

Executive Group and Secretariat meeting notes, 17 March 2025

Attendees:

Richard Stephens (Chair)
Dave Chuter (Vice Chair)
Richard Ballerand
Jo Gumbs
Ceri Steele
Yvonne Adebola (via Zoom)
John Marsh (via Zoom) (Item 2.2 onwards)
David Snelson (via Zoom)

Alison Stone
Chris Carrigan
Elizabeth Lloyd-Owen
Gladis Foster

Apologies: Samina Begum

Meeting opened at 10:45am with Welcome, Apologies & Housekeeping The Chair welcomed attendees, and the meeting etiquette was advised.

Item 1 - Where we are heading: use MY data's internal work

1.1 Governance of use MY data

Decision on Charity Commission status

The Executive Group members discussed whether a new submission should be submitted to the Charity Commission, including the format and timing of any potential new submission. It was noted that the Secretariat would have no available time before the completion of the National Patient Data Day conference, even if a new submission were to be led by a Member of the Executive Group.

The Executive Group agreed to submit a new application in the Autumn, with clearer objects and supporting evidence focusing exclusively on charitable purposes. A new application will need to strengthen the 'public benefit argument for advancing health', clarify the role of use MY data in advice and 'consultancy', and the purpose of the use MY data company will need to be clearly separate from the aims of the charity (if the company is retained).

Professional advice will be needed on the new submission and there may be a cost associated with this, although Cancer Research UK has also offered help. The preferred date for becoming a charity is by 31 March 2026.

ACTIONS

- **Executive Group** - To lead a new submission to the Charity Commission - by Autumn 2025.
- **Richard S** - Draft some thoughts on the main issues above, based on the advice received from the Charity Commission and from ChatGPT (via Jo) - for the next meeting of the Executive Group on Wednesday, 21 May.

Accounts reporting and projections

Chris updated the Executive Group with the present financial status of use MY data. The Executive Group reviewed the figure for the most recent complete financial quarter, which showed that expenditure was slightly below income. The figures demonstrated that use MY data is living within its current income, but without building reserves.

Chris presented the financial projections and cashflow. There is a critical reliance on the annual income from NHS England, which comes via the East of England Health Innovation Network. This funds the post of the Head of Programmes & Engagement and honoraria for Executive Group and Members activities. However, the funding runs only until June 2025, and unless NHS England approve next year's income, use MY data's cashflow will reduce to unsustainable levels shortly afterwards, as there will not be enough money to support the post/provide honoraria.

The Executive Group discussed potential alternative funding sources and Chris agreed to write to key contacts in these organisations, highlighting the serious nature of our position and seeking advice and financial support. This could include looking for multiple funders, considering a hybrid model (core funding plus commissioned work). The Executive Group recognise the reality that, without a fairly immediate funding commitment, use MY data may well have to plan for closure.

The names of potential funders have not been noted, due to reasons of confidentiality/sensitivity.

ACTIONS

- **Chris** - To write immediately to key contacts for funding advice - by Friday, 21 March.

Executive Group Roles

The Executive Group came into being on 15 February 2021. This followed different iterations of the Group that leads use MY data - previously the Advisory Group and, prior to that, the Coordinating Group. As a result of the lengthy and delayed process of applying for charitable status, some Executive Group Members terms and the Chairing terms, have been rolled over. The terms of six Members and the chairing roles ended recently and Alison had presented options in a paper for Executive Group consideration.

After discussion, it was agreed that the terms of the six Executive Group Members, and the roles of the Chair and Vice-Chair, will be extended to July 2025. These terms will all be revisited in the July in-person meeting.

Currently the Chairs and Secretariat meet monthly (recently reduced from fortnightly). There may be merit in opening up these informal (unminuted) meetings to the wider Executive Group, on a drop-in basis.

ACTIONS

- **Gladis** - Add Executive Group Members & Chairing terms to the July meeting agenda.

Review of Executive Group & Sec team ways of working and remit This was discussed and covered within item 1.2, Moving the Movement.

1.2 Moving the Movement

The Secretariat presented a paper, proposing updating the ways of working for the Executive Group and Secretariat. In addition to the existing elements of the Executive Group Members individual roles in representing use MY data externally, which are outlined in a 'Ways of Working' document, the Secretariat had suggested adding a 'responsibilities' section, to better define the role of an Executive Group Member. The intention of this would be to help to strengthen communications - externally and internally.

