Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 27th July 2023

09:30 – 15:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	Specialist Ethics Adviser / Co-Deputy Chair
Claire Delaney-Pope (CDP)	Independent Specialist Adviser (**Observer – new AGD member)**
Dr. Robert French (RF)	Independent Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Geoffrey Schrecker (GS)	Specialist GP 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 4.1 to 5.5)
Lucy Elliss-Brookes (LEB)	Associate Director, Data Curation Data & Analytics, Transformation Directorate (**Observer**: item 4.1)
Garry Coleman (GC)	NHS England SIRO Representative
Gemma Dodds (GD)	Faster Data Flows Programme Lead, NHS North of England CSU (**Presenter:** item 4.1)
Kate Fleming (KF)	NHS England Data & Analytics Representative (Delegate for Michael Chapman)
Dickie Langley (DL)	NHS England DPO Representative (Delegate for Jon Moore)
Karen Myers (KM)	AGD Secretariat Team
Dr Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Vicki Williams (VW)	AGD Secretariat Team (**Presenter**: items 8 and 9.1)
Tom Wright (TW)	Head of Service, Data Services for Commissioners (DSfC), Data and Analytics Directorate (**Presenter**: item 4.2)

INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof Nicola Fear (NF)	Independent Specialist Academic Adviser
Dr. Imran Khan (IK)	Specialist GP Adviser / Co-Deputy Chair
Dr. Maurice Smith (MS)	Independent Specialist GP Adviser
Jenny Westaway (JW)	Independent Lay Adviser
Miranda Winram (MW)	Independent Lay Adviser (**Observer – new AGD member)**
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 20th July 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:** There were no declarations of interest.	
BRIEFING PAPER(S)		
4.1	**Title:** Faster Data Flows Programme Briefing (IG-09278) **Presenter:** Gemma Dodds **SAT Observer:** Vicky Byrne-Watts **Observer:** Lucy Elliss-Brookes **Previous Reviews:** The Faster Data Flow Acute Patient Activity briefing paper was previously presented to IGARD on the 18th August 2022, and the Faster Data Flows for Integrated Care Boards briefing paper was previously presented to AGD on the 8th June 2023. The purpose of the briefing was to provide details of NHS England's Faster Data Flow Programme, which aims to create daily and more timely collections of patient data from acute and community care settings (the Providers). NHS England process information to support the Secretary of State for Health & Social Care to manage and improve patient flow and waiting times by delivering the Faster Data Flows Service. The Faster Data Flows Service will provide: **1)** the delivery of more timely data collections that will support proactive and reactive reporting for local, system and national decision-making across the whole health and adult social care pathway, including the development and delivery of automated daily data collections; and **2)** data reporting, to enable NHS England and Integrated Care Boards (ICBs) to fulfil their statutory functions, in connection with the provision and management of health services in England across functions in primary, secondary care, community and mental health service, for example but not limited to; acute, elective and virtual wards services. NHS England were seeking advice on the following points: 1. The Faster Data Flow Programme, 2. NHS England Deputy SIRO Request: to consider the confidentiality of patients with this being a daily flow. **Outcome of discussion:** The group welcomed the briefing and made the following observations / comments: **4.1.1** In respect of point 1 above, the group noted that the briefing paper had come with a usage request and noted that usual process was that a briefing would precede a usage request. The group noted they would **not** be providing advice on the internal use request outlined in the briefing paper.	

