

Executive Group & Secretariat - Online meeting

**Wednesday, 24 May 2023
11:00 to 12:30**

Meeting notes - confirmed

<p>Item 1.0</p>	<p>Welcome, apologies & housekeeping</p> <p>The Chair welcomed attendees and the meeting etiquette was reviewed and agreed.</p> <p>Attendees: Executive Group - Richard Stephens (Chair), Richard Ballerand, Samina Begum, Jo Gumbs, John Marsh, David Snelson Secretariat - Chris Carrigan, Alison Stone</p> <p>Apologies: Dave Chuter (Vice Chair), Pete Wheatstone</p> <p>Did not attend: Sarah Markham</p>	<p>Richard S</p>
<p>Item 2.0</p>	<p>Funding & recruitment of staff</p> <p>For discussion</p> <p>a. Funding - relationship with Cancer Research UK John, Samina, Alison and Chris attended an initial meeting with Cancer Research UK (CRUK) on 25 April and have circulated their write-up of this to the Executive Group. Monthly informal catch-ups will be held online and quarterly strategy meetings will be in-person. At least two Executive Group Members will attend each meeting, with Chris and Alison.</p> <p>A key item for discussion was the idea of exploring a joint initiative with CRUK on access to patient data, helping to lead the development of a united charity front to support NHS England in sharing the data that they collect, for the benefit of patients that supply it. This work will have a particular focus on communicating the benefits of collection and use of data, to fill an area where it is often difficult for national bodies to communicate.</p> <p>The Executive Group was supportive of exploring this initiative in principle, with the consensus that use MY data should help shape and be part of the leadership of the initiative.</p> <p>The next informal catch-up with CRUK is on 21 June, which will be followed by CRUK joining the Executive Group & Secretariat meeting (part of) on 19 July.</p> <p>b. Funding - potential new funder A UK research institute has expressed interest in providing some funding to use MY data. The Secretariat is exploring this possibility with the institute and will feedback as and when there are any developments.</p> <p>Update</p> <p>c. Recruitment of staff - latest developments We are advertising the new Secretariat roles on our website (advertising commenced</p>	<p>Chris Alison John Samina</p>

	<p>on 17 May). Chris and Alison will review responses later today (24 May), to see if the advertising needs to go wider. The closing date is 08 June, with Chris and Alison meeting on 14 June to review applications, followed by interviews on 27 and 28 June.</p> <p>CRUK has offered to help advertise the roles and this offer has been gratefully accepted. The Executive Group suggested using social media, particularly Facebook, plus LinkedIn and Indeed. The Secretariat will explore these options.</p> <p>The Executive Group felt that it would be timely to review use MY data's social media use.</p> <p>d. Summary of actions</p> <ul style="list-style-type: none"> · Alison - Report back to Cancer Research UK on the Executive Group's support for working on a joint initiative around access to patient data. · Alison - Continue to explore potential new funding with the UK research institute and report back to the Executive Group on any developments. · Alison - Arrange for a review of use MY data's social media use, once the Comms & media lead is in their role. · Chris & Alison - Widen the advertising for the Secretariat roles, using the Executive Group's suggestions. 	
<p>Item 3.0</p>	<p>Strategic direction of use MY data</p> <p>For decision</p> <p>a. Vision & mission - comments from Members; final approval</p> <p>Following the call on the 25 April to Members for a final review of the proposed changes to use MY data's vision, mission and values, the Executive Group reviewed feedback and suggestions, with thanks to those who had sent comments.</p> <p>Three specific suggestions were reviewed and discussed.</p> <p>1) Our mission: To be a Trusted Voice for patients and the public in all discussions and decisions about the use of our data to improve research and healthcare</p> <p>Suggestions: Consider using 'trustworthy' instead of 'trusted' and consider tweaking '...use of our data to improve research and healthcare to '...use of our data for research and improving healthcare'</p> <p>Decision: Amend the mission statement to the following: Our mission: To be a Trusted Voice for patients and the public in all discussions and decisions about the use of our data for research and improving healthcare</p> <p>2) Our aims: 'To advocate that data safeguarding is robust, transparent, understood, communicated and reassuring to patients and the public'</p> <p>Suggestion: The aim presupposes that the safeguarding is robust etc. Is this the intention? [Suggest] 'To advocate for robust and transparent safeguarding of data, which is clearly communicated to patients and the public'</p> <p>Decision: Amend the aim to the following: To advocate for robust and transparent safeguarding of data, which is clearly communicated to patients and the public</p> <p>3) Our values: 'Members recognise that decisions to share or not to share personal healthcare data for public benefit are matters of individual choice'</p> <p>Suggestion: Currently the National Data Opt-out (NDOO) does not give a person the power to decide whether there is sharing of their personal healthcare</p>	<p>Chris Richard S Alison</p>

data...Members may disagree with the scope of the NDOO and believe in more autonomy (or they may not). The current wording would seem to entail campaigning to change the NDO into something resembling a type one objection... A more neutral statement would be: 'Our Members recognise the importance of giving people choices in how their data is used'

