

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 9th March 2023

09:30 – 16:00

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser
Maria Clark (MC)	Lay Member Adviser (not in attendance for item 4.4)
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
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Michael Chapman (MCh)	Data and Analytics representative (not in attendance for item 2.3)
Garry Coleman (GC)	Senior Information Risk Owner (SIRO) representative
Dave Cronin (DC)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 4.4)
Dr Arjun Dhillon (AD)	Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn) (in attendance for items 4.4 to 4.5)
Louise Dunn (LD)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 4.5)
Duncan Easton (DE)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 4.3)
Dickie Langley (DL)	Data Protection Officer (DPO) representative (Delegate for Jon Moore)
Sara Lubbock (SL)	Data Access Request Service (DARS) (Observer: item 4.4)
Shaista Majid (SM)	Data Access Request Service (DARS) (Presenter: item 4.3)
Karen Myers (KM)	Secretariat Team

Dr. Jonathan Osborn (JO)	Caldicott Guardian Team representative (not in attendance for items 4.4 to 4.5)
Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: items 4.1 to 4.2)
James Watts (JW)	Data Access Request Service (DARS) (Presenter: item 4.5)
Anna Weaver (AW)	Data Access Request Service (DARS) (Presenter: items 4.1 to 4.2)
Vicki Williams (VW)	Secretariat Team
Clare Wright (CW)	Data Access Request Service (DARS) (Presenter: item 4.4)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Jon Moore (JM)	Data Protection Officer (interim)

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); Privacy, Transparency, Ethics and Legal (PTEL); the Caldicott Guardian; and the SIRO.
- Attendees would not be listed as “members” in minutes during the transitional period;
- NHS England representatives would not, during the transitional period, be formally part of any consensus that is reached, but would be active participants in the meeting;
- It was agreed to use the Data Access Request Service (DARS) Standards / Precedents in relation to applications for external data sharing.

The attendees present at the meeting considered the proposal put forward by the NHS England SIRO Representative and, as no objections were raised, it was agreed that the meeting would proceed on this basis.

	Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.	
2	Review of previous AGD minutes: The minutes of the 2 nd March 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.	
3	Declaration of interests: Maria Clark noted professional links to the University of York (NIC-682554-L6G6Q), but noted no specific connection with the application or staff involved and it was agreed this was not a conflict of interest. Dr. Robert French noted professional links to Cardiff and Vale University Health Board (NIC-682554-L6G6Q), but noted no specific connection with the application or staff involved and it was agreed this was not a conflict of interest. Paul Affleck noted professional links to the University of Leeds (NIC-387580-W0W5T-v0.15) but noted no specific connection with the application or staff involved and it was agreed this was not a conflict of interest.	
4. EXTERNAL DATA DISSEMINATION REQUESTS:		
4.1	Reference Number: NIC-361864-N8P1S-v0.19 Applicant: Newcastle University Application Title: Minimally invasive thoroscopically-guided right minithoracotomy versus conventional sternotomy for mitral valve repair: a multicentre randomised controlled trial (UK Mini Mitral). Presenters: Anna Weaver SAT Observer: Kimberley Watson Application: This was a new application. The purpose of the application is for a study that will compare heart surgery operations (sternotomy & mini thoracotomy) in 327 patients, to see how well they recover and return to normal activities. The trial's primary objective is to compare the two different types of surgery. 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 significant points: 4.1.1 In respect of the consent materials, the independent advisers noted that version 1 referred to the University of Durham in respect of taking the lead / managing the research, and that Newcastle University was briefly referred to in respect of the health economists; and that this information differed in later versions of the consent materials. The independent advisers suggested that the applicant made the Research Ethics Committee (REC) aware of this update to the consent materials. 4.1.2 In addition, the independent advisers recommended that further engagement with participants was undertaken, to ascertain whether or not members of the cohort that	

