

Meeting Description	IAPDR Group Meeting			
Meeting Date	22 June 2022	Meeting Time	10:30 -12:00	
Location	Teams Meeting			
Attendees	Chair	Professor David Forman (DF)	Secretariat	NHSD Secretariat
		Michael Chapman (MC)	Director	NHS Digital
		Dani Breitingen-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	Faculty of Public Health
		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	Ifeanyi Sargeant (IS)	Patient Representative		

1	Welcome	The chair (DF) welcomed all to the meeting
2	Approval of previous Minutes and update of Actions from previous meeting 20/04/2022	<p>The chair (DF) asked the group if they were happy that the minutes from the last meeting were an accurate reflection of the discussion held on the 20/04/2022</p> <p>The group agreed it was an accurate reflection of the meeting on the 20/04/22 and approved the minutes (V1.3)</p> <p>Outstanding Actions:</p> <p>Action 14: Open</p> <p>Once UKHSA have provided NHSD access to the legacy Release Register we can provide a link and publish.</p> <p>22/06/2022 DF As chair of the group will contact UKSHA direct. DBB agreed to this suggestion and will forward the email addresses of Tariq Malik and James Matthews.</p>

		<p>Action 21: DF to contact UKHSA over the legacy data release register. DBB will forward DF the relevant email addresses and points to raise.</p> <p>Action 18: Open</p> <p>Action 18 replaces action 3. MC will contact ABPI to see if Brian Deane’s replacement Jennifer Harris would want to attend future sessions</p> <p>22/06/2022 MC - We have vacancies. MC has written to Jennifer Harris at ABPI.</p> <p>DF We need to consider the fact that several of our constituencies still do not have representation and the number of members has therefore reduced. The Panel also has a time limited brief and new members may be unwilling to commit to membership for a short time period.</p>
<p>3</p>	<p>Update on new NDRS data release service and backlog Papers 1 & 2</p>	<p>DBB Presented papers 1 & 2 which shows the transition and how far the team have progressed.</p> <p>UKSHA are delivering the backlog service with Data services delivering the new service. DBB and MC met with UKHSA on the 23 May. UKSHA advised that they are having huge reductions in their workforce and are short staffed. The organization relied heavily on consultancy service, and this has meant they were unable to deliver the backlog in a timely manner. UKSHA should have made it clear that they were unable to progress the backlog by September, which was detailed in the MOU. NHSD has agreed to take on everything including things that have started to progress unless they are 99% completed, the only caveat is that they need to ensure that all the data is transferred over.</p> <p>Paper two shows the progress with the expired and expiring applications which are the urgent ones, we want to get the data, but we cannot because the agreement has expired or is about to expire. The team are doing an amazing job, very quickly contacting and supporting applicants to understand the DARS process, which is taking a lot of resource, but DARS have committed to putting this behind the NDRS service which is now a board KPI.</p> <p>Paper one will stop showing UKSHA backlog as that that will no longer exist due to ODR no longer progressing or accepting any new applications for NDRS. As of this week, DARS are accepting new applications and they have split out the resource. A team is taking on new applications and collaborating with the applicants daily and there is a team really focusing on reducing the backlog, contacting everyone by date. This is the metric that you will continue to see. Paper 2 highlights the kind of KPI that we internally send to the board, which has slightly more detail. The NDRS team have a data service that is embedded. It shows the progress from the beginning of an application through to IGARD and PAG and our general mechanism for data release.</p> <p>The next stage for DBB and the team is to work on the data production element. NHS Digital has a data production team, and we want this to work between the applications team and the data production team as smoothly as possible. The next phase is to make sure that the process is gold standard, the teams have never worked together before. This will take a little bit of orchestrating and SN has already been very helpful. DBB will arrange weekly meetings to make sure the right conversations are taking place at the right time. DBB feels that the work between SN’s team and her team is working well but they need to bring everybody else on that journey as it is a big organizational change but a positive step forward.</p> <p>This is resource constrained and we do not know how many in the backlog are expressions of interest versus applications and the team are working on those to clear them.</p>

		<p>MC thanked DBB, SN and SB and everybody else for the immense amount of demanding work. MC advised that he realises that it has been unsatisfying with the reports for members and others and in hindsight we could have done things differently, but we have a way forward now and things will start to improve.</p> <p>DS asked about transparency and how we make sure that we do not inadvertently lose a level of transparency in terms of what is happening in the backlog.</p> <p>DBB explained that the difference in numbers that MC mentioned versus what is on the slide is because DARS only put the ones on CRM that they have the information for. They add them as they have the full application details, so that they can be taken through the process.</p>
5	<p>IAPDR key actions Data Release Register</p> <p>Update on Goldacre Review</p>	<p>DBB confirmed that we have updated the web page as requested at the last meeting and we have also updated the release register with project titles. DF asked about providing release dates. DBB advised that she will make it clear in the date field that it is the release date, not the application date, and will take that as an action with SB. This was to provide an update item to say this has been actioned and the links are embedded in the agenda.</p> <p>DS asked about improving transparency on the backlog and date information. He understands that this may not happen for any other NHS Digital services but suggested having a clearer view of what the KPIs are for sharing the data for NDRS data release on the key actions page or somewhere similar this way it is in the public arena as to what is happening with the backlog, how it is actioned, and how quickly the turnaround is improving.</p> <p>DBB advised that she is unsure if organisationally this is something we can do but thought we could add the key highlight numbers on the website each week which she thinks is a good idea for transparency. DBB wants to protect the DARS 'team and doesn't want them to feel like they are being put under even more pressure. DBB pointed out that they are doing an amazing job managing this service that they've never managed before and she needs to manage this with the team, so it won't happen overnight. DBB will have the conversation and update at the next meeting if it hasn't happened by then.</p> <p>Action 22: DBB to investigate adding the key highlight numbers to the website each week and update at the next meeting on 16/08/2022.</p> <p>Action 16: Closed: SB 15/07/2022 Actions 16's modification is completed Reopen Action 16 as DF asked if SB could change the date label to reflect the "release date". DF noted that release titles have been added, as requested</p>
		<p>MC There has been two significant documents published since our last meeting the Goldacre review and the Laura Wade Geary report.</p> <p>MC advised that the Goldacre review is a good analysis of the challenges that we face in terms of the NHS analysing health data for its own purposes and sharing health data for research externally, and it sets out the vision for where things could go if we can implement it. MC didn't feel that many people would disagree with the broad principles that it sets out.</p> <p>Broadly, it covers the areas of an NHS analytical capability and sets out the fact that NHS has quite a lot of people in analytical roles, that are not given access to the technology or data to unleash their skills. There is a section on how we can change the analytical profession within the NHS and make that a genuine cohesive profession in the same way that other elements of government have done that.</p>

