

Executive Group & Secretariat - In-person meeting

**Wednesday, 31 July 2024
10:45 to 15:00**

Meeting notes - confirmed

<p>Item 1.0</p>	<p>Welcome, apologies & housekeeping</p> <p>The Chair welcomed attendees and the meeting etiquette was reviewed and agreed.</p> <p>Attendees Executive Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Richard Ballerand, Samina Begum, Jo Gumbs, John Marsh, David Snelson & Ceri Steele Secretariat - Chris Carrigan, Elizabeth Lloyd-Owen, Alison Stone</p> <p>Apologies Yvonne Adebola</p>
<p>Item 2.0</p>	<p>Where we are heading: use MY data’s internal work</p> <p>a. Intended output from this item:</p> <ul style="list-style-type: none"> · Delivery plan for Charitable Incorporated Organisation (CIO) status: <ul style="list-style-type: none"> - Timelines - Trustees <p>Dave presented the updated Constitution for use MY data, for the Executive Group’s review. There was agreement that the paper is nearly complete, subject to final amendments. The Executive Group and Secretariat thanked Dave for all of his work in this area.</p> <p>Key questions and follow-up points from the Executive</p> <ul style="list-style-type: none"> · Throughout the document there is reference to “members” and “associate” - these do not refer to our Members and Associate Members - and amendment is needed, to avoid confusion. · Section 5(1b) - Application of income and property - is indemnity insurance needed? Does use MY data as a Limited Company need to be wound down, or retained, as a trading company? · Section 6(2) - Scope and powers permitting trustees’ or connected persons’ benefits - are we constraining ourselves at this stage? It is best to keep things as simple as possible - there will be the option to amend the constitution, further down the line. · Section 9(2a) - Eligibility for trusteeship - query on the meaning of “every charity trustee must be a natural person” - with clarification that natural in this context means being human (rather than Artificial Intelligence). · Where does the Secretariat fit? They will be the CIO’s employees. · Section 10, Appointment of charity trustees - this will be a three-year term. Concerns expressed about Members not being specifically mentioned in the appointment of charity trustees. We will still be a member-led organisation, through seeking Members’ views and responses. It is important to write into the constitution that our work will still be Member-led. · The number of trustees will be a minimum of seven and maximum of nine. As trustees they will be doing the due diligence required. · Section 12 Retirement and removal of charity trustees - decision that a code of conduct is needed for trustees, to cover areas such as the possibility of appointed trustees not representing Members well, representing alternative values to use MY data, or not working well with the other trustees, and/or the Secretariat. · Section 15(2) - Chairing of meetings - a chair and vice chair (or co-chairs) are needed. · Section 15(3a) - Quorum - this will be 5 people (whether there are 7 or 9 trustees) and decisions can be made via email or in meetings.

- Section 16(1a) - Membership of the CIO - this should read “the voting trustees” rather than “the voting members”.
- Section 18 (1) - Patient/carer or associate (non-voting) membership - amend the line that uses the word “associate”, to avoid confusion.
- Section 18(4) - Decisions which must be made by the members of the CIO - “Except where a resolution in writing must be agreed by all the Trustees...” - the value of this clause was discussed, with the decision to retain this for now. It would be good to revisit this when the Constitution is reviewed (which ideally should be done annually). A check with the Charity Commission is needed, to be sure of all the clauses that need to be retained.
- Section 19 (2a) - Notice of general meetings of members - agreement that the minimum period of notice required to hold a general meeting (of the trustees) is to be amended to 28 days, from the current 14 days.
- Section 23 - Keeping of Registers - this is for the Secretariat to do. The word “members” needs to be removed from the line “register of its members and charity trustees”, as this does not refer to our Members and is confusing.
- Section 25 - Accounting records, accounts, annual reports and returns, register maintenance - the accounts must be done within ten months of the end of the financial year.

Dave agreed to update the paper and circulate to the Executive Group for final sign-off, following which he will submit use MY data’s application to the Charity Commission, by the end of August. Dave is hopeful that we could have the Commission’s decision within two months of submission.

