Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 22nd June 2023

09:30 – 16:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	Specialist Ethics Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Rupert Chaplin (RC)	Head of Data Science, Data & Analytics (**Presenter**: item 11)
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: item 5.6)
Garry Coleman (GC)	NHS England SIRO Representative (**Presenter**: item 10.1) *(not in attendance for item 5.1)*
Ayse Depsen (AD)	Data Access Request Service (DARS) (**Observer**: items 5.1 to 5.5)
Louise Dunn (LD	Data Access Request Service Senior Approval Team (DARS SAT) (**Presenter**: item 4.1) (**SAT Observer**: items 5.1 to 5.5)
Dan Goodwin (DG)	Data Access Request Service (DARS) (**Presenter**: item 5.6)
Alistair Jones (AJ)	Senior Information Analyst, Data & Analytics (**Observer**: item 11)
Phil Koczan (PK)	NHS England Caldicott Guardian Team Representative (Delegate for Jonathan Osborn)
Dickie Langley (DL)	NHS England DPO Representative (Delegate for Jon Moore)
Karen Myers (KM)	AGD Secretariat Team
Jodie Taylor-Brown (JTB)	Data Access Request Service (DARS) (**Observer**: item 5.6)
James Thomas (JT)	Data Access Request Service (DARS) (**Observer**: items 5.1 to 5.5)

Gemma Walker (GW)	Data Access Request Service (DARS) (**Observer**: items 5.1 to 5.5)
James Watts (JW)	Data Access Request Service (DARS) (**Observer**: item 4.1) (**Presenter**: items 5.1 to 5.5)
Vicki Williams (VW)	AGD Secretariat Team (**Presenter**: item 9)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Michael Chapman (MCh)	Data and Analytics representative
Dr Jonathan Osborn (JO)	NHS England Caldicott Guardian Team 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 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 & 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 without a Data & 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 15th 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:** There were no declarations of interest.
BRIEFING PAPER(S):	
4.1	**Title:** National Disease Registration Service (NDRS) Agreement Management **Presenter:** Louise Dunn **Observer:** James Watts **Previous Reviews:** The NDRS applications have been discussed a number of times by IGARD and AGD throughout 2022 / 23. The purpose of the briefing paper is to update AGD on a proposal to create a new NDRS Precedent which permits: **1) Extensions** – for all Public Health England (PHE) novated agreements which do not meet the NHS England DARS Standards, but wish to further extend, beyond the initial 12-months granted, until the end of the period for which data is required, without the requirement for them to meet the NHS England DARS Standards. The appropriate legal basis / security checks will be carried out; and **2) Renewals** – if the purpose is not changed and they simply require more of the same data, NHS England propose these are renewed without having to meet NHS England DARS Standards or requiring an AGD review until the end of the period for which data is required. Applications for an amendment, or a new data sharing agreement, would follow the usual NHS England DARS processes. **Outcome of discussion:** The group welcomed the briefing paper and made the following observations / comments: **4.1.1** The independent advisers noted that the risks within the paper were internal facing, i.e. risks to NHS England; and suggested that additional consideration / information was provided within the briefing paper on the risks to the data and data subjects. **4.1.2** The independent advisers noted the potential risk to NHS England in ensuring the correct data controllership arrangements were outlined within the NDRS applications; and suggested that this was made clear within the briefing paper, in addition to the risks already outlined.

