Executive Group & Secretariat - In-person meeting
Monday, 14 July
10:45 to 15:00

Meeting notes – confirmed

Welcome, apologies & housekeeping

Attendees
- Executive Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Yvonne Adebola (online and then in-person from 11:30), Samina Begum (online from 13:15) Richard Ballerand, Jo Gumbs, John Marsh, David Snelson & Ceri Steele
- Secretariat - Chris Carrigan, Elizabeth Lloyd-Owen & Alison Stone

The Chair welcomed attendees and the meeting etiquette was agreed. It was agreed that in future, the etiquette will include an additional item - if an attendee wishes to record the meeting, they should request this at the start for the Group to consider.

Part 1

The impact of use MY data

Intended outputs from this item
- NPaDD 2026 – decision on holding this and the potential focus
- HDRS work - decision on the next steps for delivering our strategy
- Devolved nations – confirm our strategy for remainder of 2025-2026

1.1 National Patient Data Day success-o-meter rating
- Impact
- Feedback from delegates, sponsors & exhibitors
- Finances
- Communications
- Interest and attendance from and by Members
- Membership recruitment generated

Key discussion points

Impact, membership and communications
- Alison highlighted that the impact document is already out of date, for good reasons – examples of NPaDD's impact continue to come in. The latest has come from Health Data Research UK and demonstrates how delegates have influenced research work.
- It is clear that the conference was a success, with most feedback highlighting the positivity of the day. Engagement opportunities for use MY data have increased as a result.
- NPaDD was worth doing and is worth repeating in some form – essential to capitalise on the positivity and success of this year.
- We have eight new Members and two Associate Members as a direct result of the event.
- Our LinkedIn page followers have increased greatly.

Impact – follow-up work
- A follow-up piece of work that is very relevant, is to focus on AI in relation to moving from process to practice and shifting the dialogue away from negativity. A position statement was discussed as a draft proposal for consultation, using direct NPaDD feedback. Who best to aim this at was touched upon, with the MHRA and King's Fund seen as possibilities. While there are several different aspects to AI concerns, the decision was made to focus on clinical practice.
- John, Dave, Yvonne and Chris volunteered to be involved in the creation of a position statement.

Impact – on the Secretariat

- The Executive Group asked the Secretariat to give an overview of the impact on them of delivering the conference. They outlined their enthusiasm for the event but also the pressure they had been under to deliver it. This was in three key areas:
  1. trying to deliver their routine work successfully, alongside delivering NPaDD
  2. concerns about the financial side and ensuring there was enough sponsorship
  3. concerns about the reputational risk to use MY data, if the event did not work.

Lessons learned

- Accessibility at the venue was an issue and this has been the key takeaway for the Secretariat. Chris, Alison and Georgina are meeting with the venue's General Manager on 16 July, in follow-up.
- Future events will include an independent assessment for suitable accessibility.

Finances

- The conference costs, including venue hire, audio visual, refreshments, signage, hotel, travel expenses for delegates and contracting our Events Manager, were all covered by the sponsorship income.
- The time that the Secretariat spent on conference work was not included in the costs.

Hosting a follow-up event

- In principle, we need to do it again, though the planning process would need to start earlier. This includes contacting potential sponsors very soon - several NPaDD sponsors have indicated interest in sponsoring another event.
- The timing was discussed, examining whether holding it every 18 months to two years could work and, if every two years, the possibility of holding a public webinar in-between.
- The case for holding an event on 24 June 2026 is that 24 June <u>is</u> National Patient Data Day and we do not want to lose momentum.
- We need to celebrate the patient voice on using patient data (making decisions about their patient data usage). We would need to bring in more patient groups/organisations, or members from them, next time.
- Do we go international next time?
- Ceri offered her time, as part of the planning and delivery team, for a follow-up event.

