# Advisory Group for Data (AGD) - Meeting Minutes

Thursday, 8<sup>th</sup> February 2024 09:30 – 13:15

(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		
Miranda Winram (MW)	Lay Adviser		
NHS ENGLAND STAFF IN ATT	TENDANCE:		
Name:	Role / Area:		
Michael Chapman (MC)	NHS England Data and Analytics Representative ( <b>Presenter</b> : item 9.1)		
Garry Coleman (GC)	NHS England SIRO Representative		
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)		
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate		
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative		
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate		
INDEPENDENT ADVISERS NO	OT IN ATTENDANCE:		
Claire Delaney-Pope (CDP)	Specialist Information Governance Adviser		
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	
Jenny Westaway (JW)	Lay Adviser	
NHS ENGLAND STAFF NOT IN ATTENDANCE:		
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 Service (DAS) 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 1<sup>st</sup> February 2024 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:

Paul Affleck noted a professional link to one of the study team at the University of Leeds (NIC-661733-V0T9G) and would not be part of the discussion. It was agreed that Paul would not remain in the room for the discussion of this application.

#### **EXTERNAL DATA DISSEMINATION REQUESTS:**

**4.1** Reference Number: NIC-701654-Q5Z9T-v0.2

**Applicant:** The Newcastle Upon Tyne Hospitals NHS Foundation Trust (FT)

Application Title: Comparison of Real-World Evidence with Trial data for

chemotherapies which have exited the Cancer Drug Fund

**Application:** This was a new application

The purpose of the application is for an initial pilot, to determine whether Real-World Evidence (RWE) from routinely collected NHS England datasets, can support development of future 'The National Institute for Health and Care Excellence' (NICE) guidance in place of, or as an adjunct to, costly trial data which may not reflect NHS practice. The methodologies developed within the context of this project may support future Cancer Drug Fund (CDF) topics, and could be adapted and applied to other programmes within NICE (Diagnostics, Interventional procedures, and Medical Technologies) to incorporate Real-World Evidence within national guidance production.

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

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

- **4.1.1** It was noted in the internal application assessment form, and the application, that The Newcastle Upon Tyne Hospital NHS Foundation Trust (FT) have honorary contracts with named individuals from Newcastle University. In addition, subcontracts were also in place between the National Institute for Health and Care Excellence (NICE) (Newcastle) External Assessment Group (EAG) (where staff are substantially employed by The Newcastle Upon Tyne Hospital NHS FT), and Newcastle University. It was therefore suggested by the group that NHS England sought further clarification from the applicant to determine whether Newcastle University had a data controllership role based on the role and activities carried out under the honorary contracts and subcontracts, in line with NHS England's DAS Standard for Data Controllers; and to update the internal application assessment form and application, as may be relevant to reflect the correct / factual information.
- **4.1.2** In addition, the group queried what data processing both The Newcastle Upon Tyne Hospitals NHS FT and Newcastle University were carrying out; and suggested that if the data processing undertaken was focussed on the substance of the work, suggested that in line with <a href="NHS England's DAS Standard for Data Controllers">NHS England's DAS Standard for Data Controllers</a>, this would suggest there were joint data controllership responsibilities. The group also asked that section 5(b) (Processing Activities) was updated so that it was clear what processing was being undertaken and by whom.
- **4.1.3** If it was determined that Newcastle University were **not** considered to be a Data Controller, the independent advisers suggested that NHS England review the honorary contracts to ensure they are appropriately countersigned by someone of an

appropriate seniority within Newcastle University; in line with <u>NHS England's DAS Honorary Contracts Standard</u>. However, it was noted that having honorary contracts and a data processing agreement was a source of ambiguity in terms of lines of responsibility.

