

Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 27th April 2023

09:30 – 16:50

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	Role:
Paul Affleck (PA)	Specialist Ethics Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Maurice Smith (MS)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	Role / Area:
Michael Ball (MB)	Data Access Request Service (DARS) (Presenter: item 6.1)
Barry Capp-Gray (BCG)	Data Management & Integration Services (DMIS) (Observer: item 6.1)
Michael Chapman (MCh)	Data and Analytics representative (In attendance for item 12 only)
Garry Coleman (GC)	Senior Information Risk Owner (SIRO) representative
Ben Cromack (BC)	Data Access Request Service (DARS) (Observer: item 5.1)
Louise Dunn (LD)	Data Access Request Service Senior Approval Team (DARS SAT) (Presenter: item 11)
Duncan Easton (DE)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: item 6.1)
Mujiba Ejaz (ME)	Data Access Request Service (DARS) (Presenter: items 5.1 to 5.2)
Forrest Frankovitch (FF)	NHS England Data & Analytics (Delegate for Michael Chapman)
Lauren Gerraghty (LG)	Data Access Request Service (DARS) (Observer: item 5.4)
Dan Goodwin (DG)	Data Access Request Service (DARS) (Presenter: item 5.3)
Dickie Langley (DL)	Data Protection Officer (DPO) representative (Delegate for Jon Moore)

Andrew Martin (AM)	NHS England Data Protection Office (DPO) (Observer: Items 1 to 12)
Karen Myers (KM)	Secretariat Team
Dr. Jonathan Osborn (JO)	Caldicott Guardian Team representative
Frances Perry (FP)	Digi-Trials (Presenter: item 5.4)
Andy Rees (ARe)	Digi-Trials (Observer: item 12)
Jodie Taylor-Brown (JTB)	Data Access Request Service (DARS) (Observer: item 5.3)
Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (SAT Observer: items 5.1 to 5.4)
Vicki Williams (VW)	AGD Secretariat Team (Presenter: items 9 and 10.1)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Prof. Nicola Fear (NF)	Specialist Academic Adviser
Dr. Imran Khan (IK)	Specialist GP Adviser
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)
OUR FUTURE HEALTH (ITEM 12)	
Dr. Michael Cook (MC)	Executive Director of Epidemiology, Our Future Health
Dr. Andrew Roddam (ARo)	Chief Executive, Our Future Health
Jackie Shears (JS)	NHS and Data Adviser, Our Future Health
HEALTH RESEARCH AUTHORITY CONFIDENTIALITY ADVISORY GROUP (HRA CAG)	
Dr. Tony Calland	Chair, HRA CAG (Observer: item 12)

1	Welcome and Introductions The NHS England Senior Information Risk Owner (SIRO) Representative advised attendees that, noting the statutory guidance and the AGD Terms of Reference (ToR) had not yet been agreed, the
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	<p>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>Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.</p>
2	<p>Review of previous AGD minutes:</p> <p>The minutes of the 20th April 2023 AGD meeting were unable to be ratified in-meeting due to lack of quoracy (no NHS England representatives or delegates had reviewed the draft minutes), and it was therefore agreed these would be ratified at the next AGD meeting on the 4th May 2023.</p>
3	<p>Declaration of interests:</p> <p>There were no declarations of interest.</p>
BRIEFING PAPER(S) / LETTER(S) OF NOTE:	
4	<p>Title: Community Services Dataset (CSDS) Version 1.6 - Letter of Note</p> <p>Presenter: None</p> <p>Previous Reviews: The CSDS briefing papers were previously presented at the IGARD meeting on the 5th July 2018, 2nd August 2018, 30th August 2018 (finalised) and the 17th January 2019 (updated). The paper provided details of CSDS version 1.6 and was for information only.</p> <p>There are existing CSDS products available for customers to access through the Data Access Request Service (DARS) at this time. These products are known as CSDS version 1.0 and version 1.5; and contain data covering the periods from October 2017 to June 2020; and from July 2020 to December 2022 respectively.</p> <p>CSDS version 1.6 will be implemented in March 2023 (starting with January 2023 data).</p>

	<p>CSDS version 1.5 and version 1.6 are similar enough in structure that they will be folded into the same product entity in NHS England's customer relationships management (CRM) system. It will not be introduced as a "new" product, rather an extension of the existing CSDS datasets.</p> <p>Applicants will be able to request contiguous data from the entire period covered by CSDS, with the caveat that fields established in CSDS version 1.6 will be nulled in records prior to January 2023.</p> <p>Outcome of discussion: The group welcomed the Letter of Note and confirmed that they had no observations / comments.</p>
EXTERNAL DATA DISSEMINATION REQUESTS:	