Summary of actions, deadlines and responsible person(s)

Responsible person(s)	Action	Deadline
John leading, Dave, Yvonne & Chris supporting	Produce a draft position statement on turning AI process into policy.	Thursday, 31 July
Chris & Alison	Contact sponsors who have indicated interest in sponsoring another event. Report back to the Executive Group.	Thursday, 31 July

1.2 Health Data Research Service (HDRS)

- Turning our Position Statement into policy - decision on next steps to deliver our strategy

Overview

- Alison gave an overview of a Member's offer/view on work with the HDRS:
  "It occurs to me that there may well be other members of use MY data who, like me, work with other data-related organisations (as well as working in studies that use patient data sets, I am a member of the Central Advisory Committee for the CPRD [Clinical Practice Research Datalink] and have just been recruited to the DARE UK and TREvolution Public Advisory Groups).
  Do you think there might be some benefit to use MY data if we all met to see how we can support the position statement - and use MY data's work more generally?"

Key discussion points

- There was much enthusiasm for this idea and for taking it forward. It is important to seek information from Members, about their connections to other patient data groups and gauge interest in being part of the proposed overarching meeting.
- David recently attended the UK Health Data Research Alliance Council's meeting, during which there was a session on the HDRS. It was confirmed that the HDRS will be based at the Wellcome Genome Campus, in Cambridge. It is not yet known who will head it up and it will be important for us to make contact, as soon as this is known.

Summary of actions, deadlines and responsible person(s)

Responsible person(s)	Action	Deadline
Alison	Report back to the Member with the HDRS offer and lead on the next steps.	Thursday, 31 July
Elizabeth & Alison	Put a call out to Members in the newsletter, to find out: 1) Who works with other data-related groups? 2) Interest in joining an overarching group?	Thursday, 14 August
Alison	Make contact with the head of the HDRS, as soon as details are announced.	N/A
Alison	Ask the Alliance Council if details of our HDRS Position Statement can be included in the meeting notes (details were entered into the chat function during the meeting).	Friday, 18 July
Alison & Ceri	Ensure Ceri is included as part of the planning and delivery team, for the next NPaDD event.	N/A

1.3 Devolved nations work 2025-2026

Intended outputs from this item:

- Confirm our strategy for remainder of 2025-2026

Overview

Alison gave an overview of upcoming opportunities, in Wales and Scotland.

- Health Data Forum Global Hybrid Summit, Wales 2025, from 24 to 26 September -
  We have been invited to take part in multiple strands of this event, including co-hosting a tutorial on 'Patient Engagement Strategies for the Secondary Use of Health Data', featuring in the main programme speaking about 'Patient-Driven Data Transparency' and hosting a round-table on the same theme. We will also have a presence in the 'Social Tech & Health Innovation Village', the area for "innovative companies, startups, and projects at the intersection of social impact and health technology".
  Ceri & Chris are confirmed to attend in-person and be co-presenters.
  Alison is to be confirmed to attend and lead on our village presence.
- Health Data Research UK Conference, Glasgow, 15 to 15 October -
  We have been invited to exhibit and attend. Alison is leading on coordinating our presence there. We hope to consolidate on our time in Scotland, with networking opportunities outside of the conference time.
- Northern Ireland –
  We will be actively seeking connections here. Unfortunately, our opening plenary at NPaDD gave the erroneous impression that we had not included Northern Ireland in the devolved nations panel. We had booked two speakers from Northern Ireland but they both had to withdraw. The short notice of the 2nd withdrawal did not leave time to fill the gap.

Summary of actions, deadlines and responsible person(s)

Responsible person(s)	Action	Deadline
Alison	Confirm attendance at the Wales Forum or make alternative plans to promote/support use MY data there, via ‘the village’.	Thursday, 31 July
Elizabeth & Alison	Lead on the Secretariat’s work to seek engagement opportunities in Scotland, around our presence at the HDR UK conference.	Thursday, 14 August
Alison	Lead on the Secretariat’s work to seek engagement opportunities within Northern Ireland, to balance our devolved nations work.	Friday, 19 September

Part 2

Funding, staffing and membership

Intended outputs from this item:
- Outline funding strategy for 2026-2027 and beyond
- Outline staffing strategy for 2026-2027 and beyond
- Identify further ways to engage Members

2.1 Core funding situation and impending financial situation (crisis)
- Current financial position
- Financial forecast to 2026 and beyond
- Secretariat staffing levels
- Secretariat current and future workloads

