

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 4th May 2023

09:30 – 16:50

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Michael Ball (MB)	Data Access Request Service (DARS) (Presenter: items 5.5 to 5.7)
Michael Chapman (MCh)	Data and Analytics representative (Presenter: item 7.1) (not in attendance for items 5.2 to 5.4)
Garry Coleman (GC)	Senior Information Risk Owner (SIRO) representative
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 5.4)
Cath Day (CD)	Data Access Request Service Senior Approval Team (DARS SAT) (Observer: item 4.1) (Presenter: item 5.1)
Louise Dunn (LD)	Data Access Request Service Senior Approval Team (DARS SAT) (Presenter: items 5.2 and 5.3)
Duncan Easton (DE)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: items 5.5 to 5.7)
Dan Goodwin (DG)	Data Access Request Service (DARS) (Presenter: item 5.4)
Wendy Harrison (WH)	Data Management Assurance Lead, Corporate Information Governance (Presenter: item 4.1)
Jackie Gray (JG)	Executive Director, Privacy, Transparency & Ethics (PTE) (Observer: items 1, 4.1 and 5.1)

Dickie Langley (DL)	Data Protection Officer (DPO) representative (Delegate for Jon Moore) (Presenter: item 6)
Karen Myers (KM)	Secretariat Team
Dr. Jonathan Osborn (JO)	Caldicott Guardian Team representative
Kathryn Salt (KS)	Data, Insights & Statistics (Observer: Items 4.1 and 5.1)
Terry Service (TS)	Data Access Request Service (Presenter: Item 7.1)
Efrosini Setakis (ES)	Data, Insights & Statistics (Observer: Items 4.1 and 5.1)
Jodie Taylor-Brown (JTB)	Data Access Request Service (DARS) (Observer: Item 5.4)
James Thomas (JT)	Data, Insights & Statistics (Observer: Items 5.2 and 5.3)
Gary Wainman (GWain)	Data, Insights & Statistics (Presenter: Item 4.1)
Gemma Walker (GWal)	Data Access Request Service Senior Approval Team (DARS SAT) (Observer: Items 5.2 and 5.3)
Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (Observer: item 4.1) (Presenter: item 5.1)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Jon Moore (JM)	Data Protection Officer (interim)

1	<p>Welcome and Introductions</p> <p>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:</p> <ul style="list-style-type: none"> • 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
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	<p>representatives covering the offices of the Data Protection Officer (DPO); the Caldicott Guardian; and the SIRO.</p> <ul style="list-style-type: none"> 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. <p>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.</p> <p>Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the 20th April 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.</p> <p>The minutes of the 27th April 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.</p>
3	<p>Declaration of interests:</p> <p>Dr. Imran Khan noted a potential conflict with NIC-395236-V3W9P as part of his roles as Deputy Chair of the Health Informatics Group at the RCGP and Co-deputy Chair of the Joint GP IT Committee.</p> <p>Dr. Geoffrey Schrecker noted that his data would be included in the cohort for NIC-616004-J8K1K, but it was agreed that this was not a conflict of interest.</p>
BRIEFING PAPER(S):	
4.1	<p>Title: Transfer of Cardiovascular diseases (CVD) Data to the Unified Data Access Layer (UDAL)</p> <p>Presenter: Gary Wainman, Wendy Harrison</p> <p>Observers: Catherine Day, Kathryn Salt, Efrosini Setakis Kimberley Watson, Jackie Gray</p> <p>The paper provided to the group details of a proposal to transfer pseudonymised personal data from the CVD Prevent Audit to NHS England’s Unified Data Access Layer (UDAL) environment; following the draft guidance from the Secretary of State to NHS England.</p> <p>Processing in this pseudonymised environment will facilitate tracking the recovery of cardiovascular services post COVID-19. It will, additionally, provide an on-going resource to inform activities supporting NHS England’s statutory functions, where necessary in combination with other data held in UDAL.</p> <p>Outcome of discussion: The group welcomed the briefing paper and made the following observations / comments:</p>