In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review:

- **4.1.4** The independent advisers noted that section 2.4 (commercial benefit evaluation) of the internal application assessment form had **not** been completed; and suggested that this was updated as may be appropriate to either clarify that there were no commercial benefits; **or** to clearly outline any commercial benefits, including, but not limited to, any commercial benefits to 'Northern Medical Physics and Clinical Engineering' as the funder.
- **4.1.5** In addition, it was suggested that if there were any commercial benefits, then this was outlined in section 5(a) (Objective for Processing) and section 5(e) (Is the Purpose of this Application in Anyway Commercial) of the application, in line with <a href="NHS England's DAS Standard for Commercial Purpose">NHS England's DAS Standard for Objective for Processing</a>.
- **4.1.6 Separate to this application:** The independent advisers highlighted the importance of the 'commercial benefit evaluation' section (2.4) of the internal application assessment form being completed by colleagues in NHS England's Data Access Service (DAS). The Data and Analytics representative took an action to reiterate this point to DAS colleagues.

**ACTION:** The Data and Analytics representative to highlight the importance of the 'commercial benefit evaluation' section (2.4) of the internal application assessment form being completed by colleagues in NHS England's DAS.

- **4.1.7** Noting the statement in section 5(a) "In the absence of Blueteq data (unavailable to external researchers to request), a comprehensive cohort of CDF patients can be implied through the intersection of the \*SACT dataset..."; the independent advisers queried why Blueteq data was not available to researchers; and were provided with a verbal update from the Data and Analytics representative, who advised that this was an ongoing area of work within NHS England, and that for this particular application, the SACT dataset would provide the application with the information required by the applicant. The group noted the verbal update, and that the research aims in this application could be achieved with the SACT data, however advised that there was a public interest in the Blueteq data being made available to researchers.
- \*National Disease Registration Service (NDRS) Systemic Anti-Cancer Therapy Dataset (SACT)
- **4.1.8** The group recognised and welcomed the patient and public involvement and engagement (PPIE) already undertaken in the work; however, noting the importance

MC

of the research and that this may be highly impactful, suggested that the researchers consider continued work as part of the PPIE, including as results emerge and if there were any potential impact of public perception on NICE approval processes. The HRA guidance on Public Involvement is a useful guide.

- **4.1.9** Noting in section 5(a) that the study was "Limited to a study cohort of adults (aged 18 and over at diagnosis)..."; it was suggested by the independent advisers, that section 5(a) should be updated with a justification as to why those aged under 18 were excluded.
- **4.1.10** The independent advisers noted in the internal application assessment form and the application that ethics approval was not required, and had **not** been sought by the applicant, due to the category of data requested. However, the independent advisers suggested that the applicant approach their institutional support, for example, The Newcastle Joint Research Office (a partnership between The Newcastle upon Tyne Hospitals NHS Foundation Trust **and** Newcastle University) and ask whether an ethical review is required; and that any supporting documentation is uploaded to NHS England's customer relationships management (CRM) system for future reference.
- **4.1.11 Separate to the application**: the independent advisers suggested that that the NHS England Data and Analytics representative remind DAS, that the NHS England's DAS Standard for Ethical Approval should be discussed with the applicant, including, but not limited to, ensuring that there is an obligation (on the applicant) to seek ethical support from their institution and in line with their organisation's policy; or for the institution to confirm that ethical support was not required.

**ACTION:** NHS England's Data and Analytics representative to remind DAS to ensure the NHS England's DAS Standard for Ethical Approval was discussed with the applicant, to ensure that there is an obligation (on the applicant) to seek ethical support from their institution and in line with their organisation's policy; or for the institution to confirm that ethical support was not required.

- **4.1.12** The independent advisers noted and commended the applicant on the information provided on the benefits outlined in section 5(d) (Benefits) of the application.
- **4.1.13** The independent advisers noted repeated text in section 7 (Ethics Approval) of the application and suggested that this was reviewed and edited as appropriate.
- 4.2 Reference Number: NIC-597255-J9M1H-v0.7

**Applicant:** The University of Manchester

**Application Title:** Long term follow-up of the UK NCRI RAPID clinical trial in early stage Hodgkin lymphoma with a particular focus on overall survival and late consequences of treatment

MC / DAS **Application:** This was a new application

Hodgkin lymphoma is a potentially curable cancer with a median age at presentation of 29 years. Standard of care treatment for early-stage disease comprises 3-4 cycles of chemotherapy (CT) followed by radiotherapy (RT) to previously involved sites of disease. In an effort to reduce the incidence of RT related second cancers and cardiovascular disease, the UK NCRI RAPID trial compared standard treatment (CT+RT) with an experimental approach using CT alone in patients who became PET scan negative after 3 cycles of CT. The initial results of RAPID are very encouraging but the second cancer and cardiovascular complications of RT take several years to manifest, and therefore the purpose of the application, is for a long term follow up of the trial population.

