

Executive Group & Secretariat - Online meeting

**Wednesday, 20 September 2023
11:00 to 12:30**

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), Jo Gumbs, John Marsh, David Snelson, Pete Wheatstone Secretariat - Chris Carrigan, Alison Stone</p> <p>Apologies: Richard Ballerand, Samina Begum</p> <p>Did not attend (apologies received post-meeting): Sarah Markham</p>	<p>Richard S</p>
<p>Item 2.0</p>	<p>Funding & recruitment</p> <p>For update</p> <p>a. Funding - NHS England b. Funding impact on work programme & recruitment plans</p> <p>use MY data’s funding from NHS England (NHSE) was due to be renewed from September 2023 to August 2024. This has not yet been renewed. NHSE is still keen to provide the funding; the difficulty is trying to work out the best route for this. Previously, this funding was processed/hosted via Leeds University and this is no longer an option. One possibility is for the money to be routed via an Academic Health Science Network (ASHN). Chris has a call on 22 September with an ASHN, to discuss possibilities.</p> <p>The amount of funding from NHSE is expected to be £49,330. The funding is intended to cover Alison’s role and to provide honoraria for use MY data Members who take part in work with NHSE. Due to the large overhead that Leeds took for 2022/2023, there was no funding for honoraria in that period.</p> <p>Chris presented a short-term financial forecast for the Executive Group’s brief review, ahead of circulating after the meeting. NHSE’s funding for 2023/2024 was not included in this forecast. Without NHSE’s funding we have enough money in the bank to take us through to the end of April 2024. Beyond that date we do not have funding for Alison’s role. If we do receive the funding, it should take us to the end of 2024 and beyond.</p> <p>Due to the funding uncertainty, the Secretariat has needed to pause recruitment to the Administrator role.</p> <p>Chris was asked about the funding for his role. Chris self-funds his role, which he is happy to do and recoups expenses as necessary (which are primarily for travel). Some Executive Group Members felt that, as a minimum, Chris should consider claiming an honorarium for formal meetings, which Chris said he would consider alongside seeing if there were funds for this. The Executive Group felt it was important that the option should at least be reflected in the budget.</p>	<p>Chris Alison</p>

	<p>There was agreement that the November meeting agenda should include an item on finance, funding/fund-raising and staffing - with time for this to be a longer discussion.</p> <p>c. Summary of actions</p> <ul style="list-style-type: none"> · Chris - Circulate the short-term financial review to the Executive Group. · Alison - Add finance, funding and staffing to the November meeting agenda, for a longer, strategic review. 	
<p>Item 3.0</p>	<p>Strategic direction of use MY data</p> <p>For update</p> <p>a. Executive Group recruitment Alison updated the Group on the very recent recruitment for the Executive Group. This followed Richard’s August briefing to Members, which highlighted the vacancy on the Group and which led to three people expressing interest in the vacancy.</p> <p>Interviews took place on 18 September, with Chris, Alison, Richard and Dave interviewing and with the result that Ceri Steele was invited to join the Group. Ceri has a research background and has been part of the patient data world for around six months and will bring fresh eyes and perspectives to the Executive Group’s work. Ceri’s start date will be Monday, 02 October, for which Alison is putting an induction programme together.</p> <p>For discussion</p> <p>b. Charitable status paper & FAQs Jo & Dave gave apologies that they have not yet been able to do this piece of work. The paper will be ready for the November meeting and it will be ready for circulation ahead of the meeting.</p> <p>c. Executive Group expansion/refresh - timing and personnel resources Alison gave a quick look ahead to 2024, when the current three-year terms for most Executive Group Members will come to an end. The roles of Chair and Vice Chair are also due to be refreshed. There will be an option to step down or apply to stay on, for a further term. When the Group does reach this point and if new Members are sought, it will be important to look at representation of our Members on the Group. The gaps at present are representation from Northern Ireland, Scotland and Wales and from ethnic minorities.</p> <p>The Executive Group and Secretariat need to decide together on the best way forward, for refreshing/recruiting Members. Ideally, any recruitment should be staggered, to avoid the situation of most Members leaving in one go. If current Members do renew, ideally this would be staggered i.e., some Members renew for one year, others for two years.</p> <p>The Group does not have Terms of Reference, at present. Previously, when the Group had an Advisory, rather than Executive function, the Group and Secretariat followed ‘Ways of Working’ guidance. It would be good to have a framework paper to bring to the November meeting. This is with an eye on us having a charitable status in future. A record of when people joined is ideal - Alison has this already and will build it into the framework.</p> <p>d. Summary of actions</p> <ul style="list-style-type: none"> · Alison - Write a framework for the November meeting on how use MY data might be managed and led, ahead of the refresh of the Executive Group. 	<p>Alison</p> <p>Dave Jo</p>

