

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 20th April 2023

09:30 – 16:30

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser (Chair) (Chair for items 1 – 5.4 and 6.1 – 10.1)
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Dr. Imran Khan (IK)	Specialist GP Adviser (Chair for item 5.5 only)
Dr. Maurice Smith (MS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Vicky Byrne-Watts (VBW)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 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) (Presenter: item 5.1)
Mujiba Ejaz (ME)	Data Access Request Service (DARS) (Presenter: items 5.5 & 6.1)
Abigail Lucas (AL)	Data Access Request Service (DARS) (Presenter: item 5.3)
Shaista Majid (SM)	Data Access Request Service (DARS) (Presenter: item 5.2)
Andrew Martin (AM)	NHS England Data Protection Office (DPO) (Observer: Items 1 to 10.1)
Kate Fleming (KF)	NHS England Data Analytics Representative (Delegate for Michael Chapman)
Dickie Langley (DL)	Data Protection Officer (DPO) representative (Delegate for Jon Moore) <i>(Not in attendance as the DPO Representative for item 8))</i>
Jon Moore (JM)	Data Protection Officer (interim) <i>(attending as the DPO Representative for item 8 only)</i>

Karen Myers (KM)	Secretariat Team
Dr. Jonathan Osborn (JO)	Caldicott Guardian Team representative
Jodie Taylor-Brown (JTB)	Data Access Request Service (DARS) (Observer: item 5.1)
Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (Presenter: item 5.4) (SAT Observer: item 5.5 & 6.1)
Vicki Williams (VW)	Secretariat Team
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Kirsty Irvine (KI)	Chair
Dr. Geoffrey Schrecker (GS)	Specialist GP Adviser
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Michael Chapman (MCh)	Data and Analytics representative
Dr Arjun Dhillon (AD)	Caldicott Guardian Team Representative (Delegate for Dr. Jonathan Osborn)

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

	<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>Paul Affleck noted and accepted the request from the NHS England SIRO Representative to chair the meeting on behalf of Kirsty Irvine; and welcomed attendees to the meeting.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the 30th March 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>Paul Affleck noted a professional link to the University of Leeds, but stated he is not directly involved in the Health Data Research Hub for Cancer (DATA-CAN) (NIC-402417-N9Z5W). It was agreed this did not preclude Paul from taking part in the discussions about this application, however it was agreed that he would not Chair this application.</p> <p>Dr. Imran Khan noted a potential conflict with any applications reviewed by the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG), 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. Imran Khan noted a potential conflict with NIC-21083-B6C5J, 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. It was agreed this did not preclude Dr. Khan from taking part in the discussions about this application.</p> <p>Dr. Jonathan Osborn noted a professional link with the RCGP (NIC-21083-B6C5J) but noted no specific connection with the application or staff involved and it was agreed that this was not a conflict of interest.</p>
BRIEFING PAPER(S)	
4	<p>National Obesity Audit (NOA) and use of Cardiovascular dataset (CVD)</p> <p>The item was withdrawn by the NHS England SIRO representative.</p>
EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-482185-K8G0F-v0.19</p> <p>Applicant: University College London (UCL)</p> <p>Application Title: UK Early Life Cohort Feasibility Study (ELC-FS)</p> <p>Presenter: Dave Cronin</p> <p>Observers: Jodie Taylor-Brown</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented at the AGD meeting on the 2nd March 2023.</p>

The application and relevant supporting documents were previously presented at the IGARD meeting on the 1st December 2022.

Application: This was a new application.

The purpose of the application is for a study that will test the proof of concept for a new national birth cohort study for the UK. It will collect rich data on babies born across the UK during two consecutive months of 2022 or 2023 and their parents, capturing the economic and social environments into which these babies are born, and their health, well-being and development in their first 6-10 months. The study is relying on s251 of the NHS Act 2006 for the flow of data out of NHS England.

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:

5.1.1 The independent advisers advised that it was reasonable to proceed with the application, however, concerns remained over the method of recruitment, and suggested that NHS England develop the capacity to take the approach recommended in the original patient and public involvement and engagement (PPIE), where invitations are sent by NHS England and recipients can opt-out before their personal information is passed to the researchers.

