Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 17th August 2023

09:30 – 15:00

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	Specialist Ethics Adviser
Claire Delaney-Pope (CDP)	Specialist Adviser **(Observer – new AGD member)**
Kirsty Irvine (KI)	Chair
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
Miranda Winram (MW)	Lay Adviser **(Observer – new AGD member)**
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Paul Cilia La Corte (PC)	Senior Policy and Implementation Manager, Data & Analytics Directorate (**Presenter**: item 4.1)
Garry Coleman (GC)	NHS England SIRO Representative (**Presenter**: items 8 and 10.1)
Kate Fleming (KF)	NHS England Data & Analytics Representative (Delegate for Michael Chapman)
Ken Harris-Jones (KHJ)	Head of Data Collections Service, Data & Analytics Directorate (**Presenter**: item 4.1)
Phil Koczan (PK)	NHS England Caldicott Guardian Team Representative (Delegate for Jonathan Osborn) (not in attendance for item 5.3)
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore) (**Presenter**: items 10.2 and 10.3)
Karen Myers (KM)	AGD Secretariat Team

Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: items 4.1 to 5.5)
Vicki Williams (VW)	AGD Secretariat Team
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Dr. Imran Khan (IK)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Michael Chapman (MC)	Data and Analytics representative
Jon Moore (JM)	NHS England Data Protection Office Representative
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team 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 10th August 2023 meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.
3	**Declaration of interests:** Paul Affleck noted professional links to Cancer Research UK as part of his role at the University of Leeds (NIC-658894-S2C0V, NIC-656761-R6H7W, NIC-656805-R5Z2Y) but noted no specific connections with the applications and it was agreed that this was not a conflict of interest. Kate Fleming noted a professional link to the National Disease Registration Service (NDRS) (NIC-701639-N6F9K, NIC-658894-S2C0V, NIC-656761-R6H7W, NIC-656841-D0P8Y, NIC-656805-R5Z2Y). It was agreed this was not a conflict of interest.
BRIEFING PAPER(S):	
4.1	**Title:** Tobacco Dependence Data Collection – Briefing Paper **Presenters:** Ken Harris-Jones / Paul Cilia La Corte **SAT Observer:** Kimberley Watson **Previous Reviews:** The briefing paper was previously presented / discussed at the IGARD meetings on the 10th March 2022 and 24th February 2022. The purpose of the briefing was to provide an update on changes to the existing Tobacco Dependence Data Collection, which supports monitoring, delivery, and outcomes for the tobacco dependence treatment services. The collection scope is being extended, from secondary care settings only, to include primary care services that have chosen to opt in and provide such services under the Tobacco Dependence Programme. The expanded scope is being rolled out in recognition of the role of Integrated Care Boards (ICBs) in health and care delivery, and the introduction of tobacco dependence treatment services through GP / Primary Care providers. NHS England were seeking advice on the following points: 1. Any particular issues and areas of risk that AGD may identify. **Outcome of discussion:** The group welcomed the briefing paper and made the following observations / comments: In response to the advice sought re point 1 above: **4.1.1** The group advised they were supportive of the Tobacco Dependence Programme and the work being undertaken in this area, however advised that it would be helpful if the purpose

