Executive Group & Secretariat - Online meeting

Wednesday, 21 May
12:00 to 13:30

Meeting notes – confirmed

Item 1.0	**Welcome, apologies & housekeeping** The Chair welcomed attendees and the meeting etiquette was agreed. **Attendees** · Executive Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Yvonne Adebola, John Marsh, David Snelson & Ceri Steele · Secretariat - Chris Carrigan, Elizabeth Lloyd-Owen & Alison Stone **Apologies** - Executive Group - Samina Begum & Jo Gumbs **Did not attend** - Richard Ballerand
Item 2.0	**Where we are heading: use MY data's internal work** To inform this discussion: · Core funding uncertainty – update from Chris · Charitable status & resubmission of application – update from Richard S Intended output from this item: · Core funding contingency plan for use MY data · Outline plan for the resubmission of the charity application, Autumn 2025 **Core funding uncertainty** We remain in the position of awaiting NHS England's (NHSE) decision on funding, following submitting our proposal for 2025 to 2026. On 21 May NHSE provided an update, to advise they will be suggesting amendments to parts of the proposal and will be back in touch with these. Our grant funding from Cancer Research UK (CRUK) will end in March 2026. We need to decide whether or not to apply for a further grant. If applying, a key aspect would be to highlight the ways in which use MY data is a unique resource in the patient data world. This is particularly pertinent as CRUK is forming its own Patient Data Group (of which John and Richard are Members). We have no contingency funds to call upon. Without receiving funding, our current forecast is that use MY data could continue until November 2025 at the latest and not beyond. Key feedback from Members of the Executive Group: · It is essential that our funding bids emphasise our uniqueness in the patient data work. Yvonne will be working with Chris over the next few weeks to explore how use MY data's unique selling point (USP) can add value to the evolving patient data landscape by mapping current needs, identifying key opportunities, and seeing how we could align our unique strengths to address emerging challenges. Summary of actions, deadlines and responsible person(s) · **Yvonne** – Liaise with Chris on the USP element of use MY data, with next stage of this work to be completed by Tuesday, 08 July.

	Charitable status & resubmission of application Richard provided an update, with the view that key to a resubmission is to establish the benefit that use MY data has for the public. We have yet to show that our work benefits the public directly. Rather we have demonstrated that we benefit organisations who make the decisions that benefit the public. The Executive Group discussed this, with the key points: · Important to remember that Members were in favour of use MY data having a charitable status. · Obtaining the status is central to obtaining grant funding in the future. · We do provide consultancy services to policymakers. So there is an overtly commercial potential in the work that use MY data does, which does not rule out becoming a charity. · A key part of our work that benefits the public is our strong education stream, which should be emphasised. Do we have the resources to scale this up, though? · It may still be tenable to resubmit an application in the Autumn. Further discussion should be postponed until we have re-positioned ourselves over the next few months and our funding is secure – at present all efforts should be focussed on NPaDD and securing core funding. · It should be possible to draft some parts of the charitable status application in advance and it would be useful for a small subset of the Executive Group to work on this. Summary of actions, deadlines and responsible person(s) · **Richard** – Lead on forming a small sub-group of the Executive Group, to begin drafting our charitable status application. The deadline to form the group is Friday, 13 June. · **Alison** – Ensure the next Executive Group & Secretariat meeting (14 July) includes a focus on the potential re-positioning of use MY data and, in tandem, our charitable status application.
Item 3.0	**Where we are heading: use MY data's external work** To inform this discussion: · NPaDD update, including funding, registrations & promotion – Secretariat · Health Data Research Service & use MY data – guide paper from Chris · External engagement work – update from Alison Intended outputs from this item: · Decision on next steps for NPaDD preparations · Proposal for involvement with the Health Data Research Service · Obtaining Executive Group steer for key engagement items **National Patient Data Day (NPaDD) update, including funding, registrations & promotion** Funding – this is currently in a healthy position, with sponsorship secured. The interest in sponsoring has been very positive and gratefully received. We have a mix of gold sponsors, silver sponsors and some bespoke sponsorship arrangements. With the sponsors and registration fees, we are currently on track to break even. Registrations – as of 21 May, 119 people are registered. This includes 29 Members and 7 patients/ members of the public outside use MY data. The number of Members interested is lower than anticipated (we were holding 80 places in total). However, the Secretariat knows of several Members who have indicated they will register but have yet to do so. The Secretariat anticipates that we will have between 225 and 250 delegate registrations in total. Promotion - Elizabeth gave an overview of the promotional work, for which the largest impact should be felt in early June. The next newsletter could include a survey to Members, focussed on reasons that they have not registered. Programme – All of the key speaker slots are filled, with just the co-chair of the opening plenary to confirm (as the confirmed co-chair needed to withdraw). Ten roundtable themes are confirmed, with two awaited. For the Patient Data Soapbox – there are five places in total and, to date, expressions of interest have been received from three delegates. Key discussions points and decisions from the Executive Group: · Reasons for the lower-than-expected registrations of patient/public registrations were discussed

and whether or not location is a factor (not on the evidence of previous in-person events).
- Sponsors, speakers and exhibitors will be expecting to have a significant number of delegates to interactive with, including use MY data Members – it's important that we provide this (for them and for our reputation).
- Richard offered to write to Members who have expressed interest and not yet registered. It was agreed that this could breach personal confidentiality, instead the Secretariat will follow up with Members who have expressed interest in attending. Executive Group Members suggested that Richard could produce another (short and focused) Chair's letter, and/or record a video message to Members.
- We feature in a Financial Times online article, published online on 20 May [further details are in the 'Any Other Business' section], for which several follow-on comments have been published. We could consider adding a comment indicating that NPaDD will be a good forum for the patient data discussion to continue.
- Agreement that we continue with plans, using all routes to publicise the event. This includes contacting Cancer Research UK to seek further help in promoting to their patient contacts and all colleagues for whom the conference is relevant.
- Post-event, we need to obtain feedback to inform discussions for our July meeting – this should include obtaining feedback from exhibitors and sponsors and finding out if they would be onboard for a repeat event.