<p>Item 4.0</p>	<p>Engagement & events</p> <p>For discussion</p> <p>a. use MY data’s work on the General Practice Data for Planning & Research</p> <p>The Executive Group reviewed and discussed in full, use MY data’s position on the Patient and Public Engagement and Communications Advisory Group Panel (PPECAP). A draft position statement, written by Richard S, had been circulated for the Executive Group’s consideration, prior to meeting.</p> <p>The discussion covered a range of aspects relating to our involvement with PPECAP and the ongoing difficulties of the 02 March Awayday notes remaining unpublished. While NHSE has committed to publishing the notes, there is no set date for publication (regrettably, previous deadlines were not met). This has resulted in the opinions of patients, on the Federated Data Programme, not being publicly known.</p> <p>Key aspects of the discussion:</p> <ul style="list-style-type: none"> • An update from our representative at the 14 September PPECAP meeting, included a quick recap of where the programme is at present. Information received at that meeting indicates that two different groups are being set up alongside PPECAP - one for the Federated Data Platform (FDP) and one for a large-scale public involvement group. • We have been giving consistent advice for 6 months now and have spent much time on this work. When the project started, the focus was on public engagement about GP data and, after covid, there was an opportunity to build on that and communicate very overtly about the benefits of using data. This is what we had very much hoped to contribute towards, in an effective way. • We have no difficulty in our advice being disregarded, as long as this is all on record. The difficulty remains that our views have been/remain withheld and our advice is not available publicly. We are working in a way which is at odds with our Transparency Principles. • NHSE had offered to produce an interim set of notes for the 02 March Awayday, which would focus on the principles discussed on the day, rather than the system models. use MY data’s Panel Pool felt that this would not be enough to satisfy our Transparency Principles. • The Terms of Reference (ToR) for PPECAP were reviewed, with regard to the publication of notes. Although the ToR state that “...agendas and action notes will be published...” it does not say when publication will be. With hindsight, this is a point on which we should have sought clarity, before signing up to the ToR. • The bureaucracy of being a patient/public Member of PPECAP is prohibitive - there has been an enormous amount of time spent on needless personal administration, for very little gain. Patient/public representatives are required to be on a zero-hours contract and this brings potential difficulties of appearing to be “contracted to be compliant”. • The very large amount of time spent on PPECAP discussions around transparency, has resulted in less time for engagement in other areas. • If we step down from PPECAP, we must follow our positive engagement strategy, with regard to any communication. We do want to continue to help and advise NHSE, as a trusted patient voice, across as many patient data areas as possible. There was a keenness to be able to input into one of the two new groups, although we would need to understand much more about the groups, before we could consider joining. 	<p>Richard Dave David John</p> <p>Chris Elizabeth Alison</p>
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Following a full discussion and review of the situation, the Executive Group arrived at the difficult and regretful decision to withdraw from PPECAP, due to NHSE's decision not to publish the 02 March Awayday notes and the conflict this has created with our Transparency Principles. We continue to support the principle of what NHSE is trying to do - to make GP data more available for research - and we would be interested in exploring the possibilities of supporting the proposed group on communication.

Richard and Alison will ensure that NHSE is informed of the decision by 22 September at the latest.

- **Post-meeting note**

On 21 September - use MY data's decision letter was sent to NHS England.

On 25 September - NHS England and use MY data met at a follow-up meeting, with key points from the discussion:

- 1) NHS England confirmed they would go ahead with creating a set of notes for the Awayday workshop. These were received on 05 October in confidence for the review of our Awayday attendees. Their comments were sent to NHS England on 12 October.
- 2) NHS England clarified that use MY data's understanding of the format of future patient engagement was incorrect - rather than three separate groups, the Federated Data Platform and Data Saves Lives engagement work would sit within PPECAP.

Although we have left PPECAP, use MY data wishes to assist NHS England's work on the GDPR and we will continue to explore this with NHS England.

- b. **Educational sessions & events for 2023**

The sessions are going well, with recent ones including Flatiron Health and the UK Health Data Research Alliance. The purpose of the session on the Alliance was specifically to give Members information about the Alliance, so they could then decide whether use MY data should join it.

For the Flatiron session, there is a delay in publishing the recording due to the inclusion of some confidential information within Flatiron's slides. Chris is working out how best to resolve this, so the recording can be shared with Members. Chris has also suggested that Flatiron might do a follow-up session, to show the details of the patient data they hold. This is with Flatiron for consideration.

