Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 6th July 2023

09:30 – 15:45

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	Specialist Ethics Adviser / Co-Deputy Chair (Chair for items 4.2 to 11)
Dr. Robert French (RF)	Independent Specialist Academic / Statistician Adviser (not in attendance for item 4.3)
Kirsty Irvine (KI)	Chair (Chair for items 1, 2, 3 and 4.1) (not in attendance for items 4.2 to 11)
Jenny Westaway (JW)	Independent Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Vicky Byrne-Watts (VBW)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: items 4.5 to 4.6)
Garry Coleman (GC)	NHS England SIRO Representative
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: items 4.1 to 4.2)
Louise Dunn (LD)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: item 4.4)
Dan Goodwin (DG)	Data Access Request Service (DARS) (**Presenter**: items 4.1 to 4.2)
Suzanne Hartley (SH)	Data Access Request Service (DARS) (**Presenter**: item 4.4)
Dickie Langley (DL)	NHS England DPO Representative (Delegate for Jon Moore) (not in attendance for item 4.5)
Abigail Lucas (AL)	Data Access Request Service (DARS) (**Presenter**: items 4.5 to 4.6)
Karen Myers (KM)	AGD Secretariat Team
Dr Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Denise Pine (DP)	Data Access Request Service (DARS) (**Presenter**: item 4.3)

Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: item 4.3) (**Observer**: item 11)
Vicki Williams (VW)	AGD Secretariat Team (**Presenter**: items 8 and 9.1)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof Nicola Fear (NF)	Independent Specialist Academic Adviser
Dr. Imran Khan (IK)	Specialist GP Adviser / Co-Deputy Chair
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Independent Specialist GP Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Michael Chapman (MCh)	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 advised attendees that, noting the statutory guidance and the AGD Terms of Reference (ToR) had not yet been agreed, the meeting could not be held under the draft ToR, until they have been approved, and recognised that the draft ToR may change as the statutory guidance evolves. As NHS England would like to seek advice on a number of areas, the NHS England SIRO Representative therefore 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; 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 and Paul Affleck noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.

	The group noted that the NHS England Data and Analytics representative and their delegates were not available to attend AGD and noted their apologies. In the absence of a final Terms of Reference it was agreed that the meeting was still quorate for all agenda items other than item 4.3, without a Data and Analytics representative (but that this would have posed an issue for quoracy had the AGD Terms of Reference been finalised in their current form).
2	**Review of previous AGD minutes:** The minutes of the 29th June 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:** Dr. Robert French noted a professional link with the applicant at Cardiff University (NIC-654590-Y0S1H) and would not be part of the discussion. It was agreed Dr. French would not remain in the meeting for the discussion of this application.
EXTERNAL DATA DISSEMINATION REQUESTS:	
4.1	**Reference Number:** NIC-650245-T6C6T-v0.3 **Applicant:** Guy's and St Thomas' NHS Foundation Trust **Application Title:** Pneumococcal Vaccination to Accelerate Immune Recovery in Sepsis Survivors (VACIRiSS) **Presenter:** Dan Goodwin **SAT Observer:** Dave Cronin **Application:** This was a new application. The purpose of the application is for a clinical trial, which aims to find out if a safe and widely used vaccine can help in preventing new infections for patients who survive an Intensive Care Unit admission with sepsis. The clinical trial will also explore if the vaccine would help those who do get new infections to recover more quickly. 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: **4.1.1** The independent advisers advised that as part of the review for this application, they would **not** be offering a view to NHS England as to whether there was a legal gateway for those individuals who did not have capacity to consent. The independent advisers also noted that they had **not** had sight of the legal advice sought and obtained from NHS England's Privacy, Transparency, Ethics and Legal (PTEL). The independent advisers suggested that NHS England clarify with PTEL and / or the National Data Guardian, whether it was consistent with the National Data Opt-out (NDO) policy to **not** uphold a previously registered NDO for a cohort member who was part of the cohort via a *"legal representative consent"*.

