

Executive Group & Secretariat - In-person meeting

Monday, 18 March 2024, 10:45 to 15:00
Friends House, London,

Meeting notes - confirmed

<p>Item 1.0</p>	<p>Welcome, housekeeping & apologies</p> <p>Attendees for the meeting were:</p> <ul style="list-style-type: none"> Executive Group - Dave Chuter (Vice Chair), Yvonne Adebole, Richard Ballerand, Samina Begum, Jo Gumbs, John Marsh, David Snelson & Ceri Steele Secretariat - Chris Carrigan, Elizabeth Lloyd-Owen & Alison Stone <p>Apologies received from:</p> <ul style="list-style-type: none"> Richard Stephens (Chair). <p>Dave, Executive Group Vice Chair, chaired the meeting, warmly welcoming all attendees and introducing Yvonne, the newest Member of the Executive Group. A round of introductions were made, with everyone sharing information about their route to working as part of the Executive Group on behalf of use MY data and the Secretariat giving details of their roles.</p>	<p>Dave</p>
<p>Item 2.0</p>	<p>Ways of working between the Secretariat & Executive Group Members</p> <p>Intended output from this item</p> <ul style="list-style-type: none"> Sign-off of the Ways of Working document. <p>Background</p> <ul style="list-style-type: none"> The Secretariat had recently updated the Ways of Working document and circulated this to the Executive Group for their review, ahead of meeting. The document is intended to be a useful guide on the best ways of working between the Executive Group and Secretariat, with information about the roles and methods of communication that can be used. <p>Feedback from the Executive Group</p> <ul style="list-style-type: none"> The document begins by referencing ‘The unique selling point of use MY data’ and feedback was that the form of wording used for this, which emphasises that we are Member-led is not, on its own, the strongest unique selling point. Emphasis is also needed on our focus on patient data and that we are advocating for patient data to be used. The unique selling point should also emphasise that the Executive Group works for and links back to Members. <p>Decisions</p> <ul style="list-style-type: none"> The Ways of Working document was accepted, subject to the two changes requested by the Executive Group. <p>Summary of actions</p> <ul style="list-style-type: none"> Secretariat - Review and update the unique selling point of use MY data, then amend the Ways of Working document and circulate/publish this. 	<p>Secretariat</p>

