

Advisory Group & Secretariat - In-person meeting

**Monday, 28 November
11:00 to 15:00**

Meeting notes - confirmed

Item 1.0	<p>Attendees: Advisory Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Richard Ballerand, Samina Begum, Jo Gumbs, John Marsh, David Snelson, Pete Wheatstone.</p> <p>Secretariat - Chris Carrigan, Emily Connearn, Alison Stone.</p> <p>Apologies received from: Sarah Markham</p> <p>The meeting Chair, Richard S, warmly welcomed all attendees to the first in-person meeting of the Advisory Group. A quick round of introductions took place, followed by housekeeping and meeting etiquette.</p>	Richard S
Item 2.0	<p>Where are we - review of current work and resources</p> <p>Following an overview from Alison and Chris, the Advisory Group discussed the formal arrangements use MY data has with external organisations, current Membership numbers, Secretariat resources and funding.</p> <p>Formal arrangements At present use MY data has formal arrangements with NHS England, NHS Digital, the Association of the British Pharmaceutical Industry (ABPI) and GRAIL. For transparency, details of all formal arrangements are published on our website organisations we engage with.</p> <p>Key points raised and discussed:</p> <ol style="list-style-type: none"> 1. Is there a tangible benefit for use MY data in the formal arrangements we have? 2. Is use MY data recognised/acknowledged on the outputs from the arrangements? - The Secretariat confirmed that this does not happen and this needs to change. 3. Are we approached by organisations across UK for input? - Only at a very minor level and we need to change this. 4. Have we asked Members across the UK, to provide information about data in their nation? - The Secretariat confirmed this has been done previously but agreed that it needs another push. <p>Agreement that the first stage of engagement is deciding where and how use MY data can make a difference and what benefit(s) and risks (which can take many forms) potentially accrue to use MY data and then, considering the recognition aspect is of secondary importance.</p> <p>Prior to the next meeting, it is vital to examine how the resource and involvement match-up. The bureaucracy involved in our arrangements with the NHS in England leaves less time, both for Members and the Secretariat, for engagement in Northern Ireland, Wales and Scotland.</p>	Alison Chris

Membership numbers

At 18 November, we have 362 in our Membership:

- Members - 203 (56%)
- Associate Members - 159 (44%).

The proportions are out of alignment at present, as previously the ratio of Members to Associate Members has been two-thirds to one-third. It is desirable to increase the number of Members, recognising there is strength in a greater number of voices supporting the work of use MY data. A Membership drive was discussed and identified as a priority, as soon as we have the communications resource to do this.

Secretariat resources

There have been some changes in Secretariat resources, due to the funding situation. Currently the roles are:

- Coordinator - 3.0 days per week
Funding is secure until 31 August 2023, with the possibility of extending to August 2024. This role is funded by NHS Digital.
- Expert Data Adviser - 2.5 days per week
The Expert Data Adviser is working in a voluntary capacity, self-funding the role (from September 2022). From September 2022 this is an increase in time, from the previous 1.0 day per week.
- Events Manager - 0.50 days per week
Funding is secure until 31 March 2023 (and uncertain beyond this date). From September 2022 this is a decrease in time, from the previous 1.0 day per week. This role is funded by Bowel Cancer Intelligence UK.

The Advisory Group expressed concern about the Expert Data Adviser needing to self-fund and strongly felt that this role should be funded. To be properly self-sustaining we need to have the structure for people, time and energy. Lots of not-for-profit organisations offer a salary, though it doesn't have to be taken.

The reduction in funding for the Events Manager means that there is now not enough time to do the role fully.

Funding

Our current funders and confirmed funding:

- NHS Digital - use MY data's funding from NHS Digital, via the University of Leeds, ends in August 2023 with the option to extend to August 2024. Discussions are taking place to novate the contract from the University of Leeds to use MY data. This is due to the large increase in overheads being paid to the University of Leeds, which has resulted in reduced funding for the Secretariat.
- Charity funding - Now that use MY data is set up as a legal identity, we will be able to receive funding from a major charity that is interested in providing this. This is now only subject to the bank account being up and running, which is in process at present. This is a hands-off grant of £235,000 across three years. The Advisory Group emphasised that it is important to know what the charity will expect from use MY data, for the grant.
- Health Data Research UK - We received a total of £30,000 in the summer, as a one-off payment. This was to contribute to the running of use MY data and to underwrite the risk of a delay in not receiving funding from NHS Digital until after existing employment contracts expired, in August 2022. The money is being held in a temporary account so that we can use it to cover some of use MY data's non-pay costs, such as honoraria and travel expenses. The balance will be moved across to use MY data's bank account, once this is set-up.