Summary of actions, deadlines and responsible person(s)

- **Dave** - Revise the constitution & send to the Executive Group - by Wednesday 07 August.
- **Executive Group** - Review the paper & either approval or send final feedback to Dave - by Saturday, 17 August.
- **Executive Group** - Decide whether or not they wish to stand as trustees and, if so, for a one-year or three-year term and notify Dave of the decision - by Saturday, 17 August.
- **Dave** - Produce the final version of the paper, for submission to the Charity Commission - By Friday, 23 August ideally and no later than Friday, 30 August.

Item 3.0

Where we are heading: use MY data’s external work

a. Intended output from this item:

- Next steps on the National Patient Data Day (NPaDD), including:
 - Conference programme
 - Conference committee
 - Fundraising direction

The Secretariat gave a brief overview of work to date and sought the Executive Group’s advice on key areas.

Venue, delegates & registration

- The Secretariat has explored University facilities in Leeds as a preferred option - unfortunately these didn’t work in terms of space allocation. The Queens Hotel is a good alternative with many benefits and is on hold for us.
- Delegate numbers are to be 250 and a wide range of stakeholders are needed. To ensure that our Members who wish to be there can be, we could operate a priority register of interest for them, ahead of general registration.
- To mitigate no-shows on the day, we could consider having a ticket cost that is refundable on attendance. This will be time-consuming to administrate, unless we use an external company. We would not wish to have any charge at all, for patients, relatives and carers.
- Another way forward could be an application to attend, rather than just open registration.
- We could also overbook with an eye on no-shows and operate a wait list.
- We can target patients & PPI representatives in the Leeds area.

Conference programme

- Focus is needed on our reason for hosting the conference, with the objectives for the day:
 - Celebrating the value of using patient data
 - Reaching parts of the UK we have yet to reach
 - Recruitment & doubling our Membership.

- We must be willing to work with all stakeholders - the day itself will be an opportunity to work together/have a say and to go home saying you have done something!
- Present pockets of best practice e.g. SAIL DataBank.
- There will be a mix of patients, public and professionals.
- Draft running time: 10:00 to 16:00 for the programme, followed by a networking reception with refreshments in the exhibition area from 16:00 to 17:30.
- Members, Associate Members and external stakeholders have sent in several ideas, the enthusiasm of which was welcomed and the ideas reviewed.
- A key-note speaker is needed and a list of potential speakers were discussed, along with the need for good accompanying information to support invitations.
- The benefits of using data need to be highlighted and improvements in the use of data for our own care. The programme should reflect what we've achieved to date and what we could further achieve.

Conference committee

- The Secretariat proposed that the committee could comprise:
 - Three Members
 - Three Executive Group Members
 - Three Secretariat Members.
- The Secretariat sought advice on whether the time given on the committee should be entirely voluntary or with honoraria. The Executive Group felt that honoraria should be offered for meetings and associated work. (There will be approximately 10 meetings.)
- Volunteers from the Executive Group - Jo and Ceri are confirmed with either Yvonne or David to take the third place (this is to be offered to Yvonne, with David as a back-up option).
- Executive Members who are not joining the committee are happy to support in other ways.
- To find Members for the committee, we can advertise in the 08 August newsletter. In addition, we can put a call out for Members who have marketing/event management experience.
- It is important that the committee keeps the Executive Group updated and notes from meetings will be needed - Ceri agreed to take these and this offer was warmly welcomed.

Fundraising direction

- Approximately £30,000 will be needed to host the conference.
- In terms of seeking sponsors, this could be broken down into platinum (£9,000), gold (£6,000), silver (£3,000).
- We need to be sure of what we can offer sponsors and mindful/careful of what we are offering - to ensure we are contracting with organisations who understand us and our mission.
- Some sponsors may not be happy to be aligned with other sponsors.
- Our first year is a selling point to attract sponsors.
- We could also have supporters, rather than sponsors - they would not help financially but could help by offering support in other ways.
- We are also launching the National Patient Data Day (a recurring date) on the same day and need key supporters for this.
- Yvonne has reviewed the funding pitch document and suggested underpinning with statistics.
- We also need to decide where our red lines are with potential sponsors.