<p>consented under version 1 of the consent materials would be surprised that Newcastle University were now the Data Controller and not the University of Durham.</p> <p>4.1.3 The independent advisers queried the statement within the honorary contract that the Newcastle University would take “...<i>all appropriate disciplinary action promptly in the event of an unauthorised disclosure or breach of confidence by the USERS in relation to the NHS Digital Data...</i>”. Noting that the honorary contract was for employees of the University of Durham, it was suggested by the independent members that the honorary contract was amended to reflect that the University of Durham would take appropriate disciplinary action and not Newcastle University.</p> <p>ACTION: NHS England to provide a copy of the honorary contract internal assessment criteria to AGD.</p> <p>4.1.4 The independent advisers noted the statement within section 1(b) (Data Controller(s)) “<i>*DSPT 21/22 - Approaching Standards (Plan Agreed)</i>” for South Tees Hospitals NHS Foundation Trust; and advised that section 1 (Abstract) was updated with further clarification as to why the DSPT was not fully met, as this was currently unclear.</p> <p>*Data Security and Protection Toolkit (DSPT)</p> <p>4.1.5 In addition, noting the special condition in section 6 (Section 6) relating to the DSPT; the independent advisers suggested that this was updated further, to provide further specificity of what was required to ensure the data supplied under the agreement is not compromised where the DSPT standards are not met, for example, staff training for anyone accessing the data supplied under this agreement.</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>4.1.7 The independent advisers noted and commended the efforts taken by the applicant on the patient and public involvement and engagement (PPIE); and noted the potential valuable and impactful outcomes from this research.</p> <p>4.1.8 The independent advisers noted the references within section 5 (Purpose / Methods / Outputs) to the recruitment, however advised that it was hard to determine whether recruitment had stopped or was ongoing; and suggested that section 5 was updated to ensure that where recruitment was referred to, it was clear that this had now ended.</p> <p>4.1.9 The independent advisers queried the reference in section 5(a) (Objective for Processing) to Newcastle University being a Data Processor; and noting that this was incorrect, advised that this was updated to reflect that Newcastle University was a Data Controller.</p> <p>4.1.10 In addition, the independent advisers noted the reference in the honorary contract to the University of Durham working on behalf of Newcastle University as a ‘separate’ Data Processor; and advised that this was updated to correctly reflect that the University of Durham were simply a Data Processor.</p> <p>4.1.11 Noting the reference in section 5(b) (Processing Activities) that the Data Processors would “...<i>involve an independent panel of experts to review HES data at their local Trusts to help determine if events identified can be deemed mitral valve-related</i>”; the independent advisers asked that further clarification was provided as to what the local Trusts would be doing, in line with the protocol.</p>	<p>NHSE</p>
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	<p>4.1.12 The independent advisers noted reference to “<i>gender</i>” in section 5 and asked that it was clarified if it was actually “<i>sex</i>”, since they were not interchangeable fields and the group noted that only a very small proportion of NHS England datasets collected “<i>gender</i>”.</p> <p>4.1.13 The independent advisers queried the expected benefit in section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care) that specifically referred policy being impacted / changed, and advised that this was updated with further clarification of how the findings will directly impact the policy, in line with NHS Digital DARS Standard for Expected Measurable Benefits.</p> <p>4.1.14 In addition, noting the reference in section 5(d) (ii) to the findings being disseminated in the summer of 2023, the independent advisers suggested that this date was reviewed and amend as appropriate as this date may now be incorrect.</p>	
4.2	<p>Reference Number: NIC-606084-D1D6T-v0.21</p> <p>Applicant: University of Cambridge</p> <p>Application Title: Genetic risk factors for cerebral small vessel disease - Long term health follow up</p> <p>Presenter: Anna Weaver</p> <p>SAT Observer: Kimberley Watson</p> <p>Application: This was a new application.</p> <p>The purpose of the application is to answer the following research question: can clinical, magnetic resonance imaging (MRI) and genetic determinants which predict future stroke, and dementia be identified in patients with Cerebral small vessel disease (SVD) by following up the study participants every two years?</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 wished to draw to the attention of the SIRO the following significant points:</p> <p>4.2.1 The independent advisers noted the internal application assessment form, provided as a supporting document, and noting that this was a pilot, referred to a study-specific privacy notice; and queried whether the patient information sheet, consent materials and other communications with the cohort met all the UK General Data Protection Regulation (UK GDPR) transparency obligations. If the UK GDPR transparency obligations had been met, then the independent advisers advised that a study-specific privacy notice would not be required.</p> <p>4.2.2 If the UK GDPR transparency obligations were not met, then the independent advisers advised that a study-specific privacy notice may be required, and that this would need to be shared with the cohort.</p> <p>4.2.3 The independent advisers suggested that NHS England may wish to consider updating the questions and answers (Q&A) for the internal assessment form, for example, to ensure various options were provided in respect of transparency, to the applicant, depending on the answers provided (as highlighted above).</p> <p>ACTION: NHS England to discuss the Q&A process for the internal assessment form at a future AGD meeting.</p>	NHSE

