Advisory Group for Data (AGD) – Meeting Minutes

Thursday, 3rd August 2023

09:30 – 15:00

(Remote meeting via videoconference)

INDEPENDENT ADVISERS IN ATTENDANCE:	
Name:	**Role:**
Paul Affleck (PA)	Specialist Ethics Adviser
Dr. Robert French (RF)	Specialist Academic / Statistician Adviser
Kirsty Irvine (KI)	Chair
Dr. Imran Khan (IK)	Specialist GP Adviser
Jenny Westaway (JW)	Lay Adviser
NHS ENGLAND STAFF IN ATTENDANCE:	
Name:	**Role / Area:**
Garry Coleman (GC)	NHS England SIRO Representative
Duncan Easton	Data Access Request Service Senior Approval Team (DARS SAT) (**SAT Observer**: items 4.1 to 4.5)
Kate Fleming (KF)	NHS England Data & Analytics Representative (Delegate for Michael Chapman)
Andrew Martin (AM)	NHS England DPO Representative (Delegate for Jon Moore)
Dr. Jonathan Osborn (JO)	NHS England Caldicott Guardian Team Representative
Kimberley Watson (KW)	Data Access Request Service Senior Approval Team (DARS SAT) (**Observer**: items 4.4)
Vicki Williams (VW)	AGD Secretariat Team (**Presenter**: item 10.1)
INDEPENDENT ADVISERS NOT IN ATTENDANCE:	
Claire Delaney-Pope (CDP)	Independent Specialist Adviser **(Observer)**
Prof Nicola Fear (NF)	Independent Specialist Academic Adviser
Dr. Geoffrey Schrecker (GS)	Independent Specialist GP Adviser

Dr. Maurice Smith (MS)	Independent Specialist GP Adviser
Miranda Winram (MW)	Independent Lay Adviser **(Observer)**
NHS ENGLAND STAFF NOT IN ATTENDANCE:	
Michael Chapman (MC)	Data and Analytics representative
Jon Moore (JM)	NHS England Data Protection Office Representative

1	**Welcome and Introductions** 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: • 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 Request Service (DARS) Standards / Precedents in relation to applications for external data sharing. The attendees present at the meeting considered the proposal put forward by the NHS England SIRO Representative and, as no objections were raised, it was agreed that the meeting would proceed on this basis. Kirsty Irvine noted and accepted the request from the NHS England SIRO Representative to chair; and welcomed attendees to the meeting.
2	**Review of previous AGD minutes:** The minutes of the 27th July 2023 AGD meeting were reviewed and subject to a number of minor amendments were agreed as an accurate record of the meeting.
3	**Declaration of interests:** Paul Affleck noted a professional link to the University of Leeds (NIC-715599-M3G8T-v0.2) and would not be part of the discussion. It was agreed that Paul would not remain in the room for the discussion of this application.

	Kate Fleming noted a professional link to the National Disease Registration Service (NDRS) and work undertaken on the wider project (NIC-715599-M3G8T-v0.2 University of Leeds). It was agreed this was not a conflict of interest. Dr Jonathan Osborn noted he was a practicing General Practitioner (GP) and a British Medical Association (BMA) Trade Union (TU) Representative (NIC-589868-W0K1B-v0.16 University of Sheffield). It was agreed this was not a conflict of interest.	
EXTERNAL DATA DISSEMINATION REQUESTS:		
4.1	**Reference Number:** NIC-696708-J3L1R-v0.5 **Applicant:** King's College London (KCL) / Guy's & St Thomas' Foundation Trust (GSTT) **Application Title:** The South London Stroke Register: improving the lives of stroke survivors with data **SAT Observer:** Duncan Easton **Application:** This was a new application The South London Stroke Register (SLSR) is a long running observational study which investigates the incidence, care and outcomes of stroke in a geographically defined area of London. The purpose of the application is for identifiable NHS England Civil Registration (Deaths) Mortality data, specifically cause of death for all register participants; date of death for any individual whose death was not previously ascertained by the register and for people whose death had previously been ascertained by the register; and date of death to verify the accuracy of the data previously collected. NHS England is seeking advice on the following points: 1. Whether an alternative legal basis needs to be sought to address the Common Law Duty of Confidentiality or whether the cohort members could be grouped as for example '*historic consent / Mental Capacity Act (MCA) 2005 – National Data Opt-outs (NDO) required",* 2. Whether it is appropriate to apply the NDO to all individuals whose historical consent / MCA 2005 status is known, and 3. For those recently recruited who have already passed away, could consent / MCA 2005 respectively be relied upon for a collection of Hospital Episode Statistics (HES) data, or would an alternative legal basis need to be sought. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group wished to draw to the attention of the SIRO the following observations: In response to the advice sought re points 1, 2 and 3 above:	