	4.1.3 In respect of transparency it was suggested by the independent advisers that NHS England should give further consideration on transparency to the public, for example, updating the NDRS webpage with further information of how NDRS applications are being managed / processed. **4.1.4** In addition, it was suggested by the independent advisers, that NHS England may want to consider providing transparency to the public, on those applicants and / or applications that do or do not meet NHS England's DARS Standards. **4.1.5** The independent advisers noted the rigorous approvals process previously undertaken by PHE, which provides some reassurance. **4.1.6** The independent advisers noted that applicants of NDRS data may have difficulty seeing the utility in providing narrative text to support NHS England's DARS Standards, noting the previous work undertaken to meet PHE standards; and suggested that this was sensitively reflected in the briefing paper. **4.1.7** The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting.	
EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-681965-Y4H5P-v0.5 **Applicant:** Cambridge University Hospitals NHS Foundation Trust (FT) **Application Title:** Melanoma PREDICT Tool - Individualising prognostic stratification in melanoma ODR1920_246 **Presenter:** James Watts **SAT Observer:** Louise Dunn **Observers:** Ayse Depsen, James Thomas, Gemma Walker **Application:** This was a new application. The purpose of the application is for a project, to create an online, interactive tool 'PREDICT Melanoma tool'. The tool will be designed for patients diagnosed with cutaneous melanoma and the healthcare professionals providing their care; and will provide predictions, based on a national population level dataset, to assist in making decisions about further investigations and treatments that are advised by current clinical guidelines currently available based on the specifics of that individual and the type of melanoma. 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 in the internal application assessment form that the applicant had sought advice from the Health Research Authority Research Ethics Committee (HRA REC), who had advised that REC approval was **not** required, and that this had also been the view of the Cambridge Central Research Ethics Committee. However, it was noted there are significant ethical issues to be considered including whether patients could be distressed by such a tool and be given information about their	

	chances of dying that they can do little about. It was suggested that NHS England obtain written confirmation from the applicant that they had discussed these issues with their *"Research and Development Governance Team"*, as referred to on the Cambridge University Hospitals NHS FT website. 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 suggested that the applicant should seek the views of Melanoma UK, or other relevant charities, at an early stage, to consider any ethical issues in respect of the tool, and what steps, if any, could be taken in respect of its development and use. **5.1.3** In addition, the independent advisers suggested that further patient and public involvement and engagement (PPIE) should be undertaken, to seek views not only on how to present the tool but also on earlier stages of the project. **5.1.4** Noting the information within the application in respect of honorary contracts, the group queried the status of the NHS England DARS Honorary Contracts Standard, following the discussion and approval of this Standard at the AGD meeting on the 8th June 2023; and asked that the NHS England SIRO Representative provide a further update on this at a future AGD meeting. **ACTION:** NHS England SIRO Representative to provide a further update on the status of the NHS England DARS Honorary Contracts Standard. **5.1.5** Noting the information in section 1(b) (Data Controllers) that the applicant's Data Security and Protection Toolkit (DSPT) status was "*baseline*"; the independent advisers suggested that this was reviewed and updated to reflect if the DSPT had been met and if there were any outstanding actions. **5.1.6** The independent advisers noted that the citation special condition in section 6 (Special Conditions) referred to the *"NHS England Access Request Service"*; and were advised by NHS England that this was an error and would need updating correctly refer to *"NHS England **Data** Access Request Service"*.	SIRO
5.2	**Reference Number:** NIC-656818-N1B5Q-v0.2 **Applicant:** University of Oxford **Application Title:** Project to Help Improve Decision Aids for Predicting Outcomes in Early Breast Cancer: (ODR1718_390) **Presenter:** James Watts **SAT Observers**: Louise Dunn **Observers:** Ayse Depsen, James Thomas, Gemma Walker **Application:** This was a renewal and extension application. The purpose of the application is for an ongoing study to Help Improve Decision Aids for Predicting Outcomes in Early Breast Cancer. It is known that survival from breast cancer has improved and that incidence and mortality of other diseases has changed; however, detailed estimates based on patients treated recently are not currently available. These estimates are needed to enable clinicians to estimate prognosis for patients treated today	