5.1.2 The independent advisers also noted that the method of recruitment was a pilot and **not** a precedent; and that the results of this pilot should inform any future applications seeking to use this recruitment method. It was also noted that careful thought should be given to the language that will be used in the consent material with regard to obtaining health data, as per the advice provided.

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

5.1.3 Following the AGD review on the 2nd March 2023, the independent advisers reviewed the previous comments / points made; and, noted that although the comments / points were all still applicable and relevant, it was recognised that they had been taken on board by NHS England / the applicant; and acknowledged the significant amount of work undertaken to update the application.

5.1.4 The independent advisers did however stress that evaluation of the pilot should consider the broader issues raised, in addition to whether it was successful in recruiting cohort members; for example, the previous issue raised in respect of whether it was possible to screen out invitations and visits to birth parents of any children who had been, or were in the process of, being adopted.

5.1.5 The independent advisers also reiterated the point previously made, in respect of the content of the communication letter, and the concern over language used, and how this could be perceived as coercive, for example *“Each baby chosen for this study is unique and cannot be replaced”*; and suggested a review of the letter to update potentially coercive language.

5.1.6 In addition, the independent advisers also reiterated the point raised, in respect of reference within the ‘advance booklet’ communication leaflet to participants answers being

	<p>made “<i>securely available to researchers via the UK Data Service and other trusted repositories</i>”. Noting the clear concerns of PPIE participants about commercial involvement and also the points in the protocol about researchers from commercial organisations potentially having access, the independent advisers suggested that the booklet was updated to be more transparent on the potential commercial organisation involvement and the purpose limitations, noting that this was not clear.</p> <p>5.1.7 Noting that National Data Opt-outs would be upheld, the independent advisers stressed the need to also respect S-flags (sensitive restriction) so that any individual who has had an S-flag applied to their NHS record do not have their sensitive information shared.</p> <p>5.1.8 Noting the volume of data that will be transferred in phase 1, the independent advisers suggested that section 5(a) (Objective for Processing) was updated with further information outlining this, for the purpose of transparency and in line with NHS Digital DARS Standard for Objective for Processing.</p> <p>5.1.9 To update section 5(d) (Benefits) to use a form of wording such as “<i>it is hoped ...</i>”, rather than “<i>it will...</i>”, in line with NHS Digital DARS Standard for Expected Measurable Benefits.</p>	
5.2	<p>Reference Number: NIC-648561-Z8L8M-v0.23</p> <p>Applicant: Archus Ltd</p> <p>Application Title: Archus Limited direct HES data feed</p> <p>Presenter: Shaista Majid</p> <p>SAT Observers: Vicky Byrne-Watts</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented at the IGARD meeting on the 1st December 2022 when the application had been deferred.</p> <p>Application: This was a new application.</p> <p>The purpose of the application is to enable Archus Limited to provide consultancy to NHS organisations with validation against the performance of other peer NHS organisations. The data would also be used to populate the software tools Archus Limited use to generate consultancy reports for its clients. Since HES data is the prime, nationally recognised and cleansed data source for hospital care in England, this represents the most reliable basis for analysis.</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 (with one independent adviser dissenting) were supportive of the application and wished to draw to the attention of the SIRO the following substantive comment:</p> <p>5.2.1 The independent advisers noted the expected benefits outlined in section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care), and suggested that this was updated in line with NHS Digital DARS Standard for Expected Measurable Benefits, to ensure that the relevant bodies were referenced, being clear what will</p>	