	of the **data collection** was made clearer within the briefing paper and any supporting documents, and not just the benefits of the Tobacco Dependence Programme. **4.1.2** The group noted the consultation that had taken place with some citizen groups but that the group were not sighted on any other consultations undertaken with user groups, and suggested that any published information, for example, the Data Protection Impact Assessment (DPIA) was updated to reflect the efforts undertaken. **4.1.3** Noting the references within the briefing paper to 'opt out referrals', it was suggested by the group that the briefing paper, and any supporting documents, were clear what the opt out options were, for example, if there is a data collection specific opt out, and if this was made clear at the point of contact with the relevant patient(s). **4.1.4** The SIRO representative suggested that a simple diagram detailing the data and how a patient can opt out (if applicable) via a type 1 objection, the National Data Opt-out (NDO), or something specific to the programme and the choices patients can make for transparency may be helpful, since it was important for a patient to know what the opt out options were **before** entering the programme. **4.1.5** Prior to the meeting, an independent adviser queried what the primary care providers will be telling their patients in respect of this data collection; and were advised by NHS England that they were not aware of a separate transparency notice being issued for the primary care providers and that transparency was outlined in the overarching Tobacco Dependence Programme Patient Level Data Collection transparency notice. In addition, NHS England advised that it was the responsibility of the service providers to have their own systems and processes in place with their patients, concerning the recording and use of their data, this being based on the supporting documentation and guidance provided by the Tobacco Dependence Programme. The independent advisers suggested that NHS England cannot completely abdicate responsibility, especially where a Direction is directing the data collection, and suggested that NHS England provide advice with regard to templated wording and transparency / offer assistance, for example by way of providing proforma templates, in respect of the transparency to ensure citizens understand the data being collected, whether they can opt out, what their rights are and how to exercise those rights etc. **4.1.6** NHS England advised the group that there would be further developments on the Tobacco Dependence Programme, and that any planned updates would be discussed with the group at a future meeting. The group noted the verbal update from NHS England and advised that they would be supportive of further discussions as and when required, including, but not limited to, providing advice on the transparency to ensure citizens are aware of what is happening with their data. **4.1.7** The group looked forward to receiving the finalised updated briefing paper, either out of committee (OOC) or tabled at a future meeting.

EXTERNAL DATA DISSEMINATION REQUESTS:		
5.1	**Reference Number:** NIC-70235-T6P9F-v6.2	

Applicant: Met Office

Application Title: Met Office Health Research Programme

SAT Observer: Kimberley Watson

Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 31st March 2022, 1st June 2017, and the 27th April 2017.

Application: This was a renewal and amendment application.

The purpose of the application is for a research programme with the aim of **1)** developing health forecasting services in order to mitigate the impact of weather on people's health and healthcare services; **2)** continual evaluation of the effectiveness of services in order to ensure they are benefiting both patients and healthcare professionals; and **3)** ongoing research into the relationship between weather and health in order to develop new services in the future.

The amendments are to **1)** request the following additional datasets - Emergency Care Data Set (ECDS) and Accident & Emergency (A&E); and **2)** a resupply of all data years for Admitted Patient Care (APC).

Should an application be approved by NHS England, further details would be made available within the Data Uses Register.

Outcome of discussion: The **majority** of 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 current transparency on the research programme was not easily accessible; and suggested that further efforts were undertaken by the applicant including, but not limited to, ensuring the transparency information specific to these uses of NHS data was more easily available / accessible, for example, linking from the general privacy notice, the general health page and / or the applied science page on the Met Office website, and that there was further information in the public domain in respect of the projects carried out under the research programme using the NHS England data; in line with Caldicott Principle 8, *"…A range of steps should be taken to ensure no surprises for patients and service users…"*.

5.1.2 The independent advisers noted that the privacy notice specific to NHS England data referred to the National Data Opt-out (NDO), however advised that this was **not** relevant, since the data flowing was pseudonymised, and suggested that this was removed from the privacy notice.

5.1.3 In respect of the research programme and the analysis undertaken, the SIRO representative queried why the data could not be provided by NHS England directly to the users of the data rather than via the Met Office, for example, are the Met Office undertaking additional processing of the data prior to it being shared with the

	users; and noting that this was unclear, suggested that further clarification was provided by the applicant. **5.1.4** In addition, if it was determined that the Met Office were undertaking additional processing of the data prior to it being shared with the users; it was advised that further information was provided on the programme access, with a view to ensuring consistency with other programme access level data sharing agreements (DSA), where NHS England data is shared. **5.1.5** Noting the work being undertaken by the Met Office around weather and climate, the independent advisers suggested that NHS England may wish to explore future opportunities for a Secure Data Environment (SDE) working with the Met Office, so that the SDE can ingest both health and climate data, without the need for NHS England to provide an extract of data to the Met Office. **ACTION:** NHS England may wish to explore opportunities for SDE working with Met Office. **5.1.6** Separate to this application, the independent advisers reiterated the advice from the AGD meeting on the 10th August 2023, that NHS England considered having an NHS England DARS Standard for programmatic access, that addressed what, if any, difference in approach would be taken for commercial programmatic access; and how any programmatic access is aligned with the Department of Health and Social Care draft data access policy update that states *"Secure data environments (SDEs) will become the default route for accessing NHS data for research and external uses. Instances of disseminating NHS data outside of an SDE for research and external uses will be extremely limited"*. **ACTION:** NHS England to consider having an NHS England DARS Standard for programmatic access. **5.1.7** Noting NHS England's legal basis to share data for the purpose of research if it is connected with health and social care, it was noted by the group that the purposes outlined in the application were connected with health and social care, however advised the applicant that **all** processing of NHS England data **must** have a connection with health, and that this should be a key consideration of the Met Office internal committee. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.1.8** The group welcomed the application and noted the importance of the research and the benefits accruing from the research. **5.1.9** The group noted the valuable benefits outlined in section 5(d) (Benefits), however queried whether **all** of the research referred to in this section had been achieved using NHS England data and was a not just a general summary of all of the Met Office health related research. If some of the research / benefits referred to in section 5(d) were **not** relevant / specifically related to the data flowing under this	NHSE NHSE

