

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 18th January 2024

09:30 – 15:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Susheela Andani (SA)	Information Governance Specialist, Privacy, Transparency and Trust (PTT), Delivery Directorate (Observer: items 1 to 10.1)
Michael Chapman (MC)	NHS England Data and Analytics Representative (in attendance for items 4.4, 4.5, 5.1, 5.2, 5.3, 6, 7 8, and 10.1 to 10.6) (Presenter: items 10.1 to 10.3, 10.5)
Garry Coleman (GC)	NHS England SIRO Representative (Presenter: items 6 and 7)
James Gray (JG)	Applications Team, Data and Analytics (Observer: Item 4.1)
Narissa Leyland (NL)	NHS England Data and Analytics Representative (Delegate for Michael Chapman) (in attendance for items 1 to 4.3, and 9)
Andrew Martin (AM)	NHS England Data Protection Office Representative (Delegate for Jon Moore)
Karen Myers (KM)	AGD Secretariat Officer, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: item 10.6)
Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Vicki Williams (VW)	AGD Secretariat Manager, Privacy, Transparency and Trust (PTT), Delivery Directorate (Presenter: item 8)

INDEPENDENT ADVISERS NOT IN ATTENDANCE:

Paul Affleck (PA)	Specialist Ethics Adviser
Claire Delaney-Pope (CDP)	Specialist Information Governance Adviser
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
Dr. Maurice Smith (MS)	Specialist GP Adviser
Miranda Winram (MW)	Lay Adviser

NHS ENGLAND STAFF NOT IN ATTENDANCE:

Jon Moore (JM)	NHS England Data Protection Office Representative
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1	<p>Welcome and Introductions</p> <p>The NHS England Senior Information Risk Owner (SIRO) Representative, noting the Advisory Group for Data (AGD) Terms of Reference (ToR) had not yet been agreed, proposed that:</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 representatives covering the offices of the Data Protection Officer (DPO); the Caldicott Guardian; Data and Analytics; and the SIRO.• Attendees would not be listed as “members” in minutes during the transitional period;• NHS England representatives would not, during the transitional period, be formally part of any consensus that is reached, but would be active participants in the meeting;• It was agreed to use the Data Access Service (DAS) Standards / Precedents in relation to applications for external data sharing. <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>

	The minutes of the 11 th January 2024 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.	
3	<p>Declaration of interests:</p> <p>Jenny Westaway noted that she had undertaken some paid contract work for Templar Executives to contribute to the development of a general e-learning course on data protection for Our Future Health. It was agreed this did not preclude the Jenny from taking part in the discussions about the Our Future Health application (NIC-414067-K8R6J).</p> <p>Michael Chapman noted a personal and professional link to one of the investigators involved in NIC-682571-Q6Z6Y (University of Leeds). It was agreed this did not preclude Michael from taking part in the discussion about this application.</p>	
EXTERNAL DATA DISSEMINATION REQUESTS:		
4.1	<p>Reference Number: NIC-414067-K8R6J-v5.2</p> <p>Applicant: Our Future Health</p> <p>Application Title: Our Future Health Recruitment Programme</p> <p>Observer: James Gray</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 2nd November 2023, 28th September 2023, 10th August 2023, 13th July 2023, 29th June 2023, 11th May 2023, 20th March 2023 and the 2nd March 2023.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 1st December 2022, 17th November 2022, 26th May 2022 and the 5th May 2022.</p> <p>Linked applications: This application is linked to NIC-411795-X5N2V</p> <p>Application: This is an amendment application.</p> <p>The purpose of the application is to help people live healthier lives for longer through better prevention, earlier detection and improved treatment of diseases. The Our Future Health research programme will aim to speed up the discovery of new methods of early disease detection, and the evaluation of new diagnostic tools, to help identify and treat diseases early when outcomes are usually better.</p> <p>This amendment is to increase the invitation mail-outs from approximately 20 million to approximately 25 million.</p> <p>NHS England were seeking advice on the following points:</p> <ol style="list-style-type: none">1. The progress made by Our Future Health and their responses to previous AGD advice.	

