

Executive Group & Secretariat - Online meeting

**Monday, 17 June 2024
12:00 to 13:00**

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), Yvonne Adebola, Richard Ballerand, Samina Begum, John Marsh, Ceri Steele Secretariat - Chris Carrigan, Elizabeth Lloyd-Owen, Alison Stone</p> <p>Apologies - David Snelson Did not attend - Jo Gumbs</p>
<p>Item 2.0</p>	<p>Where we are heading: use MY data's external work</p> <p>Intended outputs from this item:</p> <ul style="list-style-type: none"> · Confirmed date for our Patient Data Day 2025 · Engagement/event plans confirmed for July to December 2024 · Fundraising plans <p>Patient Data Day 2025 The Secretariat proposed Tuesday, 24 June 2025 as the inaugural Patient Data Day, with Leeds as the location. Fundraising and sponsorship will be key to holding the event and the Secretariat is working on a document to take this forward. Chris is investigating the cost of using event planners.</p> <p>The Secretariat asked for the Executive's go-ahead to launch the date and location, in a 'save the date' format.</p> <p>Key questions and follow-up points from the Executive</p> <ul style="list-style-type: none"> · Tuesday, 24 June 2025 was agreed as the date. · The event will be called the 'National Patient Data Day'. · For the programme - breakout discussions and networking will be an essential part of the day and we need a venue that can support this, with break-out rooms. · On numbers - 250 was agreed as a good number of delegates. · The conference will be open to all, with Members having priority attendance. It is essential that it attracts a wide variety of patient data stakeholders, for maximum influence. · Concrete outcomes of the event will be essential. · With an eye on busy-ness, June is the month that NIHR panels are held in Leeds. · We could investigate the option of universities, which may also lead to engagement with them about patient data. <p>Engagement/event plans The Secretariat presented a round-up of their recent, extensive, engagement work.</p> <p>Key questions and follow-up points from the Executive</p> <ul style="list-style-type: none"> · The importance of Members receiving engagement updates, was emphasised. · The presentation slides could be expanded and used for an annual report/yearbook. · Could there be a section on our website that records areas of use MY data's involvement - including the project, its structure, which Member is involved and their contact details. Our engagement work should be as accessible and open as possible.

- When this section of the website is set up, it should be in a format that is easy to integrate into an annual report. Standard format reports should be used - for the website work and perhaps for a monthly round-up in the newsletter.
- A lot has changed within use MY data over the last two/three years - our influence has grown significantly. There is a pinch-point in taking some aspects of the work forward, due to the limitations of the Secretariat's time.

Funding & fundraising

The Secretariat gave a brief overview of the current funding situation. Funding from NHS England is awaited, with Chris hopeful this will be received within days. Until we have the funds, we cannot proceed with expanding the Secretariat, and therefore the work of use MY data, via employing an administrator.

The Secretariat believes that use MY data now needs a dedicated fundraiser, who will work with us on the basis of retaining a percentage of the money they bring in. Elizabeth has a contact who may be able to help us in this area, and an exercise to work through with the Executive, to help identify any contacts who may be able to assist us.

Key questions and follow-up points from the Executive - on funding

- The Executive discussed whether the recruitment process should be started now, with the funding imminent. While there was consensus from the Executive that this should happen, the Secretariat were hesitant to spend time on doing this, without being 100% sure of receiving the funding. The decision was taken to await the funding before recruitment commences.
- The Secretariat confirmed that they are ready to advertise the administrative role, as soon as the funding is received. The role will have a two-year contract
- If the NHS funding is not received, is there a contingency plan for the Executive Group to support the Secretariat (and ensure that work does not fall through the cracks)?
- Once we have an administrator, they will take on meeting administration work, which will free up Alison's time, enabling more engagement work. In the interim, it is helpful for all of us to focus on the 'bigger picture' work items, as much as possible. If we do not receive the funding, then that 'bigger picture' focus will need to continue.
- On contingency plans for our finances, if we do not receive the funding and therefore do not expand, we can keep going until the end of 2024.

Key questions and follow-up points from the Executive - on fundraising

- It is important to draw on the skills and knowledge of Members, Associate Members and their connections, wherever possible. Yvonne has experience of fundraising and is willing to help.
- A charitable status will have significant implications for how we position ourselves, with regard to fundraising.
- We could consider carrying out the funding contacts exercise at the next meeting.

Summary of actions, deadlines and responsible person(s)

- **Chris** - Monitor the NHS England funding and update the Executive Group.
- **Yvonne & Secretariat** - Liaise on fundraising work.
- **Elizabeth & Alison** - Take forward the fundraising exercise with the Executive.

