Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 2nd March 2023

08:30 – 15:15

(In-person at Wellington Place, Leeds & via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	Specialist Ethics Adviser
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser (Items 7.1, 7.2 & 8.1)
Dr. Maurice Smith (MS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Richard Carthew (RC)	Programme Manager - Cass Review Project (**Observer**: item 4.1)
Michael Chapman (MCh)	Data and Analytics representative
Garry Coleman (GC)	Senior Information Risk Owner (SIRO) representative
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (**Presenter**: item 4.4)
Catherine Day (CD)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: items 4.1, 5.1, 5.2 & 5.3)
Elizabeth Flaherty (EF)	Data Access Request Service (DARS) (**Presenter**: items 5.1, 5.2 & 5.3)
Forrest Frankovitch (FF)	NHS England Data & Analytics **(Observer)**
Judy Gash (JG)	Senior Project Manager - Cass Review Project (**Observer**: item 4.1)
James Gray (JG)	Digi-Trials (**Observer**: item 8.1)
Abigail Lucas (AL)	Data Access Request Service (DARS) (**Presenter**: items 5.1, 5.2 & 5.3)
Jon Moore (JM)	Data Protection Officer (interim)

Karen Myers (KM)	Secretariat Team
Dr. Jonathan Osborn (JO)	Caldicott Guardian Team representative
Andy Rees (AR)	Digi-Trials (**Presenter**: item 8.1)
Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (**Presenter**: item 4.1) (**SAT Observer**: items 4.2 & 4.3)
Anna Weaver (AW)	Data Access Request Service (DARS) (**Presenter**: items 4.2 & 4.3)
Vicki Williams (VW)	Secretariat Team
INDEPENDENT ADVISER OBSERVERS IN ATTENDANCE:	
Claire Delaney-Pope (CDP)	Independent Specialist Adviser
Miranda Winram (MW)	Independent Lay Adviser
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Maria Clark (MC)	Lay Member Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Dr Arjun Dhillon (AD)	Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn)
Dickie Langley (DL)	Data Protection Officer (DPO) representative (Delegate for Jon Moore)

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); Privacy, Transparency, Ethics and Legal (PTEL); 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 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 23rd February 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:** Prof. Nicola Fear noted a professional link with the applicant of NIC-148056-T6T5Z Imperial College London (item 4.2); and had a professional link to Airwaves data. It was agreed that Prof. Fear would not remain in the meeting for the discussion of that application. Prof. Nicola Fear noted a personal and professional link to NIC-482185-K8G0F-v0.17 University College London (UCL) (Item 4.4). It was agreed this did not preclude Prof. Nicola Fear taking part in the discussion about this application.
4. EXTERNAL DATA DISSEMINATION REQUESTS:	
4.1	**Reference Number:** None **Applicant:** University of York **Application Title:** Cass Review **Presenters:** Kimberley Watson **SAT Observer**: Catherine Day **Observers:** Richard Carthew, Judy Gash The aim of the Review is to make recommendations about services provided by the NHS to children and young people who are questioning their gender identity. Dr Hilary Cass was commissioned to carry out the Review by NHS England in 2020 and the final report is due by the end of 2023. The Cass Review team commissioned the University of York to undertake the research to understand the outcomes experienced by those accessing such services, and NHS England have been commissioned to provide the data extract to University of York. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. NHS England were seeking advice on the following points: 1. Early engagement with AGD as it transitions to a new governance structure, 2. Thoughts and comments on the current risks and approaches, 3. Closer engagement as the work progresses ahead of the release of the final data extract to the University of York. **Outcome of discussion:** The group were supportive of the proposal put forward. The group made the following observations on the supporting documentation provided as part of the review:

