

Executive Group & Secretariat - Online meeting

**Monday, 22 January 2024
10:30 to 12:00**

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), Richard Ballerand, Samina Begum, Jo Gumbs, Sarah Markham, John Marsh, David Snelson, Ceri Steele Secretariat - Chris Carrigan, Elizabeth Lloyd-Owen, Alison Stone</p> <p>Record of thanks Pete Wheatstone, a long-serving Executive Group Member, has stepped down from this role (a little in advance of the term ending, giving extra time to help the Secretariat and Executive Group with the refresh/renewal process). Pete's dedication, time and contribution to the Executive Group and use MY data were acknowledged, with thanks.</p>	<p>Richard S</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"> · Updated engagement programme for 2024 · Updated events programme for 2024 <p>To inform this discussion:</p> <ul style="list-style-type: none"> · Discussions with national organisations - update from Chris & Alison · Engagement programme 2024 - update from Alison · Events programme 2024 - paper & update from Elizabeth <p>Discussions with national organisations The Secretariat gave a brief overview of their recent engagement work with national organisations on behalf of use MY data, since the last meeting:</p> <ul style="list-style-type: none"> · Department for Health and Social Care - Data Policy Department · NHS England - Data & Analytics Directorate - Research Advisory Group · Health Data Research UK - Director of Communications & External Affairs & Head of Public Involvement and Engagement · PEDRI (Public Engagement in Data Research Initiative) & Alliance - Public Involvement and Engagement Working Group · National Disease Registration Service (for England) · Understanding Patient Data - Steering Group. <p>Key questions and follow-up points from the Executive:</p> <ul style="list-style-type: none"> · It is important that details of the Secretariat's roles on national organisations and national engagement work is included on use MY data's website. · use MY data's letter to the CEO of NHS England about the Federated Data Platform - in response to the question about whether a reply has been received, Alison advised that this is awaited. · use MY data's work as part of the GP Data Patient and Public Engagement and Communications Advisory Panel (PPECAP) meant that our representatives on the panel needed to be employed on zero hours contract and now require P45s - the representatives are keen to receive these now. 	<p>Alison Chris Elizabeth</p>

- Research Advisory Group - the Executive is keen that representatives will not be required to be on zero hours contracts for this work and requested details of the arrangements, including for honoraria.
- PEDRI & Alliance Group - the Executive Group would welcome Elizabeth attending the next meeting (February).
- Professor Cathie Sudlow's review 'Unifying Health Data in the UK' - have the results been published? There is an invitation pending for Cathie to take part in an Education Session about the Review's results.

Engagement schedule for 2024

Alison had not produced a written schedule, as there are so many overlaps with the events schedule and due to the fluidity of the engagement work. In addition to engagement arrangements currently in place and ensuring there is time and attention for any new engagement approaches to use MY data, Alison is proactively seeking to expand use MY data's work in the devolved nations this year.

Events programme for 2024

Elizabeth gave an overview of the updated programme, highlighting some key aspects.

- Spring webinar (public facing) - the proposed UK Biobank webinar is not going ahead. An alternative webinar theme is unpicking the facts behind patient data headlines in the media. This is proposed for March and Elizabeth is currently exploring possible speakers from the media, as a starter.
- Education Session - the first of the year, 'What does my patient data look like', will take place on Friday, 26 January and there is good interest from Members.
- Education Session - a session with Genomics England is pencilled in for March.
- Cancer Research UK's Data-driven cancer research conference, in February - our presence will include Members attending, Members taking part in the programme (Richard S & Debbie Keatley) and the Secretariat hosting an exhibition stand. The Secretariat is working on materials and merchandise and on finding the best ways to bring together our Members who are attending.
- Health Data Research UK Conference, March 2024 - use MY data will have an exhibition stand.
- Patient data training day - Spring onwards, two sessions are being planned, with one session in the North and one in the South. The Secretariat and Ceri are working on the draft programme.
- Patient data event (public facing), Summer - the event, topic and venue are to be confirmed (Leeds is a possible location). Going forward depends on a sponsor.
- Dragon's Den session with a researcher, Autumn - suggested topics would be welcome from the Executive.
- Autumn/Winter webinar (public facing) - topic to be decided later this year.
- Education Session topics for April onwards:
 - Statistical terms - a rerun of a previous session (with Ceri's help)
 - NHS DigiTrials data
 - Who owns patient data
 - Unifying health data in the UK - results of the review.

Key points from the Executive Group:

- Cancer Research UK Research Data Conference - Jo will be co-chairing a session at the conference on day one and hopes to attend on day two as well and is keen to help with the exhibition stand if so. She would like to be badged as both OcuMel UK and use MY data on the programme.
- Spring webinar - It would be good to involve use MY data Members with a journalistic background.
- Consider linking up some strands of the programme i.e., would Professor Sudlow like to speak at a use MY data event this Summer, thus generating media coverage for her Review and for us, and helping to attract the external sponsors needed for the event to go ahead.
- The Covid-19 information on our website is a little out of date - this page would be a good place to post Health Data Research UK & the University of Edinburgh's new UK-wide research on the impact of Covid-19 under-vaccination.