Upcoming sessions will be on Population Health Management and Social Care Data in Scotland. Chris and Elizabeth are working out dates and details, ahead of circulating the information to our Members.

There are lots of requests coming in, for sessions that can help people with their research and aid grant applications. One of the challenges on grant applications is the timeline - how nimble we can be in organising sessions and whether we should formalise the sessions, as an offering? The sessions can be organised quite quickly. It's essential that the sessions have an educational element, for the benefit of Members. From a comms perspective, it is good to be able to promote that we are helping organisations. It would be good to bring this to the November meeting, for a strategic discussion.

Webinar - There was a brief discussion about when the next use MY data webinar should be and a possible topic. PPI contributions to research projects could be one topic (and which Members could contribute to) - what is a PPI contribution to data projects, what sort of things could PPI people be involved in? This could be opened out much more widely. It could result in a standard which, if nothing else, would act as a template for us, against which we can look at future proposals and use to influence. Timing wise, it would be realistic to host a webinar in the spring. We definitely need to learn to market ourselves better than we currently do.

	<p>For update</p> <p>c. Update on discussions with national organisations</p> <p>3) Chris gave an update on his work as part of the National Data Advisory Group. For transparency, the groups on which Chris sits as our Data Adviser are now listed on the website.</p> <p>4) The Secretariat has recently been approached by a department within NHS England, about use MY data's potential involvement with a new group. Full details will be sent to the Executive Group for their review and consideration of use MY data's involvement.</p> <p>d. Update on Secretariat's six-point engagement plan</p> <p>The next stage of this plan is to focus on the devolved nations. The Secretariat is now working on how best to take this forward. Elizabeth gave a brief update on areas of communications.</p> <p>5) The newsletter is going well, with positive feedback received from readers. Statistics show that a large percentage of Members and Associate Members open it upon delivery.</p> <p>6) Elizabeth is setting up a LinkedIn page for use MY data, which will be a useful platform, when finalised. As part of the work to focus on the devolved nations, Elizabeth would like to produce newsletter editions focused on each nation and to liaise with our Members and Associate Members in those nations, to seek their help and input.</p> <p>7) The communications plan is written and being worked through. The next goal, as part of that, is the strategic element of who are we talking to/being directed at?</p> <p>e. Summary of actions</p> <ul style="list-style-type: none"> • Alison & Richard - Write to NHS England with an update about the PPECAP decision, by 22 September. • Alison - Ensure a strategic focus of the education sessions is on the November meeting agenda. • Elizabeth - Take forward the idea for a spring webinar on the PPI contribution to data projects. 	
Item 5.0	<p>Any other business</p> <p>a) Understanding Patient Data Tender</p> <p>Understanding Patient Data (UPD) is hosting a tender process for the project 'What are the best words to use about health data?' use MY data has been approached to see if there would be interest in partnering on a bid, with two organisations (one of which involves use MY data Members).</p> <p>The Executive Group felt that, in principle, this is a good opportunity for use MY data and that the Secretariat should explore the opportunity, bearing in mind pressure on resources. On that note, the opportunity doesn't have to involve the Secretariat - the Executive Group could take it on board. If use MY data is part of a successful bid, the Secretariat could put out a call out for volunteers to take the work forward.</p> <p>b) Summary of actions</p> <ul style="list-style-type: none"> • Alison & Chris - Explore the opportunity for use MY data to be part of a tender bid, for UPD's project 'What are the best words to use about health data?' If the bid is successful, put a call out for use MY data volunteers. 	Richard S
Item 6.0	<p>Date of next meetings</p> <p>Wednesday, 29 November, 10:45 to 15:00 - in-person, London</p> <p>Health Data Research UK has offered to provide meeting facilities and this offer has been received with gratitude.</p>	Alison

	<p>Dates for 2024 - quick look ahead</p> <p>There was consensus to retain the format of six meetings for the year, alternating between 90 minutes online and all-day in-person meetings. Perhaps with some additional monthly online meetings, on one topic, as needed.</p> <p>In-person meetings could be in London or Leeds, depending on convenience for attendees and available funds to support travel/accommodation. It is important to have an option to join these meetings online, to ensure they are accessible. The location of in-person meetings can be revisited, when we know the shape of the Executive Group in 2024 (including location of Members).</p>	
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Suggestions for future meetings		
<p>29 Nov In-person</p>	<p>Key items</p> <ul style="list-style-type: none"> • Members' Census planning, for discussion • Finance, funding/fund-raising and staffing • Executive Group - a framework for leading use MY data • Education sessions - from a strategic viewpoint <p>Standing items</p> <ul style="list-style-type: none"> • Update on funding • Update on discussions with national organisations 	