	The group noted their comments were made on the basis of the verbal update from NHS England alongside the following two documents: '*CASS Review DPIA v0.3 20230130*' and '*CassReviewDataCollectionOverview_v0.1*' only. **In response to point 1:** **4.1.1** The group welcomed the early engagement from NHS England on this future application, and noted the sensitive nature of the data being discussed. **In response to point 2:** **4.1.2** The independent advisers queried the information within the NHS England Data Protection Impact Assessment (DPIA) provided, in respect of the opt out arrangements; noting that it was unclear when the National Data Opt-out (NDO) and / or the study specific opt-out would be applied. The independent advisers suggested that the DPIA was updated to clearly distinguish between the NDO and study specific opt-out, when these were applied and who was responsible for applying each. **4.1.3** In addition, the independent advisers suggested that the DPIA was not sufficiently clear as to who was handling what kind of data, at what stage, and where; noting the verbal update from NHS England in the meeting, advising that the University of York would potentially visit clinics to manually extract confidential data from paper records. This information was also contradictory to the statement within the DPIA that researchers would access "…*confidential patient data in controlled environments"*. **4.1.4** Following the relevant updates to the NHS England DPIA, the independent advisers advised that for the purpose of transparency, the University of York as Data Controller, updated, and published its DPIA, along with any other relevant supporting documents. **4.1.5** The independent advisers highlighted the risks to both NHS England and the University of York, in respect of a reputational risk if the research was not appropriately publicised. **4.1.6** The independent advisers noted that the Health Research Authority Confidentiality Advisory Group (HRA CAG) support had **not** been provided as a supporting document and advised that this would be a key supporting document at any future AGD reviews, since it would determine the expectations from HRA CAG in respect of engagement with the cohort, whether the support was for research or service evaluation; and for clarification on any processing restrictions for the University of York. **4.1.7** Noting that the University of York were stated as the sole Data Controller, the independent advisers queried whether further consideration should be given to NHS England or another executive body also having a joint data controllership role, noting that the research was being undertaken for the NHS England Cass Review; and suggested that that joint data controllership was explored further. **4.1.8** It was noted by the independent advisers that data would be discarded if there was a mismatch; and it was suggested that that whilst this did not affect the security of the data, there was a risk to the efficacy of the research outputs, if the data was too readily discarded. The independent advisers suggested that further consideration should be given to any additional processing that can be undertaken, in terms of the data held, to avoid or reconcile any mismatches, and provide a quantitative record of the linkage issues for reference in any subsequent statistical analysis using the linked data. **In response to point 3:** **4.1.9** The independent advisers advised that they would welcome closer engagement at any stage, and as the work progresses, at a future meeting of AGD.	

4.2	**Reference Number:** NIC-148056-T6T5Z-v9.9 **Applicant:** Imperial College London **Application Title:** Airwaves Health Monitoring Study (MR837) **Presenter:** Anna Weaver **SAT Observer**: Kimberley Watson **Previous Reviews:** The application and relevant supporting documents were previously presented at the IGARD meetings on the 16th March 2017, 31st August 2017 and 30th August 2018. The application was previously reviewed as part of oversight and assurance, at the IGARD meeting on the 19th September 2019. **Application:** This was a renewal, extension and amendment application. The amendments are to **1)** add new data processor (Swansea University) and **2)** add new datasets: historical Hospital Episode Statistics (HES) Critical Care, HES Outpatients, HES Admitted Patient Care, HES Accident & Emergency, Mental Health datasets, and GP data for pandemic planning & research (GDPPR), plus future drops of these datasets (excluding HES A&E) for the duration of this data sharing agreement (DSA) (3 years). Should the application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were not wholly supportive of the application as presented and wished to draw to the attention of the SIRO the following high-level comments: **4.2.1** The independent advisers noted that although the application was requesting GDPPR data, this request had not been presented to the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) as per the published PAG process due to operational reasons; and therefore the group were unable to review PAG feedback as part of the request for this dataset, as per process. **4.2.2** The independent advisers advised that there was a clear process, within the public domain, when applicants request access to the GDPPR data; and that in this instance it had not been followed, and they were therefore **not** supportive of this dataset flowing under this data sharing agreement (DSA). **4.2.3** In addition, the independent advisers advised that there did **not** appear to be a legal gateway provided, to extend the scope of the processing, to encompass COVID-19 research. **4.2.4** The independent advisers expressed concern that it had not been possible to seek the views of PAG prior to this discussion and reiterated that the process described in public facing materials for accessing the GDPPR data should be followed or those materials updated if the situation has changed. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **4.2.5** The independent advisers queried the opt out rate following circulation of the last newsletter in 2022. It was suggested that the applicant engage with a representative sample of the cohort to discuss the current and proposed processing and purposes to seek their views, for example, whether this would come as a surprise to them or not. Some cohort members may not realise the breadth of research beyond evaluating the safety of Airwave.	