	DSA, it was suggested these be removed, as may be appropriate and in line with NHS England's DARS Standard for Expected Measurable Benefits. **5.1.10** Noting that the Met Office do undertake some commercial work, it was queried whether there were any commercial uses of the data flowing under this DSA; and suggested that this was reviewed, and that section 5(e) (Is the Purpose of this Application in Anyway Commercial) and section 5(a) (Objective for Processing) were updated as necessary, in line with NHS England's DARS Standard for Commercial Purpose and NHS England's DARS Standard for Objective for Processing. **5.1.11** The independent advisers queried the statement in section 5(b) (Processing Activities) *"Access is restricted to employees or **agents** of the Met Office who have authorisation"*; and suggested that further information was provided as to what was meant by *"agents"*, and that this aligned with the Data Sharing Framework Contract (DSFC). **5.1.12** Noting that the Met Office had been processing the NHS England data for some time, it was queried by the SIRO representative, and the group, whether some data minimisation could be undertaken, in line with NHS England's DARS standard for data minimisation; or NHS England should clarify that the justification for the breadth of data required was still valid and the application updated appropriately.	
5.2	**Reference Number:** NIC-701639-N6F9K-v0.6 **Applicant:** Imperial College London **Application Title:** Integrating randomized controlled trials and real-world evidence to evaluate the efficacy of induction chemotherapies for acute myeloid leukaemia in adult patients **SAT Observer:** Kimberley Watson **Application:** This was a new application. The purpose of the application is for a project, which aims to evaluate the efficacy of induction chemotherapies for acute myeloid leukaemia (AML) in adult patients by integrating evidence from randomized controlled trials and real-world data, with a view to: **1)** produce sound evidence on the efficacy of various induction chemotherapies in adult AML patients by integrating evidence from randomized controlled trials (RCT) and non-randomized real-world data, in order to inform clinical decision-making in AML treatment; **2)** empirically explore the strengths, weaknesses, and appropriateness of various methods for integrating evidence across different study designs (randomized vs. non-randomized), to make methodological advances in this area. 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: **5.2.1** Noting that NHS England DARS had queried with the applicant if they had sought the views of the institutional Research Ethics Committee (REC), and that this point was still outstanding, the independent advisers suggested that DARS confirm with the applicant that they had the support of the institutional REC; and that supporting documentation was uploaded to NHS England's customer relationships management (CRM) system for future reference. **5.2.2** The independent advisers noted that if the applicant has **not** sought the views of its institutional REC, that it would be advisable to do so and in line with the University's REC policy. **5.2.3** Noting that the applicant was a PhD student and would **not** be able to bind Imperial College London to the data sharing agreement (DSA) because they are not an authorised signatory, it was suggested by the independent advisers that NHS England should ensure an appropriate authorised signatory signs the DSA on behalf of Imperial College London. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.2.4** The independent advisers queried the references in section 5 (Purpose / Method / Outputs) to the PhD student being *"affiliated"* with Imperial College London; and suggested that these references were updated to refer to the PhD student being *"enrolled"*. **5.2.5** Separate to this application, the independent advisers suggested that the NHS England's DARS Honorary Contract Standard, currently in the process of being approved for publication by the SIRO representative, was reviewed to ensure that there were no references to *"affiliated"*. **ACTION:** NHS England to ensure that the NHS England's DARS Honorary Contract Standard was reviewed to ensure that there were no references to *"affiliated"*. **5.2.6** The NHS England Data and Analytics Representative noted the potential benefits of the project in section 5 of the application, however, suggested that these were reviewed and updated to ensure that the benefit to health and social care was clearly outlined, in line with the legal basis to flow the data. It was suggested that information from the protocol could be replicated in section 5, ensuring that this was in language suitable for a lay reader. **5.2.7** Noting the references in section 5(a) (Objective for Processing) to *"induction chemotherapies"*, it was suggested by the independent advisers that this was updated with clarification of what this was, noting it was currently unclear. **5.2.8** Noting the references throughout section 5(c) (Specialist Outputs Expected) to *"i.e"*, it was suggested by the independent advisers that this was reviewed and	SIRO