- 4.1.1** The independent advisers did not note any significant concerns or risks in respect of the proposed transfer of CVD Prevent Audit to NHS England's UDAL environment, as outlined in the briefing paper provided.
- 4.1.2** The independent advisers did, however, highlight a potential risk around transparency; and advised NHS England that there should be transparency around the transferring of the CVD Prevent Audit to NHS England's UDAL environment, and suggested that this could be done via NHS England's existing transparency routes, and by utilising NHS England's [benchmarking](#) Network. This would ensure compliance with UK General Data Protection Regulation (UK GDPR) and provide transparency to the public.
- 4.1.3** The independent advisers advised NHS England that if the relevant privacy notices were going to be updated to reflect the processing outlined in the briefing paper, then they would be happy to review / provide input on the draft version(s) prior to these being finalised and published.
- 4.1.4** The Caldicott Guardian representative advised the group that whilst they were supportive of the processing outlined, further consideration should be given to the GP profession and whether they needed to be specifically consulted on this. NHS England noted the point raised and advised that this had been considered as part of the transparency work.
- 4.1.5** The independent advisers advised NHS England that for this briefing paper, and for any future briefing papers submitted to the group for review / information. They do not expect any "new" documents to be drafted specifically for AGD, and that, where possible, NHS England should utilise information / documents already drafted / in circulation; and that these should be provided as supporting documents at any future AGD review, in particular, the DPIA would seem to be a useful summary of the pertinent points.
- ACTION:** AGD Secretariat to ensure that there is a clear process when submitting items to AGD is outlined in any new standard operating procedures.
- 4.1.6** Noting the annex provided within the briefing paper contained a list of acronyms used within the briefing paper, the independent advisers also suggested that, for ease of reference, the acronyms within the briefing paper were clearly defined upon **first** use.
- 4.1.7** The independent advisers suggested that the briefing paper was updated to include a specific header / section, on patient and public involvement and engagement (PPIE) - or a similar section was included in the DPIA.
- 4.1.8** The independent advisers noted the information provided in the briefing paper in respect of opt-outs; and suggested that this was reviewed and updated where appropriate to reflect which opt-out was applied and when, for example, Type 1 Opt-out versus National Data Opt-out.
- 4.1.9** Noting the information provided in the briefing paper in respect of the Benefits, the independent advisers suggested that this was reviewed and updated, where appropriate, to use a form of wording such as "*it is hoped ...*", rather than "*it will...*"; and that this should be done in line with the National Data Guardian (NDG) [guidance](#) on benefits.
- 4.1.10** The group looked forward to receiving the finalised briefing paper, either out of committee (OOC) or tabled at a future meeting (before, or contemporaneously with, any first of type applications received by AGD).

EXTERNAL DATA DISSEMINATION REQUESTS:

