

**Executive Group & Secretariat
In-person meeting**

**Wednesday, 29 March 2023
11:00 to 15:00**

Meeting notes - confirmed

Item 1.0	<p>Attendees: Executive Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Richard Ballerand, Samina Begum, Jo Gumbs, John Marsh, David Snelson and Pete Wheatstone.</p> <p>Secretariat - Chris Carrigan, Emily Connearn, Alison Stone.</p> <p>Apologies received: Sarah Markham.</p> <p>The meeting Chair, Richard S, warmly welcomed all attendees, followed by the meeting etiquette and housekeeping. Thanks were noted for the support given by Health Data Research UK, who kindly supplied the room and refreshments.</p>	Richard S
Item 2.0	<p>Where we are: use MY data's resources and status</p> <p>a. Funding update The major charity funder has confirmed our funding. A wording announcement is being worked out and will be announced in the newsletter to Members on 20 April and then declared on our website. The funding is £240,000 over three years, with quarterly invoicing. The funding will cover the creation of two part-time roles.</p> <p>There is a planning meeting with the funders on 25 April, which Chris and Alison are confirmed to attend. The Executive Group felt important for a Member of the Group to attend, which Alison will arrange.</p> <p>b. Secretariat changes, expansion, ways of working - paper (Chris/Alison) Chris and Alison gave an overview of their paper, which proposed:</p> <ol style="list-style-type: none"> 1) A structure for the two new roles and 2) A way for Chris and Alison to rebalance their time - spending less time on processes around engagement and more time on actual engagement work. <p>The Executive Group agreed with the proposals, with the following feedback:</p> <ul style="list-style-type: none"> · Clarity was sought clarity about the stage of the job descriptions · The focus should be on securing administrative support, to enable Alison and Chris to focus on engagement work · Expressed support for reducing the administrative burden on Alison and Chris · Would a fortnightly newsletter ease the workload? · Consider how the charitable side/funding applications will be administered · Consideration of how best to balance the 1:1 service the Secretariat offers to Members, with an eye on our Membership expanding - Secretariat support for Members is a strength and makes us different to other organisations. <p>The next stage for the Secretariat is the recruitment process. The job</p>	Chris Alison

descriptions should be ready at the end of April, for recruitment in May. The costing structure is complete. The Executive Group noted that there will be a pinch point on Secretariat capacity when inducting the new people and time on current tasks will need to be reduced on a temporary basis.

c. Consideration of charitable status options - paper (Chris)

Chris presented the range of options and gave a brief overview of the benefits and disadvantages for each.

1) Remain as a not-for-profit company limited by guarantee (the status quo)

Pros:

- No further legal work needed
- We can securely do our work without distraction
- Our stated purposes are all clearly charitable purposes.

Cons:

- We would not be able to apply for specific charity funding
- Some organisations prefer to deal with charities.

2) Convert to a Community Interest Company (CIC)

Pros:

- Relatively straightforward process with Companies House.

Cons:

- Would not significantly alter our status.

3) Registering use MY data with the Charity Commission.

Pros:

- There are significant tax benefits
- Our stated purposes are already charitable purposes
- Moving from a company limited by guarantee, to being a charity is a common route
- It opens up opportunities to seek specific charity funding.

Cons:

- The application process would take a significant amount of Secretariat time
- We could not take this on without additional Secretariat resource
- We may need to buy-in expert advice
- There are additional reporting requirements.

Feedback from Members was presented, which was received in response to the Chair's briefing to Members on 21 March.

- There is a need for a simple breakdown of advantages and disadvantages.
- Would use MY data be restricted on campaigning and any political activity?
- How would the Trustee side of things work?
- Are the advantages mainly financial i.e., better position to obtain other funding, tax-wise?
- Are the disadvantages the high level of regulation and bureaucracy that comes with charity law?
- How, in particular, does the Secretariat feel about the proposals, since they take the work programme forward, on behalf of use MY data Members?

Following discussion, the Executive Group's key feedback:

- Are there examples of where we could have applied for funding if we had a charitable status?
- Detailed examples of benefits and risks are needed and to know if the benefits outweigh the risks - perhaps there is not enough information at the moment.
- The kudos of being a charity is not mentioned in the paper.
- Converting to a CIC does not have a strong benefit.
- What would be the lead-in time - sensible to say in six months, or a year?
- Charity Commission paperwork would probably take two/three hours a month
- As a limited company, we are required to do an annual report, and this can be