<p>4.2.4 In addition, the independent advisers queried whether the applicant was aware of their UK GDPR transparency obligations, and met them, for example, via a combination of transparency materials to the cohort.</p> <p>4.2.5 The independent advisers noted the statement within section 1(b) (Data Controller(s)) in respect of the Data Security and Protection Toolkit (DSPT) “<i>Standards Not Fully Met (Plan Agreed)</i>” for Cambridge University Hospitals NHS Foundation Trust; and advised that section 1 (Abstract) was updated with further clarification as to why the DSPT was not fully met, as this was currently unclear.</p> <p>4.2.6 In addition, noting the special condition in section 6 (Section 6) relating to the DSPT; the independent advisers suggested that this was updated further, to provide further specificity of what was required to ensure the data supplied under the agreement is not compromised where the DSPT standards are not met, for example, staff training for anyone accessing the data supplied under this agreement.</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>4.2.7 The independent advisers noted the information provided in section 4.5 (Evidence Assessment) of the internal application assessment form, in respect of the cohort members being updated when attending a recruitment centre and collecting a newsletter; and queried whether the applicant had considered other ways of how they will keep in touch with the cohort in the future.</p> <p>4.2.8 In addition, the independent advisers noted the information in section 3.4 (Data Subjects) of the internal application assessment form, that stated the original consent materials did not reference NHS Digital (now NHS England) data. Noting that the original consent materials had not been shared the group, the independent advisers queried whether NHS England data may be obtained via the original consent materials; and confirmed that they were unable to offer an opinion on this, since they had not been given sight of the original consent materials.</p> <p>4.2.9 The independent advisers noted the exclusion criteria, particularly those under the age of 18, and those who have lost capacity to consent; and asked that further justification of this was provided in section 5(a) (Objective for Processing), including, but not limited to, any potential bias and impact of the study outputs.</p> <p>4.2.10 In addition, noting that a significant number of cohort members may lose the capacity to consent, the independent advisers noted the potential loss of a number of valuable cohort members; and suggested that the applicant review this (and consider whether existing consent is sufficient, or whether consultee advice could be used).</p> <p>4.2.11 The independent advisers noted that the application referred to different maximum cohort sizes within the application; and suggested that these were reviewed, and updates were made as may be necessary to reflect the correct maximum cohort size.</p> <p>4.2.12 In addition, noting the fluctuation of the cohort sizes over time; the independent advisers advised that section 5 (Purpose / Methods / Outputs) was updated with further clarity of the reason for this, for example, due to cohort members passing away.</p> <p>4.2.13 The independent advisers queried whether any patient and public involvement and engagement (PPIE) had been undertaken; and if so, suggested that for transparency, section 5(a) was updated with clarification.</p>	
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	<p>4.2.14 The independent advisers noted the data minimisation undertaken had not been undertaken by code sets; and suggested that NHS England consider if it is pragmatic and / or advisable to do further data minimisation at source, as opposed to over-processing of the data.</p> <p>ACTION: The group to discuss data minimisation at a future AGD meeting, for example. where the data minimisation will be undertaken, who will undertake the data minimisation, for example, applicant versus NHS England, the legal basis and the nature of the data.</p> <p>4.2.15 The independent advisers noted reference to “<i>gender</i>” in section 5 and asked that it was clarified if it was actually “<i>sex</i>”, since they were not interchangeable fields and the group noted that only a very small proportion of NHS England datasets collected “<i>gender</i>”.</p> <p>4.2.16 Noting the conflicting information in section 5(a) and section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care) in respect of the percentage of strokes caused by cerebral small vessel disease, i.e. quarter versus a fifth; the independent advisers asked that this was reviewed and updated / aligned to reflect the correct figure.</p> <p>4.2.17 The independent advisers noted the reference to identification of individuals who might receive “<i>novel therapies</i>” as a benefit of the work in section 5(d) (ii), and advised that this was updated to make clear that this means recruitment into research studies, and that there are currently limited therapeutic interventions available to those identified as being at high risk of dementia; and that while the longer-term benefit may be to future patients, and the current benefit will predominantly be to researchers.</p> <p>4.2.18 Noting that the funding will expire at the same time as the expiry of the data sharing agreement (DSA); the independent advisers suggested that NHS England may wish to consider whether the DSA should end at the same time as the funding ended or whether there should be a staggered approach.</p>	NHSE
4.3	<p>Reference Number: NIC-387580-W0W5T-v0.15</p> <p>Applicant: University of Leeds</p> <p>Application Title: HERO (Home-based Extended Rehabilitation of Older people) trial.</p> <p>Presenter: Shaista Majid</p> <p>SAT Observer: Duncan Easton</p> <p>Application: This was a new application.</p> <p>The purpose of this application is for an individually randomised controlled multi-centre trial, to determine the clinical and cost effectiveness of a home- based exercise intervention for older people, with frailty as extended rehabilitation following acute illness or injury, including embedded process evaluation.</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 wished to draw to the attention of the SIRO the following significant points:</p> <p>4.3.1 The independent advisers queried whether any cohort members consented under version 1 of the consent form, and advised that they were unable to determine from the application / consent review whether any cohort members were consented under version 1 of the consent form, and were therefore unable to provide a view of this.</p>	