	4.1.2 In respect of point 1 above, the group also noted that although the faster data flow (FDF) programme had been previously discussed at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD), this was a different group with different membership and suggested that the history of the FDF programme be included in the briefing paper. **4.1.3** Separate to the briefing note, the group noted that there was also a route for the group to comment on draft Directions, and noting a draft Direction had been provided in the pack of supporting documents, noted that it was not particularly detailed with regard to: the intention; use of data; who would use the data and, noting that Directions may inadvertently exclude research use, because they were silent on wider permitted use. The group suggested that all permitted categories of future use and users – such as research connected with health – be considered, and expressly included in the draft Direction. **4.1.4** In respect of point 1 above, the independent advisers also suggested that the briefing paper be updated with a clear intent for the use of the FDF data, noting that the FDF programme was still a pilot. It was unclear how this FDF data would be used any differently to data already flowing in the system. NHS England noted that plans were in place to test the FDF data versus the usual flows of data. The group noted the verbal update and suggested that a clear paper trail was provided as evidence and the briefing paper updated as appropriate. **4.1.5** In respect of point 2 above, with regard to transparency and engagement with the public, the group noted that the transparency material should front foot the use of Foundry, be clear at what point the National Data Opt-Out (NDO) would be applied (if at all), and be clear on any data linkage. **4.1.5** The independent advisers noted that there may be a possible error in the Data Protection Impact Assessment (DPIA) provided as a supporting document, with regard to the risk scoring and suggested that NHS England check this aspect. **4.1.5** The independent advisers also noted reference in the DPIA to a Memorandum of Understanding (MoU) and, noting this was not a legal contract between parties, suggested the DPIA be updated, as may be appropriate, with reference to the contractual arrangement between the relevant parties. **4.1.6** The group looked forward to receiving the finalised briefing, either out of committee (OOC) or tabled at a future meeting, and before any internal or external data usage requests.	
4.2	**Title:** Post COVID assessment service data collection Briefing **Presenters:** Tom Wright **SAT Observer:** Vicky Byrne-Watts The purpose of the 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. Patient level data is required specifically to monitor activity and address health inequalities, and understand the impact of post-COVID services, particularly in terms of clinical outcomes of patients with long-COVID, and improving understanding of long-COVID prevalence, natural history of disease, and best practice clinical management. The collection will contribute to evaluation of post-COVID assessment services and guide future service design, planning and policy decisions. NHS England were seeking advice on the following points: 1. Risks from the proposed processing, 2. Reputational risk for NHS England. **Outcome of discussion:** The group welcomed the briefing paper and made the following observations / comments: **4.2.1** The group noted that the briefing paper had not come with a usage request, noting the usual process was that a briefing would precede a usage request. The group noted they were **not** providing advice on the internal use request, and would only be providing advice on the collection and proposed forward plan for the data. **4.2.2** The Caldicott Guardian Team Representative noted that Caldicott Guardian Team input was outstanding and agreed to action separately. **4.2.3** NHS England noted that within the briefing note there was reference to General Practice (GP) data and confirmed that there would be **no** link to GP Data. The group noted the verbal update. **4.2.4** Noting that the data usage does not include GP data, the independent advisers noted that using the current structure, only 10% of patients affected by the condition would be captured. The group suggested therefore that consideration be given to how GP data could be accessed to ensure the best quality data was available to provide for the best possible outcomes. The group noted that this was a clear case where NHS England required GP data to deliver its functions appropriately. **4.2.5** The group noted that 'long-COVID' and 'post-COVID' and other such variations, were being used interchangeably within the briefing paper and documentation provided as supporting documents. The independent GP specialist advisers noted these phrases were **not** interchangeable and had accepted clinical definitions, as outlined by the NICE guidelines. **4.2.6** The group asked that all the documentation provided be updated as appropriate with regard to accepted clinical definitions in order to ensure that the correct data was being used, plus to ensure any limitations of the collection of any	

	data was understood, for example some data collections may have limited data fields available. **4.2.7** The group noted that should GP data not be used, that this should be acknowledged in the transparency and Data Protection Impact Assessment (DPIA), since any outcomes / outputs would be at risk of bias, this was especially important because most COVID-19 patient groups were very alive to the bias if only using secondary care data. **4.2.8** Noting the Data Protection Notice (DPN) had been provided as a supporting document, the independent advisers suggested that a justification be provided, alongside an analysis, with regard to the additional data flows, including but not limited to, the identifiability of certain data fields that had not previously flowed. **4.2.9** The group noted that the DPIA was silent on any public and patient involvement and engagement (PPIE) and suggested this was essential, particularly because of the number of active and focused PPIE groups, who would be able to provide valuable input on the collection and use. **4.2.10** The group looked forward to receiving the finalised briefing, either out of committee (OOC) or tabled at a future meeting, and before any internal or external data usage	
EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-656842-S5V7V-v1.5 **Applicant:** NHS England / Healthcare Quality Improvement Partnership (HQIP) **Application Title:** National Gastrointestinal Cancer Audit Programme (GICAP) (ODR1819_260) **SAT Observer:** Vicky Byrne-Watts **Application:** This was a renew, extension and amendment application. The amendments are to **1)** add the following datasets National Disease Registration Service (NDRS) Linked Cancer Waiting Times (CWT), NDRS Linked Diagnostic Imaging Dataset (DIDS), NDRS Linked Hospital Episode Statistics (HES) Admitted Patient Care (APC), NDRS Somatic Molecular Dataset and NDRS Cancer Patient Experience Survey (CPES); and also some new items under the Cancer Outcomes and Services Dataset (COSD) which is covered under the Cancer Registration Data; **2)** a one-off provision of data for the additional datasets and for the datasets already in the application. 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:	