	updated as may be necessary, noting that *"for example"* may be clearer and more accurate.	
5.3	**Reference Number:** NIC-692602-Q6P4F-v0.5 **Applicant:** NeoHealthHub Limited **Application Title:** Medicines dispensed in Primary Care NHS Business Services Authority data **SAT Observer:** Kimberley Watson **Previous Reviews:** The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 25th May 2023. **Application:** This was a new application. The purpose of the application is for NeoHealthHub Limited to access NHS England data for the purpose of providing services to the NHS, healthcare charity organisations and NeoHealthHub Limited's private organisation clients in the health sector. The modules of analysis which will make up the service are **1)** Prescribing Safety Benchmarking, **2)** Prescribing Optimisation Evaluation, **3)** National Priority Alignment Analysis, **4)** COVID-19 Focus, and **5)** Directed Research Projects. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were **not** supportive of the application and wished to draw to the attention of the SIRO the following substantive comments, and suggested that the application be brought back to a future meeting: **5.3.1** The group noted that they had reviewed the application on the 25th May 2023, where a number of points had been raised. The group discussed each of the previous points raised, and advised that these had been adequately addressed, with the exception of the following: **5.3.1.1** The group noted that NHS England had previously advised that discussions had been held with the applicant and the NHS BSA Information Asset Owner (IAO), who had confirmed that they were content that the purpose of the study aligned with the Direction. The independent advisers queried whether the purpose of the processing was for the safety and effectiveness of medicines, as per the Direction, noting the statement in 5(a) (Objective for Processing) that analysis will be undertaken to showcase the uptake of new medicines within varying geographies, which may suggest that the purpose for processing is in fact to look at volumes of medicine used. **5.3.1.2** The group also suggested that NHS England should seek further advice on this (point 5.3.1.1 above) from NHS England's Privacy, Transparency, Ethics and Legal (PTEL).	

5.3.1.3 Noting that NHS England had previously advised that **only** Neosypher Limited would be involved with this application, and not any linked organisations and independent advisers had noted a potential reputational risk to NHS England in terms of the chain of ownership of Neosyhpher Limited; the independent advisers highlighted a risk to NHS England in respect of whether the correct company who had the appropriate authority was signing the data sharing agreement (DSA).

5.3.1.4 In respect of the previous point raised that the benefits to commercial clients may be to support their marketing activities, and that the commercial aspect of the application was more significant than was initially proposed in the application that previously came to AGD; the independent advisers advised that this had **not** been fully addressed, and noted that there were still conflicting and confusing statements in the documents provided in respect of the marketing and commercial activities.

5.3.1.4 The group noted that removing reference to *"marketing"* from the application **did not** address whether any marketing would take place.

5.3.1.4 It was previously suggested by the independent advisers that section 5(a) should be updated to make clear that an assessment had been undertaken that the commercial benefit accruing to the commercial organisation is proportionate to the benefit to health and social care, in line with NHS England's DARS Standard for Commercial Purpose. The independent advisers advised that this had **not** been fully addressed and would **not** currently align with the NDG guidance on benefits.

5.3.1.5 It was previously suggested by the independent advisers, that section 5(d) (Benefits) should be reviewed and updated to ensure the benefits aligned with the terms of the Direction; and in line with NHS England's DARS Standard for Expected Measurable Benefits. The independent advisers advised that this had not been fully addressed and advised that there were still concerns around the benefits that could realistically be achieved without any other linkage or analysis.

