

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

**Wednesday, 19 July 2023, 10:45 to 15:00
Friends House, 173-177 Euston Road, London, NW1 2BJ**

Meeting notes - confirmed

<p>Item 1.0</p>	<p>Attendees: Executive Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Richard Ballerand, Samina Begum, Jo Gumbs, Sarah Markham, John Marsh, David Snelson & Pete Wheatstone</p> <p>Secretariat - Chris Carrigan, Elizabeth Lloyd-Owen & Alison Stone</p> <p>Cancer Research UK - Melissa Lewis-Brown, Head of Research Data Strategy & Nick Jones, Policy Manager, joined the meeting for Item 4.0</p> <p>The Chair, Richard S, warmly welcomed all attendees including Elizabeth, our new Communications and Media Lead. A round of introductions were made, followed by the meeting etiquette and housekeeping.</p>	<p>Richard S</p>
<p>Item 2.0</p>	<p>Where we are: use MY data's resources and status</p> <p>Intended outputs/possible products from this item:</p> <ul style="list-style-type: none"> · Paper on charitable status options, to present to Members <p>a) To inform this discussion:</p> <ul style="list-style-type: none"> · Funding update - Chris · Secretariat recruitment update - Chris & Alison · Charitable status options - paper from Dave & Jo <p>Charitable status options Dave and Jo talked through the two options presented in their paper - 1) charity status and 2) becoming a Charitable Incorporated Organisation (CIO). They recommended that CIO status would be the best one for use MY data and this option was discussed by the Executive Group.</p> <p>Initial comments:</p> <ul style="list-style-type: none"> · A full voting member structure would be quite a change to how use MY data operates now, which relies on our Executive Group to represent Members. · A small number of Trustees for a CIO could be more efficient but would be less democratic than a larger number. · More information is needed on the benefits of being a CIO. <p>Follow-up comments:</p> <ul style="list-style-type: none"> · Pros of being a charity - it would be Member led. · Cons of being a charity - the amount of time needed to undertake the work. · At present use MY data is a company Limited by Guarantee. In company terms, individual Members do not have voting rights. · The constitution for use MY data as a charity or CIO would need to be very clear about the number of trustees and what they can decide. 	<p>Richard Dave Jo</p>

- 50% of Trustees would represent the Membership.
- Trustees are very much about governance at a top level, rather than the day-to-day running of an organisation.
- The CIO model was favoured by Executive Group Members with experience of being a Trustee, due to use MY data being an organisation where Members are extremely important. It is essential that the need for the input of Members, is written into any constitution.
- It would be very onerous to have a Trustee model, when we are trying to extend the Membership. We would also need guidelines on what the Members would be consulted on.
- A one-person, one-vote option would be too onerous for use MY data.
- Having a charitable status may open us up to more Members, engender trust in the public.
- Broad agreement that the CIO is the preferred option and with that in mind, it is necessary to define next steps.

Communicating to Members:

- Essential to involve Members in the next steps and seek interest for being part of a small working group that could develop a constitution.
- The key part is the communications for Members, rather than a technical document. The why behind the reasons is the critical part. Essential that the sequence, wording and communication are all done in the right way and with great clarity. As part of that, it is important to emphasise to Members that it is they (rather than Associate Members) who would be part of the work.

Next steps:

- Our Members need a communications piece, with the full pros and cons of the charitable status recommendation.
- As part of that, it is important that our Members understand why the Executive Group are recommending a charitable status, at this point. It is essential that the Executive Group carries the Members along, as part of this process and does not leave them behind. Losing Members is the last thing that the Executive Group would want to happen.
- As part of the next steps - we need to determine how we migrate from our current legal status to a charitable status.
- It is likely to be six to nine months before we can have a charitable status - perhaps April 2024. However, we do need to have the Administrator role in place, to underpin the work.
- We could use a company who will work pro bono, to assist with the work to change the status.
- We do have some information written on the benefits of a charitable status.
- A paper should be written for Members and this could contain accompanying FAQs, to explain what the constitution would be and could include a call for volunteers to write the constitution. Communications should have a simple message - perhaps with graphics and key facts.

Thanks were given to Dave and Jo for their work on the paper.

Funding update

Cancer Research UK - This funding is all in place and is being used to fund the Communications & Media Lead and will fund the Administrator role. We now have a payroll company in place (with thanks to Jo for her assistance in this area).