	<p>used as a basis for the report we would need to do for the Charity Commission</p> <ul style="list-style-type: none"> · Becoming a charity offers the opportunity to seek funding from other charities, across all disease areas. · If we go down the charity route, we need to think about how to construct charitable objectives/purposes and to cast these fairly widely across health data. · We could obtain professional support to establish ourselves as a charity. · The Charity Commission has templates for the constitution work, plus Dave has much experience of this process and offered his help. · There are advantages in having the status, but the con at the moment is the work needed to set up and run - the direction is probably right, it is just a question of timing. <p>The Executive Group felt the paper should be expanded and sent to Members for their consideration, possibly with a recommendation, to find out their preference. The paper needs to include a risk and benefit profile. Ahead of sending to Members, the paper needs to come back to the Executive Group.</p> <p>d) Summary of actions</p> <ul style="list-style-type: none"> · Alison - Contact use MY data's new funder and confirm that a Member of the Executive Group will attend the 25 April meeting. · Jo & Dave - Will revise and expand the charitable status paper, to circulate to the Executive Group for further input-, ahead of sharing with the Members. Aim for the first draft to be ready by the end of April. 	
<p>Item 3.0</p>	<p>Where we are heading: use MY data's internal work</p> <p>a. Vision & mission statements (draft) / trusted patient voice - paper (Richard S)</p> <p>Vision Proposed vision: Every patient in the UK wanting their data to be used to support medical research and their own care.</p> <p>Mission Proposed mission: To be a Trusted Voice for patients and the public in all discussions and decisions about the use of our data.</p> <p>Aims Proposed aims:</p> <ul style="list-style-type: none"> · To highlight the benefits of using patient data for the individual and for our communities · To ensure patient data is used to create an NHS that is better for all · To provide balance as a trusted voice in patient data, highlighting aspirations and concerns around the use of patient data · To act as a critical friend and sounding board to organisations who want to collect, store and use patient data to benefit society · To advocate that data safeguarding is robust, transparent, understood, communicated and reassuring to patients and the public · To build knowledge and expertise for patients, families and carers to help them play a more active and informed role in discussions and decisions about patient data. <p>Feedback from Members was presented, received in response to the Chair's briefing of 21 March, with the suggestions:</p> <ul style="list-style-type: none"> · 'Every patient in the UK by choice wanting their data to be used to support medical research and their own care' · Using the word 'patients' in the description of Members (as patients, relatives and carers) is not inclusive of ex-patients - could ex-patients be included too? <p>The Executive Group reviewed and discussed in detail the vision, mission</p>	<p>Richard S Alison Chris</p>

statements, aims and the proposed values, alongside our Members' suggestions, with the resulting key suggestions to:

- Mention accountability
- Have a more logical order to the Aims
- Make our Value about being inclusive implicit, rather than explicit
- Make 'removing barriers' explicit, in one of the Aims
- Consider adding that we should oppose misuse - with the conclusion that we promote responsible and accountable use of patient data, which is enough.

Communications approach including:

- **Newsletter - review of use & purpose - verbal update (Alison)**
The newsletter began as an occasional update for our Membership and has gradually morphed into a regular, weekly update. The regular feedback received indicates that it is informative for Members and Associate Members. Members who are limited in activity due to health/social issues, find it particularly useful. Associate Members who work in the patient data area, find it a useful round-up.

From use MY data's 2020 census: "The weekly email round-up is being used by over 90% of the Members who responded to the Census. We receive regular feedback that the round-up...is seen as a very useful form of communication."

The newsletter attracts new Members and Associate Members, particularly Associates - as it is often forwarded on/recommended to a colleague, who then makes contact and asks to receive it direct. Not all who make contact sign-up, as some do not wish to become Members/Associate Members.

It does take a large proportion of time each week - researching, reading, writing, editing and sending. The Executive Group discussed whether it was better to switch to a fortnightly newsletter at present. On balance, as the sending is the smaller part of the time and because some items are time critical, Alison felt best to continue to send weekly. If she hits a particular crunch point, she will miss a week, giving the Membership advance notice.

The Executive Group suggested that a line could be added, to give details of how to join use MY data, aimed at those who have received the newsletter but are not Members/Associate Members.

Website update - verbal update (Chris)

Pete and Chris have now reviewed the 'joining use MY data' section of the website. The ensuing changes will be incorporated into the new version of the website. This version is almost ready for Chris to send to reviewers. The professional communications contact who reviewed the website at an earlier stage suggested that we should amend our logo and add a strapline to it. The Executive Group felt that there was merit in adding a strapline, but that this should wait until we have a communications lead. They also felt that the bulk of the website update should wait until we have a communications lead.

b. Summary of actions

- **Richard S, Chris & Alison** - Simplify use MY data's vision and clarify the mission. Tweak the vision, mission, aims slides (Richard in the 1st instance) and send back to the Executive Group.
- **Alison** - Add a line to the newsletter, for those readers who are not yet Members/Associate Members, advising them how to join.
- **Chris** - Send the prepared version of the new website to reviewers. Hand over the website management and content, including logo/strapline, to the communications lead.