<p>realistically can hope to be delivered, and ensuring the appropriate tense was referenced throughout the application.</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>5.2.2 The independent advisers noted that when the application was reviewed by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) on the 1st December 2022, the application had been deferred pending a number of deferral points.</p> <p>5.2.3 The independent advisers discussed each deferral point and noted the efforts undertaken by NHS England and the applicant to address the points and advised that they had mostly been addressed / resolved.</p> <p>5.2.4 The independent advisers reiterated the risk identified by IGARD, in respect of contracting for the first time with a commercial entity with no track record of managing NHS England data; and that a due diligence NHS England DARS Standard would be an appropriate and valuable risk mitigation tool.</p> <p>5.2.5 In addition to the risk identified (above), the independent advisers also acknowledged and recognised the importance of having new commercial entrants in the marketplace, fostering innovation and competition.</p> <p>5.2.6 The independent advisers queried the statement in section 5(a) (Objective for Processing) <i>“Because the Coplug tool will need to slice and dice these views...”</i>; and suggested that this was updated to be more specific on Data Processor roles and responsibilities in line with NHS Digital DARS Standard for Data Processors and NHS Digital DARS Standard for Objective for Processing.</p> <p>5.2.7 The independent advisers queried what the potential commercial benefits could be to Coplug D&T Limited; and noting that this was currently unclear, asked that in line with NHS Digital DARS Standard for Commercial Purpose, section 5(e) (Is the Purpose of this Application in Anyway Commercial) was updated to reflect this; and that this text was also replicated for transparency in section 5(a), in line with NHS Digital DARS Standard for Objective for Processing.</p> <p>5.2.8 In addition, the independent advisers queried the statement in section 5(a) <i>“Archus Limited will be the sole data controller who also processes the data. Archus Limited will be the main data processor and the only processor who will hold record level data”</i>; and suggested that this was removed, and a new statement added that neither the Data Controller or Data Processor will attempt to re-identify the data.</p> <p>5.2.9 The independent advisors noted references in section 5(b) (Processing Activities) to specific software and suggested that these restrictive references be removed.</p> <p>5.2.10 The independent advisers noted the statement, <i>“Coplug will develop functionality within the tool to perform the suppression and rounding on the fly ...”</i>; and suggested that this may be technically difficult to accomplish, and advised that the applicant and Coplug should check the feasibility of such suppression and rounding.</p> <p>5.2.11 The independent advisers noted the statement in section 5(c) (Specific Outputs Expected) <i>“The various outputs will have different levels of ‘access’, but fundamental to Archus Limited's approach is transparency”</i>; and whilst acknowledging the important of this transparency to clients, also suggested that there was a need to validate such models with</p>
--

	relevant experts. In addition, the independent advisers highlighted the need for transparency / communication with the data subjects.	
5.3	<p>Reference Number: NIC-685917-H4X8G-v0.8</p> <p>Applicant: NHS Blood & Transplant (NHSBT)</p> <p>Application Title: MELODY Study (Mass evaluation of lateral flow immunoassays for the detection of SARS-CoV-2 antibody responses in immunosuppressed people) - COVID-19 related hospitalisations in solid transplant patients</p> <p>Presenter: Abigail Lucas</p> <p>SAT Observer: Vicky Byrne-Watts</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study, aiming to estimate how many immunosuppressed people in the UK have antibodies that may provide protection against COVID-19 after at least three vaccines; and then assess whether people with antibodies have lower rates of infection and severe outcomes of infection than people without antibodies. The results of this study may help assess the impact of the vaccines on the level of antibody response to COVID-19 across the UK and help guide public health policy towards vulnerable groups.</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. Whether the consent is sufficient. <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>In response to point 1</p> <p>5.3.1 The independent advisers noted and commended NHS England on the thorough consent review provided as a supporting document.</p> <p>5.3.2 The independent advisers advised that they were supportive of the approach advocated within the consent review, in that the consent was compatible, but further clarity was required to the cohort in respect of the identifiers flowing into NHS England, which was not clear within the consent materials.</p> <p>5.3.3 In addition, the independent advisers suggested that the privacy notice was updated with further transparency on the identifiers flowing into NHS England and the broader purpose of the study.</p> <p>5.3.4 The independent advisers advised that in addition to the suggested update to the privacy notice, other methods of communication to the cohort, should also be considered, for example, a newsletter.</p> <p>5.3.5 The independent advisers noted the current content of the draft privacy notice provided but suggested that this was updated further to also include 1) further clarity on the broader purpose of the study, i.e. the impact on health; 2) to provide a clear description of</p>	