NHS England - Funding for the Coordinator's post from September 2023 to August 2024 has been confirmed. Now that use MY data is a legal entity, the Secretariat had hoped to receive the funding direct from NHS England. However, NHS England has advised that is not possible at this stage, and the funding has to be paid into the Institute of Medical Research, University of Leeds, who will host the role. We are waiting to hear the percentage of overheads that the University will take, ahead of

	<p>knowing if there will be funding left to use for items such as providing honoraria for NHS England engagement work and then possibly providing other Secretariat resource.</p> <p>Health Data Research UK (HDR UK) - last year HDR UK gave use MY data a one-off amount of funding, which was extremely useful. We have a proportion of this to use and Chris will produce a financial statement.</p> <p>The Executive Group asked the Expert Data Adviser about funding for his role and he confirmed that he continues to work for free.</p> <p>Appreciation of, and gratitude for, the funding from Cancer Research UK, NHS England and Health Data Research UK were recorded.</p> <p>Secretariat recruitment Communications & Media Lead - Recruitment for this role was successful. Elizabeth was appointed and started on 18 July.</p> <p>Administrator - It was not possible to appoint to the role on the first round of recruitment. Although an offer was made to the preferred candidate, this did not proceed to an appointment. The Secretariat is now 'putting the feelers out' informally to other organisations. If they have not found a candidate by September, they will advertise the role again and do a second, formal, round of recruitment.</p> <p>b) Summary of actions</p> <ul style="list-style-type: none"> · Dave, Jo, Chris - Prepare a paper for Members, explaining why the Executive Group recommends the Charitable Incorporated Organisation (CIO) as the best way forward. Circulate to Executive Group before it goes out to Members - by early September. · Executive Group - Review the CIO paper and write-up any associated FAQs - by the end of September, ahead of sending paper to Members in early October. · Chris - To produce a financial statement and circulate to the Executive Group. 	
<p>Item 3.0</p>	<p>Where we are heading: use MY data's internal work</p> <p>Intended output/possible product from this item:</p> <ul style="list-style-type: none"> · Decision about timing for Members' census · Decision about timing for Executive Group expansion/refresh <p>a) To inform this discussion:</p> <ul style="list-style-type: none"> · Review of Secretariat tasks & priorities - paper from Chris & Alison · Executive Group recruitment update, following recent advertisement - Alison · Terms of Reference for the Executive Group - Richard <p>Review of Secretariat tasks & priorities This was produced at the Executive Group's request, after Chris and Alison had to delay organising the Members Census, due to their workload. The Executive Group said that it had been helpful and illuminating to see the paper. It could be the makings of an annual report (which is due later this year).</p> <p>What is not included in the paper is the work that it has not been possible to undertake, due to limited personnel. The Secretariat has been under-resourced by at least 50%, to date. The Executive Group expressed some concerns about work that has not been done. Now that Elizabeth is on board, she will be able to use existing work and take it forward, in a way that was not previously possible i.e., promoting our Position Statements.</p> <p>The Secretariat members were advised to be careful about their workload with regard to increasing capacity - new personnel will take time to induct, train and manage.</p>	<p>Richard S Alison Chris</p>

