

**Executive Group & Secretariat - Online meeting**  
**Monday, 22 September**  
**13:00 to 14:30**  
**Meeting notes - confirmed**

Item 1.0	<p><b>Welcome, apologies &amp; housekeeping</b></p> <p>The Chair welcomed attendees and the meeting etiquette was agreed.</p> <p><b>Attendees</b></p> <ul style="list-style-type: none"><li>• Executive Group - Richard Stephens (Chair), Dave Chuter (Vice Chair), Yvonne Adebola, Richard Ballerand, Samina Begum, Jo Gumbs, John Marsh, David Snelson &amp; Ceri Steele</li><li>• Secretariat - Chris Carrigan, &amp; Alison Stone</li></ul> <p><b>Apologies</b> - Elizabeth Lloyd-Owen</p>						
Item 2.0	<p><b>Funding &amp; resources</b></p> <p>Update from the Secretariat on:</p> <ul style="list-style-type: none"><li>• Funding - NHS England / potential funders meeting to be convened by Cancer Research UK</li><li>• Secretariat resources.</li></ul> <p><b>NHS England</b></p> <p>Our funding is awaited and we now hope to receive this in October. This will be routed via the Health Innovation Network (HIN) for the East of England, who has now received the money and is turning this around as soon as possible. Without this funding, we can only continue short-term.</p> <p><b>Meeting of potential funders</b></p> <p>In May, Cancer Research UK offered to help convene a meeting of potential funders. Alison, Chris and Matt Howard-Murray have been liaising on this, with the Secretariat and Executive Group working on a funding pitch document and list of potential funders. Matt has provided much support to use MY data, which is greatly appreciated, including connecting us with colleagues for advice.</p> <p>Although a potential date in early October has been identified for the meeting, this will not allow enough turn-around time for invitations. Instead, a date in November is needed. Alison and Matt are liaising on the next stages and will update as soon as possible.</p> <p><b>Secretariat resources</b></p> <p>Chris has reduced his working hours from 2.5 days to 2.0 days per week. This means that Alison is covering more work, without the support of an administrator. Elizabeth’s contract is due to end in July 2026.</p> <p><b>Key feedback from Members of the Executive Group</b></p> <ul style="list-style-type: none"><li>• Concern expressed about how long use MY data can continue, without receiving the funding from NHS England in October. Beyond that, we can pay wages/honoraria only in the short-term.</li><li>• The Executive Group would like to see the funding pitch document, following recent updates.</li></ul> <p><b>Summary of actions, deadlines and responsible person(s)</b></p> <table><tr><th>Responsible person(s)</th><th>Action</th><th>Deadline</th></tr><tr><td>Alison</td><td>Send the updated pitch document to the Executive Group</td><td>Friday, 26 September</td></tr></table>	Responsible person(s)	Action	Deadline	Alison	Send the updated pitch document to the Executive Group	Friday, 26 September
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**Where we are heading: use MY data's external work****Intended output from this item**

- NPaDD 2026 - decision on taking this forward
- Health Data Research Service - creation of a plan for next steps for patient/public involvement
- Network for public representatives - decision on taking this forward

**National Patient Data Day 2026**

To inform this discussion:

- Update from recent meetings with potential funders - Chris & Alison
- Update on current/projected workload of the Secretariat - Alison

Within the last week, Chris and Alison have met with two potential funders for NPaDD 2026 - they updated the Executive Group about the discussions, which were positive.

Partly due to the (very welcome) increased engagement opportunities that NPaDD 2025 has brought, the Secretariat does not have the capacity to deliver an event in the same format in 2026. Instead, they suggested hosting a series of online events around/on the 24 June (with other organisations). This date is now the National Patient Data Day and we need to capitalise on this.

