Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 21st September 2023

09:30 – 15:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	Specialist Ethics Adviser
Claire Delaney-Pope (CDP)	Independent Information Governance Specialist Adviser **(Observer – new AGD member)**
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Miranda Winram (MW)	Independent Lay Adviser **(Observer – new AGD member)**
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Garry Coleman (GC)	NHS England SIRO Representative (**Presenter**: items 8 and 9)
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: items 4.1 to 4.2 and 5.4 to 5.5)
Duncan Easton (DE)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: item 5.1 to 5.3)
Kate Fleming (KF)	NHS England Data and Analytics Representative (Delegate for Michael Chapman)
Judy Gash (JG)	Senior Project Manager, Data Services (**Observer**: item 4.1)
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Karen Myers (KM)	AGD Secretariat Team
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Richard Steele (RS)	Head of Data Delivery (**Presenter**: item 4.1)
James Thomas (JT)	Data Access Request Service (DARS) (**Presenter**: item 7)

Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (**Presenter**: item 7)
Vicki Williams (VW)	AGD Secretariat Team
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Imran Khan (IK)	Specialist GP Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Michael Chapman (MC)	Data and Analytics representative
Jon Moore (JM)	NHS England Data Protection Office Representative

1	**Welcome and Introductions** The NHS England Senior Information Risk Owner (SIRO) Representative, noting the Advisory Group for Data (AGD) Terms of Reference (ToR) had not yet been agreed, proposed that: • Kirsty Irvine (as an independent adviser) will be asked to Chair the AGD meetings; • The meeting will be minuted, with advice and minutes published; • Attendees will include both independent advisers from outside NHS England and representatives from within NHS England. Attendees from NHS England include representatives covering the offices of the Data Protection Officer (DPO); the Caldicott Guardian; Data and Analytics; and the SIRO. • Attendees would not be listed as “members” in minutes during the transitional period; • NHS England representatives would not, during the transitional period, be formally part of any consensus that is reached, but would be active participants in the meeting; • It was agreed to use the Data Access Request Service (DARS) Standards / Precedents in relation to applications for external data sharing. The attendees present at the meeting considered the proposal put forward by the NHS England SIRO Representative and, as no objections were raised, it was agreed that the meeting would proceed on this basis.

	Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.
2	**Review of previous AGD minutes:** The minutes of the 14th September 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.
3	**Declaration of interests:** Jonathan Osborn noted a professional link to the Acute Data Alignment Programme (ADAPt) - Collection of Private Healthcare Data briefing paper, as part of his role in NHS England. It was agreed this did not preclude Dr. Osborn from taking part in the discussion on this briefing paper. Paul Affleck noted a professional link to the study team at Sandwell and West Birmingham Hospitals NHS Trust (NIC-719879-K6X3J) through his role at the University of Leeds. It was agreed this did not preclude Paul from taking part in the discussion on this application. Claire Delaney-Pope noted a professional link to NIC-659293-T1G7M as part of her role at South London and Maudsley NHS Foundation Trust. It was agreed this did not preclude Claire from taking part in the discussion on this application. Kate Fleming noted a professional link to the National Disease Registration Service (NDRS) (NIC-719879-K6X3J, NIC-659293-T1G7M, NIC-656836-T2J0T). It was agreed this was not a conflict of interest.
BRIEFING PAPER(S):	
4.1	**Title:** Acute Data Alignment Programme (ADAPt) - Collection of Private Healthcare Data **Presenter:** Richard Steele **Observer:** Judy Gash **SAT Observer:** Dave Cronin The purpose of this item was to provide information on the draft Private Healthcare Hospital Data Collection Directions 2023; which are to support the aims of the Acute Data Alignment Programme (ADAPt) to bring about an alignment in data standards, measurement and reporting systems across NHS and private healthcare in order to enable greater transparency in quality and safety and to support patient choice and opportunities for improving patient care. Private healthcare hospital data will be collected from the Private Healthcare Information Network (PHIN) with the source of this data being private healthcare providers. The information will be analysed to support patient safety and the improvement of patient care, including: understanding Consultant practice across both NHS and private healthcare; understanding patient pathways and associated outcomes; comparing NHS funded and private funded care including emergency readmissions, emergency transfers of care and