	4.2.6 Noting that the last ethical opinion provided was sought from 2019, the independent advisers suggested that NHS England advised the applicant to seek a more up-to-date ethical opinion, in light of the new processing and purpose. **4.2.7** The independent advisers noted that Airwave study data would be shared with the 'Secure Anonymised Information Linkage' (SAIL), to enable linkage of the Airwave study data with Welsh Health records held in SAIL; and advised that there was no evidence provided that the cohort had been updated on this new processing; and that the UK General Data Protection Regulation (UK GDPR) had not been adhered to, in terms of informing data subjects where data was processed. **4.2.8** In addition, the independent advisers suggested that section 5(b) (Processing Activities) was updated with further information on the SAIL processing, noting that this public facing section, was currently silent on this aspect. **4.2.9** In respect of the yielded benefits in section 5(d) (Benefits) (iii) (Yielded Benefits), the independent advisers suggested that this was edited to ensure this only contained yielded benefits and not outcomes; and that any outcomes should be moved to section 5(c) (Specific Outputs Expected) in line with NHS Digital DARS Standard for Expected Outcomes and NHS Digital DARS Standard for Expected Measurable Benefits. **4.2.10** In addition, the independent advisers suggested that following the above edit of section 5(d) (iii), the yielded benefits should be clear as to which have been realised, and which have not, in line with NHS Digital DARS Standard for Expected Measurable Benefits. **4.2.11** Noting that the Airwave Tissue Bank approval was only to 2024, the independent advisers suggested that a 1-year renewal was put in place to ensure the compatibility of the consent was addressed and updated ethical support was obtained.	
4.3	**Reference Number:** NIC-184951-D1G8R-v2.9 **Applicant:** Intensive Care National Audit & Research Centre (ICNARC) **Application Title:** Renal Replacement Anticoagulant Management (RRAM) **Presenter:** Anna Weaver **SAT Observer**: Kimberley Watson **Previous Reviews:** The application and relevant supporting documents were previously presented at the IGARD meetings on the 13th September 2018, 1st November 2018, 29th November 2018, and 20th December 2018. The application was previously reviewed as part of oversight and assurance, at the IGARD meeting on the 3rd March 2022. **Application:** This was an extension and amendment. The amendments are to **1)** remove Nasstar as a data processor, **2)** add Babble Cloud (SUI) Limited as a data processor, **3)** remove the INCARC London data processing and storage location, and **4)** update the purpose section to reflect that the study has moved to archiving. Should the 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: **4.3.1** The independent advisers noted that this application was for the purpose of archiving, however queried the statements in section 5(a) (Objective for Processing) "*This Agreement*	

	*permits processing of the data for the purpose of secure storage and **back up…**"*; and suggested that the reference to *"back up"* was removed. **4.3.2** In addition, the independent advisers suggested that the beginning of section 5(a) was updated to state that the purpose of the application was for archiving **and** processing to respond to any challenge(s) only. **4.3.3** The independent advisers noted in section 6 (Special Conditions) that there was a special condition relating to the annual review; and advised that whilst they were supportive of this being in the application, that NHS England may want to consider adding a specific / revised special condition in respect of annual reviews for archiving applications. **ACTION:** NHS England to consider drafting a simplified, bespoke annual review for the purpose of archiving applications. **4.3.4** The independent advisers noted and commended the applicant on the yielded benefits in section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care), and suggested that these may be helpful to add to a case study. **4.3.5** To update section 5(c) (Specific Outputs Expected) to use a form of wording such as "*it is hoped* …", rather than "*it will*…".	DARS
4.4	**Reference Number:** NIC-482185-K8G0F-v0.17 **Applicant:** University College London **Application Title:** UK Early Life Cohort Feasibility Study (ELC-FS) **Presenter:** Dave Cronin **Previous Reviews:** The application and relevant supporting documents were previously presented at the IGARD meeting on the 1st December 2022 NHS England were seeking advice on the following point: 1. Noting the additional information provided in supporting documents following review by IGARD on the 1st December 2022, AGD are asked to consider if the response to the issues previously raised are sufficient and whether any issues remain which should be addressed prior to an updated application being submitted to AGD as part of the formal approval process. **Application:** This was an application coming for advice. The purpose of the application is for a study that will test the proof of concept for a new national birth cohort study for the UK. It will collect rich data on babies born across the UK during two consecutive months of 2022 or 2023 and their parents, capturing the economic and social environments into which these babies are born, and their health, well-being and development in their first 6-10 months. The study is relying on s251 of the NHS Act 2006 for the flow of data out of NHS England. Should the application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were broadly supportive of the application if the following significant comments were addressed, and wished to draw to the attention of the SIRO the following significant points: The group noted their comments were made on the basis of the verbal update from NHS England and a plethora of supporting documents provided, but noted that they had not been provided with a copy of the draft application.	