	<p>the flows of data, for example, how the data flows to the various bodies; and 3) to provide a clear explanation as to how cohort members can withdraw from the study.</p> <p>5.3.6 In addition to the suggested updates to the privacy notice by the independent advisers, NHS England advised the group that the applicant had updated their draft privacy notice to remove references to “<i>NHS Digital</i>” and replace with “<i>NHS England</i>” following the recent merger. The group noted and thanked NHS England for the verbal update.</p> <p>5.3.7 The independent advisers queried the size of the cohort and, noting that this was not clear within the application, asked that in line with section 3(b) (Additional Data Access Requested) and section 5(a) (Objective for Processing) were updated with an approximate size of the cohort, in line with NHS Digital DARS Standard for Objective for Processing.</p> <p>5.3.8 Separate to this application, the independent advisers suggested that NHS England may wish to give further consideration to electronic consent, and the risks / potential issues involved with this, for example, if the cohort members do not have a copy of their consent, and the webpage expires, the cohort may not be able to ascertain what they originally agreed to.</p>	
5.4	<p>Reference Number: NIC-368233-L2N0W-v8.5</p> <p>Applicant: McKinsey & Company Inc</p> <p>Application Title: Standard Extract Subscription</p> <p>Presenter: Kimberley Watson</p> <p>SAT Observer: Vicky Byrne-Watts</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 23rd March 2018 13th December 2018, 28th March 2019, 4th July 2019, 23rd April 2020 and the 30th April 2020.</p> <p>The application and relevant supporting documents were previously presented / discussed at the DAAG meeting on the 13th October 2015.</p> <p>Application: This was an extension, renewal and amendment application.</p> <p>The amendments are to 1) add sensitive ethnicity fields into the Emergency Care Data Set (ECDS); 2) to change the dissemination frequency from quarterly to monthly; 3) to add additional datasets: Diagnostic Imaging Dataset (DIDs), HES Critical Care (CC) and Community Services Data Sets (CSDS); 4) to add additional fields requested into previously held datasets; and 5) to resupply previously disseminated data – a special condition has been added to the application.</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 substantive comments:</p> <p>5.4.1 The independent advisers noted the information provided in the internal application assessment form provided, in respect of the “parent” company of McKinsey & Company Inc based in the USA, and the possibility of NHS England data being shared with them under US laws.</p>	

5.4.2 The independent advisers noted the potential risks of NHS England data flowing to the USA and the applicant's view that this was unlikely to happen; however advised that the risk remains; and referred back to the previous discussions on this subject, including the update from NHS England at the AGD meeting on the 23rd March 2023; where the independent advisers noted that the impact of the USA Patriot Act and the risks associated with this, should be determined at NHS England Board level; and that it was not necessarily the responsibility of colleagues within DARS to undertake additional checks.

5.4.3 The SIRO representative advised the group that, to further manage the risk highlighted, a robust review of the data fields would be undertaken, in line with [NHS Digital DARS standard for data minimisation](#).

5.4.4 Following the discussion on the USA Patriot Act at the AGD meeting on the 23rd March 2023, the NHS England SIRO representative advised that an interim policy position would need to be agreed within NHS England, for example, to determine what checks will be undertaken; and that further information would be provided to the group in due course.

5.4.5 The independent advisers advised that, once available, the use of NHS England's Secure Data Environment for the processing of data under this data sharing agreement (DSA) would mitigate the risks of data being shared with the USA parent company; and suggested that NHS England should discuss this with the applicant.

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

5.4.6 The independent advisers noted the amendments requested and advised that they were supportive of all the amendments; however, in respect of amendment point three, asked that, given the volume of data requested, a further justification was provided in section 5(a) (Objective for Processing) of why the additional datasets were required and in line with the [NHS Digital DARS Standard for Objective for Processing](#).

5.4.7 The independent advisers noted that section 5(e) (Is the Purpose of this Application in Anyway Commercial) provided details of the commercial purpose of the application; however, suggested that section 5(a) was updated further to include details of the commercial benefits, in line with [NHS Digital DARS Standard for Objective for Processing](#) and [NHS Digital DARS Standard for Commercial Purpose](#).

5.4.8 The SIRO representative noted the statement in section 5(e) "...the client (the data controller)..." and noting that the clients of McKinsey would **not** be the Data Controller asked that this was amended to correctly reflect that McKinsey & Company Inc were the Data Controller. The independent advisers confirmed that they were supportive of this update to the application.

5.4.9 The independent advisers queried the statement in section 5(a) "*The data sets requested will only be used in the context of services by McKinsey in England and will not be used for **non-NHS (or social care) organisations**...*"; and noting that it was unclear what the reference to "*non-NHS (or social care) organisations*" meant, suggested that if appropriate / correct, this was amended to say that "...the datasets would only be used in the context of services to public bodies..." or similar; or if this suggested update was not correct / accurate, it was suggested that NHS England have a further discussion with the applicant to clarify this point.