		<p>There is some very good analysis and sensible recommendations about how the NHS can move to modern ways of working effectively using reproducible analytical pipelines, in line with the actual book, and in line with what government organizations should be doing anyway. Importantly, while we will focus on the trusted research environment and about underpinning a real vision for how NHS analytical services can be modernized and upgraded for the 21st century, and that's important because that is why they are underpinning the data flows that others external to the NHS are going to use.</p> <p>It talks about the challenges of sharing health data. People want access to detailed data about health and care sharing detailed data with external organizations. Having the right trust and the right controls that individuals will not be reidentified in that, and that has been the fundamental problem with data access for many years. The other solution proposed by the Goldacre review is Trusted Research Environments to shift from handing out data and relying on contracts, trust, and audit. To control access to data but do that in an environment where those responsible for maintaining confidentiality can inspect what is done by the users of the data. The challenge is how to make that shift without disrupting work that is on-going, if we do there is a genuine cost to progress. There is a cost to the research and a cost to the new developments that we could have had in that time. We have got to find a way to do this as a seamless transition. This is about moving rapidly and with a degree of urgency to new models that can be safer and better. The review is very clear about GP data planning and research, and it reinforces those decisions already taken by ministers, but we must have the structure in place to ensure that those are only used within a trusted research environment. This is unless people have given their consent for it to be used elsewhere either as part of a clinical trial or other large consented observational study. Once we have moved away from Data release and data dissemination as the default mode to one of data access within a secure environment, we can start to look at the information governance.</p> <p>The following are the links to the Goldacre Review:</p> <p>Home Goldacre Review</p> <p>Laura Wade Geary Report</p> <p>Data saves lives: reshaping health and social care with data - GOV.UK (www.gov.uk)</p> <p>MC shared the implications for NHS digital:</p> <p>NHSD are working on building a national TRE that can become the default route for people to access our data and starting to move our teams to using reproducible analytical pipelines.</p> <p>Many people have seen draft versions of the data strategy document, but the new version has changed. MC explained that it is interesting to see the shift over time and the document has moved to one that says public trust is fundamental and without public trust we will not be able to do any of these good things we want to do with data. We need to start with acting in a trustworthy fashion.</p>
6	IAPDR closedown criteria and options for future version	<p>Paper three is embedded in the agenda.</p> <p>This panel transferred across as a transitional panel and is very different to what it was in PHE for reasons that are set out in the terms of reference. DBB is not calling it ODR anymore because ODR still exists, but it is not doing NDRS data. Going forward that is the</p>

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		<p>terminology you'll see. The NDRS data release function is embedded into NSD. DBB advised that we are in a very good place in terms of how this is functioning. DF, JM and DBB met last week to talk through the options and unfortunately, Sarah was not available to join the meeting.</p> <p>It is worth considering all options and considering whether some members of this panel join different groups within NHS Digital, depending on your interest, and where they would find a role most suited. Is there a version of the IAPDR panel that sits within NDRS that has a particular role around certain applications? Those were just two ideas that were discussed. DF advised that this panel is more specific to NDRS and Cancer data but also research as it is a bridge to the public and patient voice. He asked how IGARD deal with the challenges of these applications and MC advised that IGARD should ensure alignment regarding the purpose, health, and Social Care act as well as the legal basis and Opt outs.</p> <p>NK asked how the Research Advisory Group (RAG) plays into this and DBB advised that Researchers are heavily involved, and DS sits on this panel.</p> <p>Action: – DS to provide insight into RAG at a future meeting. CJ to add to a future agenda</p> <p>SN advised that she is doing wider engagement and discovery work to look at alignment and where we can integrate and share learnings. She is looking at the existing set ups and structures and looking for synergy and benefits and will bring her findings back to a future meeting.</p> <p>DF asked for a bullet to be added to the closedown criteria about the backlog and it being concluded and DBB agreed to draft and share for all to review</p> <p>Action: – DBB to draft the backlog bullet for the closedown criteria and share with the group for review</p>
7	Items for next meeting and AOB	<p>Links shared by NK</p> <p>https://www.ncri.org.uk/response-to-goldacre-review/</p> <p>https://www.ncri.org.uk/10-year-plan-response/</p>

Next Meeting	16 August 2022	Meeting Time	14:00 to 15:30
Location	Teams Meeting		