Executive Group & Secretariat meeting at the conference

- While it will not be possible for the Secretariat to support a formal meeting at the conference, they hope to arrange an informal gathering of the Executive Group and Secretariat, prior to, or following the main conference programme.

Summary of actions, deadlines and responsible person(s)

- **Chris** - Book the Queens Hotel as the venue - by 07 August.
- **Secretariat** - Issue initial key speaker invitations - by 07 August.
- **Secretariat** - Finalise the funding pitch document and seek sponsorship - by 07 August.
- **Secretariat** - Conference committee next steps - finalise the third Executive Group place and put a call out to Members to seek interest - 08 August newsletter.
- **Secretariat** - Event/marketing management - put a call out to Members to seek their experience - 08 August newsletter.

<p>Item 4.0</p>	<p>Communications & media - making a promotional film</p> <p>a. Intended output from this item:</p> <ul style="list-style-type: none"> · Short films of Executive Group Members, to promote use MY data <p>Elizabeth led on making short films of Executive Group Members, speaking on the value of being part of use MY data, the importance of their patient data being used and why they want others to allow their patient data to be used. Yvonne will be filmed separately, to complete the full set.</p> <p>Summary of actions, deadlines and responsible person(s)</p> <ul style="list-style-type: none"> · Elizabeth - Arrange for Yvonne’s promotional film to be made - by 06 September
<p>Item 5.0</p>	<p>Any other business</p> <p>a) Radio 4 Today Programme, Guest Editor scheme It appears that we have not been successful in our application, as the deadline for being informed about success has now passed. We do not know the reason behind the decision and if we are to try again, next year, it would be useful to reflect on this.</p> <p>b) Shadowing of Executive Group & Secretariat meetings A new Associate Member has enquired about shadowing a meeting of the Executive Group & Secretariat, to gain a better insight into how things are run. In principle, the Executive Group welcomes one observer per meeting. In terms of practicality (and costs), an online meeting might be the better option. There may be future possibilities for a reciprocal arrangement, where Executive Group Members could attend meetings of Associate Members’ organisations.</p> <p>c) Healthcare Communications Association (HCA) webinar We are now a member of the HCA, who have offered us a lunchtime webinar session, later in the year, to showcase use MY data’s work - “we think it could be very beneficial for our members to hear about your organisation, who you are and what great work you do”.</p> <p>Executive Group Members can register on the use MY data HCA account, for full access to all free resources and events. Richard S is interested and Alison will send follow-up information.</p> <p>d) Real-World Evidence network Health Data Research UK has invited use MY data to participate in the Real-World Evidence Network, for which Alison is liaising with the Executive Group to find a representative. This has triggered a conversation about how to involve Members more widely, in use MY data’s work. A key part of this is training and the recent offer to Members for patient data training was reviewed. Follow-up work is needed on how to find the best way to deliver training to Members.</p> <p>e) WhatsApp group & use MY data for the Executive Group Richard B asked if it would be useful for:</p> <ol style="list-style-type: none"> 1) the Executive Group to operate a WhatsApp group 2) the Executive Group to have dedicated use MY data emails. <p>Following positive response for the WhatsApp group, Richard will set this up. For the email idea, there are pros and cons for this and there was agreement to park the idea, for now.</p> <p>Summary of actions, deadlines and responsible person(s)</p> <ul style="list-style-type: none"> · Alison - Follow-up with the Associate Member interested in shadowing a meeting. · Alison - HealthCare Communications Association - send registration details to Richard S. · Richard B - Set up a WhatsApp group, for the Executive Group. · Secretariat - Continue working on how best to bring patient data training to Members.
<p>Item 5.0</p>	<p>Date of next meeting - 05 mins</p> <p>Confirmed date: Wednesday, 25 September, 12:00 to 13:30, online Dates for October to December: these are to be booked.</p>

Suggestions for future meetings

Weds, 25 Sept
12:00 to 13:30
online

Key items to consider

- Fundraising exercise
- NPaDD 2025 progress

Standing items

- Update on funding
- Update on discussions with national organisations