

**Advisory Group & Secretariat  
Online meeting**

**Wednesday, 15 September 2021  
14:00 - 16:00**

**Meeting notes - confirmed**

Item 1.0	<p><b>Attendees:</b> Advisory Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Jo Gumbs, Sarah Markham, John Marsh, Pete Wheatstone. Secretariat - Chris Carrigan, Emily Connearn, Alison Stone.</p> <p><b>Apologies received from:</b> Richard Ballerand (post-meeting), David Snelson.</p>	Richard
Item 2.0	<p><b>Work programme review</b></p> <p><b>a. Update on the revised deliverable work programme suggested by Advisory Group Members at the July meeting (including an update on funding)</b></p> <p>WORK PROGRAMME: Alison gave an overview of the work programme for the remainder of 2021 and proposals for 2022.</p> <p>After reviewing the proposed 2022 work programme, which is intended to be deliverable within current resources and pressures, the Advisory Group felt best not to add anything further at this stage. It would be good to be more proactive as an organisation, if resources allow this.</p> <p>In our work striving to become the trusted patient voice, we need to ensure that:</p> <ul style="list-style-type: none"> <li>· The voice is heard in different places</li> <li>· We are representing the views of Members - how do we know what matters to them at the moment?</li> </ul> <p>We could consider becoming a ‘think tank’ model, advocating views and ideas for others to consider or implement, without hosting everything ourselves - i.e. asking another organisation to host a citizens jury. Becoming more proactive as a ‘trusted voice’ will in turn increase and broaden our Membership.</p> <p><b>FUNDING:</b> Chris confirmed that we have funding until August 2022 for all three Secretariat posts, and sufficient to cover Advisory Group and Secretariat meetings also. For hosting public events, we could look to external organisations to pay for certain aspects. We would do this on a case-by-case basis (as we have done in the past for some events). As part of our funding is via DATA-CAN, any extension to our funding via that route, is tied to the future of DATA-CAN.</p> <p><b>b. Next use MY data workshop/webinar</b></p> <p>Emily ran through two options for the next use MY data webinar, following the email feedback from the Advisory Group.</p>	Alison Chris Emily

### **Option 1 - Webinar with Sensyne Health**

Sensyne Health has recently engaged with use MY data and would like to take part in one of our webinars, with use MY data defining the structure.

Ideas from the Advisory Group on content:

- It's important that use MY data defines and leads the content
- Balance out the panel with someone from a NHS Trust or someone from NHS Trust which has a deal with a different commercial company
- Transparency is key and it would be essential to have an open forum.

The Secretariat is having a preliminary meeting with Sensyne on 28 September, in which Advisory Group Members will be invited to take part.

**Option 2 - Webinar on turning around deep routed negatives about the use of data into understanding and trust, amongst the public and patients.**

We could consider a comparison with how Scotland approaches the use of patient data. The Secretariat is enthusiastic about the concept, but unsure about how this webinar could be delivered practically.

Ideas from the Advisory Group about how it could run:

- Have members of the public against data sharing on a panel with patients who are supportive of data sharing, chaired by a member of the NHS - the idea would be to explore why the public are against this and who is driving the lack of trust.
- It's not enough to convert minds - this is a hearts and minds issue.
- Like the idea but don't know how to execute it to convert the cynics.
- There is so misinformation out there, with very entrenched views.
- The National Data Guardian (NDG) has done a lot of work on people's attitudes towards sharing data - should we speak with the NDG and see if there is any scope for being part of the NDG's work in this area, or bring the NDG into our webinar?
- It is a topic that is interesting to/affecting many other organisations at present - is the use MY data voice better heard at their meetings and discussions? If we held our own event, what would we expect our Members to learn and/or do?

The Advisory Group voted on which webinar would be best to host next. The narrow result was that the next webinar would be the Sensyne one, in November 2021 and the public/patient attitudes could be Spring 2022.

Following meetings this week with NHSX and NHS Digital about the General Practice Data for Planning and Research (GPDP), it is now looking likely that NHS Digital may wish to take us up on our offer to host a webinar. Further information is awaited on this.