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 additional data (five million mailouts) and wished to draw to the attention of the SIRO the following substantive comments:

4.1.1 The independent advisers noted that support from the Health Research Authority Research Ethics Committee (HRA REC), only appeared to be in place for the 12 million mailouts, and queried whether support was in place for the 20 million mailouts previously requested / received; and for the additional 5 million mailouts requested under this iteration of the application. The SIRO representative advised that NHS England had received evidence of the HRA REC support for the 20 million mailouts, however evidence of the HRA REC support had not been provided for the additional 5 million mailouts as per this application, and advised that this would need addressing (in addition to any other points) before any additional data would flow. The group noted the verbal update from the SIRO representative and supported the request from the applicant for HRA REC support for the additional 5 million mailouts, and suggested that this was updated to NHS England's customer relationships management (CRM) system for future reference.

In response to points 1

4.1.2 The independent advisers noted that they had previously suggested that further work should be undertaken by OFH, to ensure the commercial involvement was made explicitly clear to the cohort; and noted that whilst some work had been undertaken, the results / responses of the research undertaken by OFH with the cohort suggested that further work should be undertaken in terms of explaining / transparency of the commercial partnerships with both the existing cohort and for any prospective cohort.

4.1.3 In addition, the group also reiterated previous advice, that the applicant should amend the cohort letters to include **all** of the partners' logos, and not just the NHS partnership logo.

4.1.4 The independent advisers noted that they had previously queried the worldwide use of data for those who had consented, and queried whether the public understand that once they participate in the Programme that their data will be used worldwide; and noted that although OFH do a follow-up with participants a month after providing consent to clarify they are content with the information received on the Programme, OFH did not specifically ask whether participants were aware of the worldwide sharing of their data.

4.1.5 The independent advisers reiterated previous concerns about the specific cohort letters shared with AGD, noting that the content of some of the letters may be perceived as being coercive or misleading, including, but not limited to, the suggested involvement / encouragement from the NHS to potential participants. The SIRO representative advised the group that the appropriate channels had been