<p>Item 4.0</p>	<p>Executive Group membership terms</p> <p>a. Review of current terms for Chair & Vice Chair roles - paper (Alison) The roles of Chair and Vice Chair of the Executive Group (then called the Advisory Group) were created in May 2022, with the primary purpose to ensure that the Group, and therefore use MY data, is patient-led. The secondary purpose is for the Secretariat to gain the Chair and Vice Chair’s input and perspective to assist with taking use MY data’s work forward on behalf of Members.</p> <p>The terms for the Chair and Vice Chair are for a period of two years, with the current terms due to end on 23 May 2024. The Executive Group reviewed whether the current terms should be extended, in light of the major changes that are happening within use MY data this year. The consensus was that continuity at this time of change is important. Rather than changing the terms, an exception could be made, for the terms of the current Chair and Vice Chair to be extended for twelve months. The current Chair and Vice Chair agreed to continue in their roles for this period of time.</p> <p>It was noted that if/when use MY data has a charitable status, the roles of Chair and Vice Chair may change accordingly.</p> <p>b. Review of current terms for Executive Group Members - paper (Alison) The current terms of Executive Group Members were reviewed.</p> <ul style="list-style-type: none"> • The current Executive Group came into being on 15 February 2021 with eight Members joining at that time and a ninth joining on 05 September 2022. • Members sit on the Group for an initial term of three years and membership can be renewed once by mutual agreement between the Member and the Secretariat. • For the current Members, the three-year term runs to 14 February 2024 for eight Members and to 04 September 2025 for one Member. <p>Again, things may change if/when use MY data has a charitable status.</p> <p>The Executive Group felt the current terms should remain and that the Secretariat should focus on filling the gaps within the Group. This is scheduled for the Summer.</p> <p>The Executive Group does not have Terms of Reference (ToR) and this is needed. As an Advisory Group, the Group and Secretariat had a ‘Ways of Working document’, which the ToR would replace.</p> <p>c. Summary of actions</p> <ul style="list-style-type: none"> • Alison - Extend the terms of the current Chair and Vice Chair for 12 months. • Dave & Jo - Draft Terms of Reference for the Executive Group & circulate to the Executive Group & Secretariat. Aim for first draft by Wednesday, 31 May. 	<p>Richard S Alison</p>
<p>Item 5.0</p>	<p>Where we are heading: use MY data’s external work</p> <p>a. Secretariat’s six-point engagement proposal - paper (Chris/Alison) The Secretariat presented their engagement proposal, for the Executive Group’s response. Key targets were the four UK nations, Understanding Patient Data and the Patients Association.</p> <p>The Executive Group consensus was that the paper made complete sense and they were happy to endorse it. Alongside that, some key points were:</p> <ul style="list-style-type: none"> • It is important to understand the drivers for each area of engagement and what use MY data wants from each relationship. • It would be useful to review our existing relationships too. • A membership drive is needed, in tandem with the engagement areas - this is 	<p>Chris Alison David John Emily</p>

pencilled in for June, but dependent on the new communications role.

b. Standards for engagement with external bodies - paper for information (Alison)

All were happy with this paper, which is used by the Secretariat for external engagement. Alison felt it would be useful for the paper to be available on our website and Chris confirmed it will be on the updated version.

c. General Practice Data for Planning & Research (GPDPR) Patient & Public Engagement & Communications Advisory Panel (PPECAP) update - papers & verbal update (David/John)

Three Members of the Executive Group sit on the PPECAP panel for the GPDPR, on behalf of use MY data. Two Members attended an in-person meeting on 02 March and gave an overview. Two different strategies were presented for data collection under the GPDPR - a national (England) system, or a federated system based on Integrated Care Boards. Our representatives reported that they had supported the national approach during the workshop and the Executive Group endorsed that approach. The most recent PPECAP meeting took place on 16 March and our representative at that meeting gave a brief overview of discussions.

The Executive Group gave thanks to the three Members for all the time they have given representing use MY data on PPECAP.

There was agreement that, in principle, it could be helpful for use MY data to write to NHS England formally about use MY data's position.

There was consensus that it is important to keep taking use MY data's voice into the project and to push for a 'keep it simple' national solution. The Group discussed use MY data's role and how best to update our Members. Our representatives will write an update for Members on recent PPECAP activity, including the 02 March meeting. We will inform NHS England that we are doing this.