5.5	<p>Reference Number: NIC-402417-N9Z5W-v4.5</p> <p>Applicant: University of Leeds</p> <p>Application Title: Enumerating the impact of COVID-19 on cancer pathways: a robust evaluation of the NHS Digital Trusted Research Environment</p> <p>Presenter: Mujiba Ejaz</p> <p>SAT Observer: Kimberley Watson</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meeting on the 21st January 2021.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 18th October, 2020, 15th October 2020, 12th November 2020, 1st December 2020, 10th December 2020 and the 17th December 2020.</p> <p>Application: This was an extension, renewal and amendment application.</p> <p>The amendment is the addition of Emergency Care Data Set (ECDS).</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>5.5.1 The independent advisers noted and commended the efforts taken by the applicant on their patient and public involvement and engagement (PPIE).</p> <p>5.5.2 The group discussed the data controllership arrangements for this application, and noting that the University of Leeds and Leeds Teaching Hospitals NHS Trust were the joint Data Controllers, were unsure why honorary contracts/visiting titles were being employed and that if these enabled collaborations whether those collaborating institutions were Data Controllers.</p> <p>5.5.3 The SIRO representative advised the group that although the application stated that the Uncurated Low Latency Hospital Data Set - Emergency Care dataset was flowing under this application, this dataset was now not required, as earlier version(s) of the Emergency Care Dataset (ECDS) would be made available, as per the amendment to the application.</p> <p>5.5.3 The independent advisers noted and thanked the SIRO representative for the verbal update in respect of the Uncurated Low Latency Hospital Data Set - Emergency Care dataset / ECDS dataset(s); and suggested that the application was updated as necessary to reflect the correct information; and that any datasets not required were removed from the application.</p> <p>5.5.4 In light of the amendment to the application to add ECDS data, the independent advisers suggested that the application was updated further to provide a clear justification of why the ECDS data was required, noting that this was currently not clear.</p> <p>5.5.5 In addition, the independent advisers suggested that further information was provided in the application of the timescales, as to when the full ECDS dataset would be made available, i.e. July 2023 or later; and that confirmation was provided in the application, that</p>	
-----	--	--

	<p>any delay to the availability of this dataset would not cause any issues / delays to the study outcomes.</p> <p>5.5.6 The SIRO representative and the Caldicott Guardian Team representative, advised the group that although the General Practice Extraction Service (GPES) data for Pandemic Planning and Research (GDPPR) dataset were requested / available under this application; the GP data usage, the data fields flowing and the purpose had not changed; therefore they were in agreement that a further review from the GDPPR – Profession Advisory Group (PAG) was not required at this time.</p> <p>5.5.7 The independent advisers noted and thanked the SIRO representative and the Caldicott Guardian Team representative for the verbal update in respect of the PAG review for this version of the application.</p> <p>5.5.8 The independent advisers queried why there were no yielded benefits for the study, noting that data had been available since March 2022. NHS England advised that there had been some technical issues with access to some of the cancer datasets requested by the applicant, and that this issue had now been resolved.</p> <p>5.5.9 The independent advisers noted the verbal update from NHS England in respect of the technical issue on the cancer datasets requested; and suggested that for transparency / future reference, this information was referenced within the application, for example, what the technical issues were, why they occurred and whether this would be a further issue in the future.</p> <p>5.5.10 In addition, the independent advisers suggested that, if not already done so, NHS England formally record the lessons learnt from this to prevent / support any similar issues in the future.</p> <p>5.5.11 The independent advisers advised NHS England, that they were unable to locate the applicant's privacy notice; and noted that the applicant should ensure this is easily accessible by the public, in line with UK General Data Protection Regulation (UK GDPR).</p> <p>5.5.12 The independent advisers noted that an honorary contract/visiting title form had been provided as a supporting document, and that although this had been signed by the University of Leeds, it had not been counter-signed by the employing bodies; and suggested that NHS England ensure that written confirmation from the applicant, that the document had been counter-signed by the employing bodies; and that the written confirmation was uploaded to NHS Digital's customer relationships management (CRM) system for future reference.</p> <p>5.5.13 The independent advisers suggested that a special condition was inserted in section 6 (Special Conditions), that any use of the NHSBSA data must be within the parameters of the relevant Direction authorising that collection.</p> <p>5.5.14 In addition, the independent advisers suggested that section 5(a) (Objective for Processing) was updated to note that any use of the NHSBSA data must be within the parameters of the relevant Direction authorising that collection.</p> <p>5.5.15 Independent advisers noted actions previously raised at the 23rd March 2023 meeting with regard to NHS BSA with regard to welcoming a discussion with the NHS BSA Information Asset Owner and being provided with a copy of the DARS onboarding instructions.</p>	
--	---	--