	5.1.1 The independent advisers noted the statement in the Health Research Authority Confidentiality Advisory Group (HRA CAG) letter dated the 31st October 2022 *"Specific conditions of support (provisional and may change in **final** support letter)"*. Noting that a final support letter had **not** been provided as a supporting document, it was suggested that the applicant provide confirmation to NHS England, that HRA CAG have provided a final support letter; and that that all HRA CAG conditions of support have been met; and that all supporting documentation on these points were uploaded to NHS England's customer relationships management (CRM) system for future reference. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.1.2** The independent advisers noted that in the HRA CAG letter dated the 31st October 2022, support had been provided subject to conditions, for the National Data Opt-Out (NDO) to be deferred for the non-research activities in the National Bowel Cancer Audit (NBOCA); and suggested that the applicant ensure that all public facing transparency materials were updated to ensure it was clear that deferring the NDO was for the purpose of processing the data for audit only. **5.1.3** It was also suggested that for transparency, section 5 (Purpose / Methods / Outputs) of the application clarified why HRA CAG have deferred the NDO for the non-research activities, noting that this was currently unclear. **5.1.4** The independent advisers suggested that in line with NHS England's DARS Standard for Expected Measurable Benefits, the benefits in section 5(d) (Benefits) were updated to provide further information as to the benefits that will flow following the deferral of the NDO, for example, in relation to patient safety. **5.1.5** It was suggested by the independent advisers that section 5 of the application was updated to clarify that **no research** may be undertaken with the data flowing under this data sharing agreement (DSA), in line with the HRA CAG support. **5.1.6** The group noted that there was information within the public domain, in respect of research that has been undertaken using the audit data; and it was suggested that NHS England confirm that any current use of the data obtained under this DSA aligns with the permitted uses. **5.1.7** An NHS England representative queried the conflicting statements in section 5(a) (Objective for Processing) that NHS Digital's Clinical Audit and Registries Management Service (CARMS) *"…do not process any data released under this Agreement"*; and the in section 5(b) (Processing Activities) that states *"The CARMS team will transfer data to the NDRS Analytical team"*; and suggested that the application was reviewed and aligned where appropriate to accurately reflect the involvement of NHS England, including any activities previously undertaken by NHS Digital's CARMS.	

