Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 29th June 2023

09:30 - 15:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN AT	TENDANCE:
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser (Chair: items 4.1, 5.2, 5.3 5.4, and 6.1)
Kirsty Irvine (KI)	Chair (Chair: items 1, 2, 3, 5.1, 5.5, 7, 9, 9, 10 and 11) (not in attendance for items 4.1, 5.2, 5.3, 5.4, and 6.1)
Dr. Imran Khan (IK)	Specialist GP Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
NHS ENGLAND STAFF IN ATTE	NDANCE:
Name:	Role / Area:
Vicky Byrne-Watts (VBW)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer : item 5.2)
Michael Chapman (MCh)	Data and Analytics representative
Garry Coleman (GC)	NHS England SIRO Representative (Presenter : item 10.1)
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer : item 5.1)
Duncan Easton (DE)	Data Access Request Service Senior Approval Team (DARS SAT) (Presenter : item 5.3)
Dan Goodwin (DG)	Data Access Request Service (DARS) (Presenter: item 5.1)
Suzanne Hartley (SH)	Data Access Request Service (DARS) (Presenter: item 5.2)
Dickie Langley (DL)	NHS England DPO Representative (Delegate for Jon Moore)
Abigail Lucas (AL)	Data Access Request Service (DARS) (Presenter: item 5.4)
Karen Myers (KM)	AGD Secretariat Team
Dr Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Fran Perry (FP)	Digi-Trials (Presenter : item 5.5)

Andy Rees (AR)	Digi-Trials (Observer : item 5.5)
Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer : item 5.4)
Vicki Williams (VW)	AGD Secretariat Team (not in attendance for items 5.1, 5.2, 5.3)
INDEPENDENT ADVISERS NOT I	N ATTENDANCE:
Prof Nicola Fear (NF)	Independent Specialist Academic Adviser
Dr. Robert French (RF)	Independent Specialist Academic / Statistician Adviser
Dr. Maurice Smith (MS)	Independent Specialist GP Adviser
Jenny Westaway (JW)	Independent Lay Adviser
NHS ENGLAND STAFF NOT IN A	TTENDANCE:
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 and Paul Affleck noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.

The minutes of the 22 nd June 2023 AGD meeting were reviewed and subject to a number of m	
amendments were agreed as an accurate record of the meeting.	inor
Declaration of interests:	
FING PAPER(S):	
Title: Cardiovascular Disease Prevention Audit (CVDPREVENT Audit) data collection	
Presenter: None	
The updated briefing paper provided details to address the points raised by IGARD on the 10 th December 2020 and the AGD meeting on the 18 th May 2023.	I
routinely recorded General Practice (GP) data will be extracted by NHS Digital via the GP Extra Service (GPES) with an initial GPES extract containing historical information and then rolling the monthly extracts of routinely recorded GP data. The data will help clinicians to understand how	action hree v well
Outcome of discussion: The group welcomed the updated briefing paper and confirmed that had no further observations / comments.	they
ERNAL DATA DISSEMINATION REQUESTS:	
Reference Number: NIC-694500-C0W0K-v0.3	
Applicant: Medicines and Healthcare products Regulatory Agency (MHRA)	
Application Title: Pelvic Floor Registry and Surgical Devices and Implant data to support medical device safety vigilance	
Presenter: Dan Goodwin	
SAT Observer: Dave Cronin	
Application: This was a new application.	
The purpose of the application is for a project, which explores the feasibility of the use of Surgical Devices and Implants Data Set (SDIDS), to support MHRA's vigilance and surveillance of pelvic mesh products. The results of this project will provide insight into the strengths and limitations of the data within the SDIDS and Pelvic Floor Registry for the purposes of supporting device vigilance.	
	An AGD NHS England representative noted they were a cohort member of the Our Future Hear research programme (NIC-414067-K8R6J). It was agreed this did not preclude the AGD NHS representative from taking part in the discussions about this application. FING PAPER(S): Title: Cardiovascular Disease Prevention Audit (CVDPREVENT Audit) data collection Presenter: None Previous Reviews: The CVDPREVENT Audit briefing paper was previously presented at the meeting on the 10 th December 2020; and discussed / presented at the AGD meetings on the 4 2023 and the 18 th May 2023. The updated briefing paper provided details to address the points raised by IGARD on the 10 th December 2020 and the AGD meeting on the 18 th May 2023. The purpose of the original briefing paper was to provide details of the CVDPREVENT Audit, v routinely recorded General Practice (GP) data will be extracted by NHS Digital via the GP Extend to an initial GPES extract containing historical information and then rolling ti monthly extracts of routinely recorded GP data. The data will help clinicians to understand how they are performing in the diagnosis and management of the six high-risk conditions for cardio disease (CVD). Outcome of discussion: The group welcomed the updated briefing paper and confirmed that had no further observations / comments. REMAL DATA DISSEMINATION REQUESTS: Reference Number: NIC-694500-C0W0K-v0.3 Application Title: Pelvic Floor Registry and Surgical Devices and Implant data to support medical device safety vigilance Presenter: Dan Goodwin SAT Observer: Dave Cronin Application: This was a new application. The purpose of the application is for a project, which explores the feasibility of the use of Surgical Devices and Implants Data Set (SDIDS), to support MHRA's vigilance and surveillance of pelvic mesh products. The results of this project will provide insight into the strengths and limitations of the data within the SDIDS and Pelvic Floor Registry for the