	deaths within 28 days of discharge from a hospital; and understanding the impact of private healthcare upon the NHS. NHS England were seeking advice on the following points: 1. The sufficiency of transparency arrangements. **Outcome of discussion:** The group welcomed the papers and made the following observations / comments: **4.1.1** The group noted the importance of the data collection. In response to point 1: **4.1.2** The group noted that there were ongoing discussion around transparency, for example within the relevant working groups; however, advised that it was essential that the transparency materials for the private healthcare providers were updated, and that any updated materials should be available as a hard copy, and should be provided to patients at the time of initial contact; and that it would **not** be sufficient to solely rely on websites. **4.1.3** In addition, it was suggested that the transparency materials provided, also contained a relevant section for patient signatures; as is already the case for some private providers who have data flowing to PHIN. **4.1.4** A query was raised by the independent advisers as to whether there were any checks and balances that could be carried out, to ensure the private healthcare providers had updated the hard copies of the transparency materials; and suggested that NHS England query how this was going to be checked. **4.1.5** Noting that there had been a public consultation, the independent advisers noted that only four private healthcare users had been consulted. The independent advisers suggested that if further steps were considered for this area of work, for example a retrospective data collection, that this would need a new approach to public consultation, to ensure this captured a more representative sample of private healthcare users. **4.1.6** In respect of opt outs, it was suggested by the independent advisers that NHS England carefully considered how they justified and documented the handling of the various opt outs for private healthcare patients and NHS patients, and whether there was any inconsistency of approach. **4.1.7** The independent IG-adviser noted the data was a ‘prospective’ data flow and highlighted the additional responsibility to the Caldicott Guardians of the private healthcare providers; and queried if they had the capacity and the capability to take on such a significant role, noting the potential reputational risk to the private healthcare providers if there were any issues. **4.1.8** The group queried if PHIN should revise any of their other data sharing agreements (DSA), noting the data flowing in both directions; and whether NHS England could do some of the linkage / analysis internally, to ensure the minimum amount of personal data was flowing; or whether PHIN could process the data within an NHS England secure environment.

	4.1.9 The independent advisers queried point 8.1 of the draft Direction, which referred to the legal powers to disseminate the data; and suggested that this was reviewed / updated to ensure the robust functionality of this point. **4.1.10** The independent advisers noted that one of the purposes of the data collection was to support patient choice, however suggested that further thought was given as to how the data could be fully utilised to support patient choice; noting that the data would not be published; and there were no specific plans of work to ensure the data was maximised to its full potential. **4.1.11** The independent advisers suggested that where appropriate, the points above should be discussed further with NHS England's Caldicott Guardian Team. **4.1.12** The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting.
4.2	**Title:** Post COVID assessment service data collection Briefing **Presenter:** None **SAT Observer:** Dave Cronin **Previous Reviews:** The Briefing Paper was previously presented at the AGD meeting on the 27th July 2023. The purpose of the original briefing paper was to inform the group about the post-COVID assessment service data collection, which is required to support the response to long-COVID, one of the most pressing ongoing national public health challenges. It enables the capture of critical unified data from post-COVID assessment services spanning a range of care settings and organisational formats, which cannot be obtained from other sources or standard commissioning datasets. **Outcome of discussion:** The group welcomed the updated briefing paper and made the following observations / comments: **4.2.1** The independent advisers noted that some of the points raised at the AGD meeting on the 17th July 2023 had been addressed and were content with the responses provided. However, a number of points remained outstanding, and advised NHS England to review the outstanding points, and provide a response to these back to the group. **4.2.2** The group looked forward to receiving a response to the outstanding points via the updated briefing paper, tabled at a future meeting.
EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	**Reference Number:** NIC-682048-S9P4H-v0.11 **Applicant:** LA-SER Europe Limited (a Certara company) **Application Title:** Clinical and economic burden of graft versus host disease in allogeneic stem cell transplant recipients in England – A retrospective cohort study **Presenter:** None