	5.1.8 The independent advisers queried the statement in section 5(b) *"The data will… be used to link the data with other record-level data already held by the recipient"*; and suggested that this was updated with further clarification of how the linkage will work in line with NHS England's DARS Standard for processing activities, noting that this was currently unclear. **5.1.9** The independent advisers queried the statement in section 5(b) "*This Agreement does not permit the Data Controllers to further disseminate NHS Digital data*"; and suggested that this was updated to refer to *"NHS England"* and not *"NHS Digital"*; and to be clear that the data **cannot** be further disseminated. **5.1.10** In addition, the independent advisers noted that section 5(c) (Specific Outputs Expected) intimated data would be shared with Trusts; and noting that this did **not** align with the point above (5.1.9), suggested this was updated to provide further clarification that was consistent with the rest of the application. **5.1.11** The SIRO representative queried the information in section 5(a) where, in respect of the justification provided for the UK General Data Protection Regulation (UK GDPR) legal basis cited, it states "…*which link back to NHS England and other national bodies with statutory responsibilities*"; and suggested that this was updated to either remove reference to "*other bodies with statutory responsibilities*", since this appeared to be not relevant, or to provide further information on which organisations this statement referred to.	
5.2	**Reference Number:** NIC-384326-R9V7S-v1.15 **Applicant:** Nuffield Department of Primary Health Sciences **Application Title:** Evaluating the effectiveness of screening for chronic kidney disease (CKD) in primary care by linking the OxRen/NewKi study with the Oxford RCGP Research and Surveillance Centre ORCHID database and NHS England data **SAT Observer:** Vicky Byrne-Watts **Previous Reviews:** The application and relevant supporting documents had previously been discussed at the IGARD BAU meeting on the 4th March 2021. **Application:** This was a renew, extension and amendment application. The amendments are to **1)** request Civil Registry Deaths (previously received Civil Registry Deaths Secondary Care Cut) and Cancer Registration data; **2)** extend the cohort to include additional participants without chronic kidney disease (CKD); **3)** to update section 5(a) (Objective for Processing) to include additional objectives for this agreement; 4) to extend the linkages between New Onset Kidney Impairment study (NewKi) data and participants' primary care records through linkage with the Oxford - Royal College of General Practitioners Research Clinical Informatics and Health Outcomes Digital Hub (ORCHID).	

	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 renewal of the previous version of the data sharing agreement (DSA) and advised that the points raised below for this version of the DSA should be addressed, and wished to draw to the attention of the SIRO the following substantive comments: **5.2.1** The group noted that the feedback from NHS England's Privacy, Transparency, Ethics and Legal (PTEL) stated that the 'Oxford - Royal College of General Practitioners (RCGP) Research Clinical Informatics and Health Outcomes Digital Hub' (ORCHID) data was "*pseudonymised*" data; and suggested that this was verified with PTEL, in line with the data flow diagram, which makes reference to linkage using the NHS number, which is an identifying data field, not a pseudonymised data field. **5.2.2** In addition, if the data was confirmed to be pseudonymised, the group noted issues with the transparency materials and the ethical issues in line with Caldicott Principle 8, *"…A range of steps should be taken to ensure no surprises for patients and service users…"*; and suggested that clarification was sought from the applicant as to whether there has been sufficient patient and public involvement and engagement (PPIE), and subsequent transparency to the cohort / wider public in respect of the use of the ORCHID data. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.2.3** The independent advisers noted the statement in section 5(a) *"At no point will NewKI study data or NHS England data be shared with RCGP who hold the ORCHID data"*; and suggested that this was removed, noting that RCGP **do not** have any involvement with the data flowing under this DSA and therefore did **not** need specifically referring to. **5.2.4** The independent advisers noted that the University of Oxford have cited Article 6(1)(f) *(legitimate interests)* of the UK General Data Protection Regulation (UK GDPR) in the ORCHID privacy notice, and Article 6(1)(e) *(Public Task)* for the processing in the application; and suggested that although this may be intentional, this was clarified with the applicant, and if this was incorrect, that the application / privacy notice was updated as may be necessary to cite the correct Article 6 UK GDPR legal basis. **5.2.5** The independent advisers noted the reference to "ORCHID-E" on the ORCHID webpage, and states this "…*populated using a rolling retrospective update of around 19 million patients registered at English and Welsh GP practices. Data undergoes a procedure of double-pseudonymisation prior to inclusion in the ORCHID-E platform*."; and suggested that NHS England confirm with the applicant that **no** NHS	