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

**Outcome of discussion:** The group were supportive of the application and wished to draw to the attention of the SIRO the following high-level comments:

- **4.2.1** The SIRO representative noted in the internal application assessment form, that the data would be downloaded from NHS England to The Christie NHS Foundation Trust (FT) (Data Controller), **and** then securely transferred to University College London (UCL) (Data Processor) for data analysis. The group suggested that for transparency, section 5(b) (Processing Activities) of the application was updated to clarify what processing of the data The Christie NHS Foundation Trust (FT) would be undertaking, noting that this was currently unclear.
- **4.2.2** In addition, noting that The Christie NHS Foundation Trust (FT) appeared to be receiving the data at the direction of UCL; it was suggested that this was fully explored by NHS England and in line with the <a href="NHS England's DAS Standard for Data Controllers">NHS England and in line with the NHS England's DAS Standard for Data Controllers</a>.
- **4.2.3** The independent advisers noted in the internal application assessment form that one of the justifications for both The Christie NHS FT and UCL receiving the data was due to The Christie NHS FT not having the required software to undertake the data analysis. It was suggested by the independent advisers, and in line with <a href="NHS England's DAS Standard for Data Minimisation">NHS England's DAS Standard for Data Minimisation</a>, that the internal application form was updated with further clarification on NHS England's views / consideration of the dual flows of data.
- **4.2.4** The independent advisers noted in the internal application assessment form, that there had **not** been any specific patient and public involvement and engagement (PPIE) for this specific study; but there had been some involvement with an independent Lymphoma Group, who were supportive of the aims of the RAPID Trial. It was suggested that the study team update the cohort on the follow-up activities via the study website (noting that there was no legal basis for the study team to contact the cohort directly); and that this may be a way of providing more awareness to the cohort, and would support the requirements of the Health

Research Authority Confidentiality Advisory Group (HRA CAG) and general transparency etc.

- **4.2.5** The group noted that the National Data Opt-out (NDO) would be applied, and that this was a requirement of HRA CAG for research applications. In addition, it was noted that the National Disease Registration Service (NDRS) specific opt out would apply to cancer registration data.
- **4.2.6** The SIRO representative queried whether the group felt a two-year data sharing agreement (DSA) was sufficient, noting the timeframes outlined in section 5(c) (Specific Outputs Expected) of the application that referred to presentations / papers being presented in 2024. The group suggested that the applicant reviewed the timeframes referred to in section 5(c) and amend as may be necessary to reflect more realistic dates (if appropriate); and agreed that they would be supportive of a longer DSA, if this was appropriately justified within the application.
- **4.3** Reference Number: NIC-661733-V0T9G-v0.9

**Applicant:** University of Leeds

**Application Title:** The Role of Patient-Reported Outcome Measure in the Prediction of Late Cancer Outcomes (Survival)

**Application:** This was a new application

The purpose of the application is for a research project, to determine whether the automated analysis of Patient-Reported Outcome Measure (PROMs) adds predictive value to routine healthcare data when predicting cancer survival; and what information in the PROMs may be useful to develop a machine learning model that predicts survival.

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:

- **4.3.1** The NHS England Data Protection Office representative noted in section 3.4 (data subjects) of the internal application assessment form, that 34,000 individuals who had been diagnosed with colorectal cancer in 2010/2011 had responded to 'The Living With and Beyond Bowel Cancer Survey' in January 2013; and advised that it would have been helpful to have been provided with further information on the survey, for example, what participants were told would happen following completion of the survey.
- **4.3.2 Separate to the application:** it was noted that the NHS England Data Protection Office (DPO) representative would discuss with the National Disease Registration Service (NDRS), the broader concept of reviewing the original survey(s), to ascertain what data subjects who completed this survey were originally

told, and whether the subsequent use of their data was in line with the <u>Caldicott</u> Principles.