### **c. Impact and opportunities arising from the forthcoming changes to funding for Understanding Patient Data**

The future of Understanding Patient Data (UPD) remains uncertain, due to the imminent end of funding by the Wellcome Trust. UPD is still seeking a potential host, but in lieu of finding this, plans to end current projects by Autumn 2022 and redeploy staff to other roles. Natalie Banner, Lead for UPD, leaves the organisation in October. The loss of the organisation may bring opportunities for use MY data's work but is a disappointment for the pro-data-sharing movement overall.

	<p><b>d. Discuss proposed 2022 work programme, especially to consider gaps and opportunities</b></p> <p>This item was incorporated into discussions above.</p> <p><b>e. Summary of actions</b></p> <p><b>Funding</b></p> <ul style="list-style-type: none"> <li>· <b>Alison</b> - Earmark in the work programme, a defined resource allocation to find new funding or extend existing funding.</li> <li>· <b>Chris</b> - Provide updates on funding to the Advisory Group at each Advisory Group and Secretariat meeting, or more urgently if there are significant developments.</li> </ul> <p><b>Webinars</b></p> <ul style="list-style-type: none"> <li>· <b>Emily</b> - Send the Advisory Group by 21 September details of the meeting with Sensyne on 28 September, to see who would like to attend.</li> <li>· <b>Emily</b> - Take forward the planning of a webinar with Sensyne for the third week of November 2021 and a webinar on public/patient trust around data security for Spring 2022.</li> </ul> <p><b>Work programme</b></p> <ul style="list-style-type: none"> <li>· <b>Alison</b> - Add as an agenda item for the first meeting in 2022 - how does use MY data become more proactive in its work to become the trusted patient voice?</li> </ul>	
<p>Item 3.0</p>	<p><b>Call to Action - My access to my health records</b></p> <p><b>a. How and when should we evaluate the impact(s) of the call to action?</b></p> <p><b>b. Summary of Members' reactions/responses to date</b></p> <p><b>c. Possible addendum to the Call - The need for access to records by those caring for the patient (flagged up at the July Advisory Group meeting)</b></p> <p>Alison provided an update. She circulated the Call to Action to our Membership on Thursday, 27 July and sent a reminder on Thursday, 19 August, emphasising the ask to our Members to act.</p> <p>“...we also need to start influencing change at a local level. You can help to do this. Over the next couple of months we would like our Members to start checking what information is available at your GP surgery about access to your own records, and to ask your GP for access to them (if you wish to have access). Please let me know how you get on (via email - <a href="mailto:alison@usemydata.org.uk">alison@usemydata.org.uk</a>) as, in the Autumn, the Advisory Group and Secretariat would like to evaluate the impact of our Members in changing things on the ground. As a patient movement, it's vital that we use our voices, individually as well as collectively, to start things moving and, just as importantly, to keep thing moving and effect change.”</p> <p>To date, no Members have responded to Alison and it is assumed that the Call to Action has not generated an impact.</p> <p>The second part of the Call to Action is a call to the NHS and when promoting this via Twitter, a GP sent a link to existing guidance - <a href="https://www.england.nhs.uk/publication/patient-access-to-records-online-prospective-record-access/">https://www.england.nhs.uk/publication/patient-access-to-records-online-prospective-record-access/</a></p>	<p>Chris &amp; Alison</p>