5.1	<p>Reference Number: NIC-395236-V3W9P-V1.2</p> <p>Applicant: Office for Health Improvement Disparities (OHID)</p> <p>Application Title: CVDPREVENT Audit</p> <p>Presenters: Catherine Day, Kimberley Watson</p> <p>Observers: Efrosini Setakis, Kathryn Salt, Jackie Gray</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meeting on the 10th December 2020.</p> <p>Application: This was an amendment application.</p> <p>The amendments are to 1) update the Data Controller from Public Health England (PHE) to the Department of Health and Social Care (DHSC) due to the closure of PHE; and 2) to add Civil Registrations (Deaths) and Hospital Episode Statistics (HES) Admitted Patient Care (APC).</p> <p>Should an application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The group were supportive of the application and wished to draw to the attention of the SIRO the following comments:</p> <p>5.1.1 The independent advisers noted that when the Cardiovascular Disease Prevention Audit (CVDPREVENT Audit) data collection – Briefing Paper was reviewed by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) on the 10th December 2020 a request was made for an updated / finalised copy of the briefing paper, following comments / feedback provided by IGARD. Noting that this had not been provided, the independent advisers reiterated the request for a final version of the briefing paper to be provided to the group for information, addressing the outstanding queries.</p> <p>ACTION: NHS England to provide a copy of the updated CVDPREVENT data collection briefing paper either out of committee (OOC) or tabled at a future meeting</p> <p>5.1.2 The independent advisers reiterated a point previously made by IGARD on the 10th December 2020 when reviewing this application; in respect of contradictory information in section 5(d) (Benefits) that referred to identifying individuals with high-risk conditions; and noting that a response was not reflected in the application, asked that this was updated to ensure that it was clear that the outputs would support clinicians to only identify the <i>features</i> of at-risk patients, not actual individual patients.</p> <p>5.1.3 Noting the amendment to add DHSC as a Data Controller following the closure of PHE at the end of September 2021; the independent advisers queried the legal basis for DHSC to assume PHE's legal status to receive data as an audit partner under the relevant Direction; and asked that, for transparency, a statement was added to section 5 (Purpose / Methods / Outputs) clarifying this.</p> <p>5.1.4 The independent advisers queried the statement in section 5(a) (Objective for Processing) <i>"Without real time data, GPs, practices and networks will have no indication of the scale of the problem or the opportunity for improvement for patients and populations..."</i>; and suggested that this was updated to be clear that GPs are able to undertake this work themselves if they so wished.</p>	CD/KW
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	<p>5.1.5 In addition, the independent advisers queried the reference to “...<i>real time data</i>...” (as per the statement outlined above) in section 5(a); and suggested that this was updated to say “<i>more up to date data</i>” or similar.</p> <p>5.1.6 Noting the yielded benefits in section 5(d) (iii) (Yielded Benefits), the independent advisers suggested that this was updated to align with the anticipated benefits outlined in section 5(a) and in line with NHS England’s DARS Standard for Expected Measurable Benefits; noting the audit was at the end of a three-year cycle, and therefore the yielded benefits to health and social care should be easier to identify.</p> <p>5.1.7 The independent advisers noted the references in section 5(a) to “<i>National Data Opt-out</i>”; and suggested that this was reviewed and updated where necessary to ensure the correct opt-out was referenced, for example, Type 1 Opt-out versus National Data Opt-out.</p> <p>5.1.8 In addition, the independent advisers suggested that section 5(a) was updated to provide a clear explanation as to what opt-outs were applied and when.</p> <p>5.1.9 The independent advisers noted the special condition in section 6 (Special Conditions) in respect of homeworking and asked that this was updated to align with NHS England’s policy on remote access.</p> <p>ACTION: NHS England to provide its position to AGD on remote access (<i>as agreed at the AGD meeting on the 2nd February 2023</i>).</p>	NHSE
5.2	<p>Reference Number: NIC-659284-W0T0H-v0.13</p> <p>Applicant: University of Cambridge</p> <p>Application Title: Multicentre Study to determine Predictive and Prognostic Biomarkers and Therapeutic Targets for Oesophageal and Junctional Adenocarcinoma including whole genome sequencing (ODR1718_082)</p> <p>Presenter: Louise Dunn</p> <p>Observers: Gemma Walker, James Thomas</p> <p>Linked applications: This application is linked to NIC-38314-C3P0Z.</p> <p>Application: This was an application coming for advice.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>NHS England were seeking advice on the following point:</p> <ol style="list-style-type: none"> 1. The assessment of the consent materials to meet the common law duty of confidentiality. <p>Outcome of discussion: The group were supportive of the application. The group made the following observation / points of advice on the application and / or supporting documentation provided as part of the review:</p> <p>In response to point 1</p> <p>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. Concern was noted, however, by the independent advisers, on the</p>	

	<p>impact on NHS England resources of this work, noting the assessment is usually co-produced with, or undertaken / provided by the applicant in the first instance.</p> <p>5.2.2 The independent advisers noted the inconsistencies between the various iterations of the consent materials identified in the consent assessment document; however, suggested that these could be addressed by a layered communication approach; including, but not limited to, an updated privacy notice. It was suggested that a communication plan was produced by the applicant, to support this work, with clear timescales of what will be done, and when.</p> <p>5.2.3 In addition, the independent advisers suggested that the applicant take proactive steps, such as engaging with a small representative sample of the cohort, to check their understanding of the proposed processing, including, but not limited to, when the ten-years of processing starts / ends.</p> <p>5.2.4 The independent advisers advised that a lack of transparency to the cohort on the processing of their data under this application may be a reputational risk to NHS England.</p> <p>5.2.5 Separate to this application, the independent advisers suggested that NHS England should consider updating the internal application assessment form, to include a section on Caldicott Principle 8 “...<i>A range of steps should be taken to ensure no surprises for patient and service users...</i>”; to determine how applicants have met this.</p> <p>ACTION: NHS England to consider updating the internal application assessment form, to include a section on Caldicott Principle 8.</p> <p>5.2.6 Noting the data was flowing to two different locations, it was suggested by the independent advisers that a rationale / justification for this was provided in section 5 (Purpose / Methods / Outputs), as the reasons for this were unclear.</p>	NHSE
5.3	<p>Reference Number: NIC-38314-C3P0Z-v3.22</p> <p>Applicant: University of Cambridge</p> <p>Application Title: Mortality data for OCCAMS cohort</p> <p>Presenter: Louise Dunn</p> <p>Observers: Gemma Walker, James Thomas</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 21st December 2017 and 8th February 2018.</p> <p>Linked applications: This application is linked to NIC-659284-W0T0H.</p> <p>Application: This was an application coming for advice.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>NHS England were seeking advice on the following point:</p> <ol style="list-style-type: none"> 1. The assessment of the consent materials to meet the common law duty of confidentiality. 	