**ACTION:** The NHS England DPO representative to discuss with NDRS, the broader concept of reviewing the original 'The Living With and Beyond Bowel Cancer Survey', to ascertain what data subjects who completed this survey were originally told, and whether the subsequent use of their data was in line with the <a href="Caldicott Principles">Caldicott</a> <a href="Principles">Principles</a>.

ΑM

- **4.3.3** The SIRO representative noted that the Data Security and Protection Toolkit (DSPT) for the University of Leeds, was for the 'Leeds Analytics Secure Environment for Research' (LASER); and asked that the application was updated to be clear as to if / how the DSPT covers the processing undertaken by the researchers at the University of Leeds.
- **4.3.4** In addition, the group noted that this application would add to the range of research undertaken within LASER, and advised that they would encourage the University of Leeds in taking the opportunity to increase transparency of that work.
- **4.3.5** The independent advisers noted that the research project was to support a PhD thesis, and acknowledged the careful handling of these types of applications by NHS England (and previously NHS Digital); and agreed that on balance in addition to the benefits in supporting the PhD thesis, there were also benefits of the research project to health and social care. In addition, it was noted that there was sufficient funding and support / supervision of the research / researchers for the PhD element of this research project.
- **4.3.6 Separate to this application:** the SIRO representative asked that where there is a PhD element to an application, that colleagues within NHS England's Data Access Service (DAS), ensure that as part of their processes, additional questions are asked of the applicant in respect of the territory of use, noting the potential geographical mobility of PhD students compared to permanent University employees.

**ACTION:** NHS England's DAS to ensure that as part of their processes and where there is a PhD element that additional questions are asked of the applicant in respect of the territory of use, noting the potential geographical mobility of PhD students.

DAS

- **4.3.7** The independent advisers queried the references in section 5 (Purpose / Method / Outputs) to the PhD student being "affiliated" with the University of Leeds; and suggested that these references were updated to refer to the PhD student being "enrolled" (assuming this is factually correct).
- **4.3.8 Separate to this application:** noting that the word "affiliated" had been incorrectly referred to in other applications, it was suggested by the independent advisers that the NHS England Data and Analytics representative remind DAS that this should only be used / noted in an application if it is correct in context, i.e. for

those with an association with an organisation but who are not substantially employed or enrolled. The aim should be to describe the relationship in the most specific sense possible.

**ACTION:** NHS England Data and Analytics representative to remind DAS that the word "affiliated" should only be used / noted in an application if correct in context; the aim should be to describe the relationship in the most specific sense possible.

MC / DAS

4.4 Reference Number: NIC-706399-T8V0C-v0.4

**Applicant:** University of Warwick

Application Title: ADAPT-Sepsis Trial. BiomArker-guided Duration of Antibiotic

treatment in hospitalised PaTients with suspected Sepsis

**Application:** This was a new application

The purpose of the application is for a multicentre three-arm randomised controlled trial with internal pilot, to deliver a UK-wide multi-centre randomised controlled trial to determine whether treatment protocols based on monitoring daily CRP (C-reactive protein) or PCT (procalcitonin) safely allow a reduction in duration of antibiotic therapy in hospitalised adult patients with suspected sepsis.

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:

- **4.4.1** The group welcomed the application and supported the premise of the research.
- **4.4.2** The NHS England Data Protection Office (DPO) representative noted that the Adapt Sepsis Webpage image from the 2<sup>nd</sup> November 2023, provided as a supporting document (SD7.9), referenced a privacy notice on the University of Warwick website. Noting that the University of Warwick were the Data Processor and The University of Manchester were the Data Controller; it was noted that the University of Manchester were also required to maintain a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible transparency notice(s) for the lifetime of the agreement, in line with the contractual requirement in section 4 (Privacy Notice) of the data sharing agreement (DSA).
- **4.4.3** The group noted and commended NHS England's Data Access Service (DAS) for the consent review provided as a supporting document; and agreed that there was a legal gateway to meet the common law duty of confidentiality for sharing the data via consent or consultee advice.
- **4.4.4** The independent advisers noted in the consent review that NHS England's DAS had advised the applicant that it should be made clear what identifiers will be

shared with NHS England to link and extract the health data; and advised that whilst they were supportive of this, they were content that the consent was still robust.