	4.1.2 The independent advisers noted that the protocol, provided as a supporting document, noted that the vaccine was being provided by Pfizer Limited, and queried whether this was being provided on a commercial arm's-length basis; and if not, suggested that for transparency, the application was updated with further details of the terms on which the vaccine was being supplied, for example, at a discount or free; and whether or not Pfizer Limited were being provided with any preferential treatment in return for providing the vaccine, for example, early sight of the summary of outputs. **4.1.3** The independent advisers also suggested that if there were any benefits to Pfizer Limited as a result of the study, then the applicant should ensure that this is made transparent to the cohort, and asked that in line with NHS England's DARS Standard for Commercial Purpose, section 5(e) (Is the Purpose of this Application in Anyway Commercial) was updated to reflect this; and that this text was also replicated for transparency in section 5(a) (Objective for Processing), in line with NHS England's DARS Standard for Objective for Processing. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **4.1.4** The group welcomed the application and noted the importance of the study, which potentially may bring substantial benefits to patients. **4.1.5** The group noted that the data processing appeared to be within the consent provided by the cohort; however, suggested that the internal application assessment form was updated to clarify that data minimisation and data handling had been considered in line with the common law duty of confidentiality and that this was compatible with the consent provided. **4.1.6** The group noted that the honorary contract that was shared prior to the meeting had expired on the 31st January 2023; but advised that the drafting of the contract itself appeared to be robust. The independent advisers suggested that NHS England ensure that an in-date honorary contract was in place between the Principal Investigator, the applicant and the Principal Investigator's home institution; and that a copy of this in-date honorary contract this was uploaded to NHS England's customer relationships management (CRM) system as per usual process, and for future reference. **4.1.7** The group noted the transparency materials that had been provided directly to the cohort, however, suggested that NHS England may wish to take a bespoke approach to the transparency for this study, and focus on how best to ensure that there was ongoing / further transparency to the cohort, including, but not limited to, an update to the study specific website, and / or communications via relevant charities / websites, for example, The UK Sepsis Trust. **4.1.8** Separate to this application, the independent advisers suggested that NHS England may wish to review / update the NHS England DARS Standard for Transparency, to reflect that for consented cohorts, it is anticipated that a substantial volume of information may be provided to the cohort as part of the consent materials, and that a "publicly accessible" transparency approach may not always be necessary in all instances. **4.1.9** Noting the statement in section 3(c) (Patient Objections) *"Participants recruited under Medicine for Human Use (Clinical Trials) Regulations 2004 have been consented into the study on behalf of their legal representative"*; the independent advisers suggested that this	

	was updated to be clear who provides consent for whom, i.e. the legal representative has provided consent on behalf of the participant. **ACTION:** NHS England to consider reviewing / updating the NHS England DARS Standard for Transparency, to reflect that for consented cohorts, a substantial volume of information may be provided to the cohort, and that a publicly accessible transparency approach may not always be necessary in all instances. **4.1.10** In addition, the group suggested that section 4 (Privacy Notice) was updated to reflect the agreed position between NHS England and the applicant, for the bespoke approach to the study transparency. **4.1.11** The independent advisers noted the reference at the end of section 5(a) to patient and public involvement and engagement (PPIE); and suggested that for transparency, further information / clarity was provided on this.	DARS
4.2	**Reference Number:** NIC-309509-L2G1J-v0.22 **Applicant:** University College London (UCL) **Application Title:** Evaluation of aid to diagnosis for congenital dysplasia of the hip in general practice: controlled randomised trial **Presenter:** Dan Goodwin **SAT Observer:** Dave Cronin **Application:** This was a new application. The purpose of the application is for a study, where GPs from 172 GP practices across England, who carry out the 6-week hip check on infants between 42 and 70 days old, will be divided into two groups. Eligible participants will be identified by general practice patient registers and infants will be invited to attend a 6-week check at the practice. One group of GP practices will be given the diagnostic aid, comprising of a video tool and a checklist (HipDyS checklist) to use in all hip checks they carry out. The other group will screen for Developmental dysplasia of the hip (DDH) as normal, without the use of the HipDyS checklist. The two groups will then be compared to see if the first group better identified infants with DDH than the second group. Researchers from the study will also evaluate whether using the checklist reduces costs for families around trips to doctors or hospitals, and costs to the NHS. 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 high level comments: **4.2.1** The independent advisers noted that the applicant had not obtained consent from the cohort for this study, but had obtained Health Research Authority Confidentiality Advisory Group (HRA CAG) and HRA Research Ethics Committee (REC) support, and were content this provided NHS England with a defensible position to flow data. Separate to this application, the independent advisers highlighted concerns that this may set a precedent in the future as there could have been an opportunity to seek consent from parents/guardians when they attended the GP with their babies for the HipDyS check. The group queried whether it undermined the principle that informed consent should be sought where possible	