	<p>Members' census - following discussion, it was decided that it would be realistic to launch this between February to May 2024 (February if we have resources). We need to make sure feedback is given to Members about the reasons for doing the census, and we need to do it properly.</p> <p>Executive Group recruitment update Alison gave a quick update following the advertisement to Members in the 15 June newsletter, about the vacancy on the Executive Group. There were no expressions of interest. The Member who was potentially interested has taken up another role, which means they do not have the time necessary for the Executive Group's work.</p> <p>As the newest Member of the Executive Group, Samina was asked for her experience of joining and what worked well or not, in understanding the nature and remit of the Group. Samina felt that it would be useful to have something on the website, perhaps a video, to explain visually what use MY data is and what the aims are. Perhaps an Executive Group Member and a Member speaking about why they are involved, with linking information to how Members can become involved. While there is a lot of information on the website, it is not easy to tease out the relevant parts to joining/becoming involved. Samina would be prepared to volunteer to take part in making a video.</p> <p>Elizabeth is already planning how to make the website more accessible and informative and how to finesse the content. It is essential that any videos are done well, which requires resource to do this and skills. It might be good to tie in the website update and presentations with our new charitable status. For the videos - it would be good to film at events, so the videos are not bland. Members' appearances at external conferences could be screen-grabbed and used.</p> <p>Terms of reference use MY data does not have a Terms of Reference and whether this is needed now, ahead of a charitable status was discussed. There was agreement that this will be deferred until we have a charitable status. However, it is important to produce a brochure/annual report of some kind. We can use existing documents, such as the Secretariat's tasks & priorities document. The audience would be Members, Associate Members, potential Members and potential funders.</p> <p>b) Summary of actions</p> <ul style="list-style-type: none"> · Alison - Bring the Members' Census planning to the November meeting, for discussion. · Elizabeth - Take forward making a publicity video, involving available Members of the Executive Group and some of our Members. This will be launched when we obtain a charitable status. · Elizabeth - Lead on producing a brochure/annual report (with the support of Chris and Alison), using existing documents such as the Secretariat's tasks & priorities document. · Elizabeth - Produce a communications plan, in due course. 	
<p>Item 4.0</p>	<p>Where we are heading: use MY data's external work</p> <p>Intended outputs/possible products from this item:</p> <ul style="list-style-type: none"> · Decision on Research Data Strategy (RDS) priorities with Cancer Research UK <p>a) To inform this discussion:</p> <ul style="list-style-type: none"> · Update on informal discussions with the RDS team - paper from Chris & Alison <p>Melissa Lewis-Brown, Head of Research Data Strategy and Nick Jones, Policy Manager, Cancer Research UK (CRUK) joined the meeting.</p>	<p>Richard Melissa</p>

Melissa gave an overview of the Research Data Strategy (RDS), which has eight foundations. Building public trust in using data for research is the first foundation and a priority.

With regard to partnership work within our funding relationship with CRUK, Melissa emphasised that the minimum expectation of CRUK supporting use MY data as an independent advocacy organisation, is for use MY data to continue its great work. But that, if there is appetite across use MY data to work in partnership with CRUK on particular activities beyond that minimum, then CRUK would love to explore that. A potential activity we could consider working together on, is influencing regarding researchers' access to patient data.

In parallel there is a piece of work around the 'Manifesto for Cancer Research and Care', being developed by the Policy & Influencing Team. Access to and use of patient data will be a thread, throughout the work. Nick expanded on this piece of work, which is CRUK's vision for the next five to ten years - on all areas related to cancer. The report is aimed to have maximum impact for the next General Election. Each policy area will have one key recommendation.

The Executive Group and Secretariat reviewed the 'Data for Research' section. A round-up of key comments, questions and answers.

- **What was meant by "cutting edge technology" in the Research Data Strategy and whether CRUK have considered inherent limitations of technologies as they emerge?** - This covers a range of new and emerging technologies, including artificial intelligence and approaches to mitigating risks.
- **Interest in whether the Manifesto will be UK or England focused.**
- **'Transparency' is missing as a word.**
- **Mindset/culture/control could be added** i.e., the culture of risk aversion (since Public Health England's demise, there is a loss of focus around stimulating data research).
- **What is CRUK doing in this area, to demonstrate they are doing what they are asking the Government to adopt** (as a role model)? - The example of CRUK's own Trusted Research Environment (TRE) was given. This was specifically created as CRUK learned that researchers were having difficulty integrating data for research in a collaborative yet secure computing environment. CRUK saw a risk of fragmentation of data, without the TRE - the CRUK TRE has the ability and neutrality to bring cancer registry data together across the four nations, for particular projects. Pilot phase now complete and has been rolled out to CRUK-funded researchers in the first instance. Broadening out will be considered, depending on the need and external landscape.
- **Suggestion to align data access processes for the TRE with the nation/sub-national TRE/Secure Data Environments (SDE)** - Melissa said as the details of NHSE's national SDE programme emerge, CRUK's TRE will seek to align as appropriate, as well as with. Health Data Research UK's (HDR UK) Health Data Alliance's work in this space. CRUK has become a core funder of HDR UK, to support at arm's length. NHS England is adamant that a sub-national SDE infrastructure is necessary for them.
- **The importance of emphasising that there are four Governments involved** - there are unintended consequences to patient care, of devolution on health data.
- **Emphasising the challenges of collecting/using rare cancer data, will the plans include all cancer types?** - In response to the answer that the Manifesto will include that, the Executive Group requested that it should be included on the slide, to make clear it includes all cancer types.
- **CRUK's inequality strategy on data research - what's in the Cancer Manifesto about that? How is CRUK listening to public and patient voices about the Manifesto?** - Melissa said that there is a really strong thread

throughout the Manifesto and that this is a priority.