	<p>The Advisory Group asked if use MY data has been required to provide a value statement for funding? This has not been required to date, though the Secretariat created an impact document to support funding bids. The Advisory Group recommended that use MY data produces an annual statement/report on our work and impact and that this would be good to have for our Members, as well as giving a professional appearance. It could be written once and adapted/used three times - for Members, the public, potential funders.</p> <p>Summary of advice</p> <p>Formal engagement with external organisations:</p> <ul style="list-style-type: none"> • Examine how the involvement and the resource match-up? Would be good to do this. • Ensure that use MY data understands the deal - what is in it for use MY data, for the Members, as well as the organisation we are engaging with. • Ask Members in Northern Ireland, Wales and Scotland for help connecting with data projects, initiatives, problems in their country. <p>Membership:</p> <ul style="list-style-type: none"> • Carry out a Membership drive as a priority, once communications support is in place. • Produce an annual report on our work and impact, for Members, the public, potential funders. <p>Funding:</p> <ul style="list-style-type: none"> • Ensure that use MY data is resourced long-term i.e., funding for our Expert Data Adviser. 	
<p>Item 3.0</p>	<p>Where do we want to go - proposals and priorities</p> <p>Vision and mission statements</p> <p>use MY data’s vision and mission statements were reviewed and discussed. There was agreement that the mission is still the right mission, but that the mission statements need a clearer framework, to be re-ordered and to include transparency.</p> <p>The vision statement needs to be reviewed, to make it more visionary and succinct, as the current vision is more of a mission statement. However, it is important to retain the data safeguarding aspect. use MY data has slightly diversified from the original mission and now focusses on highlighting the benefits of using patient data for the individual, as well as for societal benefit - use MY data to help me and help others. A lot of our position statements and projects are about creating a NHS that is better for individual care. The words care and research should probably be in the vision.</p> <p>We can be a voice of balance e.g. on the contracting of NHS data services to an organisation such as Palantir, and/or the use of data within primary care, when it is contracted out by the practice for certain research functions.</p> <p>A suggested vision statement, as a revision starting point: ‘Every patient in the UK willingly giving their data in order to support medical research and their own care’. The shorter the statement, the better. It was noted that the statement does not reference the NHS. And that it might be good to keep a reference to data protection, to aid confidence in the use of the data.</p> <p>Trusted patient voice</p> <p>The Advisory Group discussed use MY data’s position as a trusted patient voice on patient data, using the supporting paper from Richard S as a reference point. There was consensus that use MY data has to be a trusted patient voice, showing what we do is for patient benefit.</p>	

At present, we are a trusted patient voice with certain organisations, but less so with patients and the public. Part of making patients and the public aware of our work, is to obtain credit for everything that we contribute. We need to be sure that patients trust us. Growing our Membership will help to demonstrate trustworthiness.

Specific considerations:

- Should we change the trusted in ‘trusted patient voice’ to ‘trustworthy’?
- Should it be ‘the’ or ‘a’ trusted voice?

To ensure that the patient voice is trusted when it speaks, but also that it is heard, the Advisory Group supported using a set of points outlined in Richard’s paper, subject to two amendments. The set of points:

- 1) Highlight the benefits that appropriate usage of healthcare data can make, to save lives and improve care for all
- 2) Understand and address aspirations and concerns around the use of our data in healthcare delivery, in service improvement and in research
- 3) Harness and represent the patient voice in discussions and consultations with policy makers and others who hold or use our data
- 4) Increase our membership to become more representative of the patient population in the UK
- 5) Publish details of collaborative working with outside organisations, including all responses to consultations, letters to policymakers etc.
- 6) Provide members with tools (e.g., slides or position statements) to support their own activities
- 7) Communicate regularly with all members to report use MY data’s activities and to obtain their views on issues, challenges and opportunities

The sequence of the points is right and highlighting the societal benefit does not diminish the second priority.