**Key feedback from Members of the Executive Group**

- It seems best to host a bi-annual in-person NPaDD, aiming for the next one to be in 2027.
- We should keep the momentum around the 24 June now being the National Patient Data Day. This could involve inviting speakers back for catch-ups and relaying work back. Events could be online, which should mean they are easier to manage.
- Elizabeth would lead on a communications strategy for the National Patient Data Day.
- It would be good to have feedback from Members who attended NPaDD 2025.
- Consider a half-day online event, involving researchers and commercial companies, presenting what they have achieved with the use of data over the last year and relaying that back to the audience. This would continue the theme of celebrating the use of data, provide information to our Members and highlight our continuing work to promote the good use of patient data. Having those involved committing to take part and relaying their results back, would ensure a focus on outcomes and tangible outputs, rather than a focus on the event itself.
- We have two volunteers (Member/Executive Group Member) who have offered to take part in planning activities.
- For external organisations involved in online events for 2026, part of the conditions of engagement could be to agree to be a sponsor for NPaDD 2027.
- The Executive Group is keen to help the Secretariat, either with the next stages of seeking core funding or with planning use MY data's 2026 (and beyond) activities. They asked the Secretariat to advise on how best they can assist.

**Summary of actions, deadlines and responsible person(s)**

Responsible person(s)	Action	Deadline
<b>Alison &amp; Elizabeth</b>	Alison to liaise with Elizabeth about the National Patient Data Day communications strategy	Friday, 03 October
<b>Executive Group Members</b>	Send ideas for National Patient Data Day activities, to Alison - to help plan a deliverable strategy	Monday, 20 October
<b>Alison</b>	Liaise with potential committee volunteers about the role and next possible steps	Monday, 27 October
<b>Alison &amp; Chris</b>	Update the Executive Group on when the Secretariat needs help for either seeking core funding or planning activities	Ongoing - as the need arises
<b>Alison &amp; Elizabeth</b>	Seek feedback on 2026 events, from Members who attended NPaDD 2025	Friday, 31 October

### **Health Data Research Service (HDRS) - our next steps for involvement**

- Update on latest news/activity for the HDRS - Chris
- Results of Members survey on an overarching group - Alison

The two top jobs within the HDRS have been advertised - there is nothing further in the public domain at the moment. use MY data continues to push for involvement, at the earliest stage. This has been taken forward by use MY data representatives at different Health Data Research Alliance meetings, which has included highlighting our Position Statement on the HDRS.

Members survey results - 29 Members responded to a call-out via the newsletter on 28 August, about interest in joining an overarching group of Members to lead on use MY data's HDRS work. On interest in being part of an overarching group, 10 Members said yes, 14 said possibly but would like to learn more about it first and 5 said no.

### **Key feedback from Members of the Executive Group**

- It is clear that patients and the public are not being involved at the earliest stages of the HDRS's development - roles are being advertised and a framework must be developing around that.
- Would there be any route to finding out information via the research advisory groups that we have a formal place on (but which have ceased to hold meetings?)
- For the creation of our overarching group to lead on use MY data's HDRS work - it is very positive to have the interest/potential interest of a set of Members and it is important to thank them.
- To move things forward, a small number of Executive Group Members would like to meet with the Member who initiated the idea and discuss the next steps. Ceri, Jo and John volunteered for this.
- It is vital that there is adequate time and space to take ideas from Members forward.

### **Summary of actions, deadlines and responsible person(s)**

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Alison	Contact NHS England to check about the research advisory groups	Friday, 26 September
Alison	Thank all Members who have expressed interest in being part of the overarching HDRS group and update on the next steps	Friday, 10 October
Alison	Arrange a meeting with the Member who suggested the HDRS overarching group, Ceri, Jo & John, to discuss/plan activities	Friday, 31 October

### **A national network for public representatives on bodies/groups dealing with patient data matters, issues and decisions**

Members who responded to the survey provided details of other groups/networks with which they are connected. As well as being useful for the HDRS overarching group, the information will help the Executive Group and Secretariat to understand the wider influence of Members via the multiple ways in which they are connected within the patient data world. This can inform the work to create a national network.