4.4.1 When the application was last reviewed on the 1st December 2022, the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) had suggested that the applicant undertake extensive patient and public involvement and engagement (PPIE), about issues including (but not limited to) the home visits and the individual having to contact the researchers to prevent them from making a home visit. The independent advisers noted that the applicant had provided a report of its rigorous PPIE, where it had been determined that there was a clear direction from the public as to how this research should be handled to ensure trust of handling health data, in that "*overall, most parents did not support the One Step approach, seeing it as un-transparent and offering less participation control*…". Accordingly, based on the PPIE provided, the independent advisers could not see evidence of public support for the proposed processing.

4.4.2 The independent advisers suggested that the applicant may wish to give consideration to seeking / obtaining s251 support from Health Research Authority Confidentiality Advisory Group (HRA CAG), for NHS England to handle the data in respect of a mailout with individuals being able to 'opt out' before personal data is transferred to the applicant or the applicant's data processors (in line with the approach supported by the PPIE work).

4.4.3 NHS England formally sought the view, in meeting, of the Caldicott Guardian representative with regard to the potential validity of the consent taken in the circumstances outlined. The NHS England Caldicott Guardian representative noted similar concerns raised by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) on the 1st December 2022 (see point 4.4.4 below).

4.4.4 The independent advisers reiterated previous advice provided by IGARD on the 1st December 2022, that careful consideration was given to specific sensitivities of the data subjects when approaching individuals on their doorstep without prior agreement, including, but not limited to, families / individuals subjected to domestic violence; and noted concern on the data protection and confidentiality issues in respect of with one parent being asked to give details of the other parent, without the other person's consent.

4.4.5 NHS England's DPO supported and agreed with the concerns raised by both the Caldicott Guardian representative and independent advisers (see points 4.4.3 and 4.4.4 above) and asked that the group be provided with further detail as to how the applicant had come to their conclusion that narrative responses about an interviewee's partner was **not** personal data, in line with the ICO guidance on this specific point.

4.4.6 Noting the content of the communication letter, the independent advisers noted concern over language used, and how this could be perceived as coercive, for example *"Each baby chosen for this study is unique and cannot be replaced"*; and suggested a review of the letter to update to reflect less potentially coercive language.

4.4.7 In addition, the independent advisers also noted the reference within the 'advance booklet' communication leaflet to participants answers being made *"securely available to researchers via the UK Data Service and other trusted repositories"*. Noting the clear concerns of PPIE participants about commercial involvement and also the points in the protocol about researchers from commercial organisations potentially having access (but not for commercial exploitation), advisors suggested that the booklet was updated to be more transparent on the potential commercial organisation involvement and the purpose limitations, noting that this was not clear.

4.4.8 The independent advisers queried whether it was possible to screen out invitations and visits to birth parents of any children who had been, or were in the process of being adopted. The group also noted that those families who had suffered a bereavement following the birth of a child (of either the mother or baby/babies) would be screened but noted that there would

