </ul> <p><b>Engagement update</b></p> <p>Alison gave an overview of recent and upcoming engagement work, covering formal engagement pieces, one-off pieces of engagement and potential projects/exploratory work.</p> <p>As highlighted in the latest Chair's letter to Members, Alison is now producing a monthly engagement update, which is published in the first newsletter of each month. Alison presented the draft update that is intended for publication in the 03 October newsletter. This included an overview of the briefing session for Health Data Research UK's PPIE strategy, which Chris attended, and there was a brief follow-up discussion about this.</p>
<p>Item 4.0</p>	<p><b>Any other business</b></p> <p>a) <b>Securing places on external committees</b></p> <p>Richard Ballerand asked if we should establish a list of all the organisations where use MY data has representatives on committees and have a strategy for representation on future committees?</p> <p>Richard B was unexpectedly unable to attend the meeting and Richard S initiated the point on Richard B's behalf, highlighting three strands for discussion:</p> <ol style="list-style-type: none"> <li>1) use MY data's formal places on committees (and who currently represents us)</li> <li>2) use MY data Members who sit on committees/groups (about patient data) because they are Members, rather than having a formal role</li> <li>3) use MY data Members on groups whose work does/could link to our work, values &amp; aims.</li> </ol> <p>Unfortunately, Richard S suffered an internet interruption at this point, forcing him to leave the meeting. There was agreement that:</p> <ul style="list-style-type: none"> <li>· It would be good to know more of Members informal activities and to publicise these, to highlight the influence of use MY data and the work that Members are doing to support this</li> <li>· It is necessary to add a section to the website of formal roles that use MY data holds and who is</li> </ul>

	<p>doing those - however, this could be delayed until the new version of the website is ready</p> <ul style="list-style-type: none"> <li>· LinkedIn could be an alternative way to publicise our formal involvement.</li> </ul> <p>It became clear that clarity about the roles and responsibilities of Executive Group Members, who are representing use MY data in roles other than formal ones, is needed. Alison will review current guidance to see if it is suitable or needs an update.</p> <p>Due to both Richard B &amp; Richard S being absent at this point, further discussion was postponed.</p> <p><b>b) Meetings in 2025</b></p> <p>Alison asked Executive Group for their views on the format of meetings for next year. All agreed that the format of quarterly in-person strategy meetings, interspersed with online catch-ups works and that London is a good location in terms of travel.</p> <p>Summary of actions, deadlines and responsible person(s)</p> <ul style="list-style-type: none"> <li>· <b>Alison</b> - For meeting dates in 2025, ask Executive Group Members not present for their views on location and regularity.</li> <li>· <b>Alison</b> - Review our Information &amp; guidance documentation, to see if/where updates are needed, with respect to Members representing use MY data.</li> </ul>
<p>Item 5.0</p>	<p><b>Date of next meeting</b></p> <p>Wednesday, 27 November, 10:45 to 15:00</p> <p>NCVO (National Council for Voluntary Organisations), Society Building, 8 All Saints Street, N1 9RL</p>

## Suggestions for future meetings

Weds, 27 Nov  
10:45 to 15:00  
In-person

### Key items

- Fundraising exercise
- Charitable status next steps
- Work programme for 2025
- NPaDD developments

### Standing items

- Update on funding
- Update on discussions with national organisations