Publication of NHSE's notes from the 02 March meeting is essential to provide a public record and we have been assured by NHSE that the notes will be published.

Post-meeting note

NHSE advised that publication of the notes is delayed due to NHSE being under pre-election publication restrictions. We have pressed for a publication date and NHSE advised that this will be by 10 May. If the minutes are not published by this date, or do not appear to be accurate or comprehensive, our PPECAP representatives will need to consider how best to keep use MY data Members informed.

d. Proposed programme for April to December 2023 - paper (Emily)

e. Overview of events programme 2020 to 2023 - paper for information (Emily)

Webinars

Our next webinar is on 30 March on AI and patient data and Emily gave an overview of the event. There are 108 delegates registered (as of 29 March), which is positive considering the limited publicity. A key polling question for the start and end is needed.

On 24 March, Chris hosted an in-tandem educational session on the topic, to help prepare Members for the webinar.

The next webinar is provisionally scheduled for October 2023. Chris has been in talks with a research organisation to discuss the potential for a webinar on the topic of problems with different costing models for access to data, across the UK.

	<p>In-person event The Executive Group is keen that use MY data hosts an in-person patient-focused event. The (very) provisional date for this is June 2023. We could do this in tandem with other organisations, though need to ensure our Members come first.</p> <p>Educational sessions These are a great benefit of being a Member and the Executive Group felt that it is important that there is not a long gap in sessions, with Emily leaving. Emily provided a list of suggestions:</p> <ul style="list-style-type: none"> • What should you expect to see in your GP app? - A potential speaker for this session could be one of our Associate Members who is a GP. • A deep dive into Born in Bradford. • Do patients have enough presence on data access decision boards? - This would cover patient representatives on boards such as IGARD (as was). • How can Members become more involved in use MY data's work? • Who owns patient data? • How can data help our GPs diagnose cancers earlier? • What happens to data from clinical trials? • Speaking with analysts using our patient data. <p>f. Summary of actions</p> <ul style="list-style-type: none"> • Chris & Alison - Take forward the six-point engagement proposal. • Alison - Arrange for the membership drive to be taken forward, when the new communications person is appointed. • Chris & Alison - Ensure the engagement criteria with external organisations is published on our website. • David, Dave, John - Write an update for the Members on recent PPECAP activity. 	
Item 6.0	<p>Any Other Business</p> <ul style="list-style-type: none"> • National Data Guardian's (NDG) office Vicky Chico, NDG's office, has asked if a use MY data representative would be interested in helping with the 'Creating reasonable expectations' project, by joining the oversight panel, for which they are keen to have a number of patient and public representatives. Chris has been liaising with Vicky to obtain information and will follow-up further. • Department of Health & Social Care (DHSC) & NHS England Chris gave a brief overview about a recent Secretariat meeting with the DHSC. This followed use MY data's response to the 'Draft guidance on NHS England's protection of patient data'. The DHSC has been very responsive and has offered further meetings. They have also supplied follow-up information to our response and offered to expand this, ahead of sharing with use MY data's Membership. • Expenses for the Executive Group Chris ran through the process for claiming expenses. • Emily departure It was Emily's last meeting, before leaving use MY data on 31 March. The Executive Group gave a big thank you to Emily and expressed gratitude for all of Emily's work managing events for use MY data, over the last three years. <p>The development and implementation of the educational sessions was highlighted as a particular achievement.</p>	Richard S

Item 7.0	<p>Dates for next meetings</p> <p>Meetings for the remainder of 2023 are confirmed as:</p> <ul style="list-style-type: none"> ▪ Wednesday, 24 May, 11:00 to 12:30 - online ▪ Wednesday, 19 July, 11:00 to 15:00 - in-person, London ▪ Wednesday, 20 September, 11:00 to 12:30 - online ▪ Wednesday, 29 November, 11:00 to 15:00 - in-person, London. <p>Summary of actions</p> <ul style="list-style-type: none"> ▪ Richard and Alison - Review plans for the format of the 19 July meeting, to consider whether a hybrid option would be the best format. ▪ David, Richard B, Samina - Provide feedback about how the online experience was at today's meeting. 	Alison
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Suggestions for future meetings	
24 May Online	<p>Key items:</p> <ul style="list-style-type: none"> ▪ Secretariat recruitment update/progress ▪ Charitable status update/progress ▪ Members' census ▪ Executive Group expansion <p>Standing items</p> <ul style="list-style-type: none"> ▪ Update on funding ▪ Update on discussions with national organisations
19 July In-person	<p>Standing items</p> <ul style="list-style-type: none"> ▪ Update on funding ▪ Update on discussions with national organisations