5.1	<p>Reference Number: NIC-388794-Z9P3J-v7.11</p> <p>Applicant: Office for National Statistics (ONS)</p> <p>Application Title: Request for remote access to data in NHS England's environment for exploratory purposes</p> <p>Presenter: Mujiba Ejaz</p> <p>SAT Observer: Kimberley Watson</p> <p>Observer: Ben Cromack</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 9th July 2020, 16th July 2020, 17th December 2020, 1st July 2021 and the 8th July 2021.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meetings on the 14th July 2020 and the 8th December 2020.</p> <p>The application was previously presented at the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on the 8th July 2020 and the 9th December 2020.</p> <p>Linked applications: This application is linked to NIC-400304-S1P1B.</p> <p>Application: This a "new" request (new purpose under an old application number) from ONS, who require access to NHS England data via the Secure Data Environment (SDE).</p> <p>The purpose of the "new" application is to support statistical analysis through assessing the feasibility and effectiveness of processing NHS England data for future analysis and data acquisition.</p> <p>The existing purpose of this data sharing agreement (DSA) to date is no longer required; and the data previously approved under earlier iterations, has been removed from this version of the DSA.</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>5.1.1 The independent advisers queried the information within the internal Data Access Request Service (DARS) assessment form and application summary in respect of the</p>

<p>ethical approval for this application, noting that it was advised by ONS that they would only take a project to the National Statistics Data Ethics Advisory Committee (NSDEC) once it has been deemed as feasible, which this exploration activity in NHS England's Trusted Research Environment (TRE) will inform.</p> <p>5.1.2 The independent advisers queried whether it would be more appropriate for ONS to seek the view of NSDEC now, rather than only following the exploratory activity in the NHS TRE.</p> <p>5.1.3 If NSDEC view is not to be sought on the exploration activity, then it was suggested by the independent advisers that it was made clear within the application, including, but not limited to, a special condition in section 6 (Special Conditions) and an update to section 7 (Ethics Approval); that NSDEC would need to review and provide support for any future processing of the data under NIC-400304-S1P1B, regardless of the statutory route, i.e. by request or mandatory flow.</p> <p>5.1.4 Noting that ONS was processing personal data in NHS England's TRE, the independent advisers highlighted the statement in section 4 (Privacy Notice), that a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible transparency notice was maintained throughout the life of the agreement, in line with UK GDPR requirements.</p> <p>5.1.5 In addition, the independent advisers also suggested that in respect of the Data Protection Impact Assessment (DPIA), ONS could consider not drawing a distinction between accessing the data in the NHS TRE and receiving an extract for the ONS TRE; and that a DPIA could be carried out for the processing under this 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>5.1.6 NHS England advised the group that the internal application assessment form incorrectly referred to this application being linked to NIC-402417-N9Z5W; and advised that this would be updated to correctly refer to NIC-400304-S1P1B. The group noted the verbal update from NHS England and the amendment to the application.</p> <p>5.1.7 The independent advisers queried whether the opportunity to explore a dataset within the NHS TRE prior to making a further, refined application, as outlined within this application would be available to other researchers or data users; and suggested that NHS England may wish to give this further consideration.</p> <p>5.1.8 The independent advisers noted the statement in section 5(b) (Processing Activities) <i>"NHS England's Security Advisor has reviewed ONS' access arrangements and is content"</i>; and suggested that NHS England have a standardised approach in respect of including this information, i.e. either this was added to all applications where relevant; or this was removed from section 5(b) of the application and only included in the internal application assessment form or section 1 (Abstract) (where there is no internal application assessment form) of the application.</p> <p>5.1.9 Noting the first statement in section 5(b) <i>"No data will flow to NHS England for the purposes of this Agreement"</i>, the independent advisers suggested that this was updated to make clear that no <i>"cohort data"</i> was flowing into NHS England.</p>	