### **Key feedback from Members of the Executive Group:**

- It is clear that this work can only be taken forward, once funding for 2026 onwards is confirmed.
- The network has been written into our funding pitch and will require an expansion of the Secretariat to manage this piece of work.

Item 4.0	<p><b>use MY data's potential restructure</b></p> <p><b>Intended outputs from this item:</b></p> <ul style="list-style-type: none"><li>• Set date for restructure/refresh of Executive Group</li><li>• Decision on adding new Executive Group Members, in the interim period</li><li>• Decision on if/when to resume charitable status work</li></ul> <p><b>Restructure/refresh of Executive Group</b></p> <p>The Executive Group agreed that restructuring should be put on hold until our funding/future is more secure. The aim is for the next discussion to be in summer 2026. In the meantime, it is healthy to bring interested people onto the Group.</p> <p>There may be merit in an Associate Member joining the Executive Group at a future point - to bring their perspective and insight about the real-world use of patient data. They could join without having voting powers, to ensure that we remain patient-led.</p> <p><b>New Executive Group Members, in the interim period</b></p> <p>Following the Chair's letter sent by Richard S, in September 2025, two Members made contact expressing interest in the Executive Group. Following receiving initial information, one is interested in exploring further and an informal meeting has been arranged, with Richard, Alison and Chris in early October. A possible next stage could be for the interested Member to join (all, or part of) our meeting on 24 November.</p> <p>This interest was welcomed by the Executive Group, who are keen that new Members come onboard. Alison was asked to make contact with another Member, who has been very proactive, to see if they would be interested in exploring joining the Executive Group.</p> <p><b>If/when to resume charitable status work</b></p> <p>Richard has produced a paper that could be used as a basis for a future charitable status application. All agreed that an application cannot be a priority until our future is more certain. Alison will circulate the paper to the Executive Group, for information only at this stage.</p> <p><b>Summary of actions, responsible person(s) and deadlines</b></p> <table><tr><th>Responsible person(s)</th><th>Action</th><th>Deadline</th></tr><tr><td>Alison</td><td>Circulate the charitable status paper to the Executive Group, for information only at this stage</td><td>Friday, 03 October</td></tr><tr><td>Alison</td><td>Follow-up with a Member, to explore joining the Executive Group</td><td>Friday, 10 October</td></tr></table>	Responsible person(s)	Action	Deadline	Alison	Circulate the charitable status paper to the Executive Group, for information only at this stage	Friday, 03 October	Alison	Follow-up with a Member, to explore joining the Executive Group	Friday, 10 October
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Item 5.0	<p><b>Any other business</b></p> <p>a) <b>Position Statement on AI</b></p> <p>John is keen for our work on this to move forward. Chris is working on the next stages, which includes consulting for an accuracy check on a particular point and will update John on progress.</p> <p>b) <b>DARE UK Interest Group</b></p> <p>Richard B is part of this group and advised that information is awaited on whether or not the Group will continue to be funded.</p> <p><b>Summary of actions, deadlines and responsible person(s)</b></p> <table><tr><th>Responsible person(s)</th><th>Action</th><th>Deadline</th></tr><tr><td>Chris</td><td>Check progress on our AI Position Statement work and update John</td><td>Friday, 26 September</td></tr></table>	Responsible person(s)	Action	Deadline	Chris	Check progress on our AI Position Statement work and update John	Friday, 26 September			
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Item 6.0	<p><b>Date of next meeting(s)</b></p> <p>Monday, 24 November, 10:45 to 15:00 in-person (London, venue TBC)</p> <p>Monday, 06 October, 11:00 to 12:00 online - agreement to cancel this meeting, due to its proximity.</p>									

Suggestions for future meetings	
Mon, 24 Nov 10:45 to 15:00 In-person	<div>Standing items</div> <ul style="list-style-type: none"><li>• Core funding situation &amp; financial status/future</li></ul> <div>Key items</div> <ul style="list-style-type: none"><li>• HDRS work</li><li>• 2026 activities</li></ul>