INTERNAL DATA DISSEMINATION REQUESTS:

6.1	<p>Reference Number: NIC-411785-Z6X7M-v4.2</p> <p>Applicant: NHS England</p> <p>Application Title: Rapid Diagnostic Centre - Cancer TRE</p> <p>Presenter: Mujiba Ejaz</p> <p>SAT Observer: Kimberley Watson</p> <p>Application: This was a renewal and amendment application.</p> <p>The amendments are to 1) remove the Health and Social Care Information Centre (HSCIC) (NHS Digital) as a Data Processor following the merger with NHS England; and 2) to add Rapid Cancer Registration Datasets (RCRD) to be processed for the purposes already included in the dataset.</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>6.1.1 The group noted that the application would not become a 'contract', because the applicant was NHS England and that the application had been reviewed by the group in line with the same process as all other DARS applications on the understanding that it would form part of a published internal data uses register. The group noted that the process for internal flows of data applications was still being discussed within NHS England, and that the process would be brought to AGD before being finalised.</p> <p>6.1.2 Noting that the application stated the application had been submitted for a renewal and amendment, the SIRO representative requested that the group provided feedback on the amendments only.</p> <p>6.1.3 The independent advisers noted the request from the SIRO representative; and confirmed that they had no specific comments to make on the amendments to the application.</p> <p>6.1.4 The independent advisers noted that the Uncurated Low Latency Hospital Data Sets - Emergency Care dataset was flowing under this data sharing agreement (DSA); and queried whether this was correct, or whether it was in fact earlier version(s) of the Emergency Care Dataset (ECDS); and suggested that the application was updated as necessary to reflect the correct information.</p> <p>6.1.5 The independent advisers queried the statement in section 5(a) (Objective for Processing) "<i>A key wider benefit of RDCs will therefore be diagnosing serious non-cancer conditions more efficiently</i>"; and suggested that either a further justification was provided supporting this statement; or it was removed from the application.</p> <p>6.1.6 Separate to the application, the independent advisers reiterated the action from the AGD meeting on the 2nd February 2023, that further information was provided on the Precedents for the Internal Data Flow Approval Process and Precedents.</p>
-----	--

	ACTION: NHS England to attend a future AGD meeting, to provide an update on the Internal Data Flow Approval Process and Precedents.	NHSE
EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
7.1	<p>Reference Number: NIC-21083-B6C5J v1.2</p> <p>Applicant: University of Surrey</p> <p>Application Title: Secondary data linked to the Royal College of General Practitioners (RCGP) Research and Surveillance Centre's (RSC) primary care sentinel data for the purposes of infectious and respiratory diseases surveillance in England.</p> <p>Presenter: No Presenter</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 30th January 2020 and the 12th March 2020.</p> <p>This application is related to the following University of Oxford applications NIC-396119-C8W3W, NIC-381683-R6R6K and NIC-431355-B1L8W.</p> <p>Application: The purpose of the application is to look at the outcomes of care, including death to support surveillance and monitoring of vaccine efficacy on influenza. Most important health outcomes happen in hospital, where the bulk of health care costs are incurred. The focus of the work will be the impact of influenza and other infections on health the benefit-risk of influenza and other vaccinations.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval.</p> <p>7.1.1 The group thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided. The NHS England SIRO representative thanked the group for their time.</p>	
7.2	<p>Reference Number: NIC-194340-D6F3B v4.0</p> <p>Applicant: Office for National Statistics (ONS)</p> <p>Application Title: ONS Longitudinal Study</p> <p>Presenter: No Presenter</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the AGD meeting on the 23rd February 2023.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the IGARD meeting on the 22nd October 2020, 11th February 2021 and the 12th May 2022.</p> <p>Application: The purpose of the application is for the ONS Longitudinal Study, which is the largest longitudinal data resource in England and Wales. It contains linked census and life events data for an approximate 1% sample of the population of England and Wales.</p>	