Overview
- Chris summarised the current financial position with two key points:
  - NHS England funding – if we receive this funding in July, we will be stable until June 2026 at the current reduced staffing levels (which are already overstretched in terms of workload)
  - Cancer Research UK has offered to set up a meeting of potential co-funders, to aid our funding from April 2026 (when our three-year grant from CRUK ends).
- Our current core funding is £117,000 per year. To double the Secretariat size and have resources and capacity to do all that we wish to do, we need to increase the core funding to approximately £250,000 per year.
- We are not a corporate organisation, our patient-led independence makes us unique. We need to lay out what might be attractive to potential funders.
- Additionally, we need an approach to potential conference funders, to establish if they would be willing to sponsor NPaDD 2026.

Key discussion points and feedback from the Executive Group
- NPaDD has given use MY data prominence and we should capitalise on this to seek new funding opportunities.
- Future NPaDD costs should include backfill costs for the Secretariat’s time.
- We need a fundraiser, however we do not have the funds to employ one. (The Secretariat has previously met with a potential fundraiser, however the fees were outside of our budget.)
- A further catch-22 is that, while staffing levels for the Secretariat clearly need to increase, current staff do not have time to work on increasing staffing levels.
- The Secretariat is without an administrator and Alison, with Chris’s support, is filling this role. It is not possible to recruit an administrator at this point, without funding certainty.
- It is not possible to outline a staffing strategy, without the underpinning funding.

Summary of actions, deadlines and responsible person(s)

Responsible person(s)	Action	Deadline
Alison	Liaise with Cancer Research UK about the potential funders meeting and keep the Executive Group informed of progress.	Friday, 25 July
Chris	Keep the Executive Group updated about the funding from NHS England.	Thursday, 31 July
Chris & Alison	Create an overarching framework paper that builds the case of what use MY data does and can offer to organisations, with outline costings, with the first draft to be shared with the Executive Group.	Thursday, 21 August

2.2 Communications update

- User stats from newsletter, to establish where interests of the membership lies and level of that interest

Overview

- Following on from her paper, Elizabeth reported on the regular positive feedback she receives for the newsletter, which seems particularly well-received and liked by our Associate Members.
- The open rate for the newsletter has gone down slightly and is around 60%.
- Our LinkedIn profile has grown significantly and is currently standing at over 500 followers. LinkedIn users are more likely to be Associate Members, rather than Members, as it is a platform for professionals.
- The target for launching the new website is August, which is in time for conversations with potential funders. Elizabeth would then like to ‘tidy up’ the newsletter in September.

Key discussion points and feedback from the Executive Group

- The opening rates for the newsletter remain impressive and are very high in relation to average newsletter opening rates.
- There was consensus that the newsletter is quite long and suggested ideas for change were:
    - Having some patient stories, which might appeal to Members
    - Create a shortened version for those who wish to read less and have a longer monthly summary
    - Explore if the contents be sectioned within MailChimp, so that people can either subscribe or unsubscribe to particular topics?
    - Could this more targeted MailChimp approach coincide with the new website launch?
- Consider actively targeting Associate Members, to bring their own patient representatives to use MY data and join as Members.
- When Associate Members have been helped by use MY data, with a project or piece of work, consider asking them to write a summary that can be published in the newsletter.

Summary of actions, deadlines and responsible person(s)

Responsible person(s)	Action	Deadline
Elizabeth	Aim to launch the new version of the website in August. Ensure that the Executive Group is kept up to date on this timeframe and either progress or delays.	Friday, 15 August
Elizabeth	Revise the newsletter content/format to suit more Members, with the aim to launch a new version in September.	Friday, 19 September

Part 3 **Repositioning use MY data**

Intended output from this item:

- Repositioning – decision on how to do this and the timescale

Along with the outcomes of Parts 1 and 2, the Executive Group considered the following ideas.

3.1 Should use MY data now endorse research studies and/or find Members to work with the researchers (charging fee may apply)?

