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| Meeting Description | | IAPDR Group Meeting | |
| Meeting Date | | 20 April 2022 | Meeting Time 14:30 – 16:00 |
| Location | | Teams Meeting | |
| Attendees | Chair | Professor David Forman (DF) | Secretariat NHSD Secretariat |
| | Michael Chapman (MC) | | Director NHS Digital |
| | Dani BREITINGER-BLATT (DBB) | | Associate Director ODR Workstream NHS Digital |
| | Simon Branston (SB) | | Senior Project Lead NHD Digital |
| | Judith Bisatt (JB) | | Patient Representative Lay member |
| | Nicola Keat (NK) | | Head of Research Groups NCRI |
| | Sophie Newbound (SN) | | Head of Partnership and Awareness NDRS |
| | John Marsh (JM) | | Patient Representative (Deputy Chair) Lay member |
| | Dharmishta Parmar (IP) | | Faculty of Public Health Medicine |
| | Ifeanyi Sargeant (IS) | | Patient Representative Lay member |
| | David Seymour (DS) | | Executive Director HDR UK |
| | Estelle Spence (ES) | | Head of Strategic Engagement for Research and Life Sciences NHS Digital |
| | NHSD Secretariat (CJ) | | DARS Business Support NHS Digital |
| Apologies | Russ Viner (RV) | | NIHR |
| No | Title | Notes | |
| 1 | Welcome | The chair (DF) welcomed all to the meeting | |
| 2 | Approval of previous Minutes and update of Actions from previous meeting 10/02/2022 | <p>The chair (DF) asked the group if they were happy that the minutes from the last meeting and were an accurate reflection of the discussion held on the 10/02/22</p> <p>The group agreed it was an accurate reflection of the meeting and approved the minutes for 10/02/2022</p> <p>Outstanding Actions:</p> <p>3: Closed</p> <p>Post meeting update 20/06/2022: MC Action 3 is replaced by action 18.</p> <p>20/04/22 MC has been discussing the best way to engage RCGP and NDG in this as they are already involved in a lot of NHS D groups / discussions. MC advised that he and SN are attending the NDG panel in early May and may be able to link groups. MC agreed to send a letter to ABPI to reengage members</p> | |

| No | Title | Notes |
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| | | <p>6: Closed</p> <p>Post meeting update 20/06/2022: MC Action is closed</p> <p>20/04/2022 MC discussed the extent to which NHSD planned ways of working with regards to data sharing. He advised there are customer-centric and focused on improving operational delivery for service users, including plans for gathering user feedback</p> <p>14: Open</p> <p>Once UKHSA have provided NHSD access to the legacy Release Register we can provide a link and publish.</p> |
| 3 | Update on ODR service including MI and data on backlog (SB) | <p>SB presented Paper 1</p> <p>A workshop will take place between the NDRS and the DARS team to run through prioritising, unblocking and where we are. In addition, we are reviewing how NDRS can utilise the NHSD Front Door services for requests outside of DARS and UKHSA. NHSD are also focusing on how to put more standard processes in place to ensure that anything clinical is kept to the surface</p> <p>NHSD can include data releases into the Fortnightly IAPDR updates to provide extra clarity</p> <p>MC – We have lots of existing agreements and we need to make sure that future uses of NDRS data remain consistent with those agreements</p> <p>DS – It would be good to categorise uncertainty and have a full version of what is happening. We need more clarity on the issues</p> <p>SN – One of the problems we have encountered is that a large number of the original ODR personnel who are now based in UKSHA have taken their knowledge and skill set with them. NHSD are, therefore, learning new skills and knowledge to be able to deliver this service. We do not have one individual who holds this knowledge now. We need to rebuild a service that existed originally. Due to this we are struggling to deal with the backlog and what is coming through</p> |
| 4 | Discuss John Marsh's comments on the webpage (SB/ES) | <p>SB: In response to John Marsh's request, Simon acknowledged that despite the data constraints, a minimal data release registry would be published on the IAPDR web pages and updated on a monthly basis, and this would become more fulsome over time with new requests separately going through the DARS process.</p> <p>In addition, in line with the concerns raised by the group Simon also undertook to write a web page note to highlight how the project team has sought to implement mitigations to address the concerns of the group (e.g., releasing the data, undertaking the EY ODR Risk Review and accelerating standing up the DARS service).</p> <p>Action 20: Closed</p> <p>Post meeting update 20/06/2022: SB Action 20 covered in agenda 22/06/2022</p> <p>SB to draft explanatory web page note regarding mitigations</p> |
| 5 | Update on Data Access Programme and Future Plan (DBB) | <p>DBB - presented slides of the next steps NHSD will take on how we will proceed over the next few months.</p> <p>08/Apr/22 NCRAS data onboarded into DARS</p> <p>29/April/22 UKHSA ODR will cease to accept new NDRS applications</p> |