	and practicable, and suggested that NHS England liaise with HRA CAG to discuss / explore this further for future applications. **4.2.2** In addition, the independent advisers noted that the National Data Opt-out (NDO) was being applied in addition to a local opt-out which each parent would be informed about when attending the clinic. The group were advised by NHS England that where HRA CAG do **not** specifically advise that the NDO should **not** be applied, then NHS England apply it automatically. The independent advisers noted the verbal update from NHS England, and suggested that separate to this application, that NHS England discussed with HRA CAG, whether the NDO should be applied where a local opt-out was offered. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **4.2.3** The independent advisers queried the information in the internal application assessment form that states the Chief Investigator is *"substantively employed"* as a professor at UCL **and** as a clinician at Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH); and suggested that NHS England seek clarification on who the Chief Investigator's main employer is and what their relationship with UCL and GOSH was, and how the reference to being *"substantively employed"* was being defined; and that the internal application assessment form and application were updated as may be necessary with further clarification. **4.2.4** The group noted in the internal application assessment form that the data minimisation would be undertaken by NHS England's Data Production Team; and noted that the SIRO representative requested further clarification from NHS England as to whether the data minimisation efforts as outlined would be undertaken, noting current resource issues; and that the internal application assessment form and application were updated as may be necessary. **4.2.5** The independent advisers queried how identifiable the GP practices would be, and whether there was any point at which they would no longer be identifiable; and suggested that further clarity was provided in the internal application assessment form and application as may be appropriate.	
4.3	**Reference Number:** NIC-654590-Y0S1H-v0.16 Cardiff University **Applicant:** NIC-654590-Y0S1H-v0.16 Cardiff University **Application Title:** T3 Safety Study **Presenter:** Denise Pine **SAT Observer:** Kimberley Watson **Application:** This was a new application. The purpose of the application is for a Study, to determine the long-term safety of Liothyronine (T3) which is the metabolically active thyroid hormone. The project will evaluate long-term survival and adverse cardiovascular events (myocardial infarction, arrhythmias, heart failure, or strokes) in patients treated with T3 and compare these risks to control patients treated conventionally with Levothyroxine (T4) which is the conventional treatment for hypothyroidism.	

	Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **NHS England (verbal) update:** NHS England advised the group that following submission of the papers to AGD, it had been noted that **1)** an earlier version of the patient information sheet (PIS) was referenced in the Health Research Authority Confidentiality Advisory Group (HRA CAG) approval letter, however **all** amendments to later versions had been made as per the HRA CAG conditions of support; and **2)** the applicant has been advised by NHS England to amend the PIS to remove references to *"NHS Digital"* and replace with *"NHS England"*; and to remove reference to *"anonymised"* data and replace with *"pseudonymised"* data. The group noted the verbal updates. **Outcome of discussion:** The SIRO representative noted that although final AGD Terms of Reference had not yet been approved by NHS England, the group would **not** be quorate for the discussion of this application noting only two independent advisers were available; however, requested that the two independent advisers and NHS England representatives in attendance provided informal advice. The two independent advisers and NHS England representatives in attendance for this particular application were supportive of the application, and wished to draw to the attention of the SIRO the following substantive comments: **4.3.1** The independent advisers noted that prior to the meeting, a query had been raised with NHS England in respect of how The Vaccine Research Trust was meeting the Common Law Duty of Confidentiality for the records they hold; and had been advised by NHS England, that The Vaccine Research Trust was currently holding the data under s251, noting that HRA CAG had recommended that The Vaccine Research Trust continue to hold the data until the data linkage was complete, after which the data would be destroyed or, alternatively transferred to a suitable data guardian. **4.3.2** The independent advisers noted that HRA CAG had provided support for The Vaccine Research Trust to hold and transfer the data, however suggested that patients may still be surprised at the use of their data in this way and some may object, and that further transparency may mitigate this risk. In addition, the independent advisers noted that there was a public interest in the research being carried out and advised that many of the patients who had received treatment may be supportive of this research. **4.3.3** An NHS England representative queried whether the HRA CAG conditions of support in respect of communications were being met; and suggested that NHS England seek confirmation from the applicant on this point, noting the impact this may have on the study if the HRA CAG conditions were not being met. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **4.3.4** The group welcomed the application and noted the importance of the study. **4.3.5** The independent advisers noted, within the internal application assessment form that NHS England had engaged with the applicant in respect of the honorary contract; and advised that, as per usual process / advice, the honorary contract should be counter-signed by the individual's substantive employer. The independent advisers suggested that NHS	