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	<p>5.1.10 The independent advisers noted the information within paragraph 4 of section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care) that stated “<i>The analysis this request aims to support is of national public health importance and has been requested by the National Statistician, NHS England’s Chief Statistician and members of the Scientific Advisory Group for Emergencies (SAGE)...</i>”; and suggested that this was removed as it was not relevant to this iteration of the application.</p> <p>5.1.11 Noting that paragraph 5 in section 5(d) (ii) appeared to be incomplete, the independent advisers advised that this would need updating / completing as appropriate.</p> <p>5.1.12 The independent advisers suggested that section 5(d) (ii) was updated further to include a brief narrative as to the benefits to health and social care, in line with NHS England’s DARS Standard for Expected Measurable Benefits, for example, that the processing may enable ONS to produce more robust statistics, which may lead to positive steps in terms of accessing mental health support / treatment.</p> <p>5.1.13 The independent advisers noted the special condition in section 6 relating to the annual review; and suggested that this was removed as it was not necessary to include the special condition, noting this is a 12-month application.</p>	
5.2	<p>Reference Number: NIC-610798-N0G8Z-v2.6</p> <p>Applicant: National Institute for Health and Care Excellence (NICE)</p> <p>Application Title: TRE - NICE</p> <p>Presenter: Mujiba Ejaz</p> <p>SAT Observers: Kimberley Watson</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 24th February 2022, 24th March 2022 and the 20th October 2022.</p> <p>The application was previously presented at the GPES Data for Pandemic Planning and Research – Profession Advisory Group (PAG) on the 16th February 2022.</p> <p>Application: This was a renewal and amendment application.</p> <p>The amendments are to 1) update the application to reference “<i>NHS England</i>” and not “<i>NHS Digital</i>” following the merger on the 1st February 2023; and 2) the addition of Improving Access to Psychological Therapies (IAPT) v2 and Mental Health Services Data Set (MHSDS) to be accessed within the Secure Data Environment (SDE).</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>5.2.1 NHS England advised the group, that section 5(a) (Objective for Processing) and would need updating, and a special condition would need to be inserted in section 6 (Special Conditions), to state that any use of the Medicines dispensed in Primary Care (NHSBSA data) data must be within the parameters of the relevant Direction authorising that collection. The group noted the verbal update and supported the update to the application.</p>	

	<p>5.2.2 The independent advisers noted that commercial organisations do work with, or have interest in, NICE outputs; and suggested to NHS England that they keep an open dialogue with NICE in respect of this and whether the application needs to be reviewed at any point in line with NHS England's DARS Standard for Commercial Purpose.</p> <p>5.2.3 Noting the previous PAG support obtained on the 16th February 2022 for the General Practice Extraction Service (GPES) data for Pandemic Planning and Research (GDPPR) dataset; NHS England advised the group that they did not think a further PAG review was required for the processing of this dataset under this iteration of the application, noting there was no change to the processing.</p> <p>5.2.4 The independent advisers suggested that section 5(a) was updated, and a special condition was inserted in section 6, restricting the use of the GDPPR data to COVID-19 purposes as set out in the relevant Direction.</p> <p>5.2.5 Separate to this application, the independent advisers advised NHS England that there should be a clear, consistent and transparent approach to the review of applications / applicants requesting the General Practice Extraction Service (GPES) data for Pandemic Planning and Research (GDPPR) dataset; and that this was clearly communicated to the public, profession etc; for example, in respect of the process for applications that have previously received PAG support.</p> <p>5.2.6 The independent advisers noted that the application used the terms “<i>TRE</i>”, “<i>SDE</i>” and “<i>DAE</i>”, and noting that each environment was slightly different, suggested that NHS England distinguish between them.</p> <p>5.2.7 The independent advisers suggested that the application title was updated from “<i>TRE – NICE</i>” to “<i>SDE - NICE</i>”, if this is correct, since there appeared to be an inconsistency in the use of “<i>TRE</i>” and “<i>SDE</i>”.</p> <p>5.2.8 In addition, the independent advisers noted the reference in section 5(d) (Benefits) (iii) (Yielded Benefits) to NHS England's “<i>*DAE</i>” (*Data Access Environment); and suggested that this was removed and replaced with “<i>SDE</i>” if this is correct.</p> <p>5.2.9 The independent advisers noted the statement in section 5(d) “<i>These prototypes are due be finalised by March 2023</i>”; and noting this date had now passed, suggested this was updated with a more up to date deadline.</p> <p>5.2.10 An NHS England representative queried the information in section 5(b) (Processing Activities) and section 6 in respect of the suppression rules and the conflicting information that “<i>zeros should be shown</i>” and they should be “<i>rounded to 5</i>”; and suggested that this was reviewed and, if correct, to provide further narrative; or amend if not correct.</p> <p>5.2.11 The independent advisers queried the statement in section 1 (Abstract) “<i>This request requires approval from NHS England's independent advisory body, historically known as IGARD ...</i>”; and suggested that this was updated to reflect that AGD provides “<i>advice</i>” not “<i>approval</i>” and is not an independent body.</p>	