5.1.1 The independent advisers were broadly in agreement with the NHS England Data Access Research Service (DARS) consent review, provided as a supporting document.

5.1.2 The independent advisers noted and commended the work undertaken by NHS England's DARS on the internal application assessment form and consent review.

5.1.3 The independent advisers agreed with NHS England's DARS, that consent provided a legal gateway for those cohort members consented on post-2022 consent materials.

5.1.4 The independent advisers noted that for those consented on materials pre-2022, who were still living, that consent could provide a legal gateway to process the data if the steps proposed by NHS England's DARS were undertaken, and also:

5.1.4.1 it was established what is meant by the term "*recentl*y" used with regard to contacting participants, and if that contact is within 5 years. If "*recently*" is used for the contact cycle with participants longer than 5 years, then further discussion would be required.

5.1.4.2 greater detail was provided on how participants can opt out of the study, including in public-facing material such as the study website and privacy notice.

5.1.4.3 the newsletter was updated and provided to participants summarising the changes made with a link to the updated website and there is good reason to believe that this will reach a large proportion of the cohort (for example because addresses are up to date).

5.1.4.4 further work was undertaken with the Stroke Research Patients and Family Group (SRPFG) to check their understanding of the processing of the data, accessibility, and newsletter updates.

5.1.5 The independent advisers noted that they were supportive of the applicant receiving Hospital Episodes Statistics (HES) data for those living, but only if the steps outlined in 5.1.4 were undertaken.

5.1.6 The independent advisers noted that it would not be possible to provide clarification to those participants who had died. It was therefore suggested that the applicant consider seeking s251 support for these individuals.

5.1.7 The independent advisers noted that they were supportive of the applicant receiving HES data for those that were deceased, if they received s251 support.

5.1.8 The independent advisers noted that consent was sufficient for a list clean only in order to obtain death date and address, to ensure the applicant was not causing undue distress or upset to family members by sending information to deceased participants.

5.2	**Reference Number:** NIC-663093-K1B0K-v0.3 **Applicant:** Ipsos MORI UK Limited **Application Title:** OHID*/IPSOS** infant feeding survey 2023/2024 **(Office for Health Improvements and Disparities)* ***(Institut Public de Sondage d'Opinion Secteur Market and Opinion Research International)* **SAT Observer:** Duncan Easton **Application:** This was a new application The purpose of the application is for data to assist the recruitment of participants for the infant feeding survey, a long-standing survey, first run in 1975. This will be the ninth wave of the survey. The survey is to collect data that will provide national estimates on the incidence, prevalence and duration of breastfeeding and other feeding practices adopted by mothers during the first eight to ten months after their baby is born. The survey is a key commitment from the current government as part of its childhood obesity plan. NHS England is seeking advice from AGD and the Caldicott Guardian on the following points: 1. the requested dissemination, and 2. whether the proposed use of mobile phone numbers from NHS England is proportionate and appropriate. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** the group noted that they were specifically asked to provide advice in relation to the use of mobile numbers, and that the remainder of the application was subject to additional work. However, to assist in the development of the application, the group provided the following advice to the SIRO (noting that the points may not be relevant once the additional detail on the application is clear): In response to points 1 and 2 **5.2.1** The independent advisers and Caldicott Guardian Team Representative noted that there had been **no** consideration given to the Privacy and Electronic Communications Regulations (PECR) that sits alongside the Data Protection Act 2018 and UK General Data Protection Regulation (UK GDPR), and which gives specific privacy rights in relation to electronic communications. The group were **not** giving a view on whether PECR was or was not relevant, but would expect a clear statement in the application and / or internal application assessment form that PECR had been considered. **5.2.2** It was noted that a text message is less intrusive that someone arriving on the doorstep (an approach previously seen by the group). It was also noted that the	

