

Executive Group & Secretariat - Online meeting

**Monday, 23 January 2023
13:00 to 14:30**

Meeting notes - confirmed

<p>Item 1.0</p>	<p>Welcome, apologies & housekeeping</p> <p>The Chair welcomed attendees and the meeting etiquette was reviewed.</p> <p>Attendees Executive Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Richard Ballerand, Samina Begum, Jo Gumbs, John Marsh, David Snelson, Pete Wheatstone Secretariat - Chris Carrigan, Emily Connearn, Alison Stone</p> <p>Did not attend (apologies received post-meeting): Sarah Markham</p>	<p>Richard S</p>
<p>Item 2.0</p>	<p>Legal status, funding, recruitment</p> <p>a. use MY data’s legal status - any updates In relation to our legal status (currently a not-for-profit company limited by guarantee) and the possibility of obtaining a future charitable status - a use MY data Member has asked about the merits of use MY data becoming a Community Interest Company, rather than a charity. This will be discussed at the next meeting.</p> <p>b. Funding, banking & recruitment - latest developments Chris provided an update on recent developments in relation to use MY data’s bank account. The process to open an account is still underway and this is currently with NatWest, as it was not possible obtain an account with Metro Bank. The usual turn-around time with NatWest is four weeks and we should be at the point of having confirmation, or otherwise, from the bank by the end of this week (27 January). The charity that wishes to provide funds to use MY data (£235,000 over three years) is keen to be able to provide this funding as soon as possible.</p> <p>For our NHS Digital funding (which supports the Coordinator’s role) - discussions are progressing, to see if the contract can be novated from the University of Leeds (contract hosts) to use MY data. Further progress is dependent on use MY data having a bank account.</p> <p>Recruitment to expand the Secretariat - this is contingent on obtaining the charity’s funding. The Secretariat is developing the supporting information for recruitment.</p> <p>c. Summary of actions</p> <ul style="list-style-type: none"> • Chris - Obtain confirmation about our bank account status, by 27 January. • Chris - As soon as the bank account is ready, arrange for the receipt of charity funding. Clarify with the funder their desired terminology about the funding. • Secretariat - Work on the supporting information for the recruitment to the Secretariat - to be finished within two weeks of the funding being received. • Alison - Ensure that the next meeting agenda (29 March) includes use MY data’s legal status & the possibility of becoming a Community Interest Company. 	<p>Chris</p>

