

Meeting Description	IAPDR Group Meeting		
Meeting Date	14 th December 2021	Meeting Time	14:00 – 15:30
Location	Teams Meeting		
Attendees	Chair	Professor David Forman (DF)	Secretariat
			Joanna Warwick (JW)/Colleen Jones (CJ)
	Michael Chapman (MC)		Director
			NHS Digital
	Dani Breitingger-Blatt (DBB)		Associate Director ODR Workstream
			NHS Digital
	Bryan Deane (BD)		Director for Association of Pharmaceutical
			ABPI
	Iffy Sargeant (IS)		Patient Representative
	Judith Bisatt (JB)		Patient Representative
	John Marsh (JM)		Patient Representative (Deputy Chair)
Ishika Parmar (IP)		Senior Data Manager	
		QMUL	
Sophie Newbound (SN)		Head of Partnership and Awareness	
		NDRS	
Nicola Keat (NK)		Head of Research	
		NCRI	
David Seymour (DS)		Executive Director	
		HDR UK	
Joanna Warwick (JW)		DARS Business Support	
		NHS Digital	
Colleen Jones (CJ)		DARS Business Support	
		NHS Digital	
Apologies	Russ Viner	University College London	

No	Title	Notes
1	Welcome, introductions	The chair (DF) welcomed all to the meeting and attendees gave a brief introduction.
2	Update on NDRS and transitional arrangements <ul style="list-style-type: none"> Overview of the current position 	<p>DF handed over to MC and team to bring members up to date on the transition as it has been several months since the group last met.</p> <p>MC thanked everyone for their time and advised that it felt right to bring the group back together to see how the transition was evolving and ask the panel for their support over the next period of the transition. MC stated that the panel are an important component and he wanted to share the plan and ask for their help to make it work. MC pointed out that the rationale for the transition plan was to keep continuity for the applicants with the same experts dealing with applications, so that applicants did not need to start/repeat the process.</p>

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	<ul style="list-style-type: none"> Approach to NDRS data releases during transition 	<p>MC pointed out that the main driver was to have a smooth transition and maintain continuity throughout the four phases identified, with a view to all phases being completed by September 2022. MC advised that the transition moved to NHS Digital on 1st October 2021 with ODR coming across as a whole functioning team with the same staff.</p> <p>DBB took members through the transition slides and pointed out that the group are needed to challenge and support NHS Digital to ensure a timely release of data continues.</p> <p>JM asked if Tariq Malik and Rachael Brannon from ODR should join these meetings and DBB confirmed that they will be invited to future meetings, neither were available today.</p> <p>JM asked whether Management Information will be presented at future meetings and DBB advised that she will obtain the next level of detail as soon as possible.</p> <p>Action: DBB to share the next level of Management Information at the next meeting</p> <p>DBB advised that the MOU has been signed but the ways of working document is yet to be approved, due to a few outstanding items. DBB is continuing to work on these with operational and strategic meetings taking place to ensure no disruption to the end user.</p> <p>DBB confirmed that there are 50 applications in the process since the pause, pending triage and she is waiting for a target date for the backlog to be cleared. SN explained that high level communications have been sent out via the NDRS newsletter and website and she will share with members. SN explained that two members of the team are working on a second communication.</p> <p>Action: SN to share the communications with members - complete</p> <p>A discussion took place on the number of applications and how data was being sent out. DBB advised that Tariq Malik is getting data out.</p> <p>DS wasn't clear on the responsibility for the Data Uses Register and MC advised that himself, DBB and Tariq Malik are working on an end-to-end process but the current process is a separate spreadsheet to the NHS Digital Data Uses Register.</p> <p>MC is keen to work through and reduce the NCARDS grey areas and talks are on-going with Tariq Malik and Tina Clapham</p> <p>MC advised that UKHSA will publish a Data Releases Register that covers all PHE data releases and NHS Digital will release a separate spreadsheet for the ODR data release from 1st October 2021.</p> <p>Action: JM requested to see a copy of the data release register once available</p>
3	<ul style="list-style-type: none"> Discussion of updated terms of reference 	<p>DF advised that there are two gaps in the membership of the Group:</p> <ul style="list-style-type: none"> Representative of the Royal College of General Practitioners Representative of the Office of the National Data Guardian <p>Action: MC to pick up the vacancies.</p> <p>DF advised that he has met with the IGARD chair, and they agreed that both Groups will have learnings which will be mutually beneficial. They will attend relevant meetings as appropriate.</p> <p>DF advised that the IAPDR was time limited in its current form and by the end of 2022 may not be required in the same format. IS suggested that the group focus on pressure points to add value where it would matter most. DBB thought that was a good idea and key points need to be agreed. DS feels the group is still needed</p>

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		for focus and accountability and raised concern that the transition could fall down the list of priorities. DBB advised that this is her top priority, and she will ensure that the service runs and this is top of her agenda.
4	<ul style="list-style-type: none"> Administration and ways of working 	<p>The group discussed the frequency of future meetings and agreed that they should be more frequent than quarterly and agreed every 2 months to allow more movement.</p> <p>Action: JW to share a doodle poll with members to agree the next meeting date from 31/01/2022</p> <p>DF advised that, alongside consideration of the evolving relationship between NHSD and UKHSA regarding the ODR, IAPDR also has an important role in advising on the relationship between ODR and its customers especially the research community. He shared some of the plans under preparation within PHE to monitor this relationship prior to the covid pandemic, specifically an online user survey and audits of specific data releases. DF proposed to extend the objectives within the ToR to include such activity.</p> <p>Action: DBB to check and feedback whether NHS Digital asks customers for feedback through a survey</p> <p>Action: DF and DBB to draft additional objective within ToR regarding user survey and audit activity.</p> <p>DS asked if it was possible to have some quantitative management information to identify progress and DBB advised that it had been difficult to obtain for this meeting.</p> <p>Action: DBB to share more detailed Management Information at the next meeting and secretariat to add as an agenda item.</p> <p>DBB advised that she is working with HR to confirm the process to pay the Patient Representative panel members on a voucher basis.</p> <p>Action: DBB to share the payment process for Patient Representatives with the meeting minutes</p> <p>DF asked whether and how IAPDR documents, including meeting minutes, would be published within NHSD and whether there would be associated web pages (as there was within PHE). DBB responded that she would find out about this.</p> <p>Action: DBB to ascertain how IAPDR related information and documents would be published</p>
9	Items for next meeting and AOB	<p>DF thanked all for joining the meeting and wanted to recognise the difficulty with transition but thanked the panel for their support.</p> <p>Management Information to be added next agenda</p> <p>No AOB was raised.</p>

Next Meeting	TBC end Jan 2022/early Feb 2022	Meeting Time	TBC
Location	Teams Meeting		