	SAT Observer: Duncan Easton **Application:** This was a new application. The purpose of the application is for a research project with the primary objective, of aiming to describe the healthcare resource utilisation and cost burden of graft-versus-host disease (GVHD) among haematological cancer patients undergoing allogenic hematopoietic stem cell transplantation (allo-HSCT) by processing this data. It is critical to evaluate the health and economic burden of GVHD to establish the existing unmet need for payers and decision makers. For this reason, a real-world analysis of the clinical and economic burden of patients developing GVHD following allo-HSCT is proposed to be conducted in England. These findings will add to previous studies which examined the clinical and economic burden of GVHD in France and Germany. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.1.1** The independent advisers noted and commended the work undertaken by NHS England's DARS on the internal application assessment form. **5.1.2** The independent advisers queried who had access to the data, noting the conflicting information on this point in the internal application assessment form and the application; and suggested that the information was reviewed, and the relevant document(s) updated as appropriate to reflect the correct information. **5.1.3** The independent advisers noted the content of the published privacy notice; and advised that it was very generic and difficult to discern the processing under this data sharing agreement (DSA). It was suggested that this was reviewed by the applicant to ensure that the processing was accurately described, and that any inaccurate information / statements were removed. **5.1.4** Noting the information provided in section 5(a) (Objective for Processing) in respect of the legitimate interests, the independent advisers suggested that this was reviewed and updated, where appropriate, to use a form of wording such as "*it is hoped* …", rather than "*it will…*". **5.1.5** The group noted no patient and public involvement and engagement (PPIE) had taken place and suggested that the applicant undertakes PPIE, and that section 5 (Purpose / Methods / Outputs) be updated as appropriate, for example with an indicative plan of future PPIE. The HRA guidance on Public Involvement is a useful guide. **5.1.6** The independent advisers suggested that there was an ongoing assessment of the commercial benefits, in respect of whether the commercial benefit(s) accruing to the commercial organisation was proportionate to the benefit(s) to health and social care, in line with NHS England's DARS Standard for Commercial Purpose and in	

	line with the National Data Guardian (NDG) guidance on benefits. In addition, it was suggested that this was addressed as part of the applicant's annual review. **5.1.7 Separate to the application**, the independent advisers suggested that NHS England may wish to further develop the NHS England DARS Standard for Commercial Purpose, to confirm whether there is a threshold in terms of the minimum turnover / company size requirement, before an applicant can receive data. **ACTION:** NHS England to consider developing the NHS England DARS Standard for Commercial Purpose, to confirm whether there is a threshold in terms of the minimum turnover / company size requirement, before an applicant can receive data.	NHSE
5.2	**Reference Number:** NIC-674822-S2K9T-v0.4 **Applicant:** University of Oxford **Application Title:** The Children's Surgery Outcome Reporting research database (CSOR) - DigiTrials Comms Service - Vital Status **Presenter:** None **SAT Observer:** Duncan Easton **Previous Reviews:** The application and relevant supporting documents were previously presented at the AGD meeting on the 27th July 2023. **Application:** This was a new application. The purpose of the application is for the University of Oxford and Oxford University Hospitals NHS Foundation Trust to utilise the NHS DigiTrials Communications Service, to undertake Vital Status checks of their cohorts of very young children to ensure they have not passed away before sending out communications to their parents or guardians related to the project, The Children's Surgery Outcome Reporting research database (CSOR). The overall purpose of the CSOR study is to investigate whether it is possible to collect paediatric surgical outcomes data using a system that links routinely collected health data and parent reported outcomes data and provides a platform for centre specific feedback of outcomes in order to reduce unwarranted outcome variation. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were **not** supportive of the application **at this time** and wished to draw to the attention of the SIRO the following significant comments, and suggested that the application be brought back to a future meeting: **5.2.1** The independent advisers reiterated the point made at the AGD meeting on the 27th July 2023, in respect of being unclear who was included in the cohort for this application, for example, was this everyone who had provided consent, or those who	

had been included in the study without their knowledge; and suggested that the application was updated with clarification of this.

5.2.2 The independent advisers noted that the internal application assessment form described the cohort as *"consented"*; and suggested that this was reviewed and amended, noting that the cohort was also comprised of non-consented individuals, and that s251 would **not** be required if there was consent for all individuals.

5.2.3 The independent advisers noted that some of the cohort may be obtained via analysis of the Hospital Episode Statistics (HES) data; and suggested that the application was updated to ensure this processing was accurately described within section 5 (Purpose / Methods / Outputs) of the application.