	England ensure that written confirmation was received from the applicant that the document had been counter-signed by the employing body; and that the written confirmation was uploaded to NHS Digital's customer relationships management (CRM) system for future reference. **4.3.6** Noting the content of the patient opt-out notice provided as a supporting document, the independent advisers suggested that this was reviewed to ensure all the information was accurate, for example, noting the incorrect statement to there being **no** identifiable health records going outside The Vaccine Research Trust, and that this was amended as may be required to reflect the correct information. **4.3.7** The independent advisers queried the references in section 5(a) (Objective for Processing) to patient and public involvement and engagement (PPIE) with *"executives of the British Thyroid Foundation (BTF)"*; and suggested that this was reviewed and amended if the *"executives"* were not deemed to be true PPIE representatives. **4.3.8** The independent advisers suggested that in addition to the engagement with the British Thyroid Foundation, and to further support transparency / communications, the applicant also engaged with other relevant charities, including, but not limited to, The Thyroid Trust, Thyroid Friends and Thyroid UK.	
4.4	**Reference Number:** NIC-435152-C0H4N-v3.4 **Applicant:** Royal Devon University Healthcare NHS Foundation Trust (FT) **Application Title:** CLARITY IBD: Understanding the impact of biologic and immunomodulatory therapy on SARS-CoV-2 Infection and Immunity in Patients with Inflammatory Bowel Disease **Presenter:** Suzanne Hartley **SAT Observer:** Louise Dunn **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the IGARD BAU meetings on the 26th August 2021 and the 16th September 2021. The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meeting on the 23rd February 2021. **Application:** This was a renewal, extension and amendment application. The amendments are to **1)** remove Demographics data from the application; **2)** to amend the legal basis under the common law duty of confidentiality from Health Service (Control of Patient Information (COPI)) Regulations 2002, to consent (reasonable expectations); and **3)** to change the Data Controller name from 'Royal Devon and Exeter NHS Foundation Trust' to 'The Royal Devon University Healthcare NHS Foundation Trust' to take into account the organisational merger. *(From Friday 1 April 2022, the Royal Devon and Exeter NHS Foundation Trust (RD&E) and Northern Devon Healthcare NHS Trust (NDHT) formally merged to become the Royal Devon University Healthcare NHS Foundation Trust)* This change also applies to the sponsor. Should an application be approved by NHS England, further details would be made available within the Data Uses Register.	

	NHS England (verbal) update: NHS England advised the group that following submission of the papers to AGD, that the following updates had been identified and the internal application assessment form / application would need updating accordingly: **1)** the 2022/23 Data Security and Protection Toolkit (DSPT) for Imperial College London has now been met; **2)** a special condition would need adding in section 6 (Special Conditions) of the application in respect of the flow of the cohort; and **3)** the remote access would be addressed within the application, in line with recent AGD discussions. The group noted the verbal updates. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following comments: **4.4.1** The independent advisers commended NHS England on the work undertaken on the application. **4.4.2** The independent advisers noted that the research would be undertaken by staff **primarily** employed at the Royal Devon University Healthcare NHS FT and the University of Exeter; and suggested that this was checked with the applicant, noting that the usual arrangement was for staff to be primarily employed by the University with an honorary contract for work undertaken with the NHS Trust. If, however it was determined that there was an honorary contract in place, it was suggested that the NHS England DARS Honorary Contract Standard, currently in the process of being signed off by the SIRO representative was adhered to. **4.4.3** The SIRO representative queried what was happening to those cohort members who were now over the age of 16, but had not provided consent on the adult consent form; and were advised by NHS England, that the applicant would retain the data that flowed where they had previously assented as a child and their parent had consented. Noting the verbal update from NHS England, it was suggested that the internal application assessment form was updated with clarification of this for future reference. **4.4.4** The independent advisers noted and supported the content of the June 2023 newsletter, that reflected that the identifiable data would be destroyed in December 2023 and not June 2023 as originally advised. It was suggested that NHS England make the applicant aware that they would be unable to provide further data flows for the individuals once the identifiable data was destroyed. **4.4.5** Noting the role of the drug companies within this application, it was suggested by the independent advisers that the application was reviewed and updated as necessary to reflect the correct number of drug companies involved, for example, noting the references to *"four"* drug companies in section 5 (Purpose / Methods / Outputs) and the five drug companies that were subsequently listed. **4.4.6** In addition, it was suggested that if the research determined that one treatment was better than others, then in line with NHS England's DARS Standard for Commercial Purpose, it should be made clear within the application that there may be a commercial benefit to the specific drug company or companies that produce that treatment. **4.4.7** The SIRO representative noted the special condition in section 6 *"Upon instruction from NHS England, a Certificate of Data Destruction must be completed…"*; and asked that this was amended to reflect that the applicant was not to wait for NHS England to issue an	