	<p>4.3.2 In respect of all versions of the consent materials, the independent advisers advised NHS England that an assessment should be carried out with the relevant patient information sheets to determine which cohort members were consented under which consent form / PIS and whether they met the common law duty of confidentiality; noting that the current consent review provided an general overview but did not distinguish between which cohort members consented under which consent materials.</p> <p>4.3.3 The independent advisers queried the role of the University of Exeter, and whether they had any data controllership responsibilities, noting the Co-Investigator and Health Economist were employed by the University of Exeter; plus the information provided within the protocol. Noting the verbal update from NHS England, that this had already been discussed with the applicant, the independent advisers suggested that this was explored and documented further in terms of the University of Exeter's responsibilities in respect of the research, and in line with NHS Digital DARS Standard for Data Controllers.</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>4.3.4 The independent advisers noted their support for the study and the potential benefits; and were supportive of the study proceeding.</p> <p>4.3.5 In addition, the independent advisers noted and commended the efforts taken by the applicant on their PPIE.</p> <p>4.3.6 The independent advisers noted the exclusion criteria outlined in section 5(a) (Objective for Processing), and suggested that this was aligned with the protocol, for example, the references to "<i>medical conditions</i>" versus "<i>palliative care</i>".</p> <p>4.3.7 In addition, the independent advisers also asked that a justification was provided of the exclusion criteria.</p> <p>4.3.8 The independent advisers queried the cohort numbers stated, i.e. 743 recruited and 701 consented; and asked that further clarification was provided in respect of the 42 cohort members initially recruited who did not then provide consent, for example, did they decline to provide consent, or were they included via consultee advice / power of attorney.</p> <p>4.3.9 The independent advisers noted the reference in section 5(b) (Processing Activities) to the data being "<i>pseudonymised</i>"; and suggested that this was amended or removed, noting that this is incorrect if the researcher is holding the study ID with no additional contractual obligations in terms of holding the data separately.</p>	
4.4	<p>Reference Number: NIC-77142-Q4D1D-v1.5</p> <p>Applicant: University Hospitals Birmingham NHS FT</p> <p>Application Title: Epidemiology of Cancer after solid Organ Transplantation – EPCOT study</p> <p>Presenter: Claire Wright</p> <p>SAT Observer: Dave Cronin</p> <p>Observer: Sara Lubbock</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented at the IGARD meeting on the 9th April 2020.</p> <p>Application: This was an application coming for a renewal, extension and amendment.</p>	