- **4.4.5** In addition, it was suggested that the consent review was updated to reflect the transparency point outlined in point 4.4.2.
- **4.4.6** The independent advisers noted the language in section 5(a) (Objective for Processing) in respect of consenting; and suggested that this was reviewed and updated as may be necessary to ensure the correct information is reflected, for example, referring to "consultee advice" and "consent" not re-consenting.
- **4.4.7** The group noted in section 3.7 (National Data Opt-outs (NDO)) of the internal application assessment form, that NHS England had provided the applicant with two choices in respect of the application of the NDO: 1) separate the data sharing agreement (DSA) into two DSAs and one would ingest the first cohort of those under consent without the NDO applied, and the other would ingest the second cohort of those under consultee advice with the NDO applied; or 2) apply the NDO to the entire cohort. Noting that there was an additional cost element to option 1, the group noted that the applicant had chosen option 2. However, the independent advisers said it was unfair to present the applicant with such a choice and that NHS England had an obligation to uphold the NDO policy, which clearly states that where there is consent the opt-out is not applied. The NHS England Data & Analytics representative explained that NHS England would charge only for the additional work involved in preparing a parallel DSA, which would represent a small proportion of the overall cost of the application, and highlighted that the majority of the cohort were recruited under consultee advice. The approach taken was the choice of the applicant in the context of their study.
- **4.4.8 Separate to this application:** there was a wider discussion on the NDO element of this application, and it was agreed that the SIRO representative and the NHS England representatives would discuss this further outside of the meeting in respect of similar future applications, including, but not limited to, whether applicants should be given a choice or not, on how the National Data Opt-out <u>policy</u> is implemented, for example, where there is a split cohort.

**ACTION:** The SIRO representative and the NHS England representatives to discuss whether applicants should be given a choice or not, on how the National Data Optout policy is implemented, for example, where there is a split cohort.

SIRO / NHSE Reps

#### **AGD Operations**

#### 5 Statutory Guidance

The independent advisers again noted the reference to reviewing materials in accordance with "a clearly understood risk management framework" within the published <u>Statutory Guidance</u> 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 26<sup>th</sup> June 2023, and was answered by Lord Markham on the 5<sup>th</sup> July 2023: Written guestions, 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 DAS Standards and Precedents model to assess the risk factors in relation to items presented to the interim data advisory group for advice; however the independent advisers noted that the wording in the statutory guidance "...using a clearly understood risk management framework, precedent approaches and standards that requests must meet...", suggested that the risk management framework is separate to the DAS Standards and Precedents, and asked that this be clarified by NHS England. The group noted that the Deputy Director, Data Access and Partnerships, Data and Analytics attended the meeting on the 23<sup>rd</sup> November 2023, and noted that plans for this work were in train.

It had been noted previously that an Oversight and Assurance Programme of applications that had not be subject to AGD review could form part of this Risk Management Framework.

The AGD Chair referred to the requirement within the published <u>Statutory Guidance</u> for an annual review; and flagged this to the group and the SIRO representative; and suggested that this was a regular agenda item on future AGD meeting agendas. It was also noted that further thought / consideration was needed, on how the annual report would be presented, for example, on an NHS England standard template or other means.

**ACTION:** AGD Secretariat to include 'AGD annual report' as a standing agenda item

**ACTION:** The group to give further thought / consideration as needed, on how the annual report would be presented, for example, on an NHS England standard template or other means.

The SIRO representative noted an outstanding action in respect of providing a written response to AGD on the risk management framework; and noted that this was progressing under the NHS England Precedents and Standards work.