	<p>Summary of actions, deadlines and responsible person(s)</p> <ul style="list-style-type: none"> • Alison - ‘Unifying Health Data in the UK’ review - contact Professor Cathie Sudlow about the results • Alison - Contact NHS England to request the P45s for PPECAP representatives. • Alison - Research Advisory Group - double-check on honoraria arrangements. • Elizabeth - PEDRI & Alliance Working Group - attend the next meeting. • Jo - Cancer Research UK Conference - contact the organisers to request being badged on the programme as representing OcuMel UK and use MY data. • Elizabeth - Covid-19 website page - update this with details of the recent Covid-19 research study. • Elizabeth - March webinar - invite Members(s) with a journalistic background to take part. 	
<p>Item 3.0</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"> • Confirmation of Executive Group refresh of terms/expansion • Decision on census timings • Confirmation of patient data training for Members & Executive Group <p>To inform this discussion:</p> <ul style="list-style-type: none"> • Executive Group Members’ terms - update from Alison • Census timelines - paper & update from Alison • Patient data training sessions - update from Chris <p>Confirmation of Executive Group refresh of terms/expansion</p> <p>As directed by the Executive Group at the 29 November meeting, Alison has contacted all Members whose three-year term ends on 14 February 2024. Preliminary responses indicate that there will naturally be a small refresh of the Executive Group.</p> <p>There is the potential to bring a new Member onboard. This is a Member who applied to join the Executive in the previous recruitment round and, for a technical reason, could not join at that time. The Member has continued to express interest in the role and have been proactively volunteering their time and experience to assist use MY data and the Secretariat. The Executive Group asked Alison to contact the Member and discuss the possibility of joining the Executive Group.</p> <p>Decision on census timings</p> <p>Alison presented an updated proposal for the census objectives and timelines, following advice received at the 29 November meeting. The timelines would be such that the census would run from mid-April to mid-May, preliminary results would be presented at the 22 May Executive Group and Secretariat meeting and a workplan defined to take forward the objectives of the census. By mid-June a full report would be presented to Members and the follow-up work would begin.</p> <p>Timelines for the charitable status paper were touched upon, to ensure that plans for the charitable status and census work do not impact adversely on each other. Ideally, the charitable status paper would be with Members in time for responses to be received and collated to take to the 22 May meeting. Once the charitable status is decided upon, taking the work forward will depend on the appointment of the administrator but at least the direction that use MY data will go in, will be known.</p> <p>Dave and Jo are working on the paper and this will be sent to the Executive Group, for sign-off, as soon as possible and by noon on Friday, 26 January if at all possible.</p> <p>Confirmation of patient data training for Members & Executive Group</p> <p>As touched upon in the events overview, planning for the patient data training sessions for Members and for the Executive Group is underway. The Secretariat wants the sessions to be usable as possible.</p>	

In order for the sessions to run well, there will be a limit of thirty delegates per session. If there is more interest than places available, criteria will be needed to select delegates. This will include seeking information on how attendees will use the information to benefit themselves and use MY data. The merits of using the sessions as a marketing tool were briefly discussed and decided against at this stage - the primary purpose of the sessions is to benefit Members.

The future possibility of Members receiving 'points' (similar to the Continued Professional Development programme) for attending different events and training for use MY data, was discussed.

The Executive Group asked how much information is known/recorded about Members when they join, thinking about building up a picture, to aid use MY data's work. Detailed demographic information for Members is not recorded at present - only the information that Members offer when they sign-up to use MY data. There was strong agreement that, at all times, we must be extremely sensitive about Members' data.

Summary of actions, deadlines and responsible person(s)

- **Alison** - Executive Group membership - make contact with the use MY data Member who applied on the previous interview round.
- **Dave & Jo** - Charitable status paper - circulate to the Executive Group and the Secretariat by noon on Friday, 26 January, if possible.
- **Alison** - Charitable status paper review & census results - plan for the results of both to be brought to the 22 May Executive Group & Secretariat meeting.