	<p>The amendments are to 1) authorise a further cohort linkage which was not previously approved under v0.16. but was omitted in error by the applicant from their original application; and 2) to change from “Civil Registration of deaths – Secondary Care Cut” to “Civil Registration of Deaths”.</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 wished to draw to the attention of the SIRO the following high-level comments:</p> <p>4.4.1 The independent advisers advised that the applicant notify / update the Health Research Authority Confidentiality Advisory Group (HRA CAG), noting that the Health and Social Care Information Centre (HSCIC) / NHS Digital will not be undertaking the data linkage, and instead the data linkage will be undertaken by NHS Blood and Transplant, which differs from the HRA CAG support documentation provided.</p> <p>4.4.2 In addition, the group advised that they did not identify any issues with the change of organisation undertaking the linkage, but noted that HRA CAG would need formally notifying, and if content, the s251 support would need amending as per HRA CAG process.</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>4.4.3 The independent advisers queried the statement in section 5(a) (Objective for Processing) <i>“The data requested are required for the analysis to obtain the outcomes for the aims of the study, including; comparing of observed and expected risks of specific causes of death, comparing of observed and expected risks of specific cancer types post-transplantation and estimating risk of morbidity requiring hospitalisation both generally and that associated with the development of post-transplantation cancer”</i>; and asked that further clarification was provided on the reference to <i>“both generally”</i> and what was being compared, as this was unclear.</p> <p>4.4.4 The independent advisers queried the opt-out arrangements, and suggested that for the purpose of transparency, further clarification was provided within the application, as to what opt-outs were being applied and who was applying the opt-outs.</p> <p>4.4.5 The independent advisers noted that the protocol had not been provided as a supporting document, and advised that for any future AGD review, this was provided as a supporting document.</p>	
4.5	<p>Reference Number: NIC-682554-L6G6Q-v0.2</p> <p>Applicant: University of York</p> <p>Application Title: End of Life Care for Infants, Children and Young People: a mixed methods evaluation of current practice in England</p> <p>Presenter: James Watts</p> <p>SAT Observer: Louise Dunn</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study, to use data collected as part of clinical care, about around 4,000 children, teenagers and young adults treated in cancer services in England who died between 2012- 2020. Using routinely collected data sources, the University of York will assess whether the use of ‘high intensity’ treatments in children, teenagers or</p>	