	<p>followed by OFH to obtain permission to use the NHS logo on the OFH transparency materials. The group noted the verbal update.</p> <p>4.1.6 Separate to this application: the independent advisers queried whether there was an NHS England policy document that could be shared with the group, that outlines the process for seeking permission to use the NHS logo; and if so, whether this could be shared with the group for future reference and to support any future discussions.</p> <p>ACTION: The SIRO Representative to clarify whether there is an NHS England policy document that could be shared with the group, that outlines the process for seeking permission to use the NHS logo</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 SIRO representative advised the group that NHS England were looking only at the amendments requested under this iteration of the application, i.e. the additional 5 million mailouts; and were not looking at any possible future amendments at this point. The group noted the verbal update.</p> <p>4.1.8.1 The specialist academic / statistician independent adviser, noted the information in the progress report provided as a supporting document (SD19.3), provided only limited support for the proposed approach and offered to produce a one page summary detailing limitations and further questions. The SIRO representative noted and supported the production of a paper by the specialist academic / statistician adviser with some proposed additional follow-up questions about the evidence and analysis in the progress report and to further examine the case for targeted letters with names and addresses; and suggested that the applicant gave suitable consideration to the points within the paper. The independent advisers were supportive of this approach by NHS England.</p> <p>ACTION: The specialist academic / statistician independent adviser to produce a paper with some proposed additional follow-up questions, that would further examine the case for targeted letters with names and addresses.</p> <p>4.1.8.2 The specialist academic / statistician independent adviser also queried whether it would be viable for addresses only to be shared with OFH as an alternative to publicly available address file (PAF) or other sources of addresses for the dear householder letters. The SIRO representative advised that this would be challenging because of the additional approvals required from HRA CAG.</p> <p>4.1.9 The independent advisers noted that there had been a change to the data products in section 3(b) (Additional Data Access Requested) of the application; and were advised by the NHS England observer that the products outlined in section 3(b) were not available for earlier iterations of the application, however noted that the products added to the application are more appropriately designed for the purpose of the Programme and that there were no changes to the outputs, risks etc. The</p>	<p>GC</p> <p>RF</p>
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	<p>SIRO representative noted that it was difficult for the group to provide advice on products that they had not received any briefing on (as per the usual process), and asked that a briefing was provided for all new data products that had onboarded recently for discussion at a future AGD meeting.</p> <p>ACTION: NHS England's Data and Analytics to provide briefing on any new data products, including, but not limited to, the new data products included in NIC-414067-K8R6J-v5.2.</p> <p>4.1.10 The independent advisers noted the response in section 9.3 (When are outputs expected) of the internal application assessment form that stated "<i>Not applicable – this is for recruitment, not publication of a journal article</i>"; and suggested that this was discussed internally, to ensure that colleagues within NHS England's Data and Analytics were clear on the information that would need populating in an "<i>output</i>" section.</p> <p>ACTION: NHS England's Data and Analytics representative to discuss section 9.3. of the internal application assessment form with colleagues to ensure it is understood what an output is in this context and populated correctly.</p> <p>4.1.11 The group suggested that if there were further amendments to this application, then NHS England should consider bringing an updated progress report back to the group, with updates on how all of the points above are being addressed, prior to submitting an amended application.</p>	<p>NL</p> <p>NL</p>
<p>4.2</p>	<p>Reference Number: NIC-148118-VCXW9-v6.4</p> <p>Applicant: Institute of Cancer Research (ICR)</p> <p>Application Title: UK Genetic Prostate Cancer Study</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the AGD meeting on the 3rd August 2023.</p> <p>The application and relevant supporting documents were previously presented / discussed at the AGD meetings on the 8th December 2022, 10th November 2022 and the 6th October 2022.</p> <p>The application and relevant supporting documents were previously presented / discussed at the DAAG meeting in 2011 (date unknown).</p> <p>Application: This was a renewal, extension and amendment.</p> <p>The purpose of the application is for a study, which aims to find genetic changes which are associated with prostate cancer risk. If the study can find alterations in genes that increase the chances of getting prostate cancer, it may be possible in the future to use this knowledge to 1) screen other family members to see if they are also at a higher risk of developing prostate cancer; and 2) develop new prostate cancer treatments for the future.</p>	

The amendments are **1)** the addition of the s251 legal basis to address the Common Law Duty of Confidentiality (CLDoC) for any participants prior to 2009; and **2)** to allow ICR to extract and share derived data.

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

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

4.2.1 The NHS England DPO representative noted in the internal application assessment form, that the Royal Marsden NHS Foundation Trust was no longer a Data Controller, and that the application had been updated to reflect this; however, notwithstanding the questions that had been asked on this point by colleagues in the Data Access Service (DAS), suggested that in line with [NHS England's DAS Standard for Data Controllers](#), further questions were asked, to justify the Royal Marsden NHS Foundation Trust being removed as a Data Controller, for example, what has changed since 2011 (when they were considered a Data Controller), and what had prompted the review of their role, noting that this information was currently unavailable.

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

4.2.2 The group noted the two amendments outlined in the application, however noted that prior to the meeting, NHS England's Data and Analytics had advised that in relation to the second amendment "*to allow ICR to extract and share derived data*"; this was being withdrawn, and that further work would be undertaken with the SIRO representative in order to reach a conclusion on whether this had already taken place or had been proposed for the future, and that this may be resubmitted to the group at a future meeting. The group noted the request from NHS England and advised that the advice would be provided to the SIRO representative based on the removal of the second amendment.

4.2.3 The independent advisers suggested that if the application is updated to allow ICR to extract and share derived data that NHS England satisfy themselves that any commercial organisations with whom the data is being shared with (including sharing through the PRACTICAL repository) are appropriately reviewed.

4.2.4 The independent advisers queried the references in the internal application assessment form, to data being "*shared*"; and suggested that NHS England clarify who has access to the NHS England data and what the status is of this data, in particular, regarding to how the date of death data and age of death is presented, noting that this could have an impact on potential re-identification.