Suggested amendments:

- For point 2, identify whose aspirations and concerns are being referenced
- Add a point to clarify this is about ‘my health’ rather than public health
- Add a point about education on patient data, for use MY data’s Members.

Membership

We need to understand why people wish to join use MY data and what their overriding mission is, in joining. The website could be amended, to promote more effectively the benefits of joining - the content is there, but it is not prominent enough or jazzy enough. We need to promote the benefits of joining, not the features.

Why people join as Members is less important than defining what use MY data is about. We do not want to lose the personal aspect. The educational sessions for our Membership are quite special and a great benefit. It could be worth hosting another Members’ census to better understand the current make-up of our Members, why they have joined, what they want from use MY data and what they can offer.

Not all patients are happy with their data being used and we will not appeal to those people. However, we can provide information and engage in discussions.

Summary of advice

Vision and mission statements:

- Tweak the vision, to make it more concise and visionary. Use the suggested wording as a starting point.
- Amend the mission statements to provide a clearer framework. As part of this, re-order the statements and include transparency. Jo will circulate a vision and mission framework, used by her charity.

Trusted patient voice:

- Richard S will summarise the supporting paper into two pages.

	<p>Membership:</p> <ul style="list-style-type: none"> • Amend the website to better promote the benefits of joining use MY data. • Consider hosting another Members' census, to understand who our Members are and why they join. • Consider using attendance information from the educational sessions, including numbers who attend and watch the recordings afterwards, to ascertain what is of interest to Members. 	
<p>Item 4.0</p>	<p>How do we measure our progress - targets, metrics, impact assessments</p> <p>Mission statements The Advisory Group identified these as a priority. The revisions as outlined in Item 3.0 should ideally be ready in mid-January. And they could lead to the charitable purpose. Following the revisions, it is essential to consult with our Members about the prospect of becoming a charity. Vision/mission needs to lead to charitable purpose.</p> <p>Working across all UK nations We need to expand our work across the UK and for this, our work with the NHS in England is a good model to use. At present there is likely to be more happening in Scotland and Wales that use MY data could be involved with, with less in Northern Ireland. It is important to be involved as much as is possible, with each UK nation. Part of this is responding as an organisation to consultations in the devolved nations.</p> <p>It would be helpful to find out which UK nation our Members are in, in order to engage better with those Members in the devolved nations and obtain their input.</p> <p>Membership and recruitment Following on from the discussion in Item 3.0, the Advisory Group identified some specific ways we could highlight the benefits of joining use MY data and expand our Members:</p> <ul style="list-style-type: none"> • Emphasise that it is free to join, free to leave and everything in the middle is free (three frees!) • A video could be good, to provide visual information about joining, rather than just text. • We could write up promotional text and ask organisations such as Health Data Research UK and the National Cancer Research Institute to include in their regular newsletters. • For our website, we could ask our current (temporary) communications contact to write up text for the website, to highlight the benefits of joining use MY data. It could be good to include videos of newer Members of the Advisory Group, giving their view on why they joined and the benefits of being a Member. <p>Structure of use MY data We need to make sure that, before we actively recruit more Members for use MY data and for the Advisory Group, we have our information in order. For example, information should be included that we are now a limited company.</p> <p>The Advisory Group discussed the structure of use MY data, who leads it and who does the Advisory Group advise?</p> <p>Whether use MY data should become a charity was discussed. Key points for consideration:</p> <ul style="list-style-type: none"> • Would becoming a charity make a difference to Members? • Could it make use MY data seem more accountable/appealing to funders? <p>Before going down the charity status route, Members need to be consulted and should have the opportunity to be trustees. Being a charity would require a Board and</p>	

Trustees and a treasurer. It will take approximately six months from the point of application, to become a charity. Further information is needed on the responsibilities of being a charity and the amount of work involved. Additional Secretariat resources would be required to support the change in status. It could help use MY data when applying to organisations for grants - organisations would be likely to have more confidence, due to being able to view use MY data's accounts.