	using characteristics such as age, tumour size, nodal status, grade, receptor status and screening status. 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 substantive comments: **5.2.1** The independent advisers noted the statement in section 7(Ethics Approval) that ethics approval is not required because it *"Does not include the flow of confidential data";* and suggested that NHS England confirm with the applicant that they have taken **all** necessary steps to ensure that they have institutional ethical support, as outlined on the applicant's website. In addition, the Group made the following observations on the application and / or supporting documentation provided as part of the review: **5.2.2** The group noted that the University of Oxford would like to receive a file linking the old pseudo_ids with the new pseudo_ids for reference purposes; and noting that this may lead to new participants being added to the cohort, the independent advisers suggested that NHS England obtain a clear justification from the applicant as to why they may require new participants in order to carry out the objective for processing; and that the application was updated as appropriate with further information on the justification in line with NHS England's DARS standard for data minimisation. **5.2.3** Noting the statement in section 5(b) (Processing Activities) *"…students affiliated with the University of Oxford or individuals with honorary contracts with The University of Oxford…"*, the independent advisers suggested that this was updated with further clarification with regard to who may need to operate under an honorary contract. In addition, it was suggested that the relevant honorary contract special conditions were added to section 6 (Special Conditions) as per process. **5.2.4** In addition, the independent advisers noted that students at the University of Oxford would not need honorary contracts, however suggested that further information was provided in section 5(b) of when students may need to access the data. **5.2.5** The independent advisers noted that processing of the data under this data sharing agreement (DSA) could be done remotely; and suggested that NHS England needs a clear policy on remote access. **ACTION:** NHS England to provide its position to AGD on remote access *(as previously requested and agreed at the AGD meeting on the 2nd February 2023)*. **5.2.6** Noting the information in section 5(a) (Objective for Processing) in respect of the funders, the independent advisers suggested that this was updated to also state that *"The funders will have no ability to suppress or otherwise limit the publication of findings"*. **5.2.7** In addition, the independent advisers noted that the special condition, stating that the funder would not have influence on the outcomes nor suppress any of the findings of the research, was missing from section 6, and suggested that this was included as per process. NHS England advised that following the discussion at the AGD meeting on the 15th June 2023 in respect of this information being reflected in the questions and answers	NHSE