Item 3.0

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

Intended output from this item:

- Patient data training for Members - schedule beyond June
- Education Session programme publication
- Membership expansion

Patient data training for Members

The first training day was due to take place on Monday, 24 June in London, ahead of further dates across the UK. The Secretariat has taken the decision to postpone the training, due to only a small number of Members expressing interest in attending. It is essential that the training is delivered to those who have expressed interest.

It may be that the date/timing was not suitable, recognising that many Members are working and/or

busy with commitments including care responsibilities.

Key questions and follow-up points from the Executive

- Suggestion that the Secretariat contact Members who expressed interest, to see what appealed to them, about the training programme.
- Consider holding training for all Members (across the UK), in as central a location as possible.
- Would it be helpful to reframe the training as a day for new Members? On balance, it was felt best to offer the training to all who are interested - some longer standing Members will benefit, alongside new Members.
- Use the training programme to create a set of modules that can be shared with all new Members - as part of their induction and as a way of involving them and helping to ensure they feel included.

Education Session programme publication

Chris gave an overview of the schedule, ahead of circulating it to the Executive and Members (via the newsletter). The schedule could then be published on our website, to promote this great benefit of being a Member.

Membership expansion

Following previous advice from the Executive, the Secretariat has been taking forward work to recruit new Members. Numbers are growing steadily and recent advertising by Cancer Research UK and Health Data Research UK has helped greatly. Numbers of Associate Member are also growing, and that has been at a faster rate than Members.

Key questions and follow-up points from the Executive

- It would be useful for Executive Group Members to actively try and recruit Members.
- Include a check on membership numbers at each meeting, to monitor if they are going up (or otherwise!)

Summary of actions, deadlines and responsible person(s)

- **Secretariat** - Consider how best to rearrange the patient data training for Members, including asking those who expressed interest what appealed, and ensuring they receive the training.
- **Chris** - Create patient data training modules for new Members, as part of their induction.
- **Alison** - Work the training modules into the induction information for new Members.
- **Chris** - Circulate the Education Session programme to the Executive, Members and publish on the website.
- **Executive Group** - Members of the Executive will work to recruit new use MY data Members.
- **Alison** - Add monitoring Membership numbers to Executive Group & Secretariat meetings.

Item
4.0

Any other business

a) Healthcare Communications Association

Richard B had suggested consideration could be given to use MY data joining the Healthcare Communications Association (HCA), in the 'Patient Groups/Health Charities' category - <https://the-hca.org/>

"The HCA is a not-for-profit organisation, with membership comprising in-house teams, agencies, third sector and individuals working in national and global healthcare communications across diverse business sectors...The HCA welcomes your organisation to join with complementary membership. You will receive the full benefits of being members, including our increasing number of free events and networking opportunities, where knowledge and innovation from across the whole healthcare communications sector are shared..."

The Executive asked the Secretariat to check if the current membership is professionals only or also includes patient groups (such as the Patients Association or the Patient Information Forum).

b) Meeting reports & honoraria

Richard S and Alison sought the Executive's views on tweaking the procedure for the Executive's attendance at external meetings/events, providing subsequent reports and obtaining honoraria (when available).

	<p>The Executive agreed that, when representing use MY data at external events, a follow-up report is an essential part of the process, to:</p> <ol style="list-style-type: none"> 1) aid feedback to Members, helping to keep them fully informed 2) publicise our work externally, highlighting our work and influence 3) provide a basis for the annual report. <p>Once the report is submitted to the Secretariat, the honoraria process will begin.</p> <p>Summary of actions, deadlines and responsible person(s)</p> <ul style="list-style-type: none"> • Elizabeth - Investigate membership of the Healthcare Communications Association. • Executive Group Members - After representing use MY data at external meetings/events, share a report with the Executive Group and the Secretariat. • Secretariat - Ensure that Executive Group Members' reports are shared with Members, publicised externally and contribute towards an annual report.
Item 5.0	<p>Date of next meetings - 05 mins</p> <p>Confirmed dates:</p> <ul style="list-style-type: none"> • Wednesday, 31 July, 10:45 to 15:00, in-person London • Wednesday, 25 September, 12:00 to 13:30, online <p>Dates for October to December are to be booked.</p>

Suggestions for future meetings	
<p>Weds, 31 July 10:45 to 15:00 in-person</p>	<p>Key items</p> <ul style="list-style-type: none"> • Fundraising exercise • Charitable status next steps <p>Standing items</p> <ul style="list-style-type: none"> • Update on funding • Update on discussions with national organisations
<p>Weds, 25 Sept 12:00 to 13:30 online</p>	<p>Key items</p> <p>Standing items</p> <ul style="list-style-type: none"> • Update on funding • Update on discussions with national organisations