4.2.5 The independent advisers noted that Article 6(1)(e) (Public Task) of the UK General Data Protection Regulation (UK GDPR) had been cited as the legal basis for ICR to process the data; and noting that ICR referred to itself as a "*charity*" on its

	<p>website, suggested that section 5 (Purpose / Methods / Outputs) of the application was updated with further information as to why this was their cited legal basis, for example, is this due to ICR being part of the University of London, who is considered a Public Authority as defined under the Freedom of Information Act 2000.</p> <p>4.2.6 Noting that section 3(c) (Patient Objections) of the application was not clear on what opt-outs were being applied, the independent advisers suggested that this was reviewed and updated to be clear that for the consented cohort patient objections were not applied; and for the cohort covered under s251 opt-outs would be applied.</p> <p>4.2.7 The SIRO representative noted that the application was for a renewal and extension (and amendment) and noting that it could not be both a “<i>renewal</i>” and “<i>extension</i>” asked that the application was updated.</p> <p>4.2.8 The independent advisers noted that they would be supportive of NHS England undertaking a routine audit of this data sharing agreement (DSA).</p>	
4.3	<p>Reference Number: NIC-698171-K4M0B-v0.3</p> <p>Applicant: Home Office</p> <p>Application Title: Home Office Drugs Indicators</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for drug policy analysis and monitoring.</p> <p>The Home Office aims to improve the design and implementation of drugs policy by using evidence and analysis to better understand the drugs landscape and the impact of government policies on this landscape.</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 aims of the application, and at the request of the SIRO representative in-meeting, the group provided advice on this application, and suggested that the application be brought back to a future meeting.</p> <p>4.3.1 The independent advisers noted that the application and internal application assessment form more clearly articulate the benefit to health and care; and suggested that all of the activities outlined were reviewed and, in line with NHS England's DAS Standard for Expected Measurable Benefits and the National Data Guardian (NDG) guidance on benefits, it was made clear for each activity what the benefits to health and care were.</p> <p>4.3.2 In addition, it was suggested that a special condition be added to section 6 (Special Conditions) of the application, that any processing of the data under this application, must be connected with health and care.</p> <p>4.3.3 The independent advisers queried why unsuppressed data had been requested, and suggested that the internal application assessment form could have</p>	

provided further information on this point, and what discussions there had been between the Data Access Service (DAS) and the applicant on this point. It was suggested that the internal application assessment form was updated with a justification for requesting unsuppressed data and not suppressed data.

4.3.4 The group noted that they were supportive of the Home Office receiving the correct and necessary data to support the research questions, however, suggested that further checks were carried out by NHS England to ensure the data requested was necessary and proportionate to support the research questions outlined in the application; and whether access to the Secure Data Environment (SDE) would be more appropriate at any point.

4.3.5 Noting that the Home Office does have an Ethics Advisory Body; it was suggested by the independent advisers that the applicant approaches that body and seeks advice from them on the proposed work under this application; and that any written evidence related to this (for example if the Ethics Advisory Body reviews and supports the work, or, alternatively, declines to review the work as it is out of its review scope) was provided to NHS England and uploaded to NHS England's customer relationships management (CRM) system for future reference.

4.3.6 The independent advisers noted that Article 9(2)(g) (Reasons of substantial public interest (with a basis in law)) of the UK General Data Protection Regulation (UK GDPR) had been cited as the legal basis for the Home Office to process the data; and noting the 'high bar' that would need to be met to meet this legal basis, it was suggested that the internal application assessment form and section 5 (Purpose / Methods / Outputs) should be updated to provide a justification for using this legal basis, as opposed to using Article 6(1)(e) (Public Task) of UK GDPR.

4.3.7 The independent advisers also suggested that NHS England assure themselves, that the relevant conditions in Schedule 1 Part 1 of the Data Protection Act (DPA) 2018 had been satisfied; that this aligned with the purpose of the processing being connected to health and care, and that copy of the written confirmation was uploaded to NHS England's CRM system for future reference.

4.3.8 In addition, it was suggested that the Data Protection Impact Assessment (DPIA) was updated to address the impact on data subjects if Article 9(2)(g) was used for the processing of data under this application.