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

NHS England (verbal) update: NHS England advised the group that following submission of the papers to AGD, the following updates had been identified and the internal application assessment form / application would need updating accordingly: **1)** the reference to UKHSA being a Data Processor would need removing from the internal application assessment form; **2)** section 5(a) (Objective for Processing) of the application needs updating with further information of the data minimisation efforts undertaken; and **3)** the application requires confirmation that the appropriate security assurances have been approved / are in place for Microsoft Azure.

The group noted the verbal updates.

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 Noting the application addresses both regulatory work **and** research (and that two Article 9 UK General Data Protection Regulation (UK GDPR) legal bases had been cited to support this); the independent advisers noted the importance of addressing any potential ethical issues, notwithstanding the data requested is pseudonymised, and suggested that the applicant outline in the application what ethical consideration has been given / obtained for the research aspect of the application.

5.1.2 In addition, the independent advisers noted the government's <u>response</u> to the Baroness Cumberlege report of the <u>Independent Medicines and Medical Devices Safety</u> <u>Review (IMMDS Review)</u> published on the 8th July 2020; in particular recommendation 6 of the report that states MHRA "...needs to ensure that it engages more with patients and their *outcomes*"; and advised that the applicant should provide further information within the application of what patient and public involvement and engagement (PPIE) had been undertaken to date, and any future PPIE engagement planned.

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

5.1.3 The group noted that at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meeting on the 5th May 2022, a briefing paper had been presented about the Surgical Devices and Implants Data Set (SDIDS) collected and processed by NHS Digital within a single system known as the Surgical Device and Implant Information System (SDIIS); and that the finalised briefing paper had been presented at the IGARD meeting on the 16th June 2022. The group noted the points made by IGARD, in particular the suggestion that SDIDS was actively promoted to researchers as soon as possible; and that the response to this advice (at the time) from NHS Digital, was that wider access to this dataset would be achieved by 2023. NHS England advised in-meeting that due to the NHS Digital / NHS England merger at the start of 2023, and other organisational priorities, wider access to SDIDS had not been achieved, and that along with other NHS England datasets, would **not** be promoted to researchers at the current time. The independent advisers noted the verbal update from NHS England and advised that this was still a valuable dataset which would benefit from wider access.

5.1.4 In addition, noting that this was a first of type application; and as noted by IGARD on the 16th June 2022, the independent advisers reiterated the request that NHS England