	inevitably be a delay and some bereavements would not be noted in time to prevent a visit to the residence. The group stressed the importance of extreme sensitivity for any interactions with bereaved families. **4.4.9** The independent advisers advised that they were supportive of a long-term study for a birth cohort and encouraged solutions to be explored to enable this to happen.	
5. INTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-318886-M1B9L-v3.2 **Applicant:** National Institute for Cardiovascular Outcomes Research (NICOR) **Application Title:** National Audit for Percutaneous Coronary Interventions (Angioplasty) – HES tabulation data **Presenter:** Elizabeth Flaherty / Abigail Lucas **SAT Observer**: Catherine Day **Previous Reviews:** The application and relevant supporting documents were previously presented at the IGARD meetings on the 26th March 2020 and 11th February 2021. **Application:** This was a renewal, extension and amendment application. The amendments are to **1)** remove the Healthcare Quality Improvement Partnership (HQIP) as a joint data controller, **2)** change the data processor from Barts Health NHS Trust to NHS Arden & Greater East Midlands (GEM) Commissioning Support Unit (CSU), and **3)** add further lay explanations and points of clarity throughout the data sharing agreement (DSA). Should the 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 that there had been a breach of this data sharing agreement (DSA)). This was notified through NHS Digital's reporting process and no data processing concerns were identified. It was identified in the meeting that the SIRO had not been notified. NHS England will review processes to ensure SIRO is informed of such breaches of agreements. **5.1.2** Noting that the procedure codes were not specified in section 5(b) (Processing Activities), the independent advisers suggested that this was updated as appropriate to add the procedure code, in line with other similar applications, and for transparency. **5.1.3** The independent advisers noted the statement in section 1 *"Unlike other NICOR data, the tabulation data under this DSA will not be stored on Arden and GEM servers which are situated at the Redcentric Data Centre"*; and asked that this was also replicated in the public facing section 5(b). **5.1.4** In respect of the yielded benefits in section 5(d) (Benefits) (iii) (Yielded Benefits), the independent advisers suggested that this was edited to ensure this only contained yielded benefits and not outcomes; and that any outcomes should be moved to section 5(c) (Specific Outputs Expected) in line with NHS Digital DARS Standard for Expected Outcomes and NHS Digital DARS Standard for Expected Measurable Benefits. **5.1.5** In addition, the independent advisers suggested that following the above edit of section 5(d) (iii), the yielded benefits, if possible should be quantified, for example in relation to the statement *"Hospitals use the information to continue refining their approach to try and ensure*	

	all patients can receive prompt invasive treatment", and in line with NHS Digital DARS Standard for Expected Measurable Benefits. **5.1.6** The independent advisers advised that, for the purpose of transparency, the data flow was included in a release register.	
5.2	**Reference Number:** NIC-42272-S9J3L-v6.4 **Applicant:** National Institute for Cardiovascular Outcomes Research (NICOR) **Application Title:** National Heart Failure Audit – HES Tabulation data **Presenter:** Elizabeth Flaherty / Abigail Lucas **SAT Observer**: Cath Day **Previous Reviews:** The application and relevant supporting documents were previously presented at the IGARD meetings on the 22nd February 2018 and 5th April 2018. **Application:** This was a renewal, extension and amendment application. The amendments are to **1)** remove the Healthcare Quality Improvement Partnership (HQIP) as a joint data controller, **2)** change the data processor from Barts Health NHS Trust to NHS Arden & Greater East Midlands (GEM) Commissioning Support Unit (CSU), and **3)** add further lay explanations and points of clarity throughout the data sharing agreement (DSA). Should the 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: **5.2.1** The independent advisers noted that there had been a breach of this data sharing agreement (DSA)). This was notified through NHS Digital's reporting process and no data processing concerns were identified. It was identified in the meeting that the SIRO had not been notified. NHS England will review processes to ensure SIRO is informed of such breaches of agreements. **5.2.2** The independent advisers noted the statement in section 1 *"Unlike other NICOR data, the tabulation data under this DSA will not be stored on Arden and GEM servers which are situated at the Redcentric Data Centre"*; and asked that this was also replicated in the public facing section 5(b) (Processing Activities). **5.2.3** In respect of the yielded benefits in section 5(d) (Benefits) (iii) (Yielded Benefits), the independent advisers suggested that this was edited to ensure this only contained yielded benefits and not outcomes; and that any outcomes should be moved to section 5(c) (Specific Outputs Expected) in line with NHS Digital DARS Standard for Expected Outcomes and NHS Digital DARS Standard for Expected Measurable Benefits. **5.2.4** In addition, the independent advisers suggested that following the above edit of section 5(d) (iii), the yielded benefits to provide further information on how mortality rates would be improved, in line with NHS Digital DARS Standard for Expected Measurable Benefits. **5.2.5** The independent advisers advised that for the purpose of transparency, the data flow was included in a release register.	
5.3	**Reference Number:** NIC-64572-X0Q4D-v7.3 **Applicant:** National Institute for Cardiovascular Outcomes Research (NICOR)	