	(Q&A) for the internal application assessment form, confirmed that this was in the process of being updated, to reflect the standard wording previously used. **5.2.8** Noting the statement in section 5(c) (Specific Outputs Expected, including Target Date) *"All these manuscripts have been prepared jointly with NDRS staff, and NDRS staff are authors jointly with Oxford University staff"*; the independent advisers suggested that the application was updated to clarify the role of NDRS, or else remove the statement. **5.2.9** The independent advisers noted the statement in section 5(c) *"The outputs will not contain NHS Digital data…"*; and suggested that the reference to *"NHS Digital"* was amended to correctly refer to *"NHS England"*. **5.2.10** Noting the reference in section 5(d) (Benefits) (iii) (Yielded Benefits) to the extension of CRUK's programme grant being a yielded benefit, it was suggested that this was updated in line with NHS England's DARS Standard for Expected Measurable Benefits, or removed, noting that this in itself was not a yielded benefit for the provision of health or adult social care or the promotion of health . **5.2.11** The independent advisers noted that the citation special condition in section 6 referred to the *"NHS England Access Request Service"*; and were advised by NHS England that this was an error and would need updating correctly refer to *"NHS England **Data** Access Request Service"*. **5.2.12** NHS England advised the group, that the internal application assessment form incorrectly stated that data would be held up to *"December 2017"*; and advised that this would be amended to correctly state *"December 2016"*. The group noted the verbal update.	
5.3	**Reference Number:** NIC-662234-T6B7J-v0.8 **Applicant:** University of Leicester **Application Title:** Cancer survival methodological developments and their applications **Presenter:** James Watts **SAT Observer**: Louise Dunn **Observers:** Ayse Depsen, James Thomas, Gemma Walker **Application:** This was a new application. The purpose of the application for a research, with the aim of **1)** developing novel statistical approaches to report the impact of a cancer diagnosis at an individual level based on key patient characteristics both in terms of survival following a cancer diagnosis and in terms of quality of life; **2)** developing methodology in the same modelling frameworks to assess the impact of interventions (e.g., screening, and early diagnosis campaigns) or of the global pandemic due to COVID-19 (and corresponding restrictions) on the stage profile and outcome for cancer patients; and **3)** developing approaches to better inform the impact of increased survival from new treatment interventions, by selecting nationally representative samples of patients, and using the developed methodology in survival curve extrapolation and marginalisation. 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 the information in section 5(a) (Objective for Processing) in respect of the purpose for processing, however suggested that this was updated with further narrative to explain that the purpose was for research to underpin better quality research. **5.3.2** The independent advisers noted that processing of the data under this data sharing agreement (DSA) could be done remotely; and suggested that NHS England needs a clear policy on remote access. **5.3.3** In addition, the NHS England SIRO representative noted that the standard wording for university remote access was not included in section 5(b) (Processing Activities); and suggested that this was updated as appropriate. **ACTION:** NHS England to provide its position to AGD on remote access *(as previously requested and agreed at the AGD meeting on the 2nd February 2023)*. **5.3.4** Noting the information in section 5(a) in respect of the funders, the independent advisers suggested that this was updated to also state that *"The funders will have no ability to suppress or otherwise limit the publication of findings"*. **5.3.5** In addition, the independent advisers noted that the special condition, stating that the funder would not have influence on the outcomes nor suppress any of the findings of the research, was missing from section 6 (Special Conditions), and suggested that this was included as per process. NHS England advised that following the discussion at the AGD meeting on the 15th June 2023 in respect of this information being reflected in the questions and answers (Q&A) for the internal application assessment form, confirmed that this was in the process of being updated, to reflect the standard wording previously used. **5.3.6** The independent advisers noted that the citation special condition in section 6 referred to the *"NHS England Access Request Service"*; and were advised by NHS England that this was an error and would need updating correctly refer to *"NHS England **Data** Access Request Service"*.	NHSE
5.4	**Reference Number:** NIC-656752-G2L2P-v0.4 **Applicant:** University of Oxford **Application Title:** Evaluating the age extension of the NHS Breast Screening Programme (AgeX Trial) (ODR_2014_367) **Presenter:** James Watts **SAT Observer:** Louise Dunn **Observers:** Ayse Depsen, James Thomas, Gemma Walker **Application:** This was a renew, extension and amendment application. The amendments are to **1)** permit the release of Systemic Anti-Cancer Therapy (SACT) Data; and **2)** the National Radiotherapy Dataset (RTDS).	

	The newly requested datasets will be used alongside a refresh of Cancer Registry data, and data already held by the study, to evaluate the age extension of the NHS Breast Screening Programme (AgeX Trial). 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 substantive comments: **5.4.1** Noting the reference within the protocol to the 2015 "*Government Response to the House of Commons Science and Technology Committee Report on National Health Screening*"; and the clear government direction on screening and ministerial statements about the contribution the AgeX trial will make to government decision making; the independent advisers suggested that NHS England worked with the DPO representative, to explore whether this raises any data controllership issues, in line with NHS England's DARS Standard for Data Controllers. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.4.2** The group welcomed the application and noted the importance of this research both in the UK and around the world. **5.4.3** The independent advisers noted that although section 3(c) (Patient Objections) contained information in respect of patient objections applied suggested that this was updated to also include information on the study specific opt out, in line with NHS England's DARS Standard for Patient Objections. **5.4.4** In addition, the independent advisers noted the special condition in section 6 (Special Conditions) relating to opt-outs, and suggested that this was removed as it was not necessary to include. **5.4.5** Noting the reference in the Health Research Authority Confidentiality Advisory Group (HRA CAG) support to linkage of the AgeX trial database with the Million Women Quality of Life Study, the independent advisers suggested that if the linkage with the NDRS data is intended, then NHS England should confirm that the legal and ethical requirements for this have been met, in respect of both this application and also in terms of being compatible with the Million Women consent. **5.4.6** The independent advisers noted that processing of the data under this data sharing agreement (DSA) could be done remotely; and suggested that NHS England needs a clear policy on remote access. **ACTION:** NHS England to provide its position to AGD on remote access *(as previously requested and agreed at the AGD meeting on the 2nd February 2023)*. **5.4.7** Noting the information in section 5(a) (Objective for Processing) in respect of the funders, the independent advisers suggested that this was updated to also state that *"The funders will have no ability to suppress or otherwise limit the publication of findings"*. **5.4.8** In addition, the independent advisers noted that the special condition, stating that the funder would not have influence on the outcomes nor suppress any of the findings of the research, was missing from section 6, and suggested that this was included as per	NHSE