Decision: Amend the value to the following:

Our Members recognise the importance of giving people choices in how their data is used

For discussion

b. Charitable status update/progress - proposed timescales

On the overview calendar, May was the month for consultation with Members using the expanded paper from the Executive Group & Secretariat (followed by the creation of a plan to take the work forward (if decision is to do so) once the Secretariat is expanded.

More time is needed to produce the expanded paper - this needs to be drafted and brought back to the Executive Group, ahead of circulating to Members. Jo will speak with Dave about their joint work to produce the paper, with an aim for the paper to be ready for the end of June and brought to the July meeting. Alison will update the calendar.

c. Members' census 2023 - timing and personnel resources

On the overview calendar, this was pencilled in for June, subject to expanding Secretariat resources. However, this is unlikely now. The Executive Group emphasised that this work is a priority and asked for a review of Secretariat tasks and priorities at the July meeting.

d. Executive Group expansion/refresh - timing and personnel resources

On the overview calendar, this was pencilled in for June, subject to expanding Secretariat resources. This is unlikely now. However, there is potential interest from a use MY data Member in joining, following recent discussions with the Secretariat about their work and interests. The Member has a strong interest in/knowledge of primary care data and the importance of increasing diversity in patient representation, particularly from ethnic minorities.

The Executive Group discussed how best to proceed with the expansion. At present there is only one vacancy on the Group, and it is important to fill this place in the most inclusive way possible with the opportunity for all Members to apply. The Executive Group asked Alison to put a call out to Members, via the newsletter to highlight the current vacancy. If there is more interest than the available place, it may be necessary to hold over some applications for the time being, until a refresh of the Executive Group takes place.

e. Summary of actions

- **Alison** - Take forward implementing use MY data's updated vision, mission and values.
- **Jo** - To liaise with Dave on their joint work expanding the charitable status options paper for Members - aim to draft the paper by the end of June, to bring to the July Executive Group meeting.
- **Alison** - Ensure that a review of Secretariat tasks and priorities is on the agenda for the July Executive Group & Secretariat meeting.
- **Alison** - Advertise the current Executive Group vacancy in the newsletter and feedback to the potentially interested Member on this route.