	<p>Outcome of discussion: The group were supportive of the application. The group made the following observation / points of advice on the application and / or supporting documentation provided as part of the review:</p> <p>In response to point 1</p> <p>5.3.1 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. Concern was noted, however, by the independent advisers, on the impact on NHS England resources of this work, noting the assessment is usually co-produced with or undertaken / provided by the applicant in the first instance.</p> <p>5.3.2 The independent advisers noted the inconsistencies between the various iterations of the consent materials identified in the consent assessment document; however, suggested that these could be addressed by a layered communication approach; including, but not limited to, an updated privacy notice. It was suggested that a communication plan was produced by the applicant, to support this work, with clear timescales of what will be done, and when.</p> <p>5.3.3 In addition, the independent advisers suggested that the applicant take proactive steps, such as engaging with a small representative sample of the cohort, to check their understanding of the proposed processing, including, but not limited to, when the ten-years of processing starts / ends.</p> <p>5.3.4 The independent advisers advised that a lack of transparency to the cohort on the processing of their data under this application, may be a reputational risk to NHS England.</p> <p>5.3.5 Separate to this application, the independent advisers suggested that NHS England should consider updating the internal application assessment form, to include a section on Caldicott Principle 8 “...A range of steps should be taken to ensure no surprises for patient and service users...”; to determine how applicants have met this.</p> <p>ACTION: NHS England to consider updating the internal application assessment form, to include a section on Caldicott Principle 8.</p> <p>5.3.6 Noting the data was flowing to two different locations, it was suggested by the independent advisers that a rationale / justification for this was provided in section 5 (Purpose / Methods / Outputs), as the reasons for this were unclear.</p>	NHSE
5.4	<p>Reference Number: NIC-393510-D6H1D-v8.10</p> <p>Applicant: University College London (UCL)</p> <p>Application Title: Children and Families Policy Research</p> <p>Presenter: Dan Goodwin</p> <p>SAT Observer: Dave Cronin</p> <p>Observer: Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 20th July 2017, 27th June 2019, 4th March 2021, 17th February 2022 and the 26th May 2022.</p>	

Linked applications: This application is linked to NIC-381972-Q5F0V, NIC-419453-G3G1G and NIC-196263-J9Q7Z.

Application: This was a renewal, extension and amendment application.

The amendments are to **1)** amend the scope of 'objective e'; to add data on individuals up to age 55, previously under v7.1 the data was only for those age under 25 years old. UCL now requests additional data for COVID-19 UK Non-hospital Antigen Testing Results (Pillar 2) data and COVID-19 Second Generation Surveillance System (SGSS) on women up to age 56 years. This is to enable them to assess the effects of Covid infection during pregnancy and after childbirth on children's long-term health; and **2)** to add high-risk variables that indicate which COVID-19 variant a person was infected with (CH1-4 Result, Target and Value) to be able to identify infections with variants of concern. As different variants could have different health effects, information on variants is essential for research on effects of COVID-19.

Should the application be approved by NHS England, further details would be made available within the [Data Uses Register](#).

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

5.4.1 The independent advisers noted the addition of the COVID-19 Second Generation Surveillance System (SGSS) and COVID-19 UK Non-hospital Antigen Testing Results (pillar 2) datasets; and noting they were restricted to COVID-19 related research only, suggested that a special condition outlining any restrictions was inserted in section 6 (Special Conditions), in line with [NHS England's DARS Standard for Special Conditions](#).

5.4.2 In addition, the independent advisers suggested that for transparency, section 5 (Purpose / Methods / Outputs) was also updated, to state that SGSS and the pillar 2 datasets, were restricted to COVID-19 related research only; in line with [NHS England's DARS Standard for Objective for Processing](#).