	process. NHS England advised that following the discussion at the AGD meeting on the 15th June 2023 in respect of this information being reflected in the questions and answers (Q&A) for the internal application assessment form, confirmed that this was in the process of being updated, to reflect the standard wording previously used. **5.4.9** The independent advisers noted that the application did not refer to any patient and public involvement and engagement (PPIE) undertaken / planned; and suggested that the applicant undertakes **ongoing** PPIE. The HRA guidance on Public Involvement is a useful guide. **5.4.10** The independent advisers noted that the citation special condition in section 6 referred to the *"NHS England Access Request Service"*; and were advised by NHS England that this was an error and would need updating correctly refer to *"NHS England **Data** Access Request Service"*.	
5.5	**Reference Number:** NIC-675446-G2S5Q-v0.7 **Applicant:** University of Hull **Application Title:** Is travel burden associated with differences in health outcomes for patients diagnosed with breast, lung, prostate, colorectal or oral cancers living in Yorkshire & Humberside and the North East Regions. **Presenter:** James Watts **SAT Observer:** Louise Dunn **Observers:** Ayse Depsen, James Thomas, Gemma Walker **Application:** This was a new application. The purpose of the application is for a study, which plans to examine the associations between travel times and travel distances and differences in outcomes for cancer patients. It also seeks to examine in direct response to the Chief Medical Officers call in 2021 to investigate potential differences in cancer outcomes for cancer patients living in coastal communities. 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: **5.5.1** The independent advisers commended NHS England and the applicant on the work undertaken on the application. **5.5.2** The independent advisers noted and commended the efforts taken by the applicant on their patient and public involvement and engagement (PPIE). **5.5.3** The independent advisers queried the special condition in section 6 (Special Conditions) in relation to the territory of use and noting that it was unclear why this had been added, asked that the application was updated with further information; or to remove the special condition if no longer relevant.	

	5.5.4 In addition, the independent advisers queried how the applicant would evidence compliance with the territory of use outlined in section 2(c) (Territory of Use) given the remote access. **5.5.5** Noting the information in section 1(c) (Data Processors) that AIMES Management Services Ltd Data Security and Protection Toolkit (DSPT) status had expired; the independent advisers suggested that this was reviewed and updated to reflect that the DSPT had been met and there were no outstanding actions. **5.5.6** The independent advisers noted that processing of the data under this data sharing agreement (DSA) could be done remotely; and suggested that NHS England needs a clear policy on remote access. **ACTION:** NHS England to provide its position to AGD on remote access *(as previously requested and agreed at the AGD meeting on the 2nd February 2023)*. **5.5.7** Noting the information in section 5(a) (Objective for Processing) in respect of the funders, the independent advisers suggested that this was updated to also state that *"The funders will have no ability to suppress or otherwise limit the publication of findings"*. **5.5.8** In addition, the independent advisers noted that the usual wording, stating that the funder would not have influence on the outcomes nor suppress any of the findings of the research, was missing from the application, and suggested that this was included as would be expected. NHS England advised that following the discussion at the AGD meeting on the 15th June 2023 in respect of this information being reflected in the questions and answers (Q&A) for the internal application assessment form, confirmed that this was in the process of being updated, to reflect the standard wording previously used. **5.5.9** The independent advisers noted that the citation special condition in section 6 (Special Conditions) referred to the *"NHS England Access Request Service"*; and were advised by NHS England that this was an error and would need updating correctly refer to *"NHS England **Data** Access Request Service"*.	NHSE
5.6	**Reference Number:** NIC-372269-N8D7Z-v2.12 **Applicant:** College London (UCL) **Application Title:** Virus Watch: Understanding community incidence, symptom profiles, and transmission of COVID-19 in relation to population movement and behaviour **Presenter:** Dan Goodwin **SAT Observer:** Dave Cronin **Observer:** Jodie Taylor-Brown **Application:** This was an amendment application. NHS England were seeking advice on the following point: 1. The issue of continued processing of pseudonymised data in relation to individuals who were consented under parental consent whom have since turned 16 (or will turn 16 prior to the 28th February 2026).	