Advisory Group status

The Advisory Group is actually functioning as an executive group, rather than advisory, and agreed that a name change would more accurately reflect its work. Richard S is happy to carry on as chair of the current group and serve the current term of chairing.

Communications strategy and communications/marketing role - these need to be put in place as soon as possible, with a tentative date of the end of January.

Events

Emily gave details of upcoming educational sessions:

- December - Personal Health Records, with Fran Husson, use MY data Member and Patients Know Best
- January - A study using patient data to look at the link between the environments children grow up in and their health and education outcomes.

The Advisory Group suggested that it would be good to link the Born in Bradford research project to the January session.

A suggestion for a future session - what it means to be a use MY data Member, including the future direction of use MY data and how to become more involved as a Member.

Young Data Advisers (YoDAs) engagement session in Leeds - the Advisory Group supported use MY data hosting a workshop, focused on young people interested in the use of patient data.

There are no webinars booked in at present. Hosting one on NHS data and AI is a possibility. Jo has a contact who could help with this topic.

The Advisory Group felt it would be good to have an in-person data event in 2023. For patients, by patients, hosted by use MY data. This would require external funding and resources.

Summary of advice

Mission statements:

- Vision and mission tweaks/updates - to be ready mid-January. Then consult with our Members about the prospect of becoming a charity. Vision/mission needs to lead to charitable purpose.

Working across all UK nations:

- use MY data should comment on the recent Welsh Government research strategy, for which the deadline by 06 December, with Chris to lead on this. Once we have someone in a dedicated communications role, we need to publicise work such as this to the Members in that nation. At this stage we can go ahead and publicise using Twitter and our website.
- Find out which UK nation our Members are in, in order to engage better with those Members and obtain their input. Targeted communications will need to wait until we have a dedicated communications lead.

Membership and recruitment:

- Engage our temporary communications contact to write up text for the

	<p>website, to highlight the benefits of joining use MY data. Include a video - possibly with newer Members of Advisory Group.</p> <ul style="list-style-type: none"> • use MY data badges - would be good to help promote use MY data when Members attend events. We could use an electronic badge for emails, to highlight support for use MY data. • Communications role - which will support Membership recruitment - to be in place by end of January (if funding in place). <p>Advisory Group status:</p> <ul style="list-style-type: none"> • Renaming of Advisory Group - to be renamed as an Executive Group, as soon as possible • Richard S will write a piece for the newsletter, to update our Members on the direction of recent changes. <p>Events:</p> <ul style="list-style-type: none"> • Explore hosting an in-person data event in 2023. For patients, by patients, hosted by use MY data. • Consider a webinar on NHS data and AI. • Young Data Advisers (YoDAs) - explore hosting a workshop in Leeds for young people interested in the use of patient data. 	
<p>Item 5.0</p>	<p>Dates for next meetings</p> <p>Initial meetings in 2023 were agreed as:</p> <ul style="list-style-type: none"> • January, date to be confirmed 90 minutes, online • March, date to be confirmed 11:00 to 15:00, In-person, London <p>As a starting point, Alison will circulate polls to find suitable dates.</p>	<p>Richard S Alison</p>
	<p>Any Other Business</p> <ul style="list-style-type: none"> • Event information 'Enhancing patient-centric outcome measures and clinical trials with digital health' on 12/13 December was highlighted - https://medicinedevelopment.eu/. • Patient access to patient records Some Advisory Group Members are writing an article for the British Medical Journal, to provide patient perspectives on patient access to their records in England, following recent delays to access. It is hoped the article will be published in two to three weeks. Once the article is finished, it will be circulated to the Advisory Group as a whole. • Bureaucracy of being a patient representative with NHS Digital The challenges of being a lay-person representative on NHS Digital groups was raised and discussed. There is a high level of time-consuming bureaucracy around the roles, due to patients being required to become a zero-hours employee of NHS Digital - all of which could put patients off from becoming involved. Alternative options were discussed, some of which the Secretariat has previously tried to implement with NHS Digital. The favored option of representatives would be to receive reimbursement direct from use MY data, with a grant being paid from NHS Digital to use MY data. The Secretariat will revisit this with NHS Digital. 	