provided a copy of any finalised briefing papers as a supporting document alongside any first of type applications to AGD.	
ACTION: NHS England to ensure that a copy of the finalised briefing papers are provided as a supporting document alongside any first of type applications to AGD.	NHSE
5.1.5 The independent advisers suggested that the applicant should give additional consideration in respect of transparency to the public, for example, transparency beyond the information provided in the privacy notice; and suggested that the applicant could seek further guidance / views on this as part of the PPIE.	
5.1.6 The NHS England SIRO representative queried with the group whether the application should be clear that access to the data under this application would, in the future, be accessed within the NHS England Secure Data Environment (SDE); or that a justification was provided in the application for not accessing the data via the SDE once technically possible, and that this would be considered as part of the annual review and/or any approval of subsequent data sharing agreement versions. The group were supportive of the proposal outlined by the SIRO representative.	
Reference Number: NIC-658720-R3V5Z-v0.10	
Applicant: University of Warwick	
Application Title: Mammo-50: Mammographic surveillance in breast cancer patients aged 50 years or older	
Presenter: Suzanne Hartley	
SAT Observer: Vicky Byrne-Watts	
Application: This was a new application.	
The purpose of the application is for a study, investigating the most effective and safest way of monitoring women of 50 years or over at diagnosis, who have been treated surgically with curative intent for invasive and non-invasive breast cancer, and are more than three years post-surgery. It will also consider acceptability to patients and value for money. It may eventually inform national guidelines about the best way to follow up women who have had surgery for breast cancer.	
Should an application be approved by NHS England, further details would be made available within the <u>Data Uses Register</u> .	
Outcome of discussion: The group were supportive of the application and wished to draw to the attention of the SIRO the following comments:	
5.2.1 The independent advisers commended NHS England on the work undertaken to review the consent materials, and the consent review document shared with the group in advance of the meeting.	
5.2.2 The NHS England SIRO representative queried the statement in section 3(b) (Additional Data Access Requested) <i>"For each individual patient, data will only be provided from the date they joined the trial"</i> and asked if this was correct, or whether it was from the date of consent; and suggested that further clarification was provided, both in relation to this application, and as a wider point for other applications; and if this was incorrect, then the application should be updated as appropriate to reflect the correct / factual information.	
	first of type applications to AGD. ACTION: NHS England to ensure that a copy of the finalised briefing papers are provided as a supporting document alongside any first of type applications to AGD. 5.1.5 The independent advisers suggested that the applications to AGD. 5.1.5 The independent advisers suggested that the applications to AGD. 5.1.5 The independent advisers suggested that the application such as the application in respect of transparency to the public, for example, transparency beyond the information provided in the privacy notice; and suggested that the application could seek further guidance / views on this as part of the PPIE. 5.1.6 The NHS England SIRO representative queried with the group whether the application was provided in the application for not accessing the data via the SDE once technically possible, and that this would be considered as part of the annual review and/or any approval of subsequent data sharing agreement versions. The group were supportive of the proposal outlined by the SIRO representative. Reference Number: NIC-658720-R3V5Z-v0.10 Applicatin: University of Warwick Application Title: Mammo-50: Mammographic surveillance in breast cancer patients aged 50 years or older Presenter: Suzanne Hartley SAT Observer: Vicky Byrne-Watts Application: This was a new application. The purpose of the application is for a study, investigating the most effective and safest way of monitoring women of 50 years or over at diagnosis, who have been treated surgically with curative intent for invasive and non-invasive breast cancer, and are more than three years post-surgery. It will also consider acceptability to patients and value for money. It may eventually inform national guidelines about the best way to follow up women who have had surgery for breast cancer. Should an application The group were supportive of the application and wished to draw to the attention of the SIRO representative queried the statement in section 3(b) (Additional Data Access Requested) 'For each individual patient, data w