4.3.9 In addition, it was also suggested by the independent advisers that the DPIA was updated to address the impact on the data subjects and whether the views of the data subjects could be sought, for example, after being hospitalised due to serious assault.

4.3.10 It was suggested by the independent advisers that the DPIA was reviewed and updated to ensure that the data requested on children and young people was reflected / addressed, including, but not limited to, addressing any risks / mitigations

	<p>associated with the processing of this data, and the justification for requesting this data.</p> <p>4.3.11 Noting that the data would be aggregated at police force level and Local Authority level, it was suggested that this was clarified with the applicant, and that a justification was provided as to why the Home Office would need both sets of data, since in the proposed format there would be an overlap which would significantly increase the amount of small numbers in an unsuppressed extract.</p> <p>4.3.12 The independent advisers noted the information in section 5(c) (Specific Outputs Expected) of the application, outlining what will be published; however, queried if this was correct, noting the statement in the DPIA that publications required “<i>ministerial approval</i>”; and suggested that the application and DPIA were reviewed and aligned as may be required to reflect the correct information. Independent advisers noted that they would encourage publication of findings, demonstrating the public benefit of using this data.</p> <p>4.3.13 Separate to the application: the independent advisers queried whether or not any further specific contractual controls would be required, for example, in respect of any onward sharing of data.</p> <p>ACTION: The SIRO representative to clarify whether further specific contractual controls would be required, to ensure applications take into account the Digital Economy Act 2017.</p>	GC
4.4	<p>Reference Number: NIC-480151-B0M5Q-v0.15</p> <p>Applicant: University of East Anglia</p> <p>Application Title: CompreHensive geriAtRician-led MEdication Review (CHARMER) Feasibility Study</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a research programme, with a series of interlined work packages, with the aim to develop and test a way to support geriatricians (doctors working on older people’s medicine wards) and hospital pharmacists to proactively deprescribe medicines for older people whilst they are in hospital. There is an expectation from patients and carers that prescribed medicines have been reviewed for appropriateness and any inappropriate medicines stopped.</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 substantive comments:</p> <p>4.4.1 The independent advisers queried the references in the internal application assessment form to participants that have consented and “<i>enrolled</i>” under s251; and suggested that this was reviewed and updated to be clear that participants have</p>	

joined either via consent or s251 support, and that incorrect references to participants who have “enrolled” were removed.

4.4.2 In addition, it was suggested that the application and internal application form were updated to be clear how many participants have consented and how many are part of the s251 support.

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

4.4.3 The independent advisers noted in the internal application assessment form, that NHS England’s Data Access Service (DAS) had asked the applicant to update their privacy notice however no further information had been provided as to what had been suggested by DAS as amendments and asked that further information was provided to support any future discussions.

4.4.4 Noting it was not clear what DAS had said to the application with regard to the privacy notice being updated, it was suggested by the independent advisers, that the privacy notice could be updated to address how the Common Law Duty of Confidentiality has been addressed, noting that this was currently not clear.

4.4.5 The independent advisers queried whether the local sites would be updating their privacy notices, noting that there was currently only the main privacy notice; and suggested that NHS England seek further clarification.

4.4.6 The independent advisers queried the statement in the study enrolment log guide, provided as a supporting document (SD10) that stated “*If they indicate verbally to you that they wish to opt-out from the minimum dataset, please ask them if they wish to opt-out specifically for CHARMER, or all future research via the national data opt-out*”; and suggested that this was amended to be clearer that staff **cannot** exercise the National Data Opt-out on behalf of patients / potential participants.

4.4.7 It was suggested by the independent advisers that the application was clear that patient objections would **not** be applied to those participants who had provided consent.

4.4.8 Noting the statement in section 5(a) (Objective for Processing) of the application “*A Patient and Public Involvement (PPI) representative is a co-applicant*”; it was suggested that this was reviewed and either amended if the statement was incorrect; or to provide further clarity to support this statement.