	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: In response to point 1 **5.6.1** the group had considered other studies where participants reach 16 and are then asked for consent but noted significant differences with this study, including the relatively short time span of the study; the *"household"* nature of the study in which multiple members of the young person's household would have been involved and actively recording symptoms weekly and answering monthly surveys for the first part of the study, creating a high level of awareness of belonging to the study in the household; the clarity in the patient information, consent and assent materials noting that it would run for five years without any mention that participants turning 16 would need to consent to continue to be included; that assent had been sought and the relatively mature ages of the young people involved – they would have been 12-15 rather than, for example, infants when they assented. **5.6.2** the group acknowledged that it could be argued that the common law duty of confidentiality requires consent at 16 here, but in the absence of clear case law or policy this is not obvious. The counter argument is that not to flow the data would be contrary to the assent and parental consent already obtained (these individuals can only be fully included in the study they agreed to, if the data flows). It could be further argued that given all the circumstances outlined above, the young people would not have a reasonable expectation of privacy regarding the particular use. **5.6.3** the independent advisers queried if the UCL Data Protection Officer (DPO) had proffered a view. If the UCL DPO had expressed a view, positive or negative, then UCL should take account of that view. **5.6.4** The independent ethics adviser noted that, in their opinion, the ethical approach was to continue to process the young people's data in line with what was explained to the participants at recruitment. It was suggested that the views of relevant participants could be sought as to whether those turning 16 would reasonably expect that the data would flow without being consented or whether they should be contacted for consent. **5.6.5** The independent advisers queried if the researchers had considered seeking confirmation from the Health Research Authority Research Ethics Committee (HRA REC) on the ethics of continuing to process the young people's data under assent for the full five years, if though they were now 16 years or older. **5.6.6** The NHS England Caldicott Guardian Team representative considered the points made by the group in-meeting, and their view was that there were grounds to continue processing the young people's data based on the factors discussed. **5.6.7** The group did not provide any feedback on the data sharing agreement (DSA).	
EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
6.1	**Reference Number:** NIC-233512-B7C4W-v4.2 NEC Software Solutions UK Limited	

	Applicant: NIC-233512-B7C4W-v4.2 NEC Software Solutions UK Limited **Application Title:** Neurosurgical National Audit Programme (NNAP) **Presenter:** No Presenter **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 11th April 2019, 11th July 2019, 30th April 2020, 28th May 2020 and the 29th September 2022. **Application:** The purpose of the application is for an audit programme, aiming to support neurosurgical units in England to improve patient care, outcomes, safety, and experience by providing high quality, robust audit data that is analysed and presented in a consistent and clinically relevant way. **Outcome of discussion:** The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided: **6.1.1** The independent advisers noted that it stated in various places on the Internet that *"The local patient identifier (lopatid) field contains sensitive data. Access to it requires the approval of the Independent Group Advising on the Release of Data (IGARD)",* and queried if there had been a policy change so that the SIRO approval was sufficient. **6.1.2** The NHS England SIRO Representative noted the lopatid had been approved previously however due to a technical issue the data had not flowed at the time of the approval, which is why the application had progressed under the DARS SIRO precedent. The group thanked the NHS England SIRO Representative for the update. The NHS England SIRO representative thanked the group for their time.	
6.2	**Reference Number:** NIC-315716-L0F4M-v7.10 **Applicant:** Imperial College London **Application Title:** Quarterly HES Extract - Health Policy HES projects **Presenter:** No Presenter **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 1st November 2018, 29th November 2018 and the 26th November 2020. The application and relevant supporting documents had previously been presented / discussed at the DAAG meetings on the 30TH June 2015 and the 25th August 2015. **Application:** The purpose of the application is for project 2 - Quality of care for elderly patients with chronic conditions study; which is research, evaluating risk factors that lead to functional health decline in elderly population with chronic conditions. **Outcome of discussion:** The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided: **6.2.1** The independent advisers noted that this was a singular arrangement to suit one academic (remote access via honorary contract for one individual covering access from Portugal, Denmark and France, in addition to the UK), and queried if this was offered to	