	instruction to destroy data, but that this was done in line with the terms of the data sharing agreement. **4.4.8** Separate to this application, the independent advisers noted that the various citation special conditions were each worded slightly differently and suggested that NHS England revise and align **all** citation special conditions, and if appropriate seek advice / engagement from relevant bodies, for example, useMYdata. **ACTION:** NHS England to revise and align all citation special conditions, and if appropriate seek advice / engagement from this from relevant bodies, for example, useMYdata.	NHSE
4.5	**Reference Number:** NIC-667506-N6Q9G-v0.6 **Applicant:** London School of Hygiene and Tropical Medicine (LSHTM) **Application Title:** Management of patients with chronic liver disease admitted to hospital as an emergency **Presenter:** Abigail Lucas **SAT Observer:** Vicky Byrne-Watts **Linked applications:** This application is linked to NIC-708052-S1L9J (item 4.6). **Application:** This was a new application. The purpose of the application is for a research project, which aims to identify which characteristics of treatments and services for acutely ill people with chronic liver disease (CLD) impact on care processes and outcomes, in order to improve the national organisation and delivery of care for all people acutely ill with CLD. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **NHS England (verbal) update:** NHS England advised the group that following submission of the papers to AGD, it had been noted that a special condition would need adding to section 6 (Special Conditions), in respect of data destruction as per process. The group noted the verbal update. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following comments: **4.5.1** The independent advisers noted and commended the efforts taken by the applicant on their patient and public involvement and engagement (PPIE). **4.5.2** The independent advisers also commended NHS England on the work undertaken on the application. **4.5.3** The independent advisers noted that the draft privacy notice had been provided as a supporting document, however queried the statement within this *"All data sharing agreements with NHS Digital are approved by the *Independent Group Advising on the Release of Data…"* (*IGARD); and suggested that this was removed and updated to reflect that AGD reviews and provides **advice** not approval to NHS England on data sharing agreements. **4.5.4** Noting the reference in section 5(a) (Objective for Processing) to the three LSHTM PhD students, the independent advisers queried this in light of the statement in section 5(b)	

	(Processing Activities) *"Access is restricted to employees or agents of LSHTM…."*; and suggested that this was reviewed, and that the application was updated to reflect the correct / factual information. **4.5.5** In addition, the independent advisers queried the role of the PhD students, noting that this was not clear within the application; and suggested that this was clarified with the applicant, and that the application was updated with further information.	
4.6	**Reference Number:** NIC-708052-S1L9J-v0.6 **Applicant:** London School of Hygiene and Tropical Medicine **Application Title:** Management of patients with chronic liver disease admitted to hospital as an emergency – ICNARC **Presenter:** Abigail Lucas **SAT Observer:** Vicky Byrne-Watts **Linked applications:** This application is linked to NIC-667506-N6Q9G (item 4.5). **Application:** This was a new application. The purpose of the application is for a research project, which aims to identify which characteristics of treatments and services for acutely ill people with chronic liver disease (CLD) impact on care processes and outcomes, in order to improve the national organisation and delivery of care for all people acutely ill with CLD. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **NHS England (verbal) update:** NHS England advised the group that following submission of the papers to AGD, it had been noted that a special condition would need adding to section 6 (Special Conditions), in respect of data destruction. The group noted the verbal update. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments: **4.6.1** The independent advisers queried the data minimisation and whether the current plan for Intensive Care National Audit & Research Centre (ICNARC) to undertake some of the data minimisation, was fully covered by the Health Research Authority Confidentiality Advisory Group (HRA CAG) support; and suggested that the applicant confirmed this with HRA CAG. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **4.6.2** The independent advisers noted and commended the efforts taken by the applicant on their patient and public involvement and engagement (PPIE). **4.6.3** The independent advisers also commended NHS England on the work undertaken on the application. **4.6.4** The independent advisers noted that the draft privacy notice had been provided as a supporting document, however queried the statement within this *"All data sharing agreements with NHS Digital are approved by the *Independent Group Advising on the*	