ACTION: NHS England to clarify for future reference if it is possible that data can flow from the date individuals join the trial or from the date of consent.	NHSE
5.2.3 The independent advicers noted the statement in section E(s) (Objective for	
5.2.3 The independent advisers noted the statement in section 5(a) (Objective for Processing) <i>"It will also consider acceptability to patients and value for money"</i> ; and suggested that it was amended to refer to <i>"cost effectiveness"</i> or similar.	
5.2.4 The independent advisers noted that processing of the data under this data sharing agreement (DSA) could be done remotely; and suggested that further information was added to the application on the remote access arrangements; and reiterated previous advice 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 2 nd February 2023).	NHSE
5.3 Reference Number: NIC-423341-T5F3T-v0.8	
Applicant: London Borough of Islington	
Application Title: DSfC - Adult Social Care Free Text analysis	
Presenter: Duncan Easton	
Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meeting on the 13 th January 2022.	
Application: This was a new application.	
The purpose of the application is for a project, aiming to build a novel and comprehensive dataset that makes use of structured NHS and Adult Social Care (ASC) data and free text data from adult social care case notes, to identify need, escalating need and predict demand for adult social care.	
Should an application be approved by NHS England, further details would be made available within the <u>Data Uses Register</u> .	
Outcome of discussion: The group deferred the application as not all the necessary information was available to make a full assessment. The group wished to draw to the attention of the SIRO the following substantive points; and suggested that the application be brought back to a future meeting once the previous IGARD / AGD points had been sufficiently addressed (or it was clearly highlighted / justified where points were no longer applicable):	
5.3.1 The group noted that, at the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) meeting on the 13 th January 2022, they were unable to make a recommendation as not all the necessary information was available in order for IGARD to make a full assessment. The group noted that the responses from the applicant on the previous IGARD points were hard to follow and suggested the completion of an internal application assessment document, to achieve greater clarity from the applicant on the outstanding points.	
5.3.2 The independent advisers noted that one of the previous IGARD points was in relation to artificial intelligence, and highlighted the conflicting information in section 5(a) (Objective for Processing) of the application that stated <i>"The tool does not use Artificial Intelligence"</i>	

techniques...", and section 1 (Abstract) of the application which stated "...using AI to extract systematically structured indicators from free-text data into structured data...".

5.3.3 The group also noted the previous IGARD point in respect of *"free text"*, and advised that it was currently unclear to what extent the pseudonymisation was successful, and advised that they remained concerned that some of the free text may still be identifiable. The group suggested that the applicant review and confirm if the existing Data Protection Impact Assessment (DPIA) addresses this point sufficiently. In addition, the group suggested that the applicant obtain the support of their Data Protection Officer (DPO) / SIRO as may be appropriate; noting that if the pseudonymisation was not successful there may be issues with confidentiality.

5.3.4 The independent advisers noted the reference in the application to the linkage with GP data and queried how the Common Law Duty of Confidentiality was being met, noting that it appeared this would be done via a data processing agreement. The group flagged a recent <u>letter</u> from the Chair of the UK Caldicott Guardian Council and the National Data Guardian (NDG) in respect of this issue and suggested that this approach was not sufficient. The AGD Caldicott Guardian Team representative advised that this would be followed up outside of the meeting with the Chair of the UK Caldicott Guardian Council in respect of the current position.

ACTION: The AGD Caldicott Guardian Team representative to follow-up on the Common Law Duty of Confidentiality and whether this was being met for the GP data linkage with the Chair of the UK Caldicott Guardian Council.

5.3.5 Noting that IGARD had previously queried the opt-out process, the group noted that this point was still unclear and suggested that the opt-out process was clarified, for example, in respect of local opt-outs and the National Data Opt-out (NDO); noting that the transparency materials, i.e. the published privacy notice and patient information leaflet have conflicting information on this subject.

5.3.6 In addition, the group noted that the NDO should be applied by the organisation holding the confidential data and before it flows; and suggested that NHS England seek confirmation that this was happening.

5.3.7 An NHS England representative noted that the published privacy notice referred to the North East London commissioning Support Unit (NEL CSU); however, noting they were not referred to within the application, suggested that the application and transparency materials were reviewed and updated as appropriate, to ensure that all the relevant parties were accurately noted.

5.3.8 Noting that IGARD had previously queried whether the application was purely a *"commissioning"* application, the group suggested that the point was addressed noting that it was still unclear in the application; and reiterated the point made by IGARD that the high-level aims appeared to be research questions.

5.3.9 An NHS England representative queried whether the objectives in section 5(a) were all still relevant in respect of the request for data from NHS England; and suggested that there was further clarity within the application, as to whether the earlier objectives, which did not appear to require access to NHS England data, have already been achieved. If they have been achieved, then the application should focus on the use of NHS England data linked to pseudonymised adult social care free text data. If not, it was suggested that clarification was