5.3	<p>Reference Number: NIC-148219-ZHB4Z-v1.26</p> <p>Applicant: UK Health Security Agency</p> <p>Application Title: MR47 - National Registry for Radiation Workers</p>	

<p>Presenter: Dan Goodwin</p> <p>SAT Observer: Kimberley Watson</p> <p>Observer: Jodie Taylor-Brown</p> <p>Application: This was a new application.</p> <p>The purpose of the application is for a study, to investigate the effects of long-term occupational exposure to radiation on the health of workers; and assess whether radiation protection regulations and guidelines provide an adequate level of protection for UK radiation workers. The study is particularly interested in the mortality and morbidity from cancers, and mortality from all non-cancer related diseases.</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>5.3.1 The independent advisers queried the reference to processing of the data under Article 9(2)(j) (<i>Archiving, research and statistics</i>) of UK General Data Protection Regulation (UK GDPR); noting that the application relies on Regulation 3(1)(a) (<i>diagnosing communicable diseases and other risks to public health</i>), (b) (<i>recognising trends in such diseases and risks</i>), and (c) (<i>controlling and preventing the spread of such diseases and risks</i>) of the associated Health Service (Control of Patient Information (COPI)) Regulations 2002 in order to set aside the duty of confidentiality but pointed out that Article 9(2)(j) was not an appropriate UK GDPR legal basis to rely on if research was being carried out.</p> <p>5.3.2 The independent advisers advised that if any aspect of research was being carried out under this application, then, in order to set aside the duty of confidentiality, a s251 approval should be sought from the Health Research Authority Confidentiality Advisory Group (HRA CAG).</p> <p>5.3.3 If, however, it was determined that there was no research being undertaken, the independent advisers suggested that Article 9(2)(j) should be removed from the application. Other appropriate Article 9 legal basis could also be included.</p> <p>5.3.4 In respect of transparency, the independent advisers reiterated the point made at the AGD meeting on the 20th April 2023 (NIC-656767-M5W2L) that; noting the support under Regulation 3 of COPI, whether those being surveilled were aware of that surveillance and how UK General Data Protection Regulation (UK GDPR) transparency requirements were being met, particularly given the sensitive nature of what was being surveilled. 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>In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review:</p> <p>5.3.5 The group welcomed the application and noted the importance of the study.</p> <p>5.3.6 The group noted that any linked application, for example NIC-682588-Z0V8G, would not be discussed as part of the review for this application; and would need to come to a future AGD meeting for a separate discussion if required, and as per usual process.</p>	
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	<p>5.3.7 The independent advisers noted the reference in section 5(a) (Objective for Processing) to 'The National Registry for Radiation Workers Governance Group'; and suggested that further information was provided in the application, for transparency.</p> <p>5.3.8 In addition, the independent advisers suggested that section 5(a) was updated to provide further information of how the cohort had been informed by their employer(s) whilst they were workers, that they can form part of the cohort, as per the study protocol.</p>	
5.4	<p>Reference Number: NIC-620484-W0B2K-v0.4</p> <p>Applicant: University of Oxford</p> <p>Application Title: EVAREST/BSE-NSTEP Study Cohort to gather follow up data</p> <p>Presenter: Frances Perry</p> <p>SAT Observer: Kimberley Watson</p> <p>Observer: Lauren Gerraghty</p> <p>Application: This was a new application.</p> <p>Stress echocardiography is a commonly used test to assess for heart disease, and is performed routinely across the country in many different ways. The University of Oxford are examining how stress echocardiography is used in the diagnosis of heart disease; whether there are differences in how the test is performed between hospitals; and how the results of the stress echocardiogram guides patients' care. The purpose of the application is for a study, to gather information about how this test was performed and how it has helped doctors give patients the most appropriate care and will also examine how stress echocardiography is performed across the country.</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 that the application stated that there was no commercial purpose to the application; however, noting the history of commercial funding and the researcher links to the relevant commercial companies, suggested that in line with NHS England's DARS Standard for Commercial Purpose, section 5(a) (Objective for Processing) and section 5(e) (Is the Purpose of this Application in Anyway Commercial) were updated to provide a brief narrative of the history of the commercial involvement / funding, including the interests that the relevant commercial companies have in stress echocardiography.</p> <p>5.4.2 In addition, the independent advisers suggested that section 5(a) and section 5(e) were updated to also reflect any connections the researchers have with the relevant commercial companies.</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>5.4.3 The independent advisers noted and commended NHS England and the applicant on the significant amount of work undertaken on the application.</p>	