Record of actions arising from the meeting		
Action	Responsible for	Date to complete by
Formal engagement with external organisations - Examine how the involvement and the resource match-up, prior to the next meeting.	Chris & Alison	31.01.23
Formal engagement with external organisations - Ask Members in Northern Ireland, Wales and Scotland for help connecting with data projects, initiatives, problems in their country.	Alison	To be decided in 2023
Formal engagement with external organisations - Ensure that use MY data understands the nature of any arrangements/agreements entered into with external organisations, establishing what is in it for use MY data, for the Members, as well as for the organisation.	Secretariat	Ongoing
Membership - Carry out a Membership drive as a priority, once communications support is in place.	Alison	To be decided in 2023
Membership - Produce an annual report on our work and impact, for Members, the public, potential funders.	Chris & Alison	To be decided in 2023
Funding - Ensure that use MY data is resourced long-term i.e., funding for our Expert Data Adviser.	Secretariat	Ongoing
Vision and mission statements - Tweak the vision, to make it more concise and visionary, using suggested wording as a starting point. Then consult with our Members about the prospect of becoming a charity - the vision/mission needs to lead to charitable purpose.	Chris & Alison	31.01.23
Vision and mission statements - Amend the mission statements to provide a clearer framework and, as part of this, re-order the statements and include transparency. Jo will circulate a vision and mission framework, used by her charity.	Chris & Alison Jo	31.01.23
Trusted patient voice - Richard S will summarise the supporting paper into two pages.	Richard	31.01.23
Membership - Amend the website to better promote the benefits of joining use MY data.	Chris & Alison Pete	31.01.23
Membership - Consider hosting another Members' census, to understand who our Members are and why they join.	Chris & Alison	To be decided in 2023
Membership - Consider using attendance information from the educational sessions, including numbers who attend and watch the recordings afterwards, to ascertain what is of interest to Members.	Chris	To be decided in 2023
Working across all UK nations - use MY data should comment on the recent Welsh Government research strategy, for which the deadline by 06 December, with Chris to lead on this.	Chris	06.12.22
Working across all UK nations - Once we have someone in a dedicated communications role, we need to publicise our UK work such as this to the Members in that nation. At that stage, we can use our website and social media to publicise.	Comms role	To be decided in 2023

Working across all UK nations - Find out which UK nation our Members are in, in order to engage better with those Members and obtain their input. Targeted communications to these Members can begin once we have a dedicated comms person.	Alison Comms role	To be decided in 2023
Membership and recruitment - Engage our temporary communications contact to write up text for the website, to highlight the benefits of joining use MY data. Include a video - possibly with newer Members of Advisory Group.	Chris	05.12.22
Membership and recruitment - Organise for use MY data badges: 1) physical badges to help promote use MY data when Members attend events 2) electronic badges for emails, to highlight support for use MY data.	Secretariat	31.01.23
Membership and recruitment - Communications role (which will support Membership recruitment) to be in place by end of January (if funding is in place in time for this).	Secretariat	31.01.23
Advisory Group status - Rename the Advisory Group as the Executive Group, as soon as possible (once Members have been updated)	Secretariat	ASAP
Advisory Group status - Write an article for the newsletter, to update our Members on the direction of recent changes.	Richard S Alison	ASAP
Meetings in 2023 - Circulate date polls for an online meeting in March and in-person meeting in March.	Alison	07.12.22
Events - Explore hosting a 2023 in-person data event - for patients, by patients, hosted by use MY data. This would require external funding.	Emily	31.01.23
Events - Consider a webinar on NHS data and AI, with Jo to provide a potential contact to Emily.	Emily Jo	31.01.23
Events - Explore hosting a workshop in Leeds for young people interested in the use of patient data - Young Data Advisers (YoDAs).	Emily	31.01.23
Bureaucracy of being a patient representative with NHS Digital - David will send Chris supporting information, for Chris to use in liaison with NHS Digital to try and find a better solution to reimbursement for Members' time.	David & Chris	31.01.23

Suggestions for future meetings	
January	Standing items <ul style="list-style-type: none"> • Update on funding • Update on discussions with national organisations
March	Standing items <ul style="list-style-type: none"> • Update on funding • Update on discussions with national organisations