The Executive Group welcomed the suggestions in the paper and was strongly supportive of the enhanced ways of working and of more direct communication with Members. For callouts for information via the newsletter - this can happen as soon as the Secretariat has developed the methodology to support this. For the online sessions - these should be scheduled for September onwards, once NPADD and the summer holidays have passed.

The timeframe for the Executive Group to respond to Secretariat requests was reviewed. The decision was taken to reduce this from one calendar week to three working days.

ACTIONS

- **Secretariat** - Create a pro-forma/methodology for the Executive Group to use for callouts to Members (via the newsletter) - by Friday, 09 May.
- **Secretariat** - Arrange online feedback sessions for Members, the Executive Group and the Secretariat - from September 2025.
- **Alison** - Update the Ways of Working document, to reflect the additional Executive Group responsibilities and methods of communication - by Thursday, 17 April.

Item 2 - Where we are heading: use MY data's external work

2.1 National Patient Data Day (NPADD)

The Executive Group reviewed the current version of the agenda, the confirmed sponsors, potential sponsors, and exhibitors, following papers and presentations from the Secretariat.

The financial projection indicates that, thanks to our generous sponsors, we have enough funding to go ahead and may even have a small surplus. The financial assumptions are partly based on estimates at this stage (i.e. the number of delegates who will register and which quota they will be in).

The Executive Group were happy with the developments on funding and on the programme. They were keen that Cancer Research UK and Understanding Patient Data should be specifically invited to take part, possibly via hosting a roundtable discussion.

On the evening of 23 June, the Secretariat agreed to arrange an optional informal gathering for all who are staying overnight in Leeds. This could be to meet in the venue bar at 19:00, to say hello. There would then be the option for people to go on to dinner together, should they wish to. (It will be important to highlight that this is not a meal that use MY data would be able to fund.)

ACTION

- **Alison** - Put in place social arrangements for the evening of 23 June - by Friday, 04 April.

2.2 Key engagement work

Alison highlighted the uncertainty about our key relationships with NHS England, following the very recent announcement that NHS England will be abolished. She gave a quick recap of NHS England groups on which we currently have places.

An Executive Group Member has a place on:

- Research Advisory Groups - Data Enabled & Stakeholder

Our Data Adviser has a place on:

- Department of Health & Social Care/NHS England - Data Strategy Advisory Panel
- Department of Health & Social Care/NHS England - Large Scale Public Involvement Steering Group.

We await information about the future of these groups. The Executive Group agreed to write to the Secretary of State for Health and Social Care (SoS) to highlight use MY data's role on the Groups.

Ad hoc engagement work continues to grow in strength. In 2024 we were invited to take part in 17 events. To date this year, we have received several opportunities, which include:

- Cancer Research UK roundtable on industry & AI - 17 March (John Marsh)
- University of Leeds debate on Secure Data Environments - 28 April (Chris)
- European Biobanking Week (EBW) - 13/14 May - (Richard, following acceptance for poster presentations of Richard & Alison's abstracts)
- Cancer Research UK webinar - 05 June (participant to be decided)

All our engagement work (formal relationship and ad-hoc) is recorded in a monthly update for Members, via the newsletter.

ACTIONS

- **Richard S** - Draft EBW poster ideas for Elizabeth - by Tuesday, 08 April.
- **Richard S & Elizabeth** - Create a letter to the SoS for Health & Social Care, on behalf of use MY data, highlighting our work with NHS England - by Thursday, 08 May.

Item 3 - Any Other Business, plus intended output, decisions and timelines

3.1 National Data Library

David Snelson gave an overview of the development and thinking about the National Data Library. There were contrasting approaches over the need for a centralised data store and regionalised data stores (which bring data together) versus the concept of data federation (where data stays in its original location). It was unclear whether the right emphasis in some solutions was to bring together/access the data in 'whatever' format, or whether the emphasis should be on a modular move towards data interoperability.

The Executive Group agreed that a high-level position paper is needed. This is to be drafted prior to the conference. John, David and Chris agreed to take this forward, following which Elizabeth will promote it.

ACTION

- **David, John, Chris** - Write a position paper on behalf of use MY data, on a National Health Data Model, for publication (via Elizabeth) prior to NPaDD.

Item 4 - Date of next meeting

The next meeting will be Online on Wednesday, 21 May from 11:00 to 12:00.