4.4.9 The independent advisers noted that the standard special condition had been added to section 6 (Special Conditions) of the application, setting out the restraints of the Medicines dispensed in Primary Care (NHSBSA) data as per the NHS Business Services Authority (NHSBSA) medicines data Direction; however, noting that at the AGD meeting on the 2nd November 2023 (as part of the discussion for NIC-08472-V9S6K UK Biobank), the 16th November 2023 (as part of the discussion for NIC-568980-P9W7B University of Edinburgh) and the 7th December 2023 (as

	<p>part of the discussion for NIC-302994-C2Q2Y University of Oxford), the SIRO representative had advised that although the Direction did set out constraints of the use of data, it was not the only legal gateway that NHS England had to share data. It was therefore suggested that NHS England consider whether the NHSBSA special condition was required, dependant on which legal basis was being relied on for the processing of this data, and that the application was updated as may be appropriate.</p> <p>4.4.10 Separate to the application: the group reiterated the point made at the AGD meeting on the 7th December 2023, 16th November 2023 and the 2nd November, that for transparency and public trust, NHS England should explore how this could be explained, since the public may take at face value the constraints as set out in a Direction and as published on the website, and may not envisage NHS England using other legal powers to set aside restrictions in a Direction.</p> <p>4.4.11 Separate to the application: Noting the NHS BSA presentation to the group on the 20th July 2023, and that the SIRO representative at AGD on the 24th August 2023 had noted that the Direction was being reviewed and would be presented back to the group in due course; the group also reiterated a request made at the AGD meeting on the 7th December 2023, 16th November 2023, and the 2nd November 2023, for a note setting out the work undertaken to reach the position set out in 4.4.9 above, alongside the work to review the Direction be presented to AGD as soon as practicable. In addition to the transparency and public trust points raised in 4.4.10 above, the group queried whether this view would have retrospective or prospective impact on other applications using this dataset, or indeed any other applications where there were restrictions on use or dissemination of data due to wording in Directions.</p> <p>ACTION: NHS England SIRO representative to provide a note outlining the work undertaken to allow the applicant to use the data as outlined in the DSA, and to provide a copy of the work undertaken to review the Direction.</p>	GC
4.5	<p>Reference Number: NIC-682571-Q6Z6Y-v0.4</p> <p>Applicant: University of Leeds</p> <p>Application Title: Yorkshire Cancer Research Bowel Cancer Improvement Programme – PROMs</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a research project, where the overall aims of the programme, are to evaluate how much bowel cancer outcomes can be improved by engaging with multidisciplinary teams (MDTs), by collecting, and feeding back to them high quality performance data and providing training and supervision for specialists where a need is identified.</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 substantive comments:</p> <p>4.5.1 The independent advisers noted they were not furnished with a copy of the honorary contract and noting they were therefore reliant on the Data Access Service (DAS) assessment, noted that the internal application assessment form was not clear as to whether or not the honorary contract referred to had been assessed by NHS England, in line with NHS England's DAS Honorary Contracts Standard. The group suggested that this was clarified, and that further information be included within the internal application assessment form.</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>4.5.2 Noting that the programme of work may be extended until 2030, the independent advisers queried whether the participants that had consented under the earliest version of the consent forms were aware that their data may be processed for longer than originally advised and suggested that this may be a surprise to them. The independent advisers suggested that the applicant produce a communication plan to ensure future communication with this cohort to update them on the length of the proposed processing of their data. The independent advisers were clear that re-consent would not be necessary if there was a clear communications plan in place.</p> <p>4.5.3 The SIRO representative noted that the data was described as “<i>pseudonymised</i>”, and noting that this was incorrect as the applicant does have the means to re-identify, asked that the application was updated to correctly reflect that the data was “<i>identifiable</i>”.</p> <p>4.5.4 Separate to this application: it was suggested by the group that the NHS England Data and Analytics representative ensure that colleagues in DAS ensured that all applications correctly reflect the identifiability of any data.</p> <p>ACTION: the NHS England Data and Analytics representative ensure that colleagues in the DAS ensured that applications correctly reflected the identifiability of any data.</p> <p>4.5.5 The independent advisers noted and commended the applicant on the engagement of patients in developing the Patient-reported Outcome Measures (PROMs), as highlighted in section 5(d) (Benefits) of the application.</p> <p>4.5.6 The NHS England Caldicott Guardian Team representative noted that certain groups have been excluded from the study, for example, those who do not speak English or those that cannot consent for themselves; and it was suggested by the group, that the applicant should review this and see if the study can be expanded to any excluded groups.</p> <p>4.5.7 The SIRO representative noted this was a three year data sharing agreement (DSA) but that the work would be continuing for six years and queried why the DSA was not until 2030. The independent advisers suggested that this application may be</p>	MC
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	a good candidate for a longer DSA and advised that they would be supportive of this to align with the length envisaged for the study.	
EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
5.1	<p>Reference Number: NIC-148286-3RWRG-v8.4</p> <p>Applicant: University of Birmingham</p> <p>Application Title: MR503 - Adjuvant Tamoxifen Treatment - Offer -More? – ATTOM</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 7th December 2017 and the 20th July 2017.</p> <p>The SIRO approval was for a six-month extension to July 2024.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
5.2	<p>Reference Number: NIC-210151-K9C7G-v5.2</p> <p>Applicant: IQVIA Technology Services Limited</p> <p>Application Title: HES data for IQVIA clinical trial site identification</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 10th December 2020, 16th January 2020, 19th December 2019, 10th January 2019 and the 6th December 2018.</p> <p>Linked Applications: This application is linked to NIC-373563-N8Z9J and NIC-315134-L9Z6B.</p> <p>The SIRO approval was for an amendment to the data sharing agreement (DSA).</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
5.3	<p>Reference Number: NIC-243790-Y8K8C-v6.5</p> <p>Applicant: Carnall Farrar Limited</p> <p>Application Title: Carnall Farrar's request for NHS England data permitting detailed insights into population needs and challenges facing the system when shaping sustainable health and social care services</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the IGARD meeting on the 19th January</p>	