5.2.4 The independent advisers and the SIRO representative queried what data would be flowing back from NHS England to the applicant; and noting that this was currently unclear, suggested that section 3(b) (Additional Data Access Requested) was updated with further clarification, and the legal basis for this data to flow, noting that the s251 support covered the flow of *"fact of death"* data **only**.

5.2.5 Noting that the protocol, provided as a supporting document, states that *"where consent is not received from parents, all identifiable data will be removed within 13 months of being received"*; the independent advisers suggested that this was accurately reflected in section 5 of the application, including the legal basis for retaining the data for this length of time.

5.2.6 The group suggested that the purpose for processing in section 5(a) (Objective for Processing) was reviewed and amended as may be appropriate, to ensure this was accurate, noting that section 5(b) (Processing Activities) provided further information on this point.

5.2.7 The group noted the response to the point made at the AGD meeting on the 27th July 2023, in respect of the application of the National Data Opt-out (NDO), which had been upheld by Health Research Authority Confidentiality Advisory Group (HRA CAG), and had suggested that the applicant discuss this further with HRA CAG and request that the NDO was **not** upheld in respect of the fact of death, noting the nature of the disease and sensitivity of the activity being carried out. It was also suggested that it would be in the public interest to run two reports **1)** for fact of death (for which the application of the NDO may result in avoidable distress to families of the deceased), and **2)** for all other data fields. The group advised that their views on this point remained the same.

5.2.8 The group noted the response to the point made at the AGD meeting on the 27th July 2023, in respect of concern being expressed regarding the number of reminders and contact methods; and reiterated this concern.

5.2.9 The SIRO representative and SAT Observer noted the progress made since the 27th July 2023 meeting and confirmed that they would meet with colleagues within DARS and DigiTrials to offer further assistance in working through the points

	from this meeting, and those made previously. The group were supportive of this suggestion. **5.2.10** The group advised that they would be supportive of this application returning to a future AGD meeting for an advice session separate to the application review; and with any relevant NHS England staff in attendance.	
5.3	**Reference Number:** NIC-685917-H4X8G-v1.2 **Applicant:** NHS Blood and Transplant (NHSBT) **Application Title:** MELODY Study (Mass evaluation of lateral flow immunoassays for the detection of SARS-CoV-2 antibody responses in immunosuppressed people) - COVID-19 related hospitalisations in solid transplant patients **Presenter:** None **SAT Observer:** Duncan Easton **Previous Reviews:** The application and relevant supporting documents were previously presented at the AGD meeting on the 20th April 2023. **Application:** This was an amendment application. The amendment is the addition of the COVID-19 Therapeutics data. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.3.1** The group noted that they were supportive of the addition of the new dataset to the data sharing agreement (DSA), and that this appeared to be aligned with the objective for processing and the potential benefits to patients from the study. **5.3.2** The independent advisers noted the applicant's Data Security and Protection Toolkit (DSPT) status, and that NHS England had requested that an improvement plan was submitted by the 31st October 2023. It was suggested that the application was updated as per usual process to reflect the outcome of any future DSPT reviews. **5.3.3** The independent advisers noted and endorsed the comments in the internal application assessment form, in respect of NHS England's suggestions / updates to the applicant's transparency materials. They reiterated points made at the 24th August 2023 in relation to the UK Health Security Agency (UKHSA) level of transparency available to the public which appeared not to be the same level as Public Health England (PHE) and suggested that further transparency materials be provided around the high levels of data being processed, types of processing being undertaken and the parallel running envisaged, in addition to the publication of the 'Register of Dissemination'.	