	<p>The Advisory Group reflected that the gap between the webinar which produced the Call to Action (March 2021) and the publication (July 2021) was too long and had delayed impact. It would be good to review our work strategies, to be more effective. Ideally, calls to actions arising from webinars should be published within two weeks. This will mean holding back other work in the post-webinar period.</p> <p>Chris highlighted that the Call to Action was used as part of use MY data’s response to the NHSX’s consultation on the Data strategy for health and social care and was very useful.</p> <p>The Advisory Group felt that no further work should take place on the Call to Action. When the GDPR is launched, it may be useful at that point.</p> <p>It was noted that in many clubs or associations, most of the work is done by the committee and sometimes a small group of others too. Similarly, use MY data’s Membership is on the whole not proactive and, even in reactive mode, it is at present for information-receiving rather than action.</p> <p><b>d. Summary of actions</b></p> <ul style="list-style-type: none"> <li>· <b>Alison</b> - Place the Call to Action on hold. Consider reviving it when the GDPR is relaunched.</li> </ul>	
Item 4.0	<p><b>Membership update</b></p> <p><b>a. Review of numbers and nature of new members</b></p> <p>Alison gave the update:</p> <ul style="list-style-type: none"> <li>· Membership total: 332</li> <li>· Members: 191 - 57%</li> <li>· Associate Members: 142 - 43%.</li> </ul> <p>We used to have a 2:1 ratio of Members to Associate Members ratio; this ratio is now 4:3.</p> <p>New Members have recently come to us, via:</p> <ul style="list-style-type: none"> <li>· Having COVID and/or long COVID</li> <li>· Our webinars</li> <li>· GDPR</li> <li>· Our presence at events external to uMd e.g. the Charities Research Involvement Group</li> <li>· Hearing about us via other organisations e.g. the National Cancer Research Institute Consumer Forum.</li> </ul> <p>New Associate Members have recently come to us via:</p> <ul style="list-style-type: none"> <li>· Our webinars</li> <li>· GDPR</li> <li>· External events</li> <li>· Twitter</li> <li>· Colleagues sharing the weekly update.</li> </ul> <p>The Secretariat has no demographic information on individual Members, beyond gender and some geographical locations.</p> <p>The numbers of Members who leave is low (10 in 2021) and has been mostly through death, health reasons, or moving outside of the UK.</p>	Alison

The number of Members who leave is low (10 in 2021) and has been mostly through death, health reasons, or moving outside of the UK.

Some Associate Members are very proactive and use MY data could make better use of their experience and contacts, and seek their help with advocacy, lobbying and consulting.

**b. Consider timing and nature of any recruitment drive in 2022 (e.g. gaps to target; whole year campaign or burst of activity in shorter period etc.)**

After some discussion the consensus views were:

- 500 was a good amount and manageable in terms of resources while making use MY data more attractive to funders and possibly more influential as a voice.
- We could aim for 300 Members and 200 Associates, redressing the balance of Members and Associate Members.
- To drive expansion, we could use publication of reports and potentially any citizens juries work, e.g. with DATA-CAN. We could also consider tying Membership drives to public events that we host.

The overall advice was that any proactive recruitment of our Members should remain in the work programme for 2022 for now and be reviewed in due course. When this happens, we need to a) consider the impact of digital exclusion and b) know about funding beyond August 2022 (if possible by March 2022).

**c. Consider in similar fashion, any recruitment needed to expand the Advisory Group**

The Advisory Group needs to become more representative of the Members. During the last recruitment round, which was open to all Members, we did not receive applicants from Members from ethnic minorities, Northern Ireland, Scotland or Wales and we did not have a gender balance amongst applicants.

Three options were considered:

- To ask newer Members if they would like to join the Advisory Group
- To ask all Members (but emphasising specific gaps to be filled)
- To ask specific Members to join for specific reasons (e.g. to represent a devolved nation).

The Advisory Group asked the Secretariat to move forward with at least one option, in order to achieve an Advisory Group that is more representative of the Membership. It was suggested that this needs to be done this year but recognising that it may be a long and incremental process. Jo offered to work with Alison to draft some suitable text for adverts/recruitment campaigns.

The Advisory Group discussed the option of including Associate Members on the Advisory Group but the consensus was that use MY data is a Member-led (patient/relative/carer) movement. The views of Associate Members and their experience, skills and expertise can be harnessed on an ad hoc basis.

**d. Summary of actions**

- **Alison** - To consider the Advisory Group's advice about Advisory Group expansion, produce a revised work programme and bring this to the next meeting.
- **Alison & Jo** - To draft recruitment text for the Advisory Group expansion.

