

Executive Group & Secretariat - In-person meeting

**Wednesday, 27 November 2024
10:45 to 15:00**

Meeting notes - confirmed

<p>Item 1.0</p>	<p>Welcome, apologies & housekeeping</p> <p>The meeting was co-chaired by Alison & Chris. Alison welcomed attendees and introductions to Gladis were made. Housekeeping was noted and the meeting etiquette agreed.</p> <p>Attendees Executive Group - Yvonne Adeobole, Richard Ballerand, Samina Begum, Jo Gumbs, John Marsh, David Snelson & Ceri Steele Secretariat - Chris Carrigan, Gladis Foster, Elizabeth Lloyd-Owen & Alison Stone</p> <p>Apologies Richard Stephens (Chair) & Dave Chuter (Vice Chair)</p>
<p>Item 2.0</p>	<p>Where we are heading: use MY data's internal work</p> <p>Intended output from this item</p> <ul style="list-style-type: none"> · Decision on focus of newsletter · Decision on Education Session programme for the Winter <p>Update on funding</p> <p>Chris gave an overview of current funding for use MY data, for which core funding comprises Cancer Research UK's three-year grant (which runs to 2026) and NHS England funding, which is given one year at a time. Our primary funding contact at NHS England is leaving imminently; Chris is seeking information about who our contact will be going forward and hoping to meet with them.</p> <p>Small amounts of funding come in from a range of pieces of engagement work (all of which is declared on our website). While more funding is needed, our current financial situation is stable.</p> <p>Review of newsletter & recommendations for expanding Members' participation</p> <p>Elizabeth gave an overview of the newsletter, for which the 'new' format has been running for almost 18 months - it seems timely to review its usefulness and look at increasing its value to reflect wider participation.</p> <p>Other current communications/channels are our website, LinkedIn page, YouTube channel, plus our Twitter/X account (currently dormant with not much content).</p> <p>Elizabeth receives regular feedback from Associate Members about how useful the newsletter is to them in their work and thinks there is scope to ask the Associate Members to do more in terms of increasing membership and raising awareness. She could play a stronger editorial role in the newsletter and was keen to have the Executive Group's view on this. Another idea is to have guest editors, who could be Members or Associate Members.</p> <p>Elizabeth gave a recent example she received, of how patient data on the NHS App directly helped the care of a patient - the Executive Group felt that this positive use of patient data, for patient care, should be highlighted in the next edition of the newsletter.</p>

Key questions and follow-up points from the Executive Group

- Consider having a 'data myths debunked' section within the newsletter.
- It should highlight the benefits of using patient data, rather than focus on dilemmas.
- The newsletter could be linked to asking 'what are you doing with your membership?'
- It could feature Executive Group Members writing a few words about their activities - perhaps some personal reflections on their use MY data work in 2024 and where they feel they have made a difference.
- It could be good to 'target' active Members, in the same vein.
- If we want the newsletter to have more Member participation, we need to show them what that looks like.
- More of a campaigning/influencing edge is needed - we are doing this at 'high levels' i.e. national data policy groups, but this is not necessarily filtering down to Members.
- Gladis, who has the freshest eyes within the Secretariat, gave her reflections of reading the newsletter - she felt that it is not easy to understand much of the content from a lay perspective, that it needed more emphasis on the family/carer aspect and that it was lengthy and took much time to work through, from beginning to end.
- A look at applying advertising flair might enhance the image of the newsletters.
- Time/capacity of Elizabeth needs to be considered, in producing the newsletter.

Summary of actions, deadlines and responsible person(s)

- **Elizabeth** - Use the NHS App patient data story, in the newsletter of 05 December.
- **Elizabeth** - Take a stronger editorial approach to the newsletter.
- **Elizabeth** - Liaise with Alison to identify Members to approach, for news stories.
- **Elizabeth** - Liaise with the Executive Group, to obtain their stories to headline the newsletters.
- **Elizabeth** - Put guest editing into action, with Members and Associate Members.

Education Session programme

Chris gave an overview of the programme, with details of sessions booked to the end of January and the draft schedule from February to June - for which the focus will be the run up to NPADD.

Key questions and follow-up points from the Executive Group

- The programme seems to be popular but with a small number of Members - is it the same ones each time? - Fifteen to twenty percent of attendees are the same ones.
- Are Members or Associate Members attending? - Ninety to ninety-five percent are Members.
- How many views do the post-event videos receive? - This is between one and fifty.
- Whether or not to advertise the Sessions publicly, ahead of them taking place - the benefit would be to promote the sessions as a benefit of membership and attract new Members.
- We could also consider a policy to publish everything we do in this vein (including newsletters), after a time delay - i.e. publish the newsletters online/on LinkedIn, after a month.
- Session timings - consider running a session outside of the usual business hours, to see if this suits more Members (i.e. those who are working).
- Communicating the importance of the sessions - spreading the benefits of the information (the interactive element is a big advantage and should be boosted and emphasised).
- Consider a specific email targeting Members, send separately to the newsletter, to promote the sessions. Or, consider changing the subject heading of the newsletter, to highlight when details of an Education Session are included in an edition.
- Whilst scouting for a wider membership, Members should be encouraged to write blogs.