	<p>2023, 3rd March 2022, 4th November 2021, 10th December 2020, 27th February 2020, 10th October 2019 and the 26th September 2019.</p> <p>The SIRO approval was for a three-month renewal.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval and confirmed that they were supportive of this.</p> <p>The group thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>5.3.1 Noting that this was a commercial organisation, it was suggested by the independent advisers, that NHS England should consider submitting this for a review at a future AGD meeting.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
AGD Operations		
6	<p>Statutory Guidance</p> <p>The independent advisers again noted the reference to reviewing materials in accordance with “<i>a clearly understood risk management framework</i>” within the published Statutory Guidance and advised that they were not aware of an agreed risk management framework, and requested that NHS England provide further information/ clarity on this, noting this topic had been raised by Lord Hunt in the House of Lords on the 26th June 2023, and was answered by Lord Markham on the 5th July 2023: Written questions, answers and statements – UK Parliament.</p> <p>The NHS England SIRO representative had provided further clarity on the risk management framework via email to the group, which confirmed that NHS England were asking the interim data advisory group to use the NHS England DAS Standards and Precedents model to assess the risk factors in relation to items presented to the interim data advisory group for advice; however the independent advisers noted that the wording in the statutory guidance “...<i>using a clearly understood risk management framework, precedent approaches and standards that requests must meet...</i>”, suggested that the risk management framework is separate to the DAS Standards and Precedents, and asked that this be clarified by NHS England. The group noted that the Deputy Director, Data Access and Partnerships, Data and Analytics attended the meeting on the 23rd November 2023, and noted that plans for this work were in train.</p> <p>It had been noted previously that an Oversight and Assurance Programme of applications that had not be subject to AGD review could form part of this Risk Management Framework.</p> <p>ACTION: NHS England SIRO representative to provide a written response addressed to AGD with further clarity on the risk management framework.</p>	GC

Any Other Business

10.1 Special Conditions (Presenter: Michael Chapman)

It was noted that there was an outstanding action with the Data and Analytics representative, to provide the group with an update on the ongoing work with aligning the special conditions in section 6 (Special Conditions) of the applications to ensure they are consistent / accurate across all of the data sharing agreements (DSA).