	<p>5.4.4 One of the independent advisers noted that the consent for phase 1 of the study was possibly more 'open ended' than the conclusion reached by the assessment undertaken by the applicant, and suggested that the follow up for 12 months, could be read as applying to the follow up phone call only. The independent adviser noted that the applicant could have tested this with a small group of study participants but noted that the applicant had chosen to reconsent.</p> <p>5.4.5 The independent advisers queried the references in the application and some of the supporting documents to the "<i>University of Leeds</i>"; and were advised by NHS England that this was an error, and the text would need removing and replacing with the correct reference to the "<i>University of Oxford</i>". The independent advisers noted the verbal update and supported the proposed amendments to the application and any supporting documents.</p> <p>5.4.6 The independent advisers queried the role of the British Society of Echocardiography (BSE) and whether they had any data controllership responsibilities; and were advised by NHS England that this had been discussed with the applicant, who had confirmed that they were not deemed to be a Data Controller as they do not have access to the data.</p> <p>5.4.7 The independent advisers noted the verbal update from NHS England in respect of BSE, and suggested that NHS England advise in writing to the applicant, that not having access to the data was not determinative of data controllership; and suggested that written confirmation was provided by the applicant, that in line with NHS England's DARS Standard for Data Controllers, BSE has no involvement in determining the purpose and means of processing and is therefore not carrying out any data controllership activities.</p> <p>5.4.8 If, however, it was determined when the response was received from the applicant that BSE were carrying out data controllership activities, then the independent advisers advised that the application should be updated to reflect this fact.</p> <p>5.4.9 Noting the questions asked by NHS England of the applicant in respect of patient and public involvement and engagement (PPIE); and the response that there was currently no PPIE being undertaken, but there may be some in the future; the independent advisers strongly supported the applicant undertaking their PPIE as soon as reasonably practicable.</p> <p>5.4.10 The independent advisers noted the study aims in section 5(a), however suggested that this was updated further, in line with NHS England's DARS Standard for Objective for Processing; to align with the study aims outlined in the protocol, including, but not limited to, reducing the instances of false positives for detecting atherosclerosis, and reducing unnecessary interventions on patients.</p> <p>5.4.11 In addition, the independent advisers suggested that section 5(a) was reviewed in line with NHS England's DARS Standard for Objective for Processing, and any marketing text removed, as this was not necessary to include.</p> <p>5.4.12 The independent advisers queried the statement in section 5(a) "<i>The strength of this study is the diversity of the cohort...</i>"; and were advised by NHS England that this had been added in error and should be removed from the application. The independent advisers noted the verbal update from NHS England, and supported the update to the application.</p> <p>5.4.13 The independent advisers queried the statement in section 5(b) (Processing Activities) "... from 12 months after the date of participant's first consent date ..."; and noting</p>	
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	<p>this appeared to be incorrect, suggested that this was reviewed and updated as may be necessary.</p> <p>5.4.14 The independent advisers queried the references in section 5(d) (Benefits) (ii) (Expected Measurable Benefits to Health and / or Social Care) to “<i>cost burden</i>”; and suggested that this was removed as it was not quantifiably attributable to this research.</p>	
INTERNAL DATA DISSEMINATION REQUESTS:		
