

Meeting Description		IAPDR Group Meeting		
Meeting Date		29/09/2022	Meeting Time	
Location		Teams Meeting		
Attendees	Chair	Professor David Forman (DF)	Secretariat	NHSD Secretariat
		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
		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
		Estelle Spence (ES)	Head of Strategic Engagement for Research and Life Sciences	NHS Digital
		NHSD Secretariat (CJ)	DARS Business Support	NHS Digital
Apologies		Michael Chapman (MC)	Director of Research & Clinical Trials	
		Nicola Keat (NK)	Head of Research Groups	
		Ifeanyi Sargeant (IS)	Patient Representative	
		David Seymour (DS)	Executive Director	
1	Welcome	The chair (DF) welcomed all to the meeting		
2	Approval of previous Minutes and update of Actions from previous meeting 22/06/2022	<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 22/06/2022</p> <p>The group agreed it was an accurate reflection of the meeting on the 22/06/2022 and approved the minutes (V1.1)</p> <p>Outstanding Actions:</p> <p>Action 21: DF will try and contact UKSHA one more time in relation to the release register.</p> <p>The register available on the legacy webpages does not go up to the closure. The releases are not fully reflected. NHSD have started to record the latest releases, but we have missing data releases for a whole year's worth of data which was not registered by PHE</p>		

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3	Update on NDRS data release service and backlog prioritisation	<p>SB provided an update on the current backlog and prioritisation.</p> <p>ODR Folder Transfers: To date 423 folders have moved across from UKSHA to NHSD. We are waiting for a handful of outstanding folders (5 or 6) to come across from UKSHA to complete the transfer.</p> <p>Backlog Note: It was noted that ODR paused the service before transferring to NHSD on 1st October 2021. This resulted at transition in NHSD having a very large backlog and pipeline as well as new requests that were coming through at the same time.</p> <p>ODR stopped receiving requests on the 20th of June 2022 and NHSD took over. The current NHSD team are sifting through the backlog and checking each of the requirements to see if they are still required. We have prioritised the work as some of these requests have been sitting in backlog for a significant length of time. This is a priority, so the teams are acting quickly to get through the backlog and sort what needs to be actioned.</p> <p>Progress Update: To date, 423 have moved across and gone through the transfer process with 205 requests being complete. However, these will not all be releases, some will be completions of other activities e.g., enquiries or data destructions etc.</p> <p>In addition to the 205 completions, there are 77 requests actively moving through the system and from the end of September, we will start to have monthly release figures and will inform members.</p> <p>In discussion about the 141 'not started' requests, SB identified that this figure contains both new requests coming through into NHSD together with the 'paused' back log requests from ODR pre-transition that are being contacted and then prioritised for progression.</p>
4	IAPDR closedown & future governance	<p>DBB The DARS system is being improved to help researchers receive data a lot quicker and smoother. Governance is in place to release data, but this is not a quick fix.</p> <p>ES attends the Research Advisory Group and one of the things ES is looking into is having more Cancer representation within this group. Cancer requests go straight into the DARS and go through the normal assurance and governance process. Onboarding cancer into NHSD systems means we have more control and can onboard a lot quicker. ES is looking to include NCRI into the Research Advisory Group. The Research Advisory Group is made up of different communities and this is where they would highlight and voice if things are better or worse. The cancer group would use this platform to provide feedback.</p> <p>ES issued a link to RAG: Research Advisory Group - NHS Digital</p> <p>Alongside improving the DARS systems we are working on SDE (Secure Data Environment), so we have lots of improvements taking place. We are already able to make quicker decisions to review certain applications and which ones by acceptance will go via IGARD.</p> <p>TRE (Trusted Research Environment) has been renamed as SDE. This was a decision by NHS England and not an internal decision.</p> <p>DBB stated that we are getting closer to the bulk of the backlog from outstanding to completed. DF asked DBB and SB at what stage do you think the transition will be completed? SB will come back and provide DF with an update</p> <p>JM asked has the panel been of value. DBB stated that the panel have been very valuable. DF managed to get the remaining files from UKSHA across to DARS which was an immense help. The panel have asked questions, challenged us, and provided help and guidance.</p> <p>Action 23: SB to provide an update on the completion of the transition to DF.</p>
5	Communication steer	<p>SN Reiterated that the IAPDR panel had been hugely helpful especially as DARS was going through the transition and getting to grips with NDRS. This has been incredibly challenging for us but knowing we have a panel on the outside that can support and help us has been of up most benefit.</p>

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		<p>Communications have been through the website and the newsletter. Applications will start to receive 1-1 response over the next few weeks from the DARS team.</p> <p>JM asked if a general communication would be issued to show what we have achieved, where we are, and this is what the future will look like. SN advised that we have not wanted to take that approach just yet as applicants are at various stages of the process. Once we have gained natural rhythm, we can issue a broad statement but at present we are still facing huge challenges and we are due for another internal transition. SN said to leave this suggestion with her and DBB and they will come back with an update.</p> <p>Action 24: SN/DBB to provide the panel with an update on future communications before issuing to the wider business</p>
6	AOB	<p>CJ will issue dates for the next meeting in December. Once agreed a firm invite will be issued.</p> <p>Action 20: Complete</p> <p>Colleen has issued the invite for the December meeting.</p>

Next Meeting	6 December 2022	Meeting Time	10:30 – 12:00
Location	Teams Meeting		