Item 3.0	<p>Bigger picture - the changing landscape of patient involvement in data; light-touch review of use MY data's activities & priorities</p> <p>Intended output from this item</p> <ul style="list-style-type: none"> Understanding the current patient data landscape and where use MY data fits, alongside current activities, obligations, priorities and the outcomes of the Logic Model session hosted by Cancer Research UK. <p>Background</p> <ul style="list-style-type: none"> The Secretariat circulated a supporting paper on the current patient data landscape, in advance of meeting. One key aspect shown within the document, is that many patient data organisations began after us, but have overtaken us in terms of impact (as highlighted recently by one of our Members). Chris gave a brief overview of the paper and sought any questions. <p>Feedback from the Executive Group</p> <ul style="list-style-type: none"> Patient-data landscape document - suggestion to publish this on the website (recognising that the document would need to be kept up-to-date, if so). Ahead of any publication it needs to be updated to add MedConfidential. Our Membership numbers are small (Associate Member numbers are growing faster than Members) and we do need to try to grow, while keeping an eye on Members joining because they believe in our mission and vision and have experience of patient data. Our 'joining page' could be revamped to reflect this. Some key ideas were given about growing the number of our Members. <ul style="list-style-type: none"> Consider engaging with the National Association for Patient Participation Using the upcoming revamped use MY data website Use our public webinars as a way of sending follow-up information to those attendees not yet connected with use MY data Consider sponsoring a piece on Facebook Ask new Members what they can do for use MY data, as well as saying what we can do for them - provide a guide for how Members can best engage/promote Our newsletter is sometimes forwarded on to people outside of use MY data - we could try to connect with those people it is forwarded to Posting the newsletter on LinkedIn, after it has gone to Members, as a way of attracting people to use MY data (Elizabeth would like to trial this) Executive Group Members could spread the word at a regional data level, i.e. via local Integrated Care Board (ICB) Digital Assemblies (David hopes to attend his local one, as a test of this method) Consider attending non-medical events, e.g. a book festival, for promotion Consider connecting more directly with Cancer52 and Genetic Alliance (we have connections with these organisations already - direct approaches are needed). Data for young people and children - this is an important area for us to be involved with. We need to do this via connecting with other organisations' work, rather than bringing children/young people directly into use MY data. Formal roles currently held by use MY data (and for which the engagement page on our website could be refreshed to include these): <ul style="list-style-type: none"> Research Advisory Group, NHS England - we have a place on both the Data Enabled Research Advisory Group (DERAG) and the Stakeholder data-enabled research advisory group (Stakeholder RAG or SRAG) UK Health Data Research Alliance - we have a place on the Council and on the Executive Committee. Logic model session follow-up: The work and outcomes from this session are filtering through many aspects of the work programme. 	Secretariat
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	<ul style="list-style-type: none"> • Media attention: <ul style="list-style-type: none"> - What is our hook - could this be how many people have died due to research not being done - at a system level? The greatest extent of the problem is the data that has already been collected but that is not being accessed/used by researchers. We need to use a common-sense perspective. - There are good examples of patient data use on NHS England’s Data Saves Lives website (some of these examples are from use MY data Members). • Headline review of priorities & work plan <ul style="list-style-type: none"> - Engagement work - the Secretariat is focusing on a Spring webinar, a Summer in-person patient data event, alongside engagement work across the four nations. - The Executive Group felt that the patient data day could be a model for a different way of hosting a conference, with a not-for-profit aspect. The Secretariat is seeking options for funding/sponsorship, as this is required in order to host the event. The purpose of the event needs to be clear - publicity for use MY data and networking for the Members and stakeholders are two key aspects. The Executive Group cautioned on the timings and that the Secretariat’s aim of Summer may be too soon. - It is not possible for the Secretariat to host a census over Spring/Summer, due to the current workload. <p>Decisions</p> <ul style="list-style-type: none"> • Update and publish the patient data landscape document. • Finalise the media hook for use MY data and take forward the media work. • Take forward the suggestions to grow the number of Members, including making best use of Associate Members. • Define how we can ask Members to help with promotion/engagement work. • The census is postponed for the Spring/Summer at least. <p>Summary of actions</p> <ul style="list-style-type: none"> • Secretariat (Chris leading) - Update the patient data landscape document by adding MedConfidential and then publish on our website. • Secretariat (All) - Take forward suggestions to expand the number of Members, including defining how best to obtain help of Members and Associate Members • David - If given a place at the ICB, feedback to the Executive Group & Secretariat. • Secretariat (Elizabeth leading) - Finalise the media hook for use MY data’s impact. 	
<p>Item 4.0</p>	<p>Charitable status options - Members responses to Exec Group’s recommendation</p> <p>Intended output from this item</p> <ul style="list-style-type: none"> • A final decision on which charitable status option is best for use MY data <p>Background</p> <ul style="list-style-type: none"> • Ahead of the meeting, there was a call to Members for their views on the Executive Group’s recommendation that use MY data should become a Charitable Incorporated Organisation (CIO). A paper collating Members’ views was sent to the Executive Group prior to meeting, for their review. <p>Key points from the Executive Group</p> <ul style="list-style-type: none"> • Members’ time and efforts in responding was acknowledged, with gratitude. • None of the respondents were against the recommendation to become a CIO. • Members’ responses highlighted concerns about: <ul style="list-style-type: none"> - Governance and transparency around the Executive Group becoming Trustees - Ensuring use MY data remains patient-led. - Clarity is needed about the roles of Trustees and Executive Group and re-assurance must be provided to Members. If the current Executive Group are co-opted as Trustees, this will be for an interim period only. 	<p>Dave Jo</p>