<p>young adults who have died from cancer varies depending on the model of End-of-Life care that their service delivered.</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 wished to draw to the attention of the SIRO the following high-level comments:</p> <p>4.5.1 The independent advisers noted that there will be a study-specific opt-out, however, asked that the applicant provide further information of this to NHS England. The group noted that the study-specific opt-out was important, noting the limited ability of parents to exercise the NDRS or the National Data Opt-out in respect of deceased children, particularly in light of the age of some of the cohort members, for example, noting that this includes individuals up to the age of 25.</p> <p>4.5.2 In addition, the group suggested that the applicant should give further consideration to wider publicity in respect of the study-specific opt-out.</p> <p>4.5.3 The independent advisers suggested that NHS England confirm with Intensive Care National Audit and Research Centre (ICNARC) and Paediatric Intensive Care Audit Network (PICANet) that they will be applying the NDO in line with the NDO Policy.</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>4.5.4 The independent advisers noted the important research and were supportive of the outputs that may be generated and acted on.</p> <p>4.5.5 Noting that the ICNARC flow of data will include the details of both living and deceased children, the independent advisers suggested that, for transparency, the application was updated accordingly to reflect this.</p> <p>4.5.6 The independent advisers noted the verbal update from NHS England that the UK General Data Protection Regulation (UK GDPR) had been incorrectly removed from the application for the processing of the ICNARC data; and advised that the application should be updated as necessary to reflect the correct UK GDPR legal basis for the processing of the ICNARC data.</p> <p>4.5.7 In addition, the independent advisers suggested that the applicant update their privacy notice, to reflect the processing of ICNARC data and that this includes the details of both living and deceased children.</p> <p>4.5.8 The independent advisers also advised that the applicant update their privacy notice to be clear that there will be some processing of the data without consent and will have s251 support; and that where consent has been obtained, this is made clear, i.e. the parameters of the workstream.</p> <p>4.5.9 The independent advisers queried the role of the Co-Investigators; and noted the verbal update from NHS England that this had been explored with the applicant and it had been determined that they were not Data Controllers. The independent advisers advised that further clarification / a summary of the discussion(s) with the applicant was noted on the application assessment form, for future reference.</p> <p>4.5.10 Noting the statement in section 5(b) (Processing Activities) <i>“The data will be accessed onsite at the premises of the University of York and by authorised personnel via remote</i></p>	
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	<p>access”; the independent advisers 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 in relation to the listed territory of use <i>(as agreed at the AGD meeting on the 2nd February 2023)</i>.</p> <p>4.5.11 The independent advisers queried the reference to “<i>power brokers</i>” in section 5(d) (Benefits) (ii), and asked that this was removed as it was not an appropriate description.</p> <p>4.5.12 In respect of the expected benefits in section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care), the independent advisers suggested that this was edited to ensure this only contained yielded benefits and not outcomes; and that any outcomes should be moved to section 5(c) (Specific Outputs Expected) in line with NHS Digital DARS Standard for Expected Outcomes and NHS Digital DARS Standard for Expected Measurable Benefits.</p>	NHSE
EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
5.1	<p>Reference Number: NIC-172334-W0G2L-v4</p> <p>Applicant: Imperial College London</p> <p>Application Title: Effectiveness and Value for Money of Prescribed Specialised Services Commissioning for Quality and Innovation (CQUIN) - Social Network Research Amendment</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented at the IGARD meetings on the 17th May 2018, 6th February 2020 and the 29th September 2022. The application and relevant supporting documents were previously presented at the AGD meeting on the 9th February 2023.</p> <p>Application: The purpose of the application is to use data previously disseminated under this data sharing agreement (DSA) for the PSS CQUIN project, for this new project the Social Network Research Study.</p> <p>Outcome of discussion: The group noted that this application had been submitted to the group for review, at the request of the SIRO representative, following the previous AGD review on the 9th February 2023, to seek advice on the timelines quoted by the customer; and to whether attendees had any additional contact escalation points within the British Medical Association (BMA) to address a previous point made by the group. The Group thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>5.1.1 The independent advisers noted that the applicant had acted on previous advice from IGARD, in respect of liaising with the BMA Consultants Committee UK; and acknowledged that a response had not yet been received.</p> <p>5.1.2 An independent adviser confirmed that they would share further BMA contact details with NHS England colleagues out of committee.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
5.2	<p>Reference Number: NIC-381634-X8H0H-v5.2</p> <p>Applicant: DHSC (UK Health Security Agency)</p> <p>Application Title: D24 - Request to share data for Covid-19 purposes – HOSTED Project</p>	