	England data will be stored on ORCHID-E, noting this would **not** be compatible with the DSA. **5.2.6** The independent advisers noted that the citation special condition had been included in section 6 (Special Conditions), however suggested that this was updated from *"…if practicable…"* to *"…where practicable…"*, as per the current standard wording.	
5.3	**Reference Number:** NIC-655581-X0K2P-v0.12 **Applicant:** University of Oxford **Application Title:** Assessing the contributions of additional role practitioners to general practice in England (CARPE) **SAT Observer:** Vicky Byrne-Watts **Application:** This was a new application. The purpose of the application is for a project titled aiming to analyse the contributions made by additional role practitioners within and across general practices in England and explore how their work is operationalised within general practices. The project will specifically look at work package 3 - 'Conduct patient level modelling of the effects of additional role practitioners on clinical workload, health outcomes, quality indicators and patient satisfaction'; and work package 4 - 'Conduct patient level modelling of the effects of additional role practitioners on health care costs'. 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: **5.3.1** The group welcomed the application and noted the importance of the research. **5.3.2** The independent advisers noted reference to e-mail correspondence from the Health Research Authority Confidentiality Advisory Group (HRA CAG) within the internal application assessment form, in respect of the s251 support; however, suggested that NHS England should satisfy itself that HRA CAG have been provided with **all** the relevant information in respect of the processing as set out in the application, including, but not limited to, the nature and status of the data and the steps being taken to pseudonymise the data. **5.3.3** The independent advisers queried what the ethical approval covered and, noting that this was not clear, suggested that the applicant provide further information, for example, does the ethical support cover all of the processing outlined in the application; and suggested that any further supporting information was uploaded to NHS England's customer relationships management (CRM) system for future reference.	

	5.3.4 The independent advisers noted that the National Data Opt-out (NDO) was not being applied to the data being pseudonymised, however suggested that NHS England should consider reviewing this, in line with the National Data Opt-out policy, for example, noting the change of purpose of the processing. **5.3.5** An NHS England representative queried whether the quantum, breadth and the linkage being undertaken meant that the data flowing was still pseudonymised; and, if so, suggested that a clear analysis of the reasons for this were outlined within section 5 (Purpose / Methods / Outputs) of the application for transparency. **5.3.6** Noting the references to *"role practitioners"* throughout the application, the independent advisers suggested that section 5 was updated to provide clarification as to what was captured as a role practitioner as this was unclear, for example, what professions it covers.	
5.4	**Reference Number:** NIC-674822-S2K9T-v0.3 **Applicant:** University of Oxford **Application Title:** The Children's Surgery Outcome Reporting research database (CSOR) - DigiTrials Comms Service - Vital Status **SAT Observer:** Vicky Byrne-Watts **Application:** This was a new application. The purpose of the application is for a study 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. The request is for NHS England to undertake Vital Status checks of the 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). 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 fact of death aspect of the vital status check**.** The group were **not** supportive of all other aspects outlined in the application because the group were **not** clear who would be captured in the cohort. Also, concern was expressed regarding the number of reminders and contact methods. The group suggested that a further iteration of the application be brought back to a future meeting with these points addressed. The group wished to draw to the attention of the SIRO the following substantive comments:	

	5.4.1 Noting that the application of the National Data Opt-out (NDO) had been upheld by Health Research Authority Confidentiality Advisory Group (HRA CAG), the independent advisers 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 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. **5.4.2** The independent advisers were 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. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.4.3** The independent advisers noted the references to *"vital status checks"* in the application, and queried if this was a new service provided by NHS England, or if it was new terminology for a "*list clean*". The NHS England SAT observer noted that it is a different product and does not replace the current list cleaning product; and that it is specifically aimed at the user case where trials/studies are communicating with participants. The group suggested that a briefing provided to AGD. **ACTION:** NHS England to provide a briefing on 'vital status checks' **5.4.4** The independent advisers noted that the content of both the provisional and final HRA CAG letters of support differed slightly in terms of content; and suggested that it was made clear in the internal application assessment form that both HRA CAG letters should be read together. **5.4.5** Separate to the application, the independent advisers noted that at the AGD meeting on the 29th June 2023, a HRA CAG analysis as part of the application assessment document had been provided for NIC-634901-B4H8K; and advised that a similar analysis would have been useful in the application assessment for the review of this application. It was suggested that NHS England consider providing similar analysis in the application assessment for relevant applications, to provide the group with a clear summary of the HRA CAG support. **ACTION**: NHS England Data Access Request Service Senior Approval Team (DARS SAT) to consider providing a HRA CAG analysis within the application assessment document when submitting applications to AGD with s251 support. **5.4.6** The independent advisers noted that section 5(b) (Processing Activities) referred to *"analysis"* and noting that this application was **not** for the purpose of analysis, suggested that this was updated to reflect the correct purpose for processing.	NHSE DARS SAT