<p>Item 3.0</p>	<p>Strategic direction of use MY data</p> <p>a. Vision & mission tweaks - Chris Chris presented a draft paper showing proposed amendments to the vision and mission statements. This was a result of discussions at the 28 November meeting and follow-up work with Members of the Executive Group.</p> <p>Our Vision: Every patient in the UK willingly giving their data in order to support medical research and their own care</p> <p>Our Mission:</p> <ol style="list-style-type: none"> 1. To highlight the benefits of using patient data for societal benefit and for the individual 2. To ensure patient data is used to create an NHS that is better for all 3. To provide balance as a trusted patient voice in patient data, highlighting aspirations and concerns around the use of patient data 4. To be a critical friend and sounding board to organisations who want to collect, store and use patient data for societal benefit 5. To advocate that data safeguarding is robust, transparent, understood, communicated and reassuring to patients and the public 6. To build knowledge and expertise with patients, relatives and carers to help them play a more active role in discussions and decisions about patient data <p>Proposed tagline - use MY data to help others and help me</p> <p>Executive Group feedback and suggestions:</p> <p>Our Vision</p> <ul style="list-style-type: none"> · ‘Willingly giving’ - Unsure if this sounds correct, as it requires action, rather than focussing on the use of data already in the system. · Consider tweaking the wording to something along the lines of - ‘Every patient in the UK wanting their data to be used to support medical research and their own care’, or ‘...to support their own care and medical research’. <p>Our Mission</p> <ul style="list-style-type: none"> · Bullet point 2 - this should be the first bullet point, as it is the most powerful and from which everything follows on. · Bullet points 1 & 4 - ‘societal benefit’ - possibly sounds elitist and needs a tweak. · Bullet point 3 - rather than ‘highlighting aspirations and concerns’, it would be more pertinent to say ‘...helping to address concerns around the use of patient data’. · There are organisational barriers to our data being used for legitimate purposes - could this be included in the mission? · Consider moving some of the bullet points to a smart objective so that our mission is a sentence or two. There are pros and cons of doing this. · Whether to state using or sharing patient data? There are pros and cons to each. <p>b. Trusted patient voice strategy - Richard Richard has given some thought to this, with the paper to follow once there is agreement on Mission Statements.</p> <p>There has been positive feedback to the Chair’s letter and overview calendar, with responses and suggestions from use MY data Members and Associate Members.</p> <p>c. Formal engagement & use MY data resources - Alison & Chris Alison presented a draft paper for the Executive Group’s review and input, on how use MY data’s formal engagement arrangements match up (or otherwise) with use MY data’s resources - in terms of Members’ and Secretariat time. The paper identified whether the engagement and resources were proportionate or disproportionate.</p>	<p>Chris Richard S Alison</p>
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	<p>Feedback:</p> <ul style="list-style-type: none"> • Where an arrangement has been made with the NHS, even if engagement proves disproportionate to our resources, the bottom line is that helping the NHS is paramount. The purpose of this exercise is not to decide that, if engagement is identified as disproportionate, use MY data should not be doing it. Rather, it is to review and assess the balance. • It is important to articulate what the benefits of an arrangement would be, before undertaking any engagement. The engagement process needs to align the activities that use MY data undertakes with our vision and mission, and to ensure that use MY data receives the benefits of the engagement. • Thinking about the forthcoming combining of NHS Digital and NHS England, do we know how NHS England involves members of the public in its work? • Formatting tweak needed - include headings on every page. <p>Chris presented a draft paper on the problems being caused by bureaucracy around reimbursements for patient work, with the NHS in England. The paper proposes that the NHS policy should be to pay patients directly for their involvement, and not to force patients to register as employees. If the NHS is not willing or able to do this, use MY data could offer a service to pay our Members for their work with the NHS and then reclaim the amount back, plus an overhead for administrative costs.</p> <p>Executive Group feedback:</p> <ul style="list-style-type: none"> • Recent occurrences of the inappropriate bureaucracy were highlighted, with the strong concern that these present a danger that patients just will not want to continue with their work. It is essential that the NHS changes the arrangements. • There is a small risk in the suggested approach, which is taking on IR35 responsibilities. Insurance would be needed, to protect use MY data. • For some patients, the current NHS arrangements do work well and are the best option. It is important to take this into account. Therefore, it's not as straightforward as the NHS being able to offer only one option. <p>d. Summary of actions</p> <ul style="list-style-type: none"> • Chris - Tweak the vision/mission draft and recirculate to the Executive Group. • Richard - Write the draft two-page paper on the Trusted Patient Voice and set a date to send this to the Members with the next Chair's briefing letter. • Alison - Amend the engagement and resources paper and circulate to the Executive Group, for contributions. Include use MY data's engagement criteria document, for information. • Chris - Update the paper on bureaucracy around reimbursements for patient engagement, incorporating feedback. Circulate to the Executive Group for any further suggestions, ahead of liaising with the NHS. 	
Item 4.0	<p>Events programme for 2023</p> <p>a. Educational sessions</p> <p>The next session is on the 24 February with the topic 'explaining data terms - anonymisation & pseudonymisation'.</p> <p>Future topics include:</p> <ul style="list-style-type: none"> • Born in Bradford with Executive Group Member, Samina Begum • How Members can be more involved with use MY data • A session with a commercial company. <p>Executive Group feedback:</p> <ul style="list-style-type: none"> • Uncertain that an educational session is the best forum for how Members can be more involved. 	Emily