- The Secretariat outlined that they are already doing this, via producing letters of support for researchers to use in their grant submissions – once the researchers have signed up to our Standards for engagement with external organisations, Transparency Principles and Position Statements.
- Alison apologised for not keeping the Executive Group up to date about this aspect of the Secretariat's work. The Secretariat will endeavour to report back on this avenue of support to researchers, including via the monthly engagement update.

3.2 Should use MY data offer a more defined 'safe space' for patient data discussions, to the commercial and public sector worlds? (For which a charging model may be used.)

- This has already been received positively by organisations wishing to engage with us, most recently in a session with UK Biobank.
- Our future engagement proposals to funders should explicitly include this offer of a discussion 'safe space'.
- When our Members are involved in these kinds of confidential discussions, as a minimum we publish that the talks are taking place. In addition, we could take two actions, to enhance understanding of why we take part in this type of discussion:
  - Add information to the website on why some discussions take place in this manner
  - Add a line about the discussions to the criteria within our Standards for engagement with external organisations.

3.3 Charitable status – what is or could be our Public Benefit?

- The Executive Group remains certain that use MY data will benefit from a charitable status.
- Education and active citizenship are relevant angles for a new submission; proving a direct and clearly identifiable public benefit is crucial.
- NPaDD is a great example of an event hosted for the benefit of the public.
- Feedback from the last application questioned whether we are qualified to train or be "the educators". The next submission needs to emphasis our focus on "education by experience" as well as the professional expertise of our trainers.
- Using the narrative on our new website will be an important factor in resubmission.
- A small writing committee (Richard S, Ceri and Yvonne) are working on a draft for our resubmission and aim to circulate this to the wider Executive Group by noon, 31 July.

3.4 Could use MY data create/sustain a network for public representatives on bodies/groups dealing with patient data issues and decisions (even if those representatives do not wish to join use MY data)?

- We should ask Members which other patient data related groups they sit on, to better understand where our Members have wider influence.
- Place a survey in the Thursday, 31 July newsletter to gather responses, ahead of taking this work forward in September.
- Include details of the potential network and the survey, in the next Chair's letter.

3.5 Could use MY data offer training for public representatives on behalf of academic or commercial entities, needing patient/public representatives?

- Chris needs to finish developing the training course modules – this work was delayed by other aspects of his work, including NPaDD.
- Would it be feasible to support a small set of our Members to complete the training and then to train others?
- We could provide a one-hour induction session for new Members.
- Organisations could pay a small fee in to an educational fund, which would be used to help

us to develop and then deliver a wider training session. This could be available to multiple organisations.
- We can help the ABPI (the Association of the British Pharmaceutical Industry) and its members to develop case studies and good stories.

3.6 Could a patient data training programme be a marketable asset?
- Yes, as covered in 3.5.

3.7 Are we still use MY data or do we need less of the 'MY' focus – Use My Data or even USE My data (or Use Our Data)?
- As Chair, Richard S had suggested that 'use MY data' needs to emphasise the use of data as much as the personal donation/security aspects emphasised by the word 'MY' in the logo, which might also be changed.

The Executive Group felt that as the new logo (to be launched with the new website) has already been approved, the nuancing of messaging around our name does not need to change.

Summary of actions, deadlines and responsible person(s)

Responsible person(s)	Action	Deadline
Richard, Ceri & Yvonne	Circulate their draft charitable status submission to the wider Executive Group.	Thursday, 31 July – by noon
Alison	Update the 'Standards for engagement…' criteria to reflect the element of our work that offers 'safe space' discussions.	Friday, 15 August
Alison	Arrange for an update on our website, describing our 'safe space' discussion work.	Friday, 15 August
Secretariat	Take forward the work of use MY data creating/sustaining a network for public representatives on bodies/groups dealing with patient data issues and decisions – in September.	Friday, 19 September
Richard S & Alison	Include details of this network and survey, in the next Chair's letter.	Friday, 19 September
Elizabeth	Put a survey in the newsletter on Thursday, 31 July, to find out which other patient data related groups our Members sit on.	Thursday, 31 July
Chris	Complete the development of the training course modules.	Friday, 31 October
Chris	Develop a one-hour online induction session for new Members.	Tuesday, 30 September

Part 4 **Infrastructure – Members, Exec Group & Secretariat**

Intended outputs from this item:
- Decision on roles for Members
- Decision on roles for Executive Group Members
- Plan for Secretariat's future

4.1 Proposed new structure, for consideration –
- Members – ambassador pool and/or specific roles
- Executive Group – slim down and/or assign roles to specific Members
- Secretariat – rework roles/address vacancies (present & impending)

The Executive Group discussed restructuring across all levels, to serve the needs of a repositioned use MY data.