	<p>The purpose of the application is for the ONS Longitudinal Study, which is the largest longitudinal data resource in England and Wales. It contains linked census and life events data for an approximate 1% sample of the population of England and Wales.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval.</p> <p>7.2.1 The group thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided; and they looked forward to reviewing a further iteration of the application at a forthcoming AGD meeting.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.3	<p>Reference Number: NIC-656755-W4N5C v0.2</p> <p>Applicant: Queen Mary University London (QMUL)</p> <p>Application Title: An ongoing case-control study to evaluate the NHS Bowel Cancer Screening Programme (ODR1516_019)</p> <p>Presenter: No Presenter</p> <p>Application: QMUL received the data to conduct a case-control study to evaluate the impact of the National Bowel Screening Programme. This Programme of work has now finished and outputs are being finalised, with the Department of Health and Social Care (DHSC) and the National Institute for Health and Care Research (NIHR) to review. The study team wishes to retain the data to undertake further analyses or clarify any queries from DHSC or NIHR.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.3.1 The NDRS datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review.</p> <p>7.3.2 The independent advisers noted that DARS had experienced a delay with this application due to the applicant not returning the signed novation letter.</p> <p>7.3.3 The independent advisers noted that the Health Research Authority Confidentiality Advisory Group (HRA CAG) annual review, due in November 2022 had not been submitted.</p> <p>7.3.4 The independent advisers queried why the data retained needed to be “<i>identifiable</i>”; and suggested that NHS England explore this with the applicant.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.4	<p>Reference Number: NIC-656762-V9J7N v0.2</p> <p>Applicant: Queen Mary University London (QMUL)</p> <p>Application Title: An on-going case-control study to evaluate the NHS Breast Screening Programme (NHSBSP) (ODR1516_167)</p> <p>Presenter: No Presenter</p>	

	<p>Application: QMUL received the data to investigate the benefit of the National Breast Screening Programme in terms of the effect on breast cancer mortality and its detrimental impact on overdiagnosis. This work is still ongoing, and outputs are still in the process of being produced.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval.</p> <p>7.4.1 The NDRS datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review.</p> <p>7.4.2 The group thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.5	<p>Reference Number: NIC-656767-M5W2L v0.4</p> <p>Applicant: UK Health Security Agenda (UKHSA)</p> <p>Application Title: Enhanced Surveillance of Human Papillomavirus (HPV) Genotypes in Cervical Disease (ODR1516_354)</p> <p>Presenter: No Presenter</p> <p>Application: The purpose of the application is to establish systems for prospective enhanced surveillance of HPV type-specific infections and HPV vaccination history for cervical disease</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.5.1 The NDRS datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review.</p> <p>7.5.2 The independent advisers noted the support under regulation 3 of the Health Service (Control of Patient Information) Regulations 2002, but queried whether those being surveilled were aware of that surveillance and how UK GDPR transparency requirements were being met, particularly given the sensitive nature of the surveillance. It was suggested that NHS England discuss such regulation 3 reliant applications with the applicant, to ensure there is time for any necessary patient and public involvement and engagement (PPIE) prior to application renewals.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.6	<p>Reference Number: NIC-656784-C7P5B V1.2</p> <p>Applicant: Health Quality Improvement Partnership (HQIP)</p> <p>Application Title: National Audit of Breast Cancer in Older Patients (ODR1617_169)</p> <p>Presenter: No Presenter</p>	

