

**Advisory Group & Secretariat
Interim meeting - online**

**Wednesday, 19 October
14:30 to 15:30**

Meeting notes - confirmed

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| Item 1.0 | <p>Attendees</p> <p>Advisory 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, Emily Connearn, Alison Stone.</p> <p>Samina was welcomed to her first meeting and a round of introductions were made.</p> | Dave |
| Item 2.0 | <p>Legal status & funding</p> <p>a. Funding - latest developments</p> <p>Chris gave an overview of current employment contracts for the Secretariat:</p> <ul style="list-style-type: none"> • Coordinator (Alison) - 3.0 days per week, employed by University of Leeds, funded by NHS Digital • Events Manager (Emily) - 0.5 day per week, employed by University of Leeds, via a collaborative agreement with Bowel Cancer Intelligence UK • Expert Data Adviser (Chris) - 2.0 to 3.0 days per week, self-funded. <p>NHS Digital’s funding runs to the end of August 2023, with the option of an additional year’s extension, to the end of August 2024. The funding only covers the role of the Coordinator and not the Expert Data Adviser or Events Manager, as had been hoped.</p> <p>Health Data Research UK has given a one-off grant funding, to support our work.</p> <p>use MY data has been offered potential grant funding by a charity, which is dependent on us having an established legal status.</p> <p>b. use MY data’s legal status - update & proposal for next steps</p> <p>In September, the Secretariat prepared a paper for the Advisory Group, which proposed establishing use MY data as a legal entity. This was reflective of the need to have a way to manage our own finances and contracts directly, allowing for use MY data to expand. The Advisory Group were supportive of the proposal.</p> <p>use MY data is now registered with Companies House and established as a company limited by guarantee (company registration: 14425977):</p> <ul style="list-style-type: none"> • We are set up as not-for-profit, with an exemption that means we do not need to use ‘Limited’ • The Chair and Vice Chair of the Advisory Group are the joint Directors/Guarantors and Chris is the nominated company secretary • A use MY data bank account is being set up with NatWest • As a company limited by guarantee (not-for-profit), we do not have shareholders or | Chris |

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| | <ul style="list-style-type: none"> · pay dividends · All income and any surplus must be spent on the aims of use MY data. <p>Crucially, use MY data now has the ability to employ and contract people/services. The potential to bring current contracts into use MY data, rather than through the University of Leeds, was discussed. Chris noted that there was a contractual process (contract novation) that could allow this, but that it would need the mutual agreement of NHS Digital, the University of Leeds, use MY data and anyone directly affected, in this case the Coordinator.</p> <p>The Advisory Group discussed potential next steps, proposed by the Secretariat:</p> <ul style="list-style-type: none"> · Explore with the University of Leeds and NHS Digital, the potential and appetite for a novation of the NHS Digital contract to use MY data · Progress initial discussions about grant funding, with the charity that has potentially offered this · Use some of the funding given by Health Data Research UK to address the urgent need for dedicated communications and media personnel. <p>Following discussion, the Advisory Group agreed that the Secretariat should proceed with the three proposed steps. The Advisory Group noted that a marketing role would work well with the communications/media role.</p> <p>Alison highlighted that the Secretariat needs to update use MY data’s Members about the legal status, following which the information should be published on our website.</p> <p>The Advisory Group supports a longer-term intention of use MY data becoming a charitable institution. However, the full implications of this need to be understood more clearly first, as well as having more personnel in place to enable this change.</p> <p>c. Summary of advice</p> <ul style="list-style-type: none"> · Chris to arrange a discussion about contract novation, initially with University of Leeds and then, dependent on the University’s view, with NHS Digital. · The Secretariat should scope the communications/media/marketing role(s) and take the next steps necessary to find a suitable resource. · Chris to progress discussions about the potential charity grant funding. | |
| Item 3.0 | <p>Events programme November 2022 to May 2023</p> <p>a. Webinar programme - proposal based on Members’ suggestions</p> <p>Proposals from Members were reviewed, and key themes picked out.</p> <ul style="list-style-type: none"> · The role of Artificial Intelligence (AI) This would cover patients’ concerns, the current level of understanding, real-life examples of AI benefits, NHS and Government policy ambitions and other related factors. · NHS decision making boards having patient representatives We are increasingly seeing patients involved in an advisory capacity, but do we need their voices in decision making groups? · When will I have a national health record? Looking at the direction of travel on NHS policy to understand where it’s going, including the need for a common underlying data model as a key enabler. A specific Advisory Group comment on this - “The NHS is 75 years old and we still don’t have a national health record. Without a defined data model, we’re not even moving towards one”. <p>Some of these topics would work well placed within webinars with a set format and resulting in a clear call to action.</p> | Emily |

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| | <p>b. Educational sessions - proposal based on Members' suggestions</p> <p>Following review of the suggestions from Members, the Advisory Group highlighted two sessions to prioritise:</p> <ul style="list-style-type: none"> · Exploring Personal Health Records (PHRs) What do some of the more comprehensive PHRs offer? · The NHS App and other health apps How many apps are out there and what do they all do? Potentially with ORCHA (https://orchahealth.com/). <p>c. Summary of advice</p> <ul style="list-style-type: none"> · Emily and Chris to explore the three suggested webinar topics and outline the next webinar from one of these. · Chris and Emily to plan the two educational sessions before the end of the year, based on the recommendations from the Advisory Group, with at least one to take place before the end of this year. | |
| Item 4.0 | <p>Any other business</p> <p>a. Championing the use of cancer data</p> <p>John provided information about an external group which is being formed, to champion the use of cancer data, asking if the Advisory Group would support him formally representing use MY data on this new group. The Advisory Group were supportive of this, noting that if John felt anything needed to be signed off on behalf of use MY data, this could be done by the Advisory Group Chair or by the Advisory Group as a whole.</p> | Dave |
| Item 5.0 | <p>Date of next meeting</p> <p>Monday, 28 November 11:00 to 15:00 (refreshments available from 10:00) London, venue to be confirmed</p> | Alison |

| Record of actions arising from the meeting | | |
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| Action | Responsible for | Date to complete by |
| Legal status of use MY data & informing our Members - Update Members asap about the recent change of legal status. Then, update the website with details of the change. | Alison & Chris | 03 November |
| Legal status of use MY data - Circulate details to the Advisory Group about the company registration set up and the not-for-profit aspect. | Chris | 04 November |
| Legal status of use MY data & contract novation - Arrange an initial discussion with the University of Leeds about the potential for contract novation. Potentially to be followed by discussion with NHS Digital. | Chris | 04 November (initial work) |
| Legal status of use MY data & charity funding - Progress discussions about the potential charity grant funding. | Chris | 04 November |
| Expanding Secretariat personnel - Scope the communications, media and marketing roles. Take the necessary next steps to find personnel. | Alison & Chris | 11 November (initial work) |

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| Events programme - Explore the suggested webinar topics and outline the next webinar from one of these. | Emily & Chris | 04 November |
| Events programme - Plan the two educational sessions before the end of this year, with at least one to take place before the end of the year. | Emily & Chris | 04 November |
| Events programme - Share information/contacts about ORCHA and health apps, with Chris. | Richard B & Dave | 04 November |
| Events programme - AI webinar - Share contacts related to government interest in AI, with Emily. | Richard S & Chris | 04 November |
| Representing use MY data - Formally represent use MY data on the new (external) group championing the use of cancer data. | John | 04 November |

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| Suggestions for future meetings | |
| 28 November | <p>Strategy and direction of use MY data including:</p> <ul style="list-style-type: none"> • Review of current work and resources • Where do we want to go - proposals and priorities • Measuring our progress |