5.3.1.6 It was previously suggested that the application may be overstating the commercial demand for the product and the independent advisers suggested again that further evidence of the existing demand from NHS customers was provided to justify the benefit to the NHS, in relation to the commercial interest.

5.3.2 It was suggested by the SIRO representative that a short / limited pilot DSA could be trialled with the application, to **1)** work out the potential uses of the data, including identifying potential NHS customers, **2)** identify specific uses with related data for a longer period, and **3)** when proven, to consider autonomy. The group advised that they would not be supportive of the approach to flow data for a trial / pilot until a more comprehensive use case is developed with clear articulation of

	benefits to patients, in relation to benefits to commercial clients, noting that this may reviewed again once the above points had been addressed.	
5.4	**Reference Number:** NIC-658894-S2C0V-v0.4 **Applicant:** Cancer Research UK **Application Title:** MorphologyData_28/10/2022 **SAT Observer:** Kimberley Watson **Application:** This was a new application. Cancer Intelligence, part of Cancer Research UK, acquires, collates, combines, and publishes statistics on cancer incidence for the whole of the UK; which is necessary to provide stakeholders with an idea of the state of cancer in the UK. Clinical staff, the public, academic and other researchers, rely on Cancer Intelligence to continue this work and being able to access data about cancer on a single platform. The purpose of the application is for a research project, to calculate the number and proportion of cancer cases attributable to various risk factors in England (and to combine this with devolved nations to obtain corresponding UK-level results). Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following comments: **5.4.1** Noting the reference to the *"ICO's Anonymisation code of practice"* within the Legitimate Interest Assessment (LIA) provided as a supporting document, the independent advisers suggested that this was removed as it was no longer current. **5.4.2** Noting the conflicting information within the application in respect of where / how the data would be accessed, the independent advisers suggested that this be reviewed and updated to ensure the correct information was reflected / aligned throughout. **5.4.3** The independent advisers noted the conflicting information within the application in respect of the description of the data, i.e. *"pseudonymised"* versus *"aggregated – small numbers not suppressed"*; and suggested that this was reviewed and updated to ensure the state of the data is accurately described. **5.4.4** The independent advisers queried the conflicting statements within section 5(b) (Processing Activities) in respect of linkage, and suggested that this was reviewed and amended as may be appropriate, to reflect the correct information.	
5.5	**Reference Number:** NIC-288807-P0R9B-v0.8 University of Oxford **Applicant:** NIC-288807-P0R9B-v0.8 University of Oxford	

Application Title: OPAL - The Oxford Pain, Activity and Lifestyle (OPAL) Cohort Study

SAT Observer: Kimberley Watson

Application: This was a new application.

The purpose of the application is for a research project, with the aim of **1)** describing the prevalence, severity, course, and prognosis of a range of musculoskeletal problems in older people; **2)** to evaluate the impact of back pain on important health outcomes for older people (quality of life, mobility, falls and fractures); **3)** to study a range of factors hypothesised to moderate and mediate the effects of back and other musculoskeletal pain for example, co-morbidities; and **4)** perform an economic evaluation of cost of NHS resources used by participants mapped to the health conditions that were self-reported at baseline and in subsequent follow-up questionnaires.

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 point:

1. NHS England is requesting AGD review the application with specific consideration given to the consent materials (SD3.0, SD3.1, SD4.0 and SD4.1) and the consent review (SD3.2).

Outcome of discussion: The group were supportive of the application and wished to draw to the attention of the SIRO the following substantive comments:

In response to advice sought re point 1 above:

5.5.1 The group were of the view that their review of the consent form and accompanying patient information indicated that consent provided a legal gateway and adequately addressed the common law duty for confidentiality for the processing of data as outlined in the data sharing agreement (DSA).

5.5.2 The group noted that there should be further communications to the cohort, including but not limited to, clarifying the data flowing to and from NHS England, and the nature of the of the data flowing for example pseudonymised, identifiable etc.