	5.3.4 Separate to this application, it was suggested by the independent advisers, that the internal application assessment form provided to the group contained tracked changes so that it could be clearly seen what had been updated / amended since the last review and to further support the review of the application. **ACTION:** NHS England to ensure the internal application assessment form provided to the group, contains tracked changes.	DARS SAT
5.4	**Reference Number:** NIC-24422-R3W3S-v6.21 **Applicant:** University of Cambridge **Application Title:** Survival Improvement with Colecalciferol in Patients on Dialysis – The SIMPLIFIED Registry Trial **Presenter:** None **SAT Observer:** Dave Cronin **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 8th October 2020, 2nd March 2017 and the 16th February 2017. **Application:** This was a renewal, extension and amendment application. The purpose of the application is for a randomised controlled trial (SIMPLIFIED), which aims to assess the effect of colecalciferol (vitamin D) supplementation versus standard care on health outcomes in patients with kidney failure receiving dialysis, with the primary outcome being to determine whether colecalciferol is indeed beneficial for kidney failure patients through decreased mortality. Secondary outcomes include Health Related Quality of Life, cardiovascular events requiring admission, infections requiring admission, and fractures requiring admission. The amendments are to **1)** add Telefonica as a Data Processor; and **2)** to update section 5(a) (Objective for Processing) in line with NHS England's DARS Standard for Objective for Processing. NHS England were seeking advice on the following points: 1. Whether reasonable expectations are met to share A&E / Emergency Care Data Set (ECDS) Data, noting that the information provided to participants refers to "HES" and "hospital admissions" and whether it is acceptable for the applicant to retain Data already held. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:	

	5.4.1 The DARS SAT Observer noted that as outlined in the internal application assessment form, a service level agreement (SLA) was in place for a Health Economist from the University of East Anglia and Cambridge University Hospitals NHS Foundation Trust; and advised that they would look into this further to ensure it meets all of NHS England's requirements in line with NHS England's DARS Honorary Contract Standard (currently in the process of being published on the NHS England website). The group noted and supported the verbal update from the DARS SAT Observer and suggested that the SLA was also reviewed to ensure it had all of the relevant clauses, including but not limited to, the substantive employer taking disciplinary action against the "honorary contract" holder if they breached any data protection related obligations. **5.4.2** The independent advisers noted that a number of points raised previously by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) between 2017 and 2020 had **not been** fully addressed, for example, in respect of improvements to transparency and the special conditions that were included; and advised that NHS England review these points and either clarify how the points have been addressed, or, if they were no longer relevant, to provide confirmation of why they were no longer relevant. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: In response to point 1: **5.4.3** The group noted that whilst technically admissions data did **not** cover A&E or ECDS datasets, it would **not** be unreasonable to include those datasets within the flow of data under this data sharing agreement (DSA). The group noted that the data was covered by the consent taken, and it would be unlikely that in line with Caldicott Principles 8, a cohort member would be "surprised" by this. **5.4.4** The group did however suggest that the applicant send a newsletter to participants at the earliest opportunity to update the cohort on the nature of the data flowing, including A&E and ECDS. **5.4.5 Separate to the application**, the independent advisers presumed there was a contractual obligation on researchers using NHS England data to notify NHS England **immediately** if they received data, in error, that they did not apply for; and suggested that NHS England may wish to incorporate this into the relevant training for recipients of NHS England data. **ACTION**: NHS England to ensure there is a clear contractual obligation on researchers using NHS England data, to notify NHS England **immediately** if they receive data they did not apply for. **ACTION:** NHS England to ensure that it is clear within the relevant training for recipients of NHS England data, that there is a contractual obligation on researchers	NHSE NHSE

	using NHS England data, to notify NHS England **immediately** if they received data they did not apply for.	
5.5	**Reference Number:** NIC-719879-K6X3J-v0.9 **Applicant:** Sandwell and West Birmingham Hospitals NHS Trust **Application Title:** Post Endoscopy Upper Gastro-Intestinal Cancer (PEUGIC) root cause analysis project **Presenter:** None **SAT Observer:** Dave Cronin **Application:** This was a new application. The purpose of the application is for a project, with the aim of **1)** identifying all PEUGIC patients in England. Patients diagnosed with upper GI Cancer from 2017 onwards who had an endoscopy 3-36 months prior to cancer diagnosis; **2)** to develop a secure online portal that provides each NHS Trust with details on their PEUGIC which also provides access to a root cause analysis form; **3)** for Pooling/Anonymisation of national data collected in root cause analysis form, to better understand the main causes of PEUGIC nationally; **4)** to share findings to outline areas for quality improvement, to reduce the number of PEUGIC cases nationally. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following substantive comment: **5.5.1** The group noted that the application needed to be more transparent as to what the researchers are doing, and with what data, noting that this was currently not clear within the application. The NHS England Data and Analytics representative offered to work with the applicant / DARS to ensure that the application was updated / developed to ensure that sufficient information was provided on the data and methods to be used to allow full assessment. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.5.2** The group welcomed the application and noted the importance of the research. **5.5.3** The Caldicott Guardian Team Representative suggested that NHS England advised the applicant that there could be a significant impact on the research and the research outcomes, in respect of the interplay between those patients who have an endoscopy by a private healthcare provider, and those private patients who then move from a private healthcare provider to the NHS for subsequent treatment; and suggested that the applicant clarify how they might address this.	