Key discussion points and feedback from the Executive Group:
- Agreement that, based on current demand, we do need more staff
- Do we need a fundraising campaign? While this may be hard work, it is something that we may need to do.
- Jo offered the Secretariat short-term help via a team member at Ocular Melanoma UK, to talk through/advise on the skills we might need for expansion. This offer was readily accepted.
- We probably need to have a smaller group of Executive Group Members, with a larger group of Members actively involved in delivering use MY data's work.
- Alongside, we need to build a wider pool of Members, keen to represent use MY data. While this pool would be bigger and more representative, in practical terms it would not drive things – that would remain the role of the Executive Group.
- One structure could be a Council (e.g., 20 Members) plus a small Board of Trustees.
- There was agreement that, as the only independent patient data organisation in the UK, use MY data should become a hub for patients and patient groups with regard to patient-data activities.

Summary of actions, deadlines and responsible person(s)

Responsible person(s)	Action	Deadline
Jo & Alison	Follow-up discussion on help regarding expansion.	Thursday, 31 July
Richard S	Consider how best to take forward a new use MY data structure.	Thursday, 21 August

Any other business

a) **NHS 10-year health plan (England)**
David has produced a summary of the plan, in relation to use MY data's work (circulated to the Executive Group & Secretariat on 10 July).

a) **National Cancer Audit Collaborating Centre (NATCAN)**
As a result of NPaDD, several engagement opportunities have arisen and Alison presented one of the opportunities, which is with NATCAN, the National Cancer Audit Collaborating Centre. NATCAN has ten national cancer audits, each of which has their own, cancer specific PPI forums. There is a project underway (early stages) to develop a 'cross-NATCAN' group of PPI representatives. NATCAN are keen to "explore potential opportunities for our involvement – bringing our "impressive expertise in patient data" to feed into the PPI group and the work of NATCAN more broadly.

The Executive Group were positive about use MY data's involvement and the Secretariat exploring options, on behalf of use MY data. They would like the opportunity for the Executive Group to take part in sessions, explaining what they do for use MY data. They would be keen for any PPI vacancies at NATCAN to be advertised to use MY data Members.

A follow-on discussion examined how we might ensure our Members have the opportunity to take on roles, rather than the Executive Group representing use MY data for the majority of opportunities. A pool of people who are ready, able and willing to volunteer, is needed.

Summary of actions, deadlines and responsible person(s)

Responsible person(s)	Action	Deadline
Chris	Collate any further Executive Group responses on the 10-year plan and draft a summary, for publication.	Friday, 29 August
Alison	Liaise with NATCAN, to take the engagement opportunity forward and to ask if PPI vacancies can be advertised to use MY data Members.	Thursday, 31 July
Secretariat	Find more ways to open up formal engagement opportunities, to Members.	Friday, 19 September

Item 5.0

Date of next meeting

Confirmed meetings for the rest of the year:
- Monday 06 October 2025, 11:00 to 12:00, online
- Monday 24 November 2025, 10:45 to 15:00, London

The schedule was confirmed by all, with a request for an additional online meeting in September.

Summary of actions, deadlines and responsible person(s)

Responsible person(s)	Action	Deadline
Alison	Find a date for an online meeting, in September	Friday, 08 August

Suggestions for future meetings	
September Online – date TBC	Standing items ▪ Core funding situation & financial status/future Key items ▪ NPaDD2026 decision
Mon, 06 October 11:00 to 12:00 online	Standing items ▪ Core funding situation & financial status/future Key items
Mon, 24 November 10:45 to 15:00 London	Standing items ▪ Core funding situation & financial status/future Key items ▪ xxxx ▪ xxxx