Item
4.0

Any other business

a) Funding

Chris gave a quick update about the funding from NHS England that is awaited. The East of England Health Innovation Network (HIN), where the funding will be placed by NHS England, sent an update on 15 January that they should be in a position for the funding to flow to us, within a couple of weeks. Recruitment for the administrator role remains on hold until this funding is in place.

b) Expanding the Membership

Richard B is a fellow of The European Patients' Academy on Therapeutic Innovation (EUPATI) - a programme that "provides education and training to increase the capacity and capability of patients and patient representatives to understand and meaningfully contribute to medicines research and development (R&D), and to improve the availability of medical information for patients...". Data training is offered and will bring together UK fellows who want to be involved in patient training. Richard is part of work to launch an England platform for the programme (which is a current gap) towards the end of April. Richard will send more information as it arises. Executive Group Members who have used the online (free) toolbox commented on how useful it is. There could be scope within this work/training to expand the Membership and for our Members to benefit from using the toolbox - it would be useful to highlight this in a future newsletter.

c) Palantir

In response to a query about current communications with Palantir, Alison gave a quick overview. She liaised with Palantir at the end of December, to follow-up about their actions arising from our 02 November meeting with them. Palantir has advised that, at present, they cannot take part in an Education Session for Members about the Federated Data Platform (FDP), due to the terms of their contract with NHS England. Other actions for Palantir remain outstanding and the status of these is unknown. The Executive Group concluded that it would not be worth pursuing these actions further, given the constraints of the contract with NHS England.

	<p>d) Researcher’s request for endorsement/support The Executive Group discussed a researcher’s request for use MY data to endorse and/or support their research fellowship application.</p> <p>The Executive Group felt that the proposed area of research was an important and timely one. However, they did not have enough information about the proposal on which to make a decision and had not been given enough time to consider the proposal. The design or methodology of the proposal was not shared (the Executive Group acknowledged that, while they should be championing the use of patient data in methodologically sound studies, the methodological evaluation itself is not their role). Additional requested information on how the researcher planned to include patients in the research had not been received, prior to the meeting.</p> <p>While emphasising their keenness for patient data to be used for research and their wish to do everything possible to support this, the Executive Group felt unable to give support to the proposal, for two key reasons:</p> <ol style="list-style-type: none"> 1. Not enough information was provided about the research proposal, on which to make an informed decision (e.g., which patient databases are to be used) 2. The timeframe given was too short for all Executive Group members to consider the proposal (with or without additional information). <p>Alison will feedback to the researcher, on behalf of the Executive Group, who asked her to pass on their good wishes for your application and hopes for its success. They would welcome reviewing future proposals, whether for research or to explore the PPI aspects suggested in this one, within a more appropriate timeframe.</p> <p>Clear guidelines are needed for assessing researchers’ requests for support. Sadly, requests for PPI involvement are often last minute. A set of criteria is needed (in the same vein that we have standards for engagement with external organisations), with the principles for a researcher to adopt throughout their work, including what good and timely involvement and engagement is.</p> <p>Elizabeth is planning for the new version of our website to have a section for researchers that will include the criteria/principles/information needed, ahead of researchers submitting applications for us to consider. We could create resources to proactively distribute to researchers.</p> <p>These existing standards which might be useful to consider: https://researchoutreach.org/articles/v2a2-tool-promote-patient-agency-effective-patient-information/</p> <p>Summary of actions, deadlines and responsible person(s)</p> <ul style="list-style-type: none"> • Richard B - Provide updates on the EUPATI work, including the April event • Elizabeth - Highlight the EUPATI toolbox to Members, via the newsletter • Alison - Research application - send feedback to the researcher • Alison - Develop draft guidelines for engagement with researchers 	
<p>Item 5.0</p>	<p>Date of next meetings - 05 mins</p> <p>Monday, 19 February, 13:00 to 14:00 - online (single topic meeting - only if needed) Monday, 18 March, 10:45 to 15:00 - in-person, London Wednesday, 24 April 10:00 to 11:00 - online (single topic meeting - only if needed) Wednesday, 22 May, 10:30 to 12:00 - online Monday, 17 June, 12:00 to 13:00, online (single topic meeting - only if needed) Wednesday, 31 July, 10:45 to 15:00, in-person London Wednesday, 25 September, 12:00 to 13:30, online</p>	<p>Alison</p>

Suggestions for future meetings	
Mon, 19 Feb 13:00 to 14:00 one hour, online	Key item - single topic meeting
Mon, 18 March 10:45 to 15:00 in-person	Key items Standing items <ul style="list-style-type: none"> · Update on funding · Update on discussions with national organisations
Weds 24 April 10:00 to 11:00 one hour, online	Key item - single topic meeting
Weds, 22 May 10:30 to 12:00 online	Key items <ul style="list-style-type: none"> · Census 2024 - review results & define work plan · Charitable status paper - review of Members' responses Standing items <ul style="list-style-type: none"> · Update on funding · Update on discussions with national organisations
Weds, 31 July 10:45 to 15L00 in-person	Key items Standing items <ul style="list-style-type: none"> · Update on funding · Update on discussions with national organisations
Weds, 25 Sept 12:00 to 13:30 online	Key items Standing items <ul style="list-style-type: none"> · Update on funding · Update on discussions with national organisations