	5.5.4 Prior to the meeting, an independent adviser queried what data was being requested under this data sharing agreement (DSA); and were advised by NHS England it was cancer registration data with the addition of linked PEUGIC data items provided by Trusts using an online portal. The group noted and thanked NHS England for the response and suggested that the application was updated to reflect this information. **5.5.5** Prior to the meeting it was also queried by an independent adviser, why a unique person ID would flow from NHS England to enable the recipient to link the data with other record-level data they already held. NHS England advised this was an error and no such linkage would take place. The group noted and thanked NHS England for the verbal update. **5.5.6** Noting that it was unclear within the application that both national data and data from the local NHS Trusts was being used to feed into the research; the independent advisers suggested that the application was updated to make this clear. **5.5.7** The independent advisers suggested that NHS England investigate and clarify the legal basis for the NHS Trusts to populate the online portal with the data, for example is this a Direction (noting it would appear **not** to be direct care). **5.5.8** Noting that the applicant has sought and received approval from the Health Research Authority Research Ethics Committee (HRA REC); the independent advisers suggested that NHS England obtain a copy of the ethical approval; and that this was uploaded to NHS England's customer relationships management (CRM) system for future reference. **Subsequent to the meeting**: It was noted by an independent adviser as part of ratification of the minutes, that ethical approval had been sought and had been provided to the group as a supporting document. **5.5.9** The group noted no patient and public involvement and engagement (PPIE) had taken place and suggested that the applicant undertakes PPIE, and that section 5 (Purpose / Methods / Outputs) be updated as appropriate, for example with an indicative plan of planned or future PPIE. The HRA guidance on Public Involvement is a useful guide. **Subsequent to the meeting**: It was noted by an independent adviser as part of ratification of the minutes, that PPIE had been referred to in the Integrated Research Application System (IRAS) form provided as a supporting document.	
EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
6.1	**Reference Number:** NIC-659293-T1G7M-v1.7 **Applicant:** South London and Maudsley NHS FT	

	Application Title: Mental Disorder and Cancer Care: a Data Linkage Study in South London II (ODR1516_358) **Presenter:** None **Previous Reviews:** The NDRS datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review. **Application:** The purpose of the application is for a research project to **1)** compare receipt of screening uptake, referral to secondary healthcare, and timing of cancer treatments following cancer diagnosis between groups with and without mental disorder, taking into account type of cancer and spread at diagnosis; **2)** to assemble cohorts of residents in South London (Lambeth, Southwark, Lewisham, and Croydon) receiving cancer diagnoses (i.e. ascertained from NCRS) with and without prior mental disorder diagnoses, supplemented by the linkages to HES, for the analyses described below; **3)** to investigate the extent to which differences in intervention receipt for cancer account for differences between cohorts in post-diagnosis survival; and **4)** to assess the impact of cancer diagnosis/ treatment on mental health outcomes in people with pre-existing mental disorders. The SIRO approval was for a three year extension. **Outcome of discussion:** The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided: **6.1.1** Prior to the meeting, an independent adviser queried with the SIRO representative that as per a previous data sharing application involving the Maudsley Biomedical Research Centre, whether King's College London should be a Data Controller / Data Processor. The SIRO representative advised that South London and Maudsley NHS FT have advised that they are the **sole** Data controller and that the extension had been signed off on that basis. The NHS England SIRO representative thanked the group for their time.	
6.2	**Reference Number:** NIC-16016-Y9H1D-v14.0 **Applicant:** Wilmington Healthcare **Application Title:** Hospital Episode Statistics (HES), ECDS, Diagnostic Imaging Dataset (DIDs) and sensitive Mental Health data to assist disease awareness, commissioning, and help to produce longitudinal rare disease analysis and reports. **Presenter:** None **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 4th August 2022, 7th July 2022, 5th	