6.1	<p>Reference Number: NIC-139035-X4B7K-v13.2</p> <p>Applicant: NHS England (Quarry House)</p> <p>Application Title: NHS England - DSfC - NHS England Data Platform</p> <p>Presenter: Michael Ball</p> <p>SAT Observer: Duncan Easton</p> <p>Observer: Barry Capp-Gray</p> <p>Previous Reviews: The application and relevant supporting documents were previously presented / discussed at the IGARD meetings on the 25th April 2019, 15th August 2019, 17th October 2019, 12th December 2019, 13th February 2020, 19th July 2020, 17th November 2020, 17th December 2020, 28th January 2021, 19th August 2021, 27th January 2022, 10th March 2022, 10th March 2022, 12th May 2022, 19th May 2022, 26th May 2022, 22nd September 2022 and the 17th November 2022.</p> <p>The application and relevant supporting documents were previously presented / discussed at the IGARD COVID-19 response meeting on the 7th January 2021.</p> <p>Application: This was an amendment application.</p> <p>The amendments are to 1) to update the application to reflect that NHS England will act as a Data Processor for the NHS Service Providers under a Data Processing Agreement (DPA) to flow service activity and outcomes data from Providers in to DSCRO and the pseudonymisation of these data by the DSCRO on behalf of each Provider; 2) to add Leeds Beckett University as a Data Processor; 3) to add the following datasets to the application a) Adult Social Care (ASC), b) Patient Level Costing Integrated Dataset (PLICS), and c) Cardiovascular Disease Prevention Audit.</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 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 NHS England advised the group that the amendment to add Cardiovascular Disease Prevention Audit data to the application would be removed from the application and the application updated accordingly.</p> <p>6.1.3 The group noted that the verbal update in respect of removing the Cardiovascular Disease Prevention Audit data from the application; and advised that they would not provide advice on this point as part of this review, and noted that the application would be updated.</p> <p>6.1.4 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 22nd September 2022, they had expressed concern that the applicant did not seem to have a publicly available privacy notice covering this processing and noted that they'd been unable to find any publicly available information on the website about the activities generally, noting that NHS Digital had also agreed with this point in-meeting. At this time, IGARD had noted there was a significant reputational and legal risk factor to NHS England, in respect of the lack of transparency to the public in the form of a privacy notice. The AGD independent advisers therefore wished to draw to the attention of NHS England, the statement in section 4 (Privacy Notice), that a UK General Data Protection Regulation (UK GDPR) compliant, publicly accessible transparency notice will be maintained throughout the life of the agreement, in line with NHS England's DARS Standard for Transparency (fair processing).</p> <p>6.1.5 In addition to reiterating the previous point made by IGARD in respect NHS England's privacy notice, the independent advisers also highlighted some out-of-date references within the published pdf privacy notice, including, but not limited to, the references to "<i>Clinical Commissioning Groups (CCGs)</i>" which they suggested should be removed and replaced with "<i>Integrated Care Boards (ICBs)</i>" where appropriate.</p> <p>6.1.6 Separate to this application, the independent advisers suggested that the DPO representative lead on an action to discuss with NHS England colleagues, whether the lengthy published privacy notice (circa 123 pages), was "accessible", and whether it should be separated for ease of access, for example, by having separate privacy notices for research, commissioning etc.</p> <p>ACTION: The DPO representative to discuss with NHS England colleagues, whether the lengthy published privacy notice was accessible, and whether it should be separated for ease of access.</p> <p>6.1.7 The independent advisers suggested that section 5(b) (Processing Activities) should be updated, to state that any use of the Medicines dispensed in Primary Care (NHSBSA data) data must be within the parameters of the relevant Direction authorising that collection.</p> <p>6.1.8 The independent advisers noted that it was not clear within the application, what the outputs and benefits were from the addition of the additional datasets in this iteration of the application; and suggested that section 5(c) (Specific Outputs Expected) was updated in line with NHS England's DARS Standard for Expected Outcomes and in line with NHS England's DARS Standard for Expected Measurable Benefits section 5(d) (Benefits) was updated to reflect this.</p> <p>6.1.9 In addition, the independent advisers suggested that section 5(d) was reviewed and updated throughout, as may be necessary, in line with the National Data Guardian public benefit guidance that was published on the 14th December 2022.</p>	DL
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EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