	Application Title: Myocardial Ischaemia National Audit Project (MINAP) – HES Tabulation data **Presenter:** Elizabeth Flaherty / Abigail Lucas **SAT Observer**: Cath Day **Previous Reviews:** The application and relevant supporting documents were previously presented at the IGARD meetings on the 31st January 2017 and 20th July 2017. **Application:** This was a renewal, extension and amendment application. The amendments are to **1)** remove the Healthcare Quality Improvement Partnership (HQIP) as a joint data controller, **2)** change the data processor from Barts Health NHS Trust to NHS Arden & Greater East Midlands (GEM) Commissioning Support Unit (CSU), and **3)** add further lay explanations and points of clarity throughout the data sharing agreement (DSA). Should the 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 independent advisers noted that there had been a breach of this data sharing agreement (DSA)). This was notified through NHS Digital's reporting process and no data processing concerns were identified. It was identified in the meeting that the SIRO had not been notified. NHS England will review processes to ensure SIRO is informed of such breaches of agreements. **5.3.2** The independent advisers noted the statement in section 1 *"Unlike other NICOR data, the tabulation data under this DSA will not be stored on Arden and GEM servers which are situated at the Redcentric Data Centre"*; and asked that this was also replicated in the public facing section 5(b) (Processing Activities). **5.3.3** In respect of the yielded benefits in section 5(d) (Benefits) (iii) (Yielded Benefits), the independent advisers suggested that this was edited to ensure this only contained yielded benefits and not outcomes; and that any outcomes should be moved to section 5(c) in line with NHS Digital DARS Standard for Expected Outcomes and NHS Digital DARS Standard for Expected Measurable Benefits. **5.3.4** In addition, the independent advisers suggested that following the above edit of section 5(d) (iii), the yielded benefits to provide further information on how mortality rates would be improved, in line with NHS Digital DARS Standard for Expected Measurable Benefits. **5.3.5** The independent advisers advised that for the purpose of transparency, the data flow was included in a release register.	
AGD Operations		
6	**Standard operating procedures** The ongoing forward plan of work for creating Standard Operating Procedures was discussed.	To note
7 **7.1**	**New Operational Actions & those carried forward from previous meetings of AGD:** **Inside Scope of IR35** The NHS England representatives noted that NHS England was still considering the issue of IR35 and the impact on independent advisers who were previously on IGARD.	

	ACTION: NHS England to provide an update at the 9th March 2023 meeting.	DL
7.2	**Outstanding IGARD actions** The group discussed the outstanding actions from the Independent Group Advising on the Release of Data (IGARD), as outlined in the final IGARD minutes from the 26th January 2023. It was agreed that these actions would become AGD actions and further updates provided at future AGD meetings.	To note
Any Other Business		
8.1	Our Future Health: Our Future Health Recruitment Programme (Presenter: Andy Rees) NIC 414067-K8R6J-v0.2 Andy Rees, a member of NHS England's Digi-Trials Team, attended the meeting to provide a verbal update on Our Future Health, following the last update at the IGARD meeting on the 17th November 2022 and the 1st December 2022 (under 'AOB'). The group were advised that the applicant intends to submit an urgent amendment to their data sharing agreement (DSA) to request permission to increase the number of potential participants contacted for the study from the current 12 million. Ultimately, Our Future Health are likely to need to contact up to 45 million potential participants: which is the entire adult population of England. In addition, Our Future Health has submitted an amendment application to Health Research Authority Confidentiality Advisory Group (HRA CAG), seeking s251 permission to send an invitation to every adult in England via the Digi-Trials service, subject to national and local data opt out registrations. The group thanked colleagues in Digi-Trials for attending the meeting and for the briefing paper provided in advance of the meeting; and made the following high level comments: Independent advisers expressed concerns over the potentially excessive processing of personal data to send invitations via Digi-Trials, and how this would affect future researchers. The advisors also queried whether it was justified processing all adults' confidential data rather than a *"Dear Householder"* mail out approach. It was also noted that the research programme was initially looking at reaching underrepresented groups, and queried the extent to which this has been achieved in the current sample. The independent advisers also noted that potential issue with transparency, as per the risk factor previously articulated by IGARD in that participants may not be aware of the depth of the significant commercial involvement. It was suggested that more robust PPIE was carried out around the commercial involvement and that this was more transparently disclosed in the mail out (cf online privacy notices). the overall objective for the research programme in that it was initially looking at underrepresented groups, general advertising of the research programme with partners and whether this could be improved. The group advised NHS England that they would welcome this back at a future meeting to discuss further.	
	Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.	