	plan was for up to seven approaches to an individual via letters/text messages, which could be seen as so numerous as to be coercive. In addition, it was suggested that thought should be given as to whether recipients of the first text message would know they will receive a text, and know who it is coming from, especially relevant due to the number of scam messages. **5.2.3** The independent advisers and the Caldicott Guardian Team Representative, did judge mobile phone communications via short message service (SMS) to be an acceptable method of communication. **5.2.4** The independent advisers noted the care taken to exclude, where possible, those that had died, and commended the applicant on this. **5.2.5** The independent advisers were unclear of the timeframes with regard to accessing the data and at what point a child / young person would start in the survey and noting the foster care system was not static, suggested that the applicant consider whether or not more care / steps should be taken for those children / young people who were in and out of the foster care system, since the applicant may be contacting the birth family when this was not appropriate. **5.2.6** In addition, and noting the independent advisers were unclear of the timeframes with regard to accessing the data and at what point a child / young person would start in the survey, noting the adoption system was not static, suggested that consideration be given to those children / young people who had been adopted, since the applicant may be contacting the birth family when this was not appropriate. **5.2.7** Noting points 5.2.4 to 5.2.6 above, acknowledgement should also be given to the fact that the system is not foolproof and IPSOS may receive data for those who had died (mums and children), had been taken into foster care, or had been adopted, and the applicant should ensure they have the relevant systems in place to deal with complaints, if the wrong family members were being contacted. **5.2.8** The independent advisers noted that supporting document (SD) 4.3 '*invite letter'* noted that "*your name was chosen at random from a list of mothers who gave birth…*" and noting this was incorrect, suggested that the invite letter explain how confidential data is obtained, by referencing the Health Research Authority Confidentiality Advisory Group (HRA CAG), which is consistent with other direct approaches where research projects are relying on s251 support. **5.2.9** Noting SD6.0 ('*confirmation no ethics required email*') and SD6.1 ('*HRA CAG confirmation email no ethics required*') provided as part of the documentation pack, independent advisers queried whether or not HRA CAG had been made aware of the plans for a research database. Noting the research database would use pseudonymised data, the independent advisers queried whether the HRA CAG support extended to that research, since the application was silent on this point.	

	5.2.10 The independent advisers noted reference within section 3(b) (Additional Data Access Requested) to a "*professional registration entry identifier"* and noting this is an identifier, queried why this data field was flowing and how it was relevant to the study. In addition, the independent advisers queried if this identifier was covered by the HRA CAG s251 support. **5.2.11** The independent advisers noted that the University of Dundee's Schools of Health Sciences and Dentistry Research Ethics Committee (REC) had reviewed and approved an application submitted by the applicant with regard to 'infant feeding survey 2023/2024', and noting no analysis had been provided as to their involvement, suggested that consideration be given to whether they are a Data Controller or Data Processor, in line with the NHS England DARS Standard for Data Controllers / NHS England DARS Standard for Data Processors. **5.2.12** The independent advisers noted that the 'Cabinet Office' had been listed as a Data Processor, and queried if they were the correct legal entity; and in line with the NHS England DARS Standard for Data Processors suggested NHS England check that the right entity was identified in all relevant documentation. **5.2.13** Noting the involvement of the Cabinet Office and how they were described in section 5 (Purpose / Methods / Outputs) of the application, the independent advisers suggested that NHS England seek assurance from the applicant that the Cabinet Office **do not** have data controllership responsibilities, in line with the NHS England DARS Standard for Data Controllers. **5.2.14** The independent advisers queried why IPSOS couldn't send the sampling criteria to NHS England to avoid having to disseminate data for this purpose and suggested that a robust analysis be included in section 1 (Abstract) and section 5 (Purpose / Methods / Outputs). In addition, the independent specialist statistician queried how ethnicity, geography and deprivation were being oversampled, and suggested more detail be included in section 5. **5.2.15** The independent advisers queried how the applicant would include those who **did not** have a mobile phone / smart phone, and suggested that this be acknowledged, since it may lead to bias. **5.2.16** Noting that under 16s were being excluded from the study, section 5 should be updated to explain why (those aged under 16 are included in other research activities). **5.2.17** Consideration should be given to appropriate data destruction and the independent advisers suggested that a special condition be included in section 6 (special conditions), given the applicant is handling a large amount of confidential data.	
5.3	**Reference Number:** NIC-680546-S0V4K-v0.3 **Applicant:** University College London (UCL)	