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| | | <p>02/May/22 NDRS data released in Minimum Viable Product (MVP) form in NHSD</p> <p>30/Sep/22 All data sets onboarded to NHSD for release</p> <p>UKSHA have been operating over different systems and this has caused problems. To speed up the process, we will move everything from October 2021 into NHSD. Our team will manage this and focus on contracts that have expired, expiring and backlog. New requests will be prioritised. The new team structure will make a difference to the level of detail we have as they will own the applications. This process will give us more control and understanding of the applications from the beginning. We will respond to individual enquires and explain to people on an individual basis what their situation is with their application. This is happening on a day-to-day basis.</p> <p>DS – With having a large backlog, how do we know if the applicant is aware of this and is the application still needed</p> <p>DBB - Case Officers will contact the applicants to discuss if their application is still needed</p> |
| 6 | Data Release Register for ODR in NHSD (SB) | <p>DBB – As it is the responsibility of UKHSA, there is no Release Register prior to October 21. Since then, we have faced the challenge of operating across different systems and the issue of transferring files from one system to another. The delay in obtaining the supporting detail for historic and new applications has added to the complexity of producing data release publications until now.</p> <p>SB shared a slide detailing an interim release register. This was highlighted as a minimal starting point as we needed to get something out for transparency but would endeavour to build on this going forward and to provide as much data as possible.</p> <p>Action 16: Closed</p> <p>Post meeting update 20/06/2022: SB Item 16 covered in agenda 22/06/2022</p> <p>SB would add the data release dates and if not initially possible, would going forward also look to include project titles in future monthly Data Release Register publications</p> <p>Click on link to access the Release Register here:</p> <p>https://digital.nhs.uk/services/independent-advisory-panel-on-data-release/data-release-register</p> |
| 7 | Items for next meeting and AOB | <p>DF raised the future of the panel and whether members wished to carry on as is, or whether new members should be invited to attend. It was agreed that inviting new members at this stage given the short amount of time the meetings must run, would be a challenge. New members would need a period to get their knowledge up to speed.</p> <p>Action 17: Closed</p> <p>Post meeting update 20/06/2022: DF Russ Viner no longer has a NIHR responsibility and has, therefore, stepped down from IAPDR. Dharmishta Parmar will attend the next meeting (22/06/2022) but can't make subsequent dates.</p> <p>DF to contact Russ Viner and Dharmishta Parmar to see if they are still interested in attending future meetings</p> <p>Action 18: Open</p> <p>Post meeting update: Action 18 replaces action 3. MC will contact ABPI to see if Brian Deane's replacement Jennifer Harries would want to attend</p> |

Independent Advisory Panel on Data Release

| No | Title | Notes |
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| | | <p>Action 19: Open</p> <p>MC NHSD to facilitate presentation on Goldacre for 22/6 meeting</p> <p>DF would like to see a presentation on the Goldacre review at the next meeting to appreciate the implications for NHSD and the role of IAPDR.</p> |

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| Next Meeting | 22/06/2022 | Meeting Time | 10:30 to 12:00 |
| Location | Teams Meeting | | |