5.5.3 The independent advisers noted that the Principal Investigator had moved from the University of Oxford to the University Exeter and that the data was being held by the University of Oxford with the Principal Investigator and five academics from University of Exeter accessing the data via honorary contracts. The independent advisers noted that the honorary contract provided as a supporting document should be counter-signed by the individual's substantive employer, as per usual process / advice. The independent advisers suggested that NHS England ensure that written confirmation was received from the applicant that the document had been counter-signed by the employing body; and that the written confirmation was uploaded to

	NHS England's customer relationships management (CRM) system for future reference. **5.5.4** The independent advisers suggested that NHS England should explore what involvement there is by the University of Exeter, and whether the six academics from the University tips the balance for the University of Exeter to be considered a joint Data Controller with the University of Oxford, or the sole Data Controller, and 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: **5.5.5** Noting no onward sharing was permitted under this DSA, the independent advisers noted a statement in the study protocol to a "*data management and sharing plan*" and suggested that a special condition be inserted in section 6 (Special Conditions) that onward sharing is **not** permitted. **5.5.6** The independent advisers noted that should the applicant wish to onwardly share data, then they should submit an amendment application to NHS England, in addition to considering whether the consent permitted any onward sharing of data. **5.5.7** The independent advisers suggested that NHS England ensure an appropriate authorised signatory and substantive employee of University of Oxford signed the DSA on behalf of the University. **5.5.8** The NHS England Data and Analytics Representative noted reference in the application and supporting documentation to the '*Better Outcomes for Older people with Spinal Trouble (BOOST) Research Clinical Trial (RCT)*', and suggested that section 5 (Purpose / Methods / Outputs) of the DSA was updated to ensure it was relevant to the OPAL study, and in addition that supporting documents provided as part of the review were only relevant to the OPAL study, removing any text from the application or supporting documents relating to the BOOST study. **5.5.9** The independent advisers suggested that section 3(b) (Additional Data Access Requested) be updated in line with the NHS England DARS Standard for Data Minimisation to be clear that data minimisation efforts had been undertaken to relevant fields. **5.5.10** The independent advisers noted reference in section 5 to definitive language, and noting this was a study to determine if access and participation in an intervention can or cannot improve outcomes, suggested the wording be amended as appropriate, so as not to predetermine the outcome of the study.	
EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
6.1	**Reference Number:** NIC-12784-R8W7V-v13.4 **Applicant:** Genomics England	

	Application Title: Genomics England (MR1418) - Renewal Request for tranche of data across multiple data sets. **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 13th April 2017, 7th February 2019, 13th August 2020 and the 28th April 2022. The application and relevant supporting documents had previously been presented / discussed at the DAAG meetings on the 15th March 2016, 5th April 2016, 1s November 2016, 6th December 2016 and the 20th December 2016. **Application:** The purpose of the application is to support the national Genomic Medicine Service (GMS), building on the 100,000 Genomes Project. This includes a national Whole Genomic Sequencing provision and supporting informatics infrastructure developed in partnership with Genomics England. Genomics England will therefore undertake genomic sequencing and clinical data collection for the GMS. The SIRO approval was for a three-month renewal, to permit the provision of the next quarterly data release for inclusion in the GE National Genomics Research Library (NGRL); with a request for the application to be brought back to a future AGD meeting. **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** It was queried by the independent advisers whether an independent view should have been sought on the scope of participant consent before "*inclusion in the GE National Genomics Research Library*". In response, the SIRO Representative said that the extension is to enable an application for that inclusion, which will come to AGD. The NHS England SIRO representative thanked the group for their time.	
6.2	**Reference Number:** NIC-656761-R6H7W-v1.8 **Applicant:** University of Leeds **Application Title:** Yorkshire Specialist Register of Cancer in Children and Young People (ODR1516_163). **Previous Reviews:** The National Disease Registration Service (NDRS) datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review. **Application:** The purpose of the application is for a research project, with the aim of studying **1)** Mortality trends paper examining changes over time and differences	