Michael advised the group that this work was still ongoing within the Data Access Service (DAS) and that this work would be submitted to the group for a further discussion on the substantive points at a future AGD meeting.

The group noted the verbal update and advised that they looked forward to receiving further information in due course

10.2 Annual Confirmation Report (Presenter: Michael Chapman)

It was noted that there was an outstanding action with the Data and Analytics representative to provide the group with an update on the annual confirmation report, including some statistics, to further support the discussion. This was an essential update since a significant number of applications were progressing with longer contractual terms, relying on an Annual Confirmation Report.

Michael advised the group that this work was still ongoing within the Data Access Service (DAS) and that this work would be submitted to the group for a further discussion on the substantive points at a future AGD meeting.

The group noted the verbal update and advised that they looked forward to receiving further information in due course.

10.3 Applications for access to NHS England's Secure Data Environment (SDE) (Presenter: Michael Chapman)

Michael advised the group that this work was still ongoing within Data and Analytics in respect of the approach for reviewing applications who require access to NHS England's SDE.

It was also noted that other areas of NHS England would be involved with this, including, but not limited to the SIRO and Privacy, Transparency and Trust (PTT); and advised that AGD would be engaged at an appropriate point as this work progressed.

The group noted the verbal update and advised that they looked forward to receiving further information in due course; and noted that should NHS England require any support from an AGD independent adviser(s) out of committee (and before this is discussed at a future AGD meeting), then they would be happy to support this.

10.4	<p>Radio 4 interview with Prof. Cathy Sudlow</p> <p>It was noted by an independent adviser that on the 16th January 2024, Prof. Sudlow had been interviewed on Radio 4 on the results of the 'Undervaccination and severe COVID-19 outcomes: meta-analysis of national cohort studies in England, Northern Ireland, Scotland and Wales'. It was noted that as part of this interview, reference was made to patient choice, in respect of opting out. It was noted that on the NHS England Data Uses Register it was not clear whether opt outs had been applied under the data sharing agreement (access via a trusted research environment (TRE)) related to this specific area of work.</p> <p>The SIRO representative noted the interview that had taken place, and the reference to the input of independent people into the decision making process, which was of relevance to the group.</p> <p>The Data and Analytics representative noted the point raised in respect of the opt-outs, and took an action to clarify whether the Data Uses Register picks up the information for opt-outs when dealing with anonymised data regardless of how it is accessed.</p> <p>ACTION: The Data and Analytics representative to clarify whether the Data Uses Register picks up the information for opt-outs when dealing with anonymised data regardless of how it is accessed.</p>
10.5	<p>Data Access Request Service (DARS) Online (Presenter: Michael Chapman)</p> <p>Michael advised the group that the new DARS online service had gone live on the 15th January 2024.</p> <p>The group noted and thanked Michael for the verbal update, and requested that further information was presented to the group at a future AGD meeting, to further support the group's knowledge on this area.</p> <p>ACTION: Data and Analytics to provide further information at a future AGD meeting on the new DARS online service.</p>
10.6	<p>Service Improvements (Presenter: Karen Myers)</p> <p>A verbal update was provided to the group by Karen in respect of the quarterly service improvement programme of work, where a number of 'observations' and 'actions' were highlighted following initial feedback from the independent advisers and NHS England.</p> <p>Karen noted that a further discussion would take place with the group in April 2024 in respect of the frequency of AGD service improvement feedback requests in 2024/25 and how feedback is requested, alongside the next quarterly service improvement report.</p> <p>ACTION: AGD Secretariat to discuss with the group the frequency of AGD service improvement feedback requests in 2024/25 and how feedback is requested in April 2024.</p> <p>Subsequent to the meeting: The AGD Secretariat noted that a verbal update on the quarterly service improvement programme of work, had been provided to the group at the</p>

	AGD meeting on the 14 th September 2023, however noted that this had not been noted in the AGD minutes.
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Meeting Closure

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