<p>Item 5.0</p>	<p><b>Any other business</b></p> <p><b>a. Feedback from our Member on the National Data Guardian’s panel - John</b></p> <p>It would be good to invite Maisie McKenzie, the patient representative on the National Data Guardian’s panel, to our next meeting and hear about her work with the new National Data Guardian and have the opportunity to provide feedback to Maisie.</p> <p><b>b. Update on General Practice Date for Planning and Research - Pete</b></p> <p>In response to a request from Pete about an update on the GDPR, Alison gave an overview of two very recent meetings with NHSX on 14 September and NHS Digital on 15 September.</p> <p><b>Meeting with NHSX - Tuesday, 14 September</b>  Tim Donohoe, Senior Responsible Officer for GP data / Director for Data Delivery, Assurance and Operations. The meeting was at Tim’s request, to make contact, provide an update on GDPR developments and hear use MY data’s views.</p> <p><b>Key points:</b></p> <ul style="list-style-type: none"> <li>· Advice from NHSX to the Ministerial team about GDPR was based in part on use MY data’s 01 July letter to NHS Digital.</li> <li>· We referenced our 21 July letter to NHS Digital which detailed the actions still to be addressed and our request for details of GDPR oversight groups.</li> <li>· Ahead of launching the GDPR communications/engagement strategy, NHSX is undertaking a listening exercise as a first step, which is why there have been no further communications - we emphasised this delay has created a vacuum about communications and a public update on what is happening behind the scenes would provide assurance.</li> <li>· Type 1 opt-outs will not be retired for at least 12 months.</li> <li>· The Trusted Research Environment for the GDPR is likely to be ready in Spring 2022.</li> </ul> <p><b>Meeting with NHS Digital - Wednesday, 15 September</b>  Vicky Maskell - Communications &amp; Engagement Working Group for GDPR (on secondment from the Cabinet Office)  Eva Simmonds - Programme Head, GP data  Susannah Strong, Senior Communications Manager (data)</p> <p><b>Key points:</b></p> <ul style="list-style-type: none"> <li>· Apologies for the delay in replying to our 21 July letter and assurance that a reply will be forthcoming over the next couple of weeks</li> <li>· NHS Digital has been commissioned by NHSX to deliver the GDPR, and NHS England and the Department of Health and Social Care (DHSC) are on board.</li> <li>· The stages that have been defined are: Assurance, Listening, Consultation, Information and finally Delivery.</li> <li>· NHS Digital would like to bring use MY data in - recognising we can provide support and challenge.</li> <li>· We sought details of the oversight groups for the GDPR and specifically the inclusion of patients and the public.</li> </ul> <p><b>c. Summary of actions</b></p> <ul style="list-style-type: none"> <li>· <b>Alison</b> - Invite Maisie McKenzie to the next Advisory Group meeting, to hear an update on her work with the National Data Guardian’s panel and to have the opportunity to provide information to Maisie.</li> </ul>	<p>Richard</p>
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Item 6.0	<b>Date of next meetings</b> <ul style="list-style-type: none"> <li>• Wednesday, 20 October from 13:00 to 15:00</li> <li>• Tuesday, 30 November from 13:00 to 15:00</li> <li>• 2022 meetings - frequency &amp; format to be decided</li> </ul>	Richard
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<b>Suggestions for future meetings</b>		
October	<ul style="list-style-type: none"> <li>• Review of work programme with Advisory Group Membership added.</li> <li>• Review of Position Statements - are they still fit for purpose(s), has anybody used or queried them, do they still represent our position.</li> <li>• 2022 meetings - frequency &amp; format to be decided</li> </ul> <p>Standing items:</p> <ul style="list-style-type: none"> <li>• Update on funding</li> <li>• Update on the future of Understanding Patient Data</li> <li>• Update on discussions with national organisations (NHS Digital, NHSX etc.)</li> </ul>	
November	<ul style="list-style-type: none"> <li>• How does use MY data become more proactive in its work to become the trusted patient voice?</li> </ul> <p>Standing items:</p> <ul style="list-style-type: none"> <li>• Update on funding</li> <li>• Update on the future of Understanding Patient Data</li> <li>• Update on discussions with national organisations (NHS Digital, NHSX etc.)</li> </ul>	
Date TBC, 2022	<ul style="list-style-type: none"> <li>• How does use MY data become more proactive in its work to become the trusted patient voice?</li> </ul> <p>Standing items:</p> <ul style="list-style-type: none"> <li>• Update on funding</li> <li>• Update on the future of Understanding Patient Data</li> <li>• Update on discussions with national organisations (NHS Digital, NHSX etc.)</li> </ul>	