	according to ethnicity, deprivation and stage, and **2)** Evaluation of cardio-metabolic fatalities, examining differences according to ethnicity, deprivation, stage and treatment. The SIRO approval was for a one-year extension. **Outcome of discussion:** The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided: **6.1.2** The independent advisers noted the statement in the internal application assessment form that "…*applicant confirmed that an appropriate contract between the individual and the University of Leeds is in place*…". Noting it was not clear, the independent advisers suggested that NHS England ensure that written confirmation was received from the applicant that the honorary contract document had been counter-signed by the employing body; and that the written confirmation was uploaded to NHS England's customer relationships management (CRM) system for future reference. The NHS England SIRO representative thanked the group for their time.	
6.3	**Reference Number:** NIC-656841-D0P8Y-v1.8 **Applicant:** University of Oxford **Application Title:** Tumours of the Central Nervous System (CNS): Incidence, Survival and Variation in Treatments (ODR1819_255) **Previous Reviews:** The National Disease Registration Service (NDRS) datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review. **Application:** The purpose of the application is for a research project, which will aim to **1)** characterise the incidence of developing various types of primary Central Nervous System (CNS) tumours since 1971; **2)** characterise survival following a primary CNS tumour diagnosis; and **3)** characterise the medical histories leading to a primary CNS tumour diagnosis The SIRO approval was for a one-year extension. **Outcome of discussion:** The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided: **6.1.3** The independent advisers noted the work undertaken by the applicant for consulting individuals affected by the CNS tumour (patients and carers), seeking Research Ethics Committee (REC) support, and starting an initiative to improve	

	"*…the completeness and quality of data on CNS tumours in cancer registries across the four nations…".* The NHS England SIRO representative thanked the group for their time.	
6.4	**Reference Number:** NIC-656805-R5Z2Y-v1.3 **Applicant:** Cancer Research UK **Application Title:** How much geographical variation in access to Ovarian Cancer treatment is there in England and to what extent is this affected by health care system level factors? (ODR1718_153) **Previous Reviews:** The National Disease Registration Service (NDRS) datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review. **Application:** The purpose of the application is for a project, which will aim to develop a better understanding of the extent and causes of geographic variation in access to ovarian cancer treatments by: **1)** comparing the treatment access rates between Cancer Alliances and Trusts; **2)** determining the extent to which this can be explained by regional differences in patient demographics, such as age and socio-economic status; and **3)** investigating the influence of healthcare system levels factors on access to treatment, such as provider and type, and consultant volume and specialisation. The SIRO approval was for a one-year extension. **Outcome of discussion:** The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided: **6.1.4** Noting that the applicant had cited Article 6(1)(f), the independent advisers queried if the applicant had carried out a legitimate interest assessment (LIA) suggested that NHS England ensure that written confirmation was received from the applicant; and that the written confirmation was uploaded to NHS England's customer relationships management (CRM) system for future reference. 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, noting this topic had been raised by Lord Hunt in the House of Lords on the 26th June 2023, and was answered by Lord Markham on the 5th July 2023: Written questions, answers and statements - UK Parliament. The NHS England SIRO Representative had provided further clarity on the risk management framework via email to the group, which confirmed that NHS England were asking the interim data advisory group to use the NHS England DARS Standards and Precedent model to assess the risk factors in relation to items presented to the interim data advisory group for advice.	To note
8	**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
9	**Standard operating procedures** The ongoing forward plan of work for creating Standard Operating Procedures was discussed.	To note
10. Any Other Business		
10.1	**Faster Data Flows for Integrated Care Boards (ICBs)** The updated briefing paper had come to AGD for advice on the 8th June 2023 to request that the faster data flow product (Acute Activity Dataset) is permitted to be disseminated to the Integrated Care Boards via the NHS England DARS Process and had requested that the first of type application was submitted to AGD for review / advice. Garry Coleman, NHS England SIRO Representative, gave a verbal update to the group, ahead of the updated briefing paper being received by the group at the next meeting on the 24th August 2024, confirming that no ICB application would be presented to a future AGD meeting, since the datasets for commissioning are added to the list of datasets an ICB can request for commissioning purposes, via their current commissioning application.	
10.2	**Legal Privilege** Andrew Martin provided a verbal update with regard to independent advisers being able to view legally privileged advice. NHS England had reviewed and accepted the external legal advice received that independent advisers on the group were part of the client group, and noted relevant documentation was in the process of being written / amended by NHS England to the independent advisers, and that he would provide a further update in due course.	
10.3	**Legal basis for dissemination**	

	Andrew Martin noted that the legal privilege item (10.2 above) needed to be resolved before NHS England could consider sharing any relevant documentation on NHS England's legal basis for dissemination and that he would provide an update in due course.

Meeting Closure

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