### 6 AGD Terms of Reference (ToR)

The independent advisers noted that over eight months had passed since the <u>Statutory Guidance</u> had been published, requiring a ToR to be agreed and published.

The Director of Privacy and Information Governance, Privacy, Transparency and Trust, Jackie Gray, attended the meeting on the 1<sup>st</sup> February 2024, to advise the group that following the workshop on the 27<sup>th</sup> November 2023, the draft ToR had been updated further following feedback from other stakeholders, and that a further draft version of the updated ToR would be shared with the group for information,

VW / KM

AGD

the Board.  The AGD Chair noted that following the meeting on the 1st February 2024, a further iteration of the draft ToR had been shared with the Chair, SIRO representative and the Data and Analytics representative, for comments on recent updates made to the document. It was noted that as previously discussed, a final version of the draft ToR was expected to be shared with the group prior to this being submitted to the NHS England Board / subcommittee of the Board.  ACTION: The SIRO representative to provide a copy of the final draft of the ToR prior to this document being submitted to the NHS England Board / subcommittee of the Board.  The group reiterated the request that the version control on the ToR be updated to reflect the full circulation of the document and the timing of such circulation.  Following Jackie Gray's attendance at the AGD meeting on the 1st February 2024, the group reiterated that they looked forward to further information as to when the ToR would be considered by the NHS England Board / subcommittee of the Board.  ACTION: The SIRO representative to provide further information to the group as to when the draft ToR, including when this would be considered by the NHS England Board / subcommittee of the Board.  Standard Operating Procedures (SOPs)  The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.  It was noted that some of the independent advisers and the SIRO representative were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.  The group noted the update and looked forward to further discussions at future AGD meetings.		prior to this document being submitted to the NHS England Board / subcommittee of	
iteration of the draft ToR had been shared with the Chair, SIRO representative and the Data and Analytics representative, for comments on recent updates made to the document. It was noted that as previously discussed, a final version of the draft ToR was expected to be shared with the group prior to this being submitted to the NHS England Board / subcommittee of the Board.  ACTION: The SIRO representative to provide a copy of the final draft of the ToR prior to this document being submitted to the NHS England Board / subcommittee of the Board.  The group reiterated the request that the version control on the ToR be updated to reflect the full circulation of the document and the timing of such circulation.  Following Jackie Gray's attendance at the AGD meeting on the 1st February 2024, the group reiterated that they looked forward to further information as to when the ToR would be considered by the NHS England Board / subcommittee of the Board.  ACTION: The SIRO representative to provide further information to the group as to when the draft ToR, including when this would be considered by the NHS England Board / subcommittee of the Board.  Standard Operating Procedures (SOPs)  The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.  It was noted that some of the independent advisers and the SIRO representative were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.  The group noted the update and looked forward to further discussions at future AGD meetings.		1.	
prior to this document being submitted to the NHS England Board / subcommittee of the Board.  The group reiterated the request that the version control on the ToR be updated to reflect the full circulation of the document and the timing of such circulation.  Following Jackie Gray's attendance at the AGD meeting on the 1st February 2024, the group reiterated that they looked forward to further information as to when the ToR would be considered by the NHS England Board / subcommittee of the Board.  ACTION: The SIRO representative to provide further information to the group as to when the draft ToR, including when this would be considered by the NHS England Board / subcommittee of the Board.  Standard Operating Procedures (SOPs)  The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.  It was noted that some of the independent advisers and the SIRO representative were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.  The group noted the update and looked forward to further discussions at future AGD meetings.		iteration of the draft ToR had been shared with the Chair, SIRO representative and the Data and Analytics representative, for comments on recent updates made to the document. It was noted that as previously discussed, a final version of the draft ToR was expected to be shared with the group prior to this being submitted to the NHS	
reflect the full circulation of the document and the timing of such circulation.  Following Jackie Gray's attendance at the AGD meeting on the 1st February 2024, the group reiterated that they looked forward to further information as to when the ToR would be considered by the NHS England Board / subcommittee of the Board.  ACTION: The SIRO representative to provide further information to the group as to when the draft ToR, including when this would be considered by the NHS England Board / subcommittee of the Board.  GCO  Standard Operating Procedures (SOPs)  The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.  It was noted that some of the independent advisers and the SIRO representative were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.  The group noted the update and looked forward to further discussions at future AGD meetings.		prior to this document being submitted to the NHS England Board / subcommittee of	GC
the group reiterated that they looked forward to further information as to when the ToR would be considered by the NHS England Board / subcommittee of the Board.  ACTION: The SIRO representative to provide further information to the group as to when the draft ToR, including when this would be considered by the NHS England Board / subcommittee of the Board.  Standard Operating Procedures (SOPs)  The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.  It was noted that some of the independent advisers and the SIRO representative were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.  The group noted the update and looked forward to further discussions at future AGD meetings.			
when the draft ToR, including when this would be considered by the NHS England Board / subcommittee of the Board.  7 Standard Operating Procedures (SOPs)  The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.  It was noted that some of the independent advisers and the SIRO representative were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.  The group noted the update and looked forward to further discussions at future AGD meetings.		the group reiterated that they looked forward to further information as to when the	
The ongoing forward plan of work for creating Standard Operating Procedures was discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.  It was noted that some of the independent advisers and the SIRO representative were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.  The group noted the update and looked forward to further discussions at future AGD meetings.		when the draft ToR, including when this would be considered by the NHS England	GC
discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the progression of the AGD ToR.  It was noted that some of the independent advisers and the SIRO representative were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.  The group noted the update and looked forward to further discussions at future AGD meetings.	7	Standard Operating Procedures (SOPs)	
were supporting the progression of the SOPs out of committee; and that a workshop would be held with the group in March 2024, to discuss this further.  The group noted the update and looked forward to further discussions at future AGD meetings.		discussed and noted that although this could not progress further without sight of the final ToR, work was ongoing to progress and finalise the AGD SOPs, in line with the	To note
meetings.		were supporting the progression of the SOPs out of committee; and that a workshop	
8 AGD Action Log			
i	8	AGD Action Log	
The group reviewed the outstanding actions on the AGD action log, that consists of all actions captured at AGD meetings from the 2 <sup>nd</sup> February 2023.			
action log to ensure they were forwarded to the team before Wednesday so that		action log, to ensure they were forwarded to the team before Wednesday so that	To Note
Any Other Business		·	