Summary of actions, deadlines and responsible person(s)

- **Chris** - Arrange an evening Education Session, to trial if this suits a larger number of Members.
- **Chris & Elizabeth** - Work together on the communications around the Educations Sessions.
- **Elizabeth** - Publish newsletters on our website/LinkedIn account, one month after circulation internally and monitor the uptake.

<p>Item</p> <p>3.0</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"> · Next steps for National Patient Data Day plans · Work programme for 2025 <p>National Patient Data Day (NPADD) developments</p> <p>Alison gave an overview of recent work on NPADD and key developments, seeking particular advice on the draft programme and a potential charging structure.</p> <p>We now have an Event Manager, Georgina, who starts on Monday, 02 December, working the equivalent of one day a week (this will increase in the month prior to our event). Georgina will be in charge of all the planning and logistics.</p> <p>The Conference Committee has helped to develop and shape the programme and provided advice on speakers. Richard S had also suggested a draft outline. The subsequent draft programme was presented to the Executive Group, for their views and the programme was broadly welcomed.</p> <p>The Committee had discussed a charging model for registration, with several ideas about how this might work and Alison sought the Executive Group's decision on the best model to use. Up to this point, all use MY data events have been free to attend and delegates have not needed to pay a deposit. This has resulted in a large number of no-shows for each event we have run - whether in-person or online (and when events have been at capacity, with a waiting list). Sometimes of course, no-shows are unavoidable, due to illness or travel problems.</p> <p>Following a full discussion, the Executive Group voted and agreed unanimously on the model:</p> <ul style="list-style-type: none"> · The conference should be free to attend · In order to secure a place, and as an incentive to turn-up, there should be a deposit scheme · The deposit will be £50.00 per delegate · The deposit will be returnable, either direct to the delegate or (only if they wish) donated to use MY data · If making a deposit is a barrier for patients, relatives & carers, concessionary places will be offered · The process of charging a deposit and offering concessions must be carefully articulated to appease participants. <p>Alison will draft the text about the deposit system, for sign-off by the Executive Group.</p> <p>We need to manage travel and accommodation needs for patients, relatives and carers, to enable them to attend the conference. Under our current policy, travel and accommodation (if required) will be covered. It will be best to book travel in advance, where possible, to reduce costs. This needs to be addressed at the registration stage. Alison will liaise with Georgina on the best options and report back to the Executive Group.</p> <p>Key questions and follow-up points from the Executive</p> <ul style="list-style-type: none"> · Developing the event as a whole: the Executive Group should take responsibility for the next stages of developments and decisions, with the Secretariat continuing to drive the work forward on behalf of Members - alongside this it is essential to keep Conference Committee Members in the loop and call on them as needed. · Funding ideas: The Association of the British Pharmaceutical Industry (ABPI) / Wellcome / the UK Medicines and Healthcare products Regulatory Agency. · Including rare diseases: David offered to advertise to the rare disease community that he is part of. · Exhibition: Other ideas were to involve industry, commercial, pharma, UK Biobank and Our Future Health. · Filming: could we arrange filming of the conference highlights? Sponsorship would be needed for this - separate to sponsorship already planned. · Targeting organisations to be involved: our membership of the Healthcare Communications Association might aid us in this area. · Programme - refocus the proposed angle of the media presentation.
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Work programme for 2025

Alison gave an overview of proposed work for 2025. The first half of the year will be dominated by NPaDD, with regular formal engagement work, education sessions and ad-hoc pieces of engagement work running alongside. To date this year, use MY data has taken part in seventeen events with other organisations and this type of engagement seems to work well for promoting our work and expanding our influence. She asked the Executive Group if there were any key engagement priorities, they would like the Secretariat to take forward.

Key questions and follow-up points from the Executive

- Continue to respond to opportunities as normal.
- For Executive Group Members, when responding to various invitations, it's important to have a good set of slides to use if required and, at present, a slide that promotes NPaDD.
- Elizabeth highlighted that presentation training for the Executive Group is still available, for those that want it.
- Request to target some tailored communications to Members, who might want to speak on behalf of use MY data, externally.
- It would be good to see use MY data maintain relationships with industry and have a guiding role, with reference to our position statements and transparency principles. Can we be an ally to those types of organisations? We definitely have a role to play.
- We need to be actively recruiting more Members.
- We need to consider how best to work with those Members who have opted out of sharing their data - ask them what they would like to see before they opt back in.