	Release of Data…" (*IGARD); and suggested that this was removed and updated to reflect that AGD reviews and provides **advice** not approva**l** to NHS England on data sharing agreements. **4.6.5** Noting the reference in section 5(a) (Objective for Processing) to the three LSHTM PhD students, the independent advisers queried this in light of the statement in section 5(b) (Processing Activities) *"Access is restricted to employees or agents of LSHTM…."*; and suggested that this was reviewed, and that the application was updated to reflect the correct / factual information. **4.6.6** The independent advisers suggested that section 5(a) was updated with further information on the estimated sample size if this information was available.	
EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
5.1	**Reference Number:** NIC-656838-J7H7S-v1.4 **Applicant:** Imperial College Healthcare NHS Trust **Application Title:** Braina CaVa: Care, variation, outcomes, and costs in patients with brain tumours in England. (ODR1819_236) **Presenter:** No Presenter **Previous Reviews:** The application and relevant supporting documents had previously been discussed at the IGARD meeting on the 3rd November 2022. **Application:** The purpose of the application is for a project which aims to: **1)** provide a comprehensive view of patterns of care, patient events, outcomes and costs of care in adult patients with primary Central Nervous System tumours in England; **2)** to assess variations in care, systematic drivers of variation in care, and associations between variations in care and outcomes and costs; **3)** to explore the correlation between biology and outcomes by comparing the relative impact of tumour biology vs. treatment effect on outcomes, admissions and costs. 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. **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.	
5.2	**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:** No Presenter	

	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 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. **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.	
5.3	**Reference Number:** NIC-656873-Q2C7L-v1.2 University of Bristol **Applicant:** NIC-656873-Q2C7L-v1.2 University of Bristol **Application Title:** Brain tumour diagnoses by hospital eye services: is there evidence of a Barker effect? (ODR1920_288) **Presenter:** No Presenter **Application:** The purpose of the application is to determine the time of diagnosis and outcome of patients with intracranial tumours before vs after the Honey Rose court case in 2016; to **1)** determine whether time to diagnosis depends on route to diagnosis before/after Honey Rose; **2)** to determine whether outcomes (mortality/survival) depend on time and/or route to diagnosis for patients before/after Honey Rose; and **3)** to determine whether time and route to diagnosis and outcomes are influenced by tumour type, sex, ethnicity, smoking, age, geography and deprivation. 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. **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.	
AGD Operations		
6	**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. **ACTION:** NHS England SIRO Representative to provide further clarity on the risk management framework.	GC

7	**AGD Terms of Reference (ToR)** Garry Coleman noted that NHS England were still receiving comments from stakeholders on the AGD ToR and that the draft AGD ToR had not been approved by NHS England on the 28th June 2023, as per the plan originally advised to AGD. **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
8	**Standard Operating Procedures** The ongoing forward plan of work for creating Standard Operating Procedures was discussed.	To note
9 **9.1**	**New Operational Actions & those carried forward from previous meetings of AGD:** **Zero Hours contracts for independent advisers** Vicki Williams noted that a number of independent advisers were due to move to NHS England zero hours contracts from Monday, 26th June 2023, one adviser had transitioned to a zero hours contract on the 31st May 2023. Vicki noted that NHS England were actively working to put the remaining zero hours contracts in place before the end of July 2023.	To note
Any Other Business		
11	**Q&A Documentation Review** AGD noted that following various comments / suggestions at previous AGD meetings on the content of the Q&A document that supports the completion of NHS England's DARS internal application assessment form (for DARS applications); that NHS England had provided an updated copy of the Q&A document to the group for review comments. The group discussed the content of this document with Louise Dunn and Kimberley Watson, who had attended the meeting on behalf of DARS; and various comments / suggestions were provided by the group in-meeting. In addition, an updated document with comments / suggestions was provided by the group out of committee, to further support DARS with updating this document. The Co-Deputy Chair thanked Louise and Kimberley for attending the meeting and advised that they were happy to provide any ongoing support as may be required; and looked forward to receiving a final version of the Q&A document in due course.	
Meeting Closure As there was no further business raised, the Co-Deputy Chair thanked attendees for their time and closed the meeting.		