	<p>Application: The purpose of the application is for The National Audit of Breast Cancer in Older Patients (NABCOP), which is a national clinical audit commissioned by HQIP as part of its National Clinical Audit Patient Outcomes Programme. The project began in April 2016 and is a collaboration between the Association of Breast Surgery (ABS) and the Clinical Effectiveness Unit (CEU) of The Royal College of Surgeons of England (RCS). It was commissioned in response to calls for better information about the quality of breast cancer services in England and Wales.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided.</p> <p>7.6.1 The NDRS datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review.</p> <p>7.6.2 The group noted the comments in the SIRO documentation in respect of determining whether the date of death was identifiable or not; and supported the relevant actions being taken by NHS England with the data sharing agreement.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.7	<p>Reference Number: NIC-656823-G0Q2C v0.6</p> <p>Applicant: University of Leeds</p> <p>Application Title: Understanding the outcomes of patients with cirrhosis and hepatocellular carcinoma (HCC) in the England (ODR1718_432)</p> <p>Presenter: No Presenter</p> <p>Application: The purpose of the application is to exploit routine health data, to investigate how variation in baseline characteristics at HCC diagnosis and geographical location influence treatment allocation and clinical outcomes. In addition to overall survival, the rate of progression of underlying liver disease will also be investigated, to understand the competing mortality of HCC and cirrhosis.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval.</p> <p>7.7.1 The NDRS datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review.</p> <p>7.7.2 The group thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.8	<p>Reference Number: NIC-656843-D8M4Z v0.5</p> <p>Applicant: University Hospital Plymouth NHS Foundation Trust (FT)</p> <p>Application Title: Demographics and survival outcomes of young colorectal cancer patients. Implications for population-based screening, awareness and management. (ODR1819_262)</p>	

	<p>Presenter: No Presenter</p> <p>Application: The purpose of the application is for a project, looking at the demographics and long-term survival of young colorectal cancer patients in England. Studying the outcomes and demographics of young colorectal cancer (CRC) patients has become more critical in recent years because there has been an increase in the number of patients with this type of cancer. This project aims to establish baseline data which can be used as a point for comparison on the survival of young CRC patients in England; and will also compare the outcomes of young colon cancer patients and older cancer patients.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval. The group thanked NHS England for the written update and made the following observations on the documentation provided:</p> <p>7.8.1 The NDRS datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review.</p> <p>7.8.2 The group noted the statement in section 7 (Ethics Approval) <i>“Ethics approval is not required because Clinical Audit”</i>; and suggested that NHS England discuss this further with the applicant, for example, in respect of whether the work outlined in the application was a clinical audit or research, and whether ethical support should be sought.</p> <p>7.8.3 The group noted within the application, that the University of Plymouth was not considered a joint Data Controller; and suggested that this was reviewed in line with NHS Digital DARS Standard for Data Controllers noting they appeared to have Data Controller responsibilities.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.9	<p>Reference Number: NIC-656854-T9G6P v1.3</p> <p>Applicant: University of Manchester</p> <p>Application Title: Favourable Outcome of Cancer Therapy (ODR1920_062)</p> <p>Presenter: No Presenter</p> <p>Application: The purpose of the application is for a project to update the contribution of the three main cancer treatments, i.e. surgery, radiotherapy and chemotherapy.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval.</p> <p>7.9.1 The NDRS datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review.</p> <p>7.9.2 The group thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.10	<p>Reference Number: NIC-656880-K7V7P v1.2</p> <p>Applicant: Health IQ Ltd</p>	

	<p>Application Title: Treatment Pathway of HR+/HER2- Metastatic Breast Cancer in England (ODR2021_059)</p> <p>Presenter: No Presenter</p> <p>Application: The purpose of the application is for an epidemiological research study, which aims to describe the lines of therapy received by all HR+/HER2- mBrCA patients post-diagnosis along with systemic therapies received under each line of therapy.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval.</p> <p>7.10.1 The NDRS datasets requested under this DSA had previously flowed from Public Health England (PHE) prior to its closure at the end of September 2021; and therefore, had not had a previous independent review.</p> <p>7.10.2 The group thanked NHS England for the written update and advised that they had no further comments to make on the documentation provided.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
8	Confidential Advice Session	
AGD Operations		
9	<p>Standard operating procedures</p> <p>The ongoing forward plan of work for creating Standard Operating Procedures was discussed.</p>	To note
10 10.1	<p>New Operational Actions & those carried forward from previous meetings of AGD:</p> <p>IR35 / Zero Hours contracts for independent advisers</p> <p>Vicki Williams advised that, as discussed at the AGD meeting on the 30th March 2023, the independent advisers would continue outside the scope of IR35 for a short transitional period, up to the 31st July 2023; and that NHS England were actively working on putting zero hours contracts in place for all independent advisers.</p>	
Any Other Business		
	<p>Meeting Closure</p> <p>As there was no further business raised, the Deputy Chair thanked attendees for their time and closed the meeting.</p>	