5.4.3 The independent advisers noted that the date of death has been requested, and suggested that to ensure this does not become an identifying field, NHS England should explore whether processing could render this non-identifiable and / or to discuss this with the National Data Guardian (NDG) and Health Research Authority Confidentiality Advisory Group (HRA CAG), to seek confirmation on previously received advice.

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

5.4.4 The independent advisers welcomed the application and noted the importance of the study.

5.4.5 NHS England advised the group, that in addition to the amendments outlined in the application, there would be an additional amendment to add Amazon Web Services (AWS) as a Data Processor. It was advised that the omission of AWS in UCL data sharing agreements (DSA) had been identified via an audit that had been undertaken by NHS England on another UCL DSA; and that, as a result, **all** UCL applications were in the process of being reviewed by NHS England, to ensure that AWS were listed as a Data Processor. The group noted the verbal update by NHS England.

	<p>5.4.6 NHS England advised the group that, noting the funding expired in December 2023, discussions were still ongoing with the Department of Health and Social Care (DHSC) to seek approval for funding beyond this date. The group noted the verbal update by NHS England.</p> <p>5.4.7 The independent advisers suggested that, noting the volume of data flowing, sufficient steps were taken to ensure that all data minimisation efforts had been explored to ensure that the minimum amount of data was flowing; and that the minimum amount of processing was being undertaken, in line with NHS England's DARS standard for data minimisation, for example, noting that some of the data would be deleted if it did not meet certain criteria, for example, for those under the age of 25; it was suggested that the application was updated to be clear on exactly what was going to be deleted and what data would be left</p>	
5.5	<p>Reference Number: NIC-616004-J8K1K-v1.2</p> <p>Applicant: NHS South Yorkshire Integrated Care Board (ICB)</p> <p>Application Title: DSFC - NHS South Yorkshire Integrated Care Board- IV, RS & Comm</p> <p>Presenter: Michael Ball</p> <p>SAT Observer: Duncan Easton</p> <p>Application: This was an amendment application.</p> <p>The amendment is to change the data minimisation for commissioning to include patients within Bassetlaw.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p> <p>Outcome of discussion: The group were supportive of the application and confirmed that they had no comments to make on the application or supporting documentation provided as part of the review.</p>	
5.6	<p>Reference Number: NIC-616029-Y7G7K-v2.2</p> <p>Applicant: NHS Derby & Derbyshire Integrated Care Board (ICB)</p> <p>Application Title: DSfC - NHS Derby And Derbyshire Integrated Care Board - IV, RS & Comm</p> <p>Presenter: Michael Ball</p> <p>SAT Observer: Duncan Easton</p> <p>Application: This was an amendment application.</p> <p>The amendment is to add linkage to Musculoskeletal (GetUBetter) data.</p> <p>GetUBetter is a service that has been procured by the ICB for patients managing Musculoskeletal (MSK) injuries. The service allows patients to self-manage their conditions through an app. The ICB has a requirement to receive and link this data to ensure the service is effective.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p>	

	<p>Outcome of discussion: The group were supportive of the application if a legal basis for the data to flow from GetUBetter could be evidenced and wished to draw to the attention of the SIRO the following significant comment:</p> <p>5.6.1 The independent advisers queried what the legal basis was for the data to flow from GetUBetter to the Commissioning Support Unit (CSU); and noting that this was unclear, suggested that this was confirmed with the applicant, and that the application was updated with clarification.</p> <p>In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.6.2 The independent advisers queried the transparency arrangements, in respect of ensuring that users were aware of where their data was flowing; and noting that the privacy notice did not address this, suggested that the applicant should explore providing updates to the users of the app when they register / log-on, to make them aware that their data will be flowing to the CSU.</p> <p>5.6.3 The independent advisers noted that section 5(e) (Is the Purpose of this Application in Anyway Commercial) stated that there was “no” commercial purpose of the application; however, suggested that section 5(a) (Objective for Processing) and section 5(e) were updated further to include details of any commercial benefits to the commercial organisation, in line with NHS Digital DARS Standard for Objective for Processing and NHS Digital DARS Standard for Commercial Purpose.</p> <p>5.6.4 In addition, the independent advisers suggested that section 5(a) was 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 Digital DARS Standard for Commercial Purpose.</p>	
5.7	<p>Reference Number: NIC-627119-M2CF-V0</p> <p>Applicant: Class Action (ICB Clinical Registries)</p> <p>Application Title: Clinical registries for commissioning data</p> <p>Presenter: Michael Ball</p> <p>SAT Observer: Duncan Easton</p> <p>Previous Reviews: The Clinical Registry databases was previously discussed at the IGARD BAU Meetings on the 11th July 2019, 7th November 2019, 5th December 2019, 13th February 2020, 17th September 2019, 7th April 2022 and 16th June 2022.</p> <p>The Clinical Registry briefings was previously discussed at the IGARD COVID-19 response meeting on the 22nd September 2020.</p> <p>Application: This was an amendment application.</p> <p>The amendment is for all Integrated Care Boards (CBs) in England to receive Clinical registries for commissioning data.</p> <p>Should the application be approved by NHS England, further details would be made available within the Data Uses Register.</p>	