	5.4.7 In addition, it was suggested that if there was any *"templated"* wording used within this application, the application was reviewed throughout to ensure the processing described was correct.	
5.5	**Reference Number:** NIC-360208-K1T4F-v1.30 **Applicant:** Cambridge University Hospitals NHS Foundation Trust **Application Title:** MR1474 - UK-PBC Project - cohort datasets **SAT Observer:** Vicky Byrne-Watts **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the IGARD BAU meeting on the 21st February 2019 and the 23rd May 2019. **Application:** This was a renew, extension and amendment application. The amendments are to **1)** add the Emergency Care Data Set (ECDS) as a replacement product for Hospital Episode Statistics Accident & Emergency (HES A&E); **2)** to add the Civil Registration Deaths dataset which will replace Medical Research Information Service (MRIS) Cause of Death dataset; **3)** to update section 5(a) (Objective for Processing); **4)** to add Medicines dispensed in Primary Care dataset (NHSBSA 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 high-level comments: **5.5.1** The independent advisers noted that the internal application assessment form had noted as part of the consent review that other pharmaceuticals funders were involved, as documented in supporting document 1.1, the January 2015 newsletter to participants, however it is **not** clear what the involvement of the pharmaceutical companies was. The independent advisers suggested that, for transparency, the application and internal application assessment form were updated with further details. For example, if medication was supplied at a discount or free; and whether the companies would receive any preferential treatment such as early sight of summary outputs. **5.5.2** The independent advisers noted that should enquiries around the pharmaceutical companies reveal any data controllership issues, then NHS England should revert to AGD, noting the NHS England DARS Standard for Data Controllers. **5.5.3** 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.	

	5.5.4 Separate to the application, the group suggested that NHS England form a policy position, as a matter of urgency, with regard to PPIE, especially because other bodies with the ability to share data with data controllers were making PPIE an essential part of their application process. **ACTION:** NHS England to consider a policy position with regard to PPIE In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.5.5** Noting the limited information in the internal application assessment form and data sharing agreement (DSA), the independent advisers suggested that a further justification be provided for the breadth of data requested, including but not limited to, a clear case for the pre-diagnosis data. **5.5.6** In addition, the DSA and internal application assessment form should clearly articulate how any other data held is being used to verify the data held and obtained from NHS England. **5.5.7** The group noted that the consent forms provided as part of the supporting documentation, referenced the sharing of data, but noted that this DSA **did not** permit the sharing of data. Should the applicant wish to share data, as outlined in their consent materials, the applicant should submit an amendment application to NHS England. **5.5.8** The group noted that a group of circa 2,000 had **not** been consented using the latest version of the consent materials, for example due to lost contact, and suggested that the applicant may wish to approach the Health Research Authority Confidentiality Advisory Group (HRA CAG) to see if s251 may be available to bring those lost to contact back into the cohort.	SIRO
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, 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. **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 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
8	**Standard operating procedures** The ongoing forward plan of work for creating Standard Operating Procedures was discussed. The group suggested that the draft '*How AGD consults with the Profession re General Practice Extraction Service (GPES) Data for Pandemic Planning & Research (COVID-19) (GDPPR) Data Standard Operating Procedure'* be circulated to AGD / Data Access Request Service Senior Approvals Team (DARS SAT) as an interim document to support any GDPPR applications, since that interim document outlined the current interim arrangements put in place by the Profession Advisory Group (PAG) Chair. **ACTION:** AGD Secretariat Manager to circulate the interim draft document to AGD / DARS SAT for information only.	To note VW
9 **9.1**	**New Operational Actions & those carried forward from previous meetings of AGD:** **Zero Hours contracts for independent advisers** Vicki Williams noted that eight independent advisers had now moved to NHS England zero hours contracts, with just two independent advisers due to move from 1st August 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	**National Data Advisory Group** As discussed at the AGD meeting on the 13th and 20th July 2023, the SIRO representative provided a brief verbal update on the 'National Data Advisory Group' within the recently published '*Data Saves Lives Implementation Update'* (published 27th June 2023); and advised that there were ongoing discussions within NHS England in respect of AGD and the National Data Advisory Group, and that further information would be presented to the group in due course.	To note
Meeting Closure		

As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.