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sought as to how they were being addressed / achieved and whether NHS England data is actually required while that work takes place. **5.3.10** Noting there was a potential risk of bias with regard to automated processing and sample size, the independent advisers flagged the need to ensure the samples used for developing the natural language engines covered the diversity of the population affected. 5.4 Reference Number: NIC-634901-B4H8K-v0.9 Applicant: Barts Health NHS Trust **Application Title:** Mortality and morbidity outcomes after aortovascular surgery in patients with Marfan Syndrome Presenter: Abigail Lucas SAT Observer: Kimberley Watson Application: This was a new application. The purpose of the application is for a study aiming to undertake a 10-year secondary analysis of linked national data (National Institute of Cardiovascular Outcome Research (NICOR), and NHS England Civil Registration death and Hospital Episode Statistics (HES) data) to identify the UK incidence and outcome of aortovascular surgery in patients with Marfan syndrome (MFS). This includes associated hospital length of stay, mortality and morbidity rates. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. NHS England (verbal) update: NHS England advised the group that following submission of the papers to AGD, that the following updates had been identified and the internal application assessment form / application would need updating accordingly: 1) the application to be updated with the security assurance details for Microsoft Limited and NHS Arden and Greater East Midlands (GEM) Commissioning Support Unit (CSU) to reflect the latest available information; 2) to update section 5(a) (Objective for Processing) to a) remove erroneous references to the Office for National Statistics, b) remove the statement about "surgical burden", and c) to change the statement "will significantly contribute to the UK and international evidence base" to "should significantly contribute...". In addition, NHS England advised that 1) they had received a copy of Barts Health NHS Trust's draft privacy notice, and confirmed that they were content that the detail in the privacy notice aligns with the detail in the application; and 2) Barts Health NHS Trust have advised that they are actively working on the additional Cloud security assurances as per the proposed special condition in section 6 (Special Conditions). The group noted the verbal updates. 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** The independent advisers commended NHS England and the applicant on the work undertaken on the application and the Health Research Authority Confidentiality Advisory Group (HRA CAG) support analysis.

	5.4.2 NHS England advised the group that, prior to the meeting, the length of the application had been discussed internally, and that they were proposing the term of the application was	
	amended from two years to three years. The group advised that they were content with this approach.	
	5.4.3 The independent advisers noted the information in the internal application assessment form that stated that the applicant had advised there was currently not a platform to publish their privacy notice, due to the lack of a specific research website; and that it had been discussed that the privacy notice would be published on the patient charity websites of the organisations who have agreed to support the study on an interim basis. It was advised that it would be the responsibility of the Data Controller (Barts Health NHS Trust) to make the privacy notice easily accessible, and it was suggested that the applicant either publish one on their own website, and / or that relevant weblinks to the charity websites were added to the Barts Health NHS Trust website.	
	5.4.4 Noting that NHS England are now responsible for the 'National Institute for Cardiovascular Outcomes Research' (NICOR), it was suggested by the group that consideration should be given to NHS England undertaking the linkage and not Barts Health NHS Trust; and that the application should be updated accordingly, or that a justification be provided as to why NHS England cannot carry out the linkage.	
	5.4.5 The independent advisers noted the special conditions in section 6 relating to the data destruction, and queried what was meant by data being destroyed <i>"as soon as possible"</i> ; and suggested that this was replaced with a date, timeframe or a trigger.	
	5.4.6 The independent advisers noted that a poster had been provided as a supporting document, which provided further information on the study to the public; however noted that there was no reference on the poster to opt outs, and suggested that the applicant should review and update their transparency materials in respect of informing the public about whether opting out is possible, with regard to any local opt out and the National Data Optout.	
5.5	Reference Number: NIC-414067-K8R6J-v3.2	
	Applicant: Our Future Health	
	Application Title: Our Future Health Recruitment Programme	
	Presenter: Frances Perry	
	Observer: Andy Rees	
	Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meetings on the 2 nd March 2023, 30 th March 2023 and 11 th May 2023.	
	The application and relevant supporting documents had previously been presented / discussed at the IGARD BAU meetings on the 5 th May 2022, 26 th May 2022, 17 th November 2022 and 1 st December 2022.	
	Application: This was an amendment application.	
	The amendment is to increase the total number of invitation mailouts from approximately 16 million to approximately 20 million, to allow recruitment to proceed whilst Our Future Health	

discuss a further increase to the invitation numbers with the Health Research Authority Confidentiality Advisory Group (HRA CAG).