	<p>Outcome of discussion: The group were supportive of the application, with some caveats, and wished to draw to the attention of the SIRO the following comments:</p> <p>5.7.1 The independent advisers noted that when the Clinical Registries for Commissioners_– Briefing Paper was reviewed by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) on the 16th June 2022; a request was made for an updated / finalised copy of the briefing paper, following comments / feedback provided by IGARD. Noting that this had not been provided, the independent advisers reiterated the request for a final version of the briefing paper to be provided, that will address the points raised previously.</p> <p>ACTION: NHS England to provide a copy of the updated Clinical Registries for Commissioners briefing paper either out of committee (OOC) or tabled at a future meeting</p> <p>5.7.2 The independent advisers noted that if the underlying data sharing agreements (DSA) were updated to include “research”, this would have a significant impact on the utilisation of this data, noting many registries have special requirements if the data they gather is to be used for research.</p> <p>5.7.3 The independent advisers advised that it is essential that the transparency materials of the relevant registries are updated to encompass sharing data for commissioning.</p>	<p>NHSE</p> <p>MB/DE</p>
6	<p>OpenSAFELY</p> <p>Dickie Langley advised the group that there is a new Health Service (Control of Patient Information (COPI)) Regulations 2002 Notice from the Secretary of State, specifically in relation to the OpenSAFELY service (an NHS England service which carries out research using GP and non-GP data); with an expiry date of 1st July 2023.</p> <p>The group were advised that NHS England is working with the GP profession to put the OpenSAFELY service on a new legal basis (the COVID-19 Public Health Directions), before the 1st July 2023.</p> <p>Dickie advised that NHS England expects to engage with AGD at a future AGD meeting on the OpenSAFELY service; and independent advisers were asked what information they might wish to see as part of that discussion; in addition to the legal basis and data protection risks (the Data Protection Impact Assessment, DPIA).</p> <p>The independent advisers advised that, in addition to the future discussion points raised, they would also like to discuss transparency (Data Provision Notice (DPN) and communication materials), if there are plans to expand this beyond the purpose of COVID-19, and whether all COVID-19 research would be covered by regulation 3 of COPI (given that medical research is covered by regulation 5).</p> <p>The group thanked Dickie for the verbal update and looked forward to a further discussion at a future AGD meeting.</p>	
Any Other Business		
7.1	<p>NHS England DARS application backlog</p> <p>Michael Chapman and Terry Service advised the group that they would be bringing a paper to the next AGD meeting, on how to ensure that AGD time is focused on applications that increase the risk profile</p>	

7.2	<p>of NHS England's processing of patient data. The aim is to make best use of limited agenda time and progress the large volume of applications in the system.</p> <p>The group were advised that NHS England will provide a paper for discussion detailing a proposed assurance approach that would focus advice on new applications and higher risk amendments and renewals. This builds on discussions with IGARD in 2022 with adjustments based on feedback from IGARD and subsequently AGD.</p> <p>The group noted the verbal update and looked forward to receiving the paper for discussion at the next AGD meeting.</p> <p>AGD minutes interim ratification</p> <p>The group noted the quoracy issues with ratifying the draft AGD minutes from the 20th April 2023, in the AGD meeting on the 27th April 2023 because the draft minutes had not been reviewed by an NHS England representative(s).</p> <p>The group agreed that as interim measure, and until a Standard Operating Process was in place; the AGD SIRO representative would review / confirm contentment or suggested amendments on behalf of the AGD NHS England representatives only where an NHS England representative(s) was unable to review the draft minutes prior to the next meeting of AGD, when ratification would take place.</p>
8	<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>