	Application Title: PreHOspital Triage for potential stroke patients: lessONs from systems Implemented in response to COVID-19 (PHOTONIC) **SAT Observer:** Duncan Easton **Application:** This was a new application The purpose of the application is to provide robust evidence on how pre-hospital video triage affects patient outcomes and cost effectiveness, with the results used to improve care, assessing how pre-hospital triage for suspected stroke patients was set up, run and experienced by patients, carers and staff during the COVID-19 pandemic. 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: **5.3.1** The independent advisers noted in the internal application assessment form and section 3 (Datasets Held / Requested) of the application, that the full date of death had been requested and that the applicant had confirmed that once the mortality flags have been created, the full date of death would be no longer required, however there had been no analysis by NHS England as to whether it rendered the data identifiable with the other types of data flowing. **5.3.2** The independent advisers queried if the processing outlined in the application could be undertaken with the data requested, noting the limitations of the study set out in section 5 (Purpose / Methods / Outputs). The independent advisers queried if the applicant could identify the proposed samples and relevant individuals with the data requested from NHS England. In addition, the group made the following observations on the application and / or supporting documentation provided as part of the review: **5.3.3** Noting that the whole of England's population data was being requested and then used as a 'control group' for the study, the independent advisers suggested that a more robust justification be included in section 5 to explain why the applicant cannot have a smaller control group, since by using the whole of England population data, there was a potential risk that the control group may have bespoke interventions and not be a true control group. **5.3.4** The independent advisers noted that processing of the data under this data sharing agreement (DSA) could be done remotely; and suggested that further information was added to the application on the remote access arrangements in England and Wales **only**; and reiterated previous advice that NHS England needs a clear policy on remote access. **ACTION:** NHS England to provide its position to AGD on remote access *(as previously requested and agreed at the AGD meeting on the 2nd February 2023)*.	NHSE

	5.3.5 The group commended the applicant on the excellent patient and public involvement and engagement (PPIE) across all stages of the study and suggested this be used by NHS England as an exemplar.	
5.4	**Reference Number:** NIC-715599-M3G8T-v0.2 **Applicant:** Cystic Fibrosis Trust / University of Leeds **Application Title:** Understanding the incidence of and outcomes from cancer in individuals with cystic fibrosis **SAT Observer:** Duncan Easton **Observer:** Kimberley Watson **Application:** This was a new application. The purpose of the application is to link together data from the Cystic Fibrosis Registry to NHS England to link to the National Disease Registration Service (NDRS) (cancer registration and Hospital Episodes Statistics (HES)), with work undertaken in the NHS England Secure Data Environment (SDE) to investigate the relationship between Cystic Fibrosis status and cancer incidence. NHS England were seeking advice solely on the consent materials for the study and are seeking advice on the following points: 1. If the consent material, as it stands, is sufficient to support the flow of data from the Cystic Fibrosis Registry to NHS England to link to the NDRS (cancer registration and HES) data and be accessed by the University of Leeds in the SDE, and 2. If the consent material is not considered sufficient what, if anything, could be done to augment the material so that it could support the flow of data, without having to reconsent the cohort. Should an application be approved by NHS England, further details would be made available within the Data Uses Register. **Outcome of discussion:** The group noted that they were asked to provide advice in relation to the consent materials only, and that the remainder of the application was subject to additional work. However, to assist in the development of the application, the group provided the following advice to the SIRO (noting that the detail may not be relevant once the additional detail on the application is clear): In response to points 1 and 2: **5.4.1** The group was of the view that that the consent was **not** compatible with the processing outlined in the documentation provided as part of the review. **5.4.2** The independent advisers noted the restrictions outlined in the consent materials and other public-facing information about the registry to sharing identifiable data, which they judged would also preclude sharing data in the secure data environment (SDE). NHS England asked the group to consider whether consent	