- **Primary care data is needed, such as that in the Clinical Practice Research Datalink (CPRD)** - Melissa said that the lack of primary care data is picked up within the Manifesto. Other datasets are missing e.g., national screening datasets.
- **What does 'NHS data' allude to?** That phrase needs to be explained as patients see it very much as 'patient data'.
- **Cancer care and long-term effects is missing** and this is important. Data is important to the patient, not just to clinical outcomes. What is the impact on the quality of life? Is CRUK focused on research or on care for cancer patients?
 - Melissa replied that the focus is on research primarily and on care. When we talk about use of patient data by CRUK, it is definitely about both.

Nick would welcome further feedback - from the Executive Group as a whole and from individuals, within the next three weeks. There was agreement on working together when the Manifesto is published, to spread the word and perhaps do an advocacy piece.

Other related comments:

- SDEs - use MY data has a workshop with NHS England on 25 July on this topic, for use MY data Members. The national/regional topic is likely to be raised.
- The NHS is sharing information via the FutureNHS platform - the Secretariat needs to register for this.
- In support of data for research, it is equally important that patients are able to see (and quality check) their own patient records - data that we as individuals are able to see about ourselves is as important as researchers being able to see it for their work. "The NHS is 75 years old and we do not yet have a national health record."

Melissa asked two questions:

1. NHS England says that patients feel more comfortable if their data does not move out of the area it's collected in. Is this a view familiar to use MY data?
2. For cancer data specifically - would it feel like a backwards step if cancer registry data was to be regional again?

The Executive Group strongly felt that the views of patients are not being taken into account about the use of their data and whether it should be collected and used at a regional or national level.

For Question 1 - This view was not familiar to the Executive Group, who emphasised the importance of being able to see evidence about the data options that patients feel most comfortable with, for transparency.

For Question 2 - There was consensus that it would be a backward step, for cancer registry data and for the wider spectrum of patient data for research and planning.

The Executive Group asked for conversations about patient data to be included in other more general patient meetings or events organised by CRUK. Melissa agreed and highlighted that February 2024 is the first data driven conference. There could be an opportunity to have satellite meetings, a patient body on the main agenda as speakers and panel members. The original aim of the Conference was to bring the research community together, but it has now been expanded to include members of the public. The primary focus is researchers and they will be briefed that the public will be part of the audience. Chris suggested that use MY data could host pre-conference lay person's explainer sessions, as an off-shoot of our educational sessions. This could be accompanied by downloadable resources - cheat/crib sheets.

In summary, the Executive Group highlighted that one of the problems the NHS has is getting people's confidence when talking about data, as the NHS is not a trusted

	<p>voice. Charities and patients together have an opportunity to be a trusted public voice - improving public confidence around using patient data.</p> <p>b) Summary of actions</p> <ul style="list-style-type: none"> • Melissa - Arrange for the Cancer Manifesto slide to be sent for Executive Group's review/input. • Alison & Executive Group - Coordinate the Executive Group's feedback and suggestions to Nick on the Cancer Manifesto. • Chris or Alison - Register for the FutureNHS platform. 	
Item 5.0	<p>Any Other Business</p> <ul style="list-style-type: none"> • Palantir Palantir has contacted David, as they wish to speak with use MY data on patient data topics. Following a quick discussion, there was agreement that David will suggest that Palantir may wish to take part in an educational session and put them in touch with the Secretariat for the next steps. 	Richard S
Item 6.0	<p>Dates for next meetings</p> <p>Meetings for the remainder of 2023 are confirmed as:</p> <ul style="list-style-type: none"> • Wednesday, 20 September, 11:00 to 12:30 - online • Wednesday, 29 November, 11:00 to 15:00 - in-person, London. 	Richard S

Suggestions for future meetings	
20 September Online	<p>Key items:</p> <ul style="list-style-type: none"> • Charitable status paper & FAQs • Secretariat recruitment update <p>Standing items</p> <ul style="list-style-type: none"> • Update on funding • Update on discussions with national organisations
29 November In-person	<p>Key items:</p> <ul style="list-style-type: none"> • Members' Census planning, for discussion <p>Standing items</p> <ul style="list-style-type: none"> • Update on funding • Update on discussions with national organisations