	November 2020, 16th May 2019, 26th July 2018, 11th January 2018, 21st December 2017, 19th October 2017 and the 5th October 2017. **Application:** The purpose of the application is to support the NHS either directly through the delivery of tools and bespoke analysis, or indirectly through non-NHS organisations, where solutions are provided with the NHS as the end beneficiary. The SIRO approval was for a three month extension. **Outcome of discussion:** The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided. The NHS England SIRO representative thanked the group for their time.	
6.3	**Reference Number:** NIC-656836-T2J0T-v1.4 **Applicant:** Manchester University NHS FT **Application Title:** Multifrequency Bioimpedance in the Early Detection of Lymphoedema (ODR1819_219) **Presenter:** None **Previous Reviews:** The application and relevant supporting documents were previously discussed at the AGD meeting on the 6th July 2023. The NDRS datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review. **Application:** The purpose of the application is for a study, to determine how socioeconomic status, obesity and diabetes relate to breast cancer recurrence and death. The SIRO approval was for a twelve month extension. **Outcome of discussion:** The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided. The NHS England SIRO representative thanked the group for their time.	
6.4	**Reference Number:** NIC-382794-T3L3M-v7.4 **Applicant:** University of Oxford **Application Title:** QResearch-Oxford Data Linkage Project **Presenter:** None	

	Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meetings on the 17th November 2022, 11th August 2022, 16th June 2022 and the 3rd March 2022. The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 2nd March 2021, 19th January 2021 12th January 2021 and the 7th April 2020. **Application:** The purpose of the application is for a linked research database (QResearch linked database) for the following reasons: **1)** for use by the University of Oxford for specific research purposes, as described in this Data Sharing Agreement (DSA); **2)** for use by the University of Oxford for ongoing research studies, as described in this DSA; and **3)** for onward sharing to UK universities via a sublicensing agreement. The SIRO approval was for a three month renewal. **Outcome of discussion:** The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided: **6.4.1** Prior to the meeting, an independent adviser reiterated to the SIRO representative, previous advice by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) had previously raised issues in respect of the wider transparency of the database, for example, by providing a list or map of the participating GP practices and to update its transparency materials regarding sub-licensing. **6.4.2** In addition, an independent adviser also advised that information in the published privacy notice differed to the information in the application regarding opt-out arrangements. The NHS England SIRO representative noted the points raised and thanked the group for their time.	
7	**Confidential Advice Session**	
AGD Operations		
8	**Statutory Guidance** The independent advisers again noted the reference to reviewing materials in accordance with *"a clearly understood risk management framework"* within the published Statutory Guidance and advised that they were **not** aware of an agreed risk management framework, and requested that NHS England provide further information/ clarity on this, noting this topic had been raised by Lord Hunt in the	

	House of Lords on the 26th June 2023, and was answered by Lord Markham on the 5th July 2023: Written questions, answers and statements – UK Parliament. The NHS England SIRO Representative had provided further clarity on the risk management framework via email to the group, which confirmed that NHS England were asking the interim data advisory group to use the NHS England DARS Standards and Precedent model to assess the risk factors in relation to items presented to the interim data advisory group for advice; however the independent advisers noted that the wording in the in the statutory guidance "…*using a clearly understood risk management framework, precedent approaches and standards that requests must meet*…", suggested that the risk management framework is **separate** to the DARS Standards and Precedents, and asked that this be clarified by NHS England. **ACTION:** NHS England SIRO representative to provide a written response addressed to AGD with further clarity on the risk management framework.	GC
9	**AGD Terms of Reference (ToR)** The independent advisers noted that nearly four months had passed since the Statutory Guidance had been published, and queried whether there was any further updated on the progress of the AGD ToR. Garry Coleman noted that NHS England were still considering comments from stakeholders on the AGD ToR. **ACTION:** The NHS England SIRO representative noted a previous action to clarify when a revised draft of the AGD ToR would be presented to AGD and when the AGD ToR was scheduled to be considered by the NHS England Board / subcommittee of the Board.	GC
10	**Standard operating procedures** The ongoing forward plan of work for creating Standard Operating Procedures was discussed.	To note
11	**Independent Adviser recruitment** The independent advisers noted that recruitment to outgoing independent adviser roles had not commenced, noting six independent advisers were due to roll off the group in the first half of next year, unless otherwise extended by NHS England. The SIRO representative noted the concerns raised.	To note
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.		