Summary of actions, deadlines and responsible person(s)

- **David** - Advertise NPaDD to the Addison's Support Group (a rare disease support society, which David is a member of).
- **Alison** - Draft the text about having a deposit system for the NPaDD registration and send to the Executive Group, for their sign-off.
- **Alison** - Update Georgina about the deposit system and decide when registration will open.
- **Alison** - Update the Conference Committee on latest developments.
- **Alison** - Send the NPaDD promotional PowerPoint slide to the Executive Group.
- **Elizabeth** - Send the NPaDD email signature banner to the Executive Group.

Fundraising exploration

Intended outputs from this item

- Pool of potential funders (once funding pitch/angles are defined)

Elizabeth gave an overview of an exercise, to aid obtaining a pool of potential funders, via Executive Group contacts.

Key questions and follow-up points from the Executive

- A menu of opportunities is needed, to highlight the different ways that funders could support use MY data.
- We need to look more closely at a balance between people/organisation who may wish to support us, people who want to pay us for providing services or trained advocates and the opportunities we have ourselves to market services and opportunities. This probably needs to sit alongside increasing membership.

The Executive Group and Secretariat then dived into pooling their ideas, compiling a long list, then a shortlist of three, for initial contact.

Summary of actions, deadlines and responsible person(s)

- **Chris** - Agreed to approach the Association of Medical Research Charities (AMRC) & ABPI to use them as channels to their membership both to seek funding and to seek opportunities
- **David** - Look into whether the Worshipful Company of Information Technologists could be a source of funding.

<p>Item 5.0</p>	<p>Any other business</p> <p>a) Data-enabled Research Advisory Group (DERAG) David gave an overview report of the latest NHS England DERAG meeting, which he attended on 25 November, on behalf of use MY data. There were two key topics: the Data Access Release Service (DARS) and the Sudlow Review.</p> <p>DARS is seeking a PPIE rep and David was keen that use MY data make contact to offer assistance with this role. This could be in terms of spreading the word via our communications channels and/or offering access to resources within use MY data, for the person undertaking the role.</p> <p>Details about DERAG are available publicly, which includes membership information - https://digital.nhs.uk/services/engagement-with-the-data-enabled-research-community/data-enabled-research-advisory-group</p> <p>Within Any Other Business at the meeting was an item about the use of existing data - the Secretary of State has directed that some of those datasets be used for other research. The Executive Group discussed OpenSAFELY in relation to this, from which it was clear that an Education Session on this topic would be welcomed.</p> <p>b) Royal Society of Arts, Commerce & Manufacturing (RSA) Richard B is a fellow of the RSA and highlighted that the RSA is expanding into the data world and that he has set up a health section within the RSA. If becoming a fellow is of interest to Executive Group & Secretariat, please let Richard know and he will nominate. This could be very good for networking opportunities, as there are 31,000 members.</p> <p>c) EUPATI Conference Richard B gave an update on engagement related to the European Patients' Academy on Therapeutic Innovation (EUPATI). Richard has been promoting use MY data's work within the programme, which "provides education and training to increase the capacity and capability of patients and patient representatives to understand and meaningfully contribute to medicine research and development (R&D), and to improve the availability of medical information for patients. Richard Stephens having completed the training is now a EUPATI Fellow.</p> <p>d) Financial Times contact At the end of October, a journalist from the Financial Times made contact with use MY data, to seek input with regard to "disparate IT systems and patient record keeping in use across the NHS". Elizabeth has led on the follow-up, linking up Members with the journalist, to provide their information direct and linking Chris in, to provide back-ground patient data information.</p> <p>e) Members who have opted out of their data being use (in England) There was a brief discussion about the importance of constructively engaging with Members who have opted out, to find out why and what might encourage them to opt back in.</p> <p>Summary of actions, deadlines and responsible person(s)</p> <ul style="list-style-type: none"> · Alison - Contact Michael Chapman with regard to the proposed PPIE rep for DARS - to offer use MY data's assistance. · Chris & Samina - Follow-up with OpenSAFELY about taking part in an Education Session. · Richard Stephens - Spearhead further and delve deeper into the issue of Members who have opted out.
<p>Item 6.0</p>	<p>Date of next meetings</p> <p>Dates for 2025 are confirmed:</p> <ul style="list-style-type: none"> · Wednesday 22 January, 11:00 to 12:00, online · Monday 31 March, 10:45 to 15:00, London · Wednesday 21 May, 11:00 to 12:00, online · Monday 14 July, 10:45 to 15:00, London · Monday 06 October, 11:00 to 12:00, online · Monday 24 November, 10:45 to 15:00, London

Suggestions for future meetings	
22 January Online	<p>Key items to consider</p> <ul style="list-style-type: none">· NPaDD 2025 progress· Charitable status position <p>Standing items</p> <ul style="list-style-type: none">· Update on funding· Update on discussions with national organisations