could be relied on to anonymise the data, then place such data into the SDE for onward sharing. The independent advisers suggested that relying on such a solution was **not** appropriate when the proposed processing was so radically different from the processing outlined in the consent materials, on an ethical basis and in line with Caldicott Principle 8, "…*A range of steps should be taken to ensure no surprises for patients and service users…";*

5.4.3 The independent advisers were of the view that a layered approach with additional transparency to participants to augment the deficient consent materials would **not** be sufficient to provide a legal gateway under consent.

5.4.4 Noting the application is around understanding the incidence of and outcomes from cancer in individuals with cystic fibrosis, the group were surprised that the only reference to 'cancer' was in the data sharing agreement (DSA), and that **no** reference was made to 'cancer' in any of the consent materials shared as part of the review. It appears that there has been a fundamental widening of the purposes to which registry data would be put to now include research about cancer in individuals with cystic fibrosis, and this was a key change, which again, could not be augmented by additional transparency to participants.

5.4.5 The group also noted that they were **not** suggesting that the cohort be reconsented by the applicant.

5.4.6 The group noted that they could only provide the above advice based on the information provided as part of the supporting documentation pack, and were unclear if further communications had been undertaken with the participants and so were unclear if the cohort were aware that data would be shared or added to the SDE or used for wider purposes.

5.4.7 Noting the applicant and the research team undertaking the research were from the University of Leeds, but were not listed as a Data Controller or Data Processor within the application, the independent advisers suggested that NHS England seek assurance that the University of Leeds **do not** have data controllership responsibilities, in line with the NHS England DARS Standard for Data Controllers.

5.4.8 Noting that '*the pharmaceutical company'* sees the report as outlined in the '*patient information sheet adult Aug 2018'*, the independent advisers suggested that further transparency be provided to cohort members with regard to what was being shared with 'the pharmaceutical company'.

5.4.9 Noting it was beyond the scope of the request from NHS England, the independent advisers queried the plan to reconsent those individuals who were originally consented at age 13 to 15, when they reach the age of 16.

5.4.10 Noting it was beyond the scope of the request from NHS England, the independent advisers queried the plan for those who were originally added to the study aged 12 and younger on the basis of parental consent.

	5.4.11 The group noted that a possible way forward may be via s251 from the Health Research Authority Confidentiality Advice Group (HRA CAG) or a Direction, but in either case this was **not** to take away from the fact that active and robust transparency for the cohort was required, and future consent materials would need a radical uplift and revision if not relying on s251 or a Direction. **5.4.12** The group queried if there was a predecessor database, and if so, further detail should be included in the DSA.	
5.5	**Reference Number:** NIC-589868-W0K1B-v0.16 **Applicant:** University of Sheffield **Application Title:** CUREd Research Database **SAT Observer:** Duncan Easton **Application:** This is a new application. The purpose of the application is for the University of Sheffield to access NHS England data for the Centre for Urgent and Emergency Care Research Database Refresh (CUREd+) research programme, which is a longitudinal linkage database aiming to provide a coherent picture of urgent and emergency care demand in England from 2011 to 2023. 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: **5.5.1** The independent advisers noted that there was **no** assessment by NHS England with regard to s251 support and suggested that NHS England satisfy itself that the Health Research Authority Confidential Advisory Group (HRA CAG) had received the applicant's annual review and that all HRA CAG conditions of support continue to be met / had been met. **5.5.2** Separate to the application, the independent advisers noted that at the AGD meeting on the 29th June 2023, a HRA CAG analysis as part of the application assessment document had been provided for NIC-634901-B4H8K; and advised that a similar analysis would have been useful in the application assessment for the review of this application. It was suggested that NHS England consider