	<ul style="list-style-type: none"> • For an organisation of our size, only one group is needed - i.e. we do not need an Executive Group and Trustees. • The Executive Group were keen for the CIO recommendation to be taken forward, on behalf of Members. • Practicalities were discussed, as a result of the Secretariat emphasising they are at full capacity work-wise. Our NHS England funding should be coming through by the end of Friday, 22 March and this will enable the recruitment process for an Administrator to begin. The Administrator will have some capacity for the charitable status work - but this will be in a few months' time, at the earliest. • The external project manager we have engaged can advise the Executive Group on the next steps. Once we are up and running, the work should be straight forward. • We have a draft constitution and this can be finalised. • Honoraria for Trustees - clarity is needed on whether it will be possible for Trustees to receive honoraria, when they are undertaking specific activities to represent use MY data. If this is possible, the process will need to be declared. Dave will investigate if this is possible and provide an update. • If current Executive Group Members do not wish to become a Trustee, they can be co-opted to stay on as Executive Group Members, for the interim period. • Trustees come from the Members - this is essential. Some Members of the Executive Group were concerned that there would not be enough transparency around Executive Group Members becoming Trustees. This was balanced by others feeling confident that the Trustees will only be interim and that, once the interim roles end, all Members can apply. <p>Decisions</p> <ul style="list-style-type: none"> • use MY data should become a Charitable Incorporated Organisation (CIO). • Trustees will only be drawn from the Members. • All Executive Group Members who wish to become Trustees will become so for an interim period only, prior to an election of Trustees drawn from Members. <p>Summary of actions</p> <ul style="list-style-type: none"> • Secretariat (Alison leading) - Arrange for Members to be informed about the decision and reassured about the Trustee aspect, via a Chair's letter. • Dave - Speak with our project manager about the next stages of obtaining CIO status, including whether honoraria can be paid to Trustees. • Secretariat - Assess what is possible, capacity-wise, to take forward the CIO work. 	
Item 5.0	<p>Any other business</p> <p>Prix Galien UK</p> <ul style="list-style-type: none"> • In great news for use MY data, we have been invited to take part in a panel session at the Prix Galien forum at the Science Museum, London on 30 May. The panel session is on 'Data Driven Medicine: The NHS as a strategic partner for Life Sciences' and Richard Stephens, Executive Group Chair has been confirmed as use MY data's representative. <p>Federated Data Platform (FDP) - letter to the Chief Executive of NHS England</p> <ul style="list-style-type: none"> • To date, we do not appear to have received a response to our 10 January 2024 letter to Amanda Pritchard, CEO of NHS England. The letter, from our Chair and Vice Chair, requested timescales for the publication of further parts of the FDP contract and asked that the redactions we have highlighted be published. We have withheld publication of the letter, to date, to give time for a response. A follow-up letter is now needed, requesting a response within a set time-frame. <p>Research Advisory Group, NHS England - Developing Champions work</p> <ul style="list-style-type: none"> • At the recent meeting of the Stakeholder data-enabled research advisory group, the opportunity to take part in 'developing champions' work was raised. This is potentially of interest, but further information is needed ahead of a decision. 	Dave

	<p>GP Data Patient & Public Engagement & Communications Advisory Panel</p> <ul style="list-style-type: none"> Following stepping down from the GP Data Patient and Public Engagement and Communications Advisory Panel (PPECAP) in September 2023, our panel representatives (who were required by NHS England to be employed on zero hours contract) are still awaiting their P45s. They requested that Alison chase this up again, on their behalf. <p>The European Patients’ Academy on Therapeutic Innovation (EUPATI)</p> <ul style="list-style-type: none"> Richard B - With an eye on increasing our Membership/profile, Richard will promote use MY data at the next meeting of The European Patients’ Academy on Therapeutic Innovation (EUPATI) (of which Richard is a Fellow). The programme “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...”. <p>Webinar plans</p> <ul style="list-style-type: none"> A draft brief for the next webinar was presented - with a proposal that this could be on federated data platforms, across the UK. <p>UK Health Data Research Alliance - Council meeting & patient data showcase</p> <ul style="list-style-type: none"> Alison highlighted that the 22 May meeting of the Executive Group & Secretariat clashes with the UK Health Data Research Alliance Council meeting, which will be followed by a patient data showcase. Thought is needed about how to manage attendance at both and a review of our meeting plans is needed. <p>Summary of actions</p> <ul style="list-style-type: none"> Alison - FDP letter - Arrange for use MY data to send a follow-up letter, chasing for a reply to our 10 January letter, within a requested timeframe. Alison - Research Advisory Group - contact NHS England to obtain information about the ‘developing champions’ work and feedback to the Executive Group. Alison - PPECAP - contact NHS England again, about the P45s for our representatives on the panel. Richard B - Promote use MY data at the next meeting of The European Patients’ Academy on Therapeutic Innovation (EUPATI). Alison - Resolve the Executive Group & Alliance meeting clash on 22 May. 	
Item 6.0	<p>Date of next meetings</p> <p>Wednesday, 24 April 10:00 to 11:00 - online (single topic meeting, if needed) Wednesday, 22 May, 10:30 to 12:00 - online Monday, 17 June, 12:00 to 13:00 - online (single topic meeting, if needed) Wednesday, 31 July, 10:45 to 15:00 - in-person London Wednesday, 25 September, 12:00 to 13:30 - online</p>	Alison

Suggestions for future meetings

Weds, 22 May
Online

Key items

Standing items

- Update on funding
- Update on discussions with national organisations

Weds, 31 July
In-person

Key items

Standing items

- Update on funding
- Update on discussions with national organisations

Weds, 25 September
Online

Key items

Standing items

- Update on funding
- Update on discussions with national organisations