Summary of actions, deadlines and responsible person(s)
- **Elizabeth** – Contact Cancer Research UK to follow-up about NPaDD promotion.
- **Elizabeth** – Follow up on Financial Times article comment/NPaDD promotion.
- **Richard & Secretariat** – Produce a Chair's message to Members (via a letter, video, or both).
- **Secretariat** – Ensure post-conference work includes surveying exhibitors/sponsors.
- **Executive Group Members** – Update Georgina about 23 June accommodation, if not yet booked.

Health Data Research Service & use MY data
Chris ran through the overview paper on the new Health Data Research Service (HDRS), which had been circulated prior to meeting for comment/input from the Executive Group.

Those who commented on the paper, all agreed that use MY data needs to make itself known to those who will be in charge of developing/running the HDRS and to suggest where we can and should fit in. Whilst all of the advancements in health data for patients are positive, what patients want to see is impact **now** – use MY data is best placed to help the HDRS deliver for those patients, including explaining the research and/or the safeguards around access.

Discussion and key points
- At present, information about the strategy of the HDRS, or of its leadership, is not available and therefore it is difficult for use MY data to offer specific input. However, we can welcome and support the concept of the HDRS, in tandem with highlighting the need for patient involvement - we are ready to provide patient input and leadership. The HDRS is UK-wide and so are we, therefore we can help to steer a UK-wide patient data project, for public benefit.
- We would best serve the Members by producing a Position Statement and sending this to all relevant stakeholders. John, Richard and Chris offered to produce this, and to work on the accompanying letter – both to be ready by Friday, 30 May.
- The Executive Group suggested sending the Position Statement to around 40 stakeholders. Regrettably, the Secretariat's time in June will not permit this. The Secretariat will review diaries to determine the amount of time available for dissemination of the Position Statement. The Executive Group suggested a compromise would be to have the Position Statement on the website before NPaDD, thus making it public for all attendees at the event.

Summary of actions, deadlines and responsible person(s)
- **Richard S & Chris** – Health Data Research Service - lead on producing a Position Statement and accompanying letter, by the end of Friday, 30 May.
- **Alison** – Health Data Research Service – lead on assessing the Secretariat's time to disseminate the Position Statement to stakeholders and/or place it on our website. Update the Executive Group with the outcome of the assessment.

	External engagement work Alongside our formal places on committees/boards, we are continuing to receive a steady stream of invitations to take part in external events. Alison gave a quick round-up of upcoming events: · Hybrid community workshop in Glossop, Derbyshire with patients and professionals to discuss patient access to personal health records - 06 June · Cancer Research UK - PPIE webinar – 16 July (rearranged from 05 June) · Health Data Research UK Conference – 15 & 16 October, Glasgow – we will be exhibiting · Cancer Research UK - Data-Driven Cancer Research Conference, 24 to 26 February 2026, Edinburgh – our role/presence is to be confirmed (we have offered a range of ideas). Key points: · Clarity sought on how Chris is invited to take part in events – is it with a use MY data hat, or as an independent data expert? Chris explained that it can be either of those options. However when receiving an invitation on behalf of use MY data, he will always ask the organisers to include a Member on the agenda - either instead of him, or alongside him. · use MY data made its debut at European Biobanking Week (EBW), which ran from 13 to 16 May in Bologna. We were represented by Richard, who presented a poster which was highly commended. Richard gave a three-minute poster presentation, for which he received a judges' commendation for "the most enthusiastic and entertaining" presentation at EBW.
Item 4.0	**Any other business** a) **UK Health Data Research Alliance - Executive Committee (AEC)** Richard Ballerand represents use MY data on the Committee and, on his behalf, Alison asked if the Executive Group had any items to suggest for the next AEC meeting on 12 June. b) **Financial Times article featuring use MY data** We featured in an online Financial Times (FT) article, published on Tuesday, 20 May - 'Patient data could power the NHS. Much of it is still stuck on paper'. The article features David and references use MY data. David and Chris both contributed to the article, via an interview and input into the graphics, respectively. As the FT is behind a paywall, Elizabeth is liaising with the journalist to obtain a copy to share with Members and we will receive this once the article is published in print. It would be good to highlight the article on the homepage of our website. Summary of actions, deadlines and responsible person(s) · **Elizabeth** – Comment on the FT article, highlighting NPaDD as a forum for follow-on discussions. · **Elizabeth** – Share the FT article with Members, once the print copy is received. · **Chris** – Add the FT article to the homepage of the website.
Item 5.0	**Date of next meeting** Confirmed meetings for the rest of the year: · Monday, 14 July, 10:45 to 15:00, London · Monday 06 October 2025, 11:00 to 12:00, online · Monday 24 November 2025, 10:45 to 15:00, London

Suggestions for future meetings	
Mon, 14 July 10:45 to 15:00 In-person	Standing items ・Core funding situation & financial status/future Key items ・NPaDD feedback ・Charitable status next steps ・Role & remit of use MY data