### 9.1 Radio 4 interview with Prof. Cathy Sudlow (Presenter: Michael Chapman)

It was noted that at the AGD meeting on the 18<sup>th</sup> January 2024, an independent adviser had advised the group that on the 16<sup>th</sup> January 2024, Prof. Sudlow had been interviewed on Radio 4 on the results of the '<u>Undervaccination and severe COVID-19 outcomes: meta-analysis of national cohort studies in England, Northern Ireland, Scotland and Wales</u>'. It was noted that, as part of this interview, reference was made to patient choice. It was noted that on the NHS England <u>Data Uses Register</u> it was not clear whether opt outs had been applied under the data sharing agreement related to this specific area of work.

The Data and Analytics representative advised that work was ongoing within NHS England to make it more visible that National Data Opt-outs do not apply for pseudonymised data within the Secure Data Environment.

The group noted and thanked the Data and Analytics representative for the verbal update.

### 9.2 NHS England Data and Analytics colleagues observing AGD

Following the discussion at the AGD meeting on the 14<sup>th</sup> December 2023; the group reiterated their support for colleagues from NHS England's Data and Analytics to attend future meetings to observe the applications part of the meeting, as part of their professional learning and development.

### **9.3 AGD Stakeholder Engagement (**Cyber Risk and Security Committee (CRSC))

**Subsequent to the meeting:** It was noted that on the 30<sup>th</sup> January 2024, the AGD Chair had attended the Cyber Risk and Security Committee (CRSC) with the AGD SIRO representative and Data and Analytics representative; to present / discuss how AGD had been operating during the interim process and how this complied with the <u>Statutory Guidance</u>.

It was noted following the meeting, that this information had not been included in the AGD minutes from the 1<sup>st</sup> February 2024.

#### **Meeting Closure**

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