7.1	<p>Reference Number: NIC-20951-D2K6S-v11.2</p> <p>Applicant: Office for National Statistics (ONS)</p> <p>Application Title: Provision of data via PDS to ONS</p> <p>Presenter: No Presenter</p> <p>Previous Reviews: The application and relevant supporting documents had previously been presented / discussed at the DAAG meetings on the 22nd June 2016 and the 12th July 2016.</p> <p>The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 15th October 2020, 22nd July 2021, 9th December 2021, 17th March 2022 and the 16th June 2022.</p> <p>Application: The purpose of the application is to use the data in conjunction with other administrative data for estimating internal and international migration, the local authority distribution of international migrants component of change for the mid-year estimates and small area population estimates within England and Wales and estimating migration between England and Wales, Scotland and Northern Ireland.</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 observation on the documentation provided:</p>	

	<p>7.1.1 The independent advisers suggested that a review of the transparency was undertaken, when describing what data may flow when an s-flag has been applied; noting that the current, publicly available text may not align with this application.</p> <p>The NHS England SIRO representative thanked the group for their time.</p>	
7.2	<p>Reference Number: NIC-656850-Y1V4Q-v1.5</p> <p>Applicant: Leiden University</p> <p>Application Title: Comparison of treatment and survival in European patients with a gastrointestinal stromal tumor-EURECCA (ODR1920_015)</p> <p>Presenter: No Presenter</p> <p>Application: The purpose of the application is for a study, with the aim of describing and comparing the treatment and (overall and relative) survival of patients diagnosed with Gastrointestinal stromal tumours (GIST) in European countries participating in the EURECCA consortium.</p> <p>Outcome of discussion: The group noted that the NHS England SIRO had already provided SIRO approval.</p> <p>7.2.1 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>7.2.2 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>	
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 reiterated 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		
11	<p>Data sharing standard 7a - Ethical Approval</p> <p>Louise Dunn attended the meeting to provide a further verbal update following the previous discussion at the AGD meeting on the 30th March 2023, where it was outlined that there was an ongoing issue with the National Disease Registration Service (NDRS) applications that were novated from Public</p>	

	<p>Health England (PHE) following its cessation in 2021; and the issues with obtaining Health Research Authority ethics approval for these applications, which was previously required by PHE.</p> <p>The group noted that prior to the meeting, an updated draft copy of NHS England's DARS Data sharing standard 7a - Ethical Approval had been provided as part of the meeting pack, which was brought to the group for advice on the proposed amendments.</p> <p>The independent advisers thanked NHS England for the updated documents; and advised that they were supportive of the proposed amendments to the DARS Standard, in respect of NDRS pseudonymised data applications not requiring HRA REC approval, and in line with other similar applications progressing via the NHS England DARS process.</p> <p>The independent advisers noted that the Independent Group Advising (NHS Digital) on the Release of Data (IGARD) had reviewed the DARS Ethical Approval Standard in February and March 2022 and provided tracked change copies back to NHS Digital at the time, and asked that these proposed revisions addressing other aspects of ethical review be considered by NHS England as part of the update to the DARS Standard.</p>
12	<p>Our Future Health Meet and Greet Session</p> <p>Following conclusion of the AGD business as usual section of the meeting, AGD held a meet and greet session with Dr. Andrew Roddam, Dr. Michael Cook and Jackie Shears from Our Future Health.</p> <p>Also in attendance as an observer was Dr. Tony Calland, the Chair of the Health Research Authority Confidentiality Advisory Group (HRA CAG).</p> <p>Our Future Health provided an overview of their organisation noting that they aim to be the UK's largest health research programme and that it is designed to help people live healthier lives for longer through the discovery and testing of more effective approaches to prevention, earlier detection, and treatment of diseases.</p> <p>The group thanked colleagues from Our Future Health for attending and for providing a briefing paper which addressed some of the points raised previously by AGD and IGARD, during review / discussions of Our Future Health applications at AGD and IGARD meetings.</p> <p>The AGD Chair thanked NHS England for arranging the session, and thanked Our Future Health, the group and NHS England for their time.</p> <p>In addition, the group thanked Dr Calland for attending as an observer.</p>
	<p>Meeting Closure</p> <p>As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.</p>