	<p>Previous Reviews: The application and relevant supporting documents had previously been presented at the IGARD business as usual (BAU) meeting on the 18th March 2021. Aspects of this application had been previously seen by the IGARD – NHS Digital COVID-19 Response meeting on the 28th September 2021.</p> <p>Application: The purpose of the application is for a DHSC – UK Health Security Agency (UKHSA) surveillance system on household transmission of COVID-19 to enhance the national public health surveillance of Covid-19 infections in the population of England.</p> <p>Outcome of discussion: The group noted that the application had been submitted for information, in respect of an administrative error, whereby the date that data is allowed to flow up until, was not updated in version 4 from 31st March 2023 to the 25th August 2023.</p> <p>NHS England were seeking views from the AGD on whether it was appropriate and logical for this administrative fix to be undertaken via a simple amendment; and that Security Assurances of the Data Processor and Data Controller were being checked and verified, Storage and Processing locations have been removed as per the new DARS process, but no other substantive changes have been made to the DSA, including the expiry date.5.2.1 The group noted and thanked NHS England for the written update and advised that they had no additional comments to make.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
AGD Operations		
6	<p>Standard operating procedures</p> <p>The ongoing forward plan of work for creating Standard Operating Procedures was discussed.</p>	To note
7	<p>New Operational Actions & those carried forward from previous meetings of AGD:</p> <p>7.1 Inside Scope of IR35</p> <p>Garry Coleman provided a verbal update in respect of IR35 and the impact on independent advisers who were previously on IGARD, noting that they would fall inside scope of IR35 from the 1st April 2023.</p> <p>In addition, Garry Coleman advised that consideration was being given to an uplift to the current day rate for independent advisers and in line with business case policy and from the 1st April 2023</p> <p>The independent advisers noted the verbal update from NHS England, and noted that this would impact both the current group of advisers, and future recruitment to the group.</p> <p>The independent advisers noted that they would need to consider their individual circumstances due to the impact of the IR35 change.</p> <p>NHS England noted the position and concerns raised by independent advisers, and welcomed further discussions in the coming days / weeks.</p> <p>Both independent advisers and NHS England noted a significant risk to AGD, noting that independent advisers would be inside scope of IR35 from the 1st April 2023; and therefore individual decisions on whether to continue on this basis would need to be confirmed by the 31st March 2023 to the AGD Secretariat.</p>	

7.2	<p>DARS Standards and Precedents</p> <p>Michael Chapman advised the group that there was an ongoing programme of work to review the DARS Standards and Precedents where appropriate to align with the AGD responsibilities once the statutory guidance had been approved; and that a list of the Standards and Precedents would be shared with the group in due course.</p> <p>It was also confirmed that there would be a structured approach to reviewing / updating the Standards and Precedents, and that further information on the approach would be shared with the group.</p>	
7.3	<p>DARS Commercial Purpose Standard DARS Expected Measurable Benefits Standard</p> <p>It was agreed that further discussions would take place out of committee between NHS England and a small group of independent advisers in respect of updating the DARS Commercial Purpose and Expected Measurable Benefits Standards; and that a further update would be provided at a future AGD meeting.</p>	
7.4	<p>AGD Terms of Reference (ToR) and statutory guidance</p> <p>Michael Chapman noted that the Department for Health & Social Care was still receiving comments from various organisations and so the AGD ToR and statutory guidance were still in draft; and the next steps were further stakeholder engagement.</p> <p>The independent advisers noted that they would welcome the opportunity to have sight of an update draft prior to this going to Ministers for review / sign-off. NHS England advised that they would see if this was a possibility and provide an update as soon as possible.</p>	
Any Other Business		
	<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>	