	<p>b. Webinars</p> <p>Emily is planning the March webinar, with the topic ‘AI in relation to healthcare data’ and is working through supporting information from Executive Group Members. There are two possible case studies being considered at present:</p> <ul style="list-style-type: none"> • Metastatic breast cancer data - a recent Swedish study used machine learning to produce statistics on survival after metastatic breast cancer data. This work has been highlighted by use MY data Member, Jo Taylor. Since the Swedish patent data is similar to UK data, could this be something the UK could undertake too? • Scottish Ambulance Service - the use of AI to examine huge amounts of ambulance activity data and create an algorithm, to determine where ambulances should be stationed for best response times. <p>Executive Group feedback:</p> <ul style="list-style-type: none"> • It is important to have an example of individual care. • It would be good to run an educational session two weeks or so prior to the webinar, to introduce the topic and explain data terminology. • It would be good to see how AI can help to reduce health inequalities • The webinar should be Member focussed rather than too theoretical - we do not need to repeat what other organisations are doing/have done. • Idea for a future session - How to interpret your GP record. <p>c. In-person event</p> <p>There was nothing to report on this at present.</p> <p>d. Summary of actions</p> <ul style="list-style-type: none"> • Emily - Take forward the next stage of the March webinar, on AI in relation to healthcare data. • Emily & Chris - In advance of the webinar, arrange an Educational Session as an introduction to AI, to help Members play a full part in the webinar. 	
Item 5.0	<p>Any other business</p> <p>a. Chair business</p> <p>The Chair of the Executive Group has said that he intends to stand down, when the term ends in May. However, as use MY data is going through a period of much change, would it be good to retain the Chair, for the coming year?</p> <p>Alison gave a quick a recap of the terms that the Chair and the Vice Chair were appointed under and the process for appointing to the roles. The Executive Group asked for the appointment process/terms to be reviewed at the next meeting.</p> <p>b. Website information about joining use MY data</p> <p>The Executive Group agreed that this information needs bolstering, with specific points to consider:</p> <ul style="list-style-type: none"> • Check the meaning of/use of ‘patient advocates’, in relation to our Members • Consider having an online form for sign-up (there are pros and cons for this). <p>There was a brief discussion about the role/value of the newsletter in attracting new Members. Should we let non-Members have the newsletter, even if they do not wish to join? Are we seeking just numbers of new people, or people who wish to be active within use MY data? The Executive Group felt that this should come back to the next meeting.</p> <p>Chris is almost at the stage of engaging reviewers to look at the (hopefully) final version of the refreshed website. This version will include an updated ‘Joining use MY data’ page. Pete emphasised his keenness to work on this, with the Secretariat.</p>	Richard S

	<p>c. Summary of actions</p> <ul style="list-style-type: none"> • Alison - Ensure the next meeting agenda (29 March) includes a review of the appointment of/terms of the Executive Group’s Chair and Vice Chair roles. • Alison - Ensure the next meeting agenda (29 March) includes a review of the use of the newsletter, with respect to attracting new Members to use MY data. • Pete, Chris & Alison - Work together on updating the ‘Joining use MY data’ section of the website, by 10 February. • Chris - Send the final draft version of the refreshed website to reviewers, by 15 February. 	
Item 6.0	<p>Date of next meeting</p> <p>a. Dates Wednesday, 29 March 11:00 to 15:00 (Refreshments from 10:00) London, venue to be confirmed (likely to be the Euston area)</p> <p>Richard sought feedback on the possibility of the meeting starting at 10:30 and whether travel would permit that (in view of a possibly packed agenda). For the majority, this seemed possible.</p> <p>Meetings from April onwards are to be decided and Alison will follow-up on this.</p> <p>b. Summary of actions</p> <ul style="list-style-type: none"> • Richard & Alison - Determine/confirm the start time for the March meeting. • Alison - Find dates for meetings from April to December 2023. 	Alison

Suggestions for future meetings		
29 March	<ul style="list-style-type: none"> • Consideration of charitable status (including social enterprise and similar options) • Review of use of newsletter in relation to attracting Members • Review of Chair and Vice Chair terms <p>Standing items</p> <ul style="list-style-type: none"> • Update on funding • Update on discussions with national organisations 	