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

Outcome of discussion: The group deferred the application as not all the necessary information was available to make a full assessment. The group wished to draw to the attention of the SIRO the following substantive points; and suggested that the application be brought back to a future meeting **at the earliest opportunity** once the previous IGARD / AGD points had been sufficiently addressed (or it was clearly highlighted / justified where points were no longer applicable):

5.5.1 The group noted that the review of this application would be in relation to the amendment only, which was to increase the total number of invitation mailouts from approximately 16 million to approximately 20 million **only**; and they would **not** be providing any advice on future steps for the application.

5.5.2 The group noted that Health Research Authority Confidentiality Advisory Group (HRA CAG) had supported an increase in the invitation mailouts from approximately 16 million to approximately 20 million, subject to specific conditions of support.

5.5.3 The group noted and applauded the applicant on now taking forward the pilot of the *"Dear Householder"* mail out approach as discussed / suggested at previous Independent Group Advising (NHS Digital) on the Release of Data (IGARD) / AGD meetings. However, it was suggested by the group that NHS England may wish to consider stopping the flow of data, until the letter had been piloted and initial findings reported on.

5.5.4 In addition, and noting that recruitment was also taking place through GP practices and hospitals, the independent advisers queried whether there had been a comparison across the three recruitment methods; and suggested that clarification was provided within in the application of any comparison data available, which would go to supporting the case that using confidential data was necessary to achieve the stated aims of increasing participation of "hard to reach" groups.

5.5.5 As discussed at the AGD meeting on the 2nd March 2023, noting the objective of increasing recruitment from underrepresented groups, the independent advisers queried whether this was being achieved and whether this method of recruitment was working. The independent advisers noted that given the numbers signing up, there should be early signs as to whether hard to reach groups were being successfully recruited; and suggested that further information be provided on this point within the application.

5.5.6 The independent advisers reiterated the point previously made at the AGD meeting on the 2nd March 2023, in respect of the potential issue with transparency, as per the risk factor previously articulated by IGARD, in that participants may not be aware of the depth of the commercial involvement, including the potential use of health data by pharmaceutical, diagnostic and health tech companies, ; and suggested that further clarification was provided as to how this point had been considered and addressed.

5.5.7 An AGD NHS England representative queried whether an assessment had been undertaken of the commercial benefits and whether they were proportionate in terms of

	balancing with public benefits, particularly in respect of underrepresented groups; and suggested that further clarification was provided.	
EXTE	RNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL	
6.1	Reference Number: NIC-331142-P5K6M-v2.10	
	Applicant: University of Bristol	
	Application Title: National Child Mortality Database (NCMD) request for mortality data (COVID-19)	
	Presenter: No Presenter	
	Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 19 th August 2021 and the 18 th November 2021.	
	The application and relevant supporting documents had previously been presented / discussed at the IGARD – NHS Digital COVID-19 response meetings on the 7 th July 2020 and the 24 th November 2020.	
	Application: The purpose of the application is for The National Child Mortality Database (NCMD) Programme, a national data collection and analysis system, which is the first of its kind anywhere in the world to record comprehensive data, standardised across a whole country (England), on the circumstances of children's deaths. The purpose of collating information nationally is to ensure deaths are learned from, learning is widely shared and actions are taken, locally and nationally, to reduce the number of children who die.	
	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 advised that they would welcome this application for an AGD review at the earliest possible stage.	
	The NHS England SIRO representative thanked the group for their time.	
AGD	Operations	
7	Statutory GuidanceThe independent advisers again noted the reference to reviewing materials in accordancewith "a clearly understood risk management framework" within the published StatutoryGuidanceGuidanceand 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 SIRO Representative to provide further clarity on the riskmanagement framework.	GC
8	AGD Terms of Reference Garry Coleman noted that NHS England were still receiving comments from stakeholders on the AGD ToR and that the draft AGD ToR had not been approved by NHS England on the 28 th June 2023, as per the plan originally advised to AGD.	

	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	New Operational Actions & those carried forward from previous meetings of AGD:	
10.1	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, 26 th June 2023, joining one adviser had transitioned to a zero hours contract on the 31 st May 2023.	To note
	Vicki noted that NHS England were actively working to put the remaining zero hours contracts in place before the end of July 2023.	
Meeti	ng Closure	1
As the	ere was no further business raised, the Chair thanked attendees for their time and closed the m	eeting.