	all applicants. The independent advisers suggested that NHS England needs a clear policy on remote access. **ACTION:** NHS England to provide its position to AGD on remote access *(as previously requested and agreed at the AGD meeting on the 2nd February 2023)*. **6.2.2** The independent advisers noted that the honorary contract did not appear to align in all respects with AGD expectations around honorary contracts, as requested by the SIRO in giving approval, and suggested that the recently approved DARS Standard for Honorary Contracts is promulgated across DARS so that all staff are aware of what is expected. The NHS England SIRO representative thanked the group for their time.	SIRO
6.3	**Reference Number:** NIC-419335-H5P8T-v1.7 **Applicant:** University of Oxford **Application Title:** Outcomes of Patients who survived Treatment on an Intensive Care unit for COVID-19 in England and Wales (OPTIC-19): a comparative retrospective cohort study. **Presenter:** No Presenter **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the IGARD BAU meetings on the 15th July 2021 and the 16th September 2021. **Application:** The purpose of the application is for a retrospective cohort study, which aims to estimate the risk of adverse outcomes (death, emergency hospital readmission, heart attacks, strokes) in patients treated on an intensive care unit with COVID-19 in England and Wales, one year after discharge from hospital. The study team will compare these risks to patients treated in ICU for other conditions. **Outcome of discussion:** 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		
7	**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 to provide further clarity on the risk management framework.	NHSE
8	**AGD Terms of Reference (ToR)** Garry Coleman noted that NHS England were still receiving comments from stakeholders on the AGD ToR. The independent advisers queried if the AGD ToR would still be submitted for NHS England Board / subcommittee of the Board sign off on the 28th June 2023. The NHS	

	England SIRO Representative took an action to clarify when the AGD ToR would be presented to the NHS England Board / subcommittee of the Board.	SIRO
9	**AGD Standard operating procedures** The ongoing forward plan of work for creating Standard Operating Procedures was discussed.	To note
10 **10.1**	**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, joining one adviser who 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	**Analysis to generate Artificial Data** Rupert Chaplin attended the meeting, to provide a verbal update to AGD, on the Artificial Data Pilot that helps data users understand the columns, data types and approximate value ranges that would appear in real data. Whilst the data sets can be used to improve understanding of data sets and data platforms, and for building and testing data pipelines, they cannot be used to analyse data. During this pilot, NHS England hope to understand how artificial data can be valuable to data users, identify other datasets for which it would be useful to provide artificial extracts, and gather further feedback on how to enhance the service. The AGD Chair thanked NHS England for the update and noted the excellent initiative which they were supportive of, noting this was a way of analysing personal data without processing. In addition, AGD would welcome a copy of the presentation materials Rupert presented in-meeting.	
12	**DHSC Data access policy update** The group noted at the AGD meeting on the 15th June 2023, that DHSC had published a draft data access policy update, and that comments on this were due by the 23rd June 2023. AGD noted that comments had been collated out of committee prior to the meeting, which were discussed in-meeting, and it was agreed by AGD to return the comments to NHS England's Privacy, Transparency, Ethics & Legal (PTEL) by the 23rd June 2023 deadline.	
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.		