<p>Item 4.0</p>	<p>Engagement & events</p> <p>For discussion</p> <p>a. use MY data’s work on the General Practice Data for Planning & Research The Executive Group discussed use MY data’s work and position on the Patient and Public Engagement and Communications Advisory Panel (PPECAP) for the General Practice Data for Planning & Research (GPDPR). This follows the lack of publication of meeting notes for a pivotal meeting on 02 March, a subsequent update to Members and call for their input on possible next steps for use MY data and NHS England’s (NHSE) response to this.</p> <p>Earlier today (24 May) Chris and Alison met with Lorna Branton, Head of communications & engagement for GP data, NHSE to discuss the current position of both NHSE and use MY data. Consequently, Lorna was invited to write an article for the newsletter, to provide a direct update from NHSE to use MY data Members. Lorna accepted this invitation, and the article will feature in either the 25 May or 08 June newsletter. The Executive Group welcomed that Lorna will be providing information direct to our Members.</p> <p>The Executive Group agreed that it was important for our PPECAP representatives to continue to push for the publication of the minutes and for transparency around discussions.</p> <p>Feedback from Members was supportive of use MY data firmly and strongly continuing to push for transparency.</p> <p>Updates</p> <p>b. Update on discussions with national organisations Chris gave a round-up of recent discussions.</p> <ul style="list-style-type: none"> • Cancer Research UK (CRUK) Data Advisory Board - Chris is a member of the Board and at the May meeting asked that information about the Board is made available, for use MY data Members. • NHS England (NHSE) Charity session: Chris attended the first NHSE update session specifically for charities and voluntary groups. The information discussed was largely covered in other NHSE update sessions, with the exception that the charities present, asked how NHSE digital content (e.g., the NHS website) will direct people to condition-specific charities. This will be covered at a future session. • Prostate Cancer Research: Chris attended a meeting about the proposed data platform for prostate cancer research. This followed an initial meeting held at the IQVIA offices by Prostate Cancer Research. • National Data Advisory Group: Chris represents use MY data on this Group, which is hosted by the Department for Health & Social Care (DHSC) and which contains different expert voices. It is a closed Group, for confidential discussions, and the meeting notes are marked as “official, sensitive”. • Association of British Pharmaceutical Industry (ABPI): Chris was part of a follow-up meeting to an ABPI workshop in March, chaired by Chris and attended by Richard S for use MY data. • Health Data Research UK (HDR-UK) Alliance Council Meeting: Chris spoke about the work of use MY data at the first meeting of the expanded Alliance. The expansion now includes organisations which are not data controllers (the previous requirement for entry), but who have an interest in health data. The Secretariat will meet with the Alliance to discuss (in the first instance) the possibility of use MY data joining. • Association of British Pharmaceutical Industry (ABPI) Annual Conference 2023: Chris was invited by the ABPI to attend. Richard S attended too, as a National Cancer Research Institute (NCRI) Consumer and the NCRI had a stand in 	<p>Chris Alison</p>
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	<p>the exhibition area. An important message was from the final Question & Answer session with the Secretary of State (SoS) for Health and Social Care. The SoS was asked about the ways in which charity and patient organisations could be most useful in helping to grow the UK as a leading global centre for life sciences and his answer was in “a conversation with patients about data”.</p> <p>c. Update on Secretariat’s six-point engagement plan The Secretariat’s engagement plan has key targets for engagement of the four UK nations, Understanding Patient Data and the Patients Association. Alison updated the Executive Group on work on this plan, since it’s sign-off by the Executive Group on 29 March.</p> <ul style="list-style-type: none"> • Patients Association - Chris and Alison are meeting with Rachel Power, CEO & Maya Anaokar, Head of Communications & Marketing on 07 June. Our request for this meeting follows on from the Patients Association’s recent work on patient data and access to records in England - to share information about use MY data’s work in this area and to see if there is scope for joint working. • Understanding Patient Data - Chris has a place on the Board and the first meeting will take place on 03 July. Chris will report back to Members and to the Executive Group after this. • Work across the four UK nations - England is still the focus at present. Once the Secretariat has more personnel, focussing on Northern Ireland, Scotland and Wales will be a priority. <p>d. Educational sessions & events for 2023 Chris updated on upcoming educational sessions, following suggestions from Members and offers from Associate Members and key stakeholders. Current plans are:</p> <ul style="list-style-type: none"> • Statutory guidance: NHS England’s protection of patient data - a session with the Department of Health & Social Care (DHSC) to give Members the opportunity to ask any questions they wish & discuss the guidance direct with DHSC. The Executive Group felt that mid-June to mid-July would be good timing. • Population Health Management - suggested by a Member and Chris is currently seeking a speaker for this. • National Disease Registration Service (NDRS) - suggested by an Associate Member who is a senior analyst with the NDRS - session confirmed for 19 June. • Data around clinical trials - suggested by a Member and Chris is exploring this with them. • Federated analytics & what it is in reality • Trusted Research Environments s & Secure Data Environments. <p>External events are on hold at present, pending expanding the Secretariat.</p> <p>e. Summary of actions Chris - Provide a report for Members on Cancer Research UK’s Data Advisory Board. Alison - Ensure the PPECAP article from Lorna Branton, NHSE is included in either the 25 May or 08 June newsletter. Chris - Book the DHSC educational session for mid-June to mid-July.</p>	
Item 5.0	<p>Any other business</p> <p>There was no further business.</p>	Richard S
Item 6.0	<p>Meetings for the remainder of 2023</p> <ul style="list-style-type: none"> • 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 	Alison

Suggestions for future meetings		
<p>19 July In-person</p>	<p>Key items:</p> <ul style="list-style-type: none"> ▪ Research Data Strategy partnership work with CRUK ▪ Charitable status options ▪ Executive Group expansion ▪ Review of Secretariat tasks & priorities, including Members' census 2023 ▪ Secretariat recruitment <p>Standing items</p> <ul style="list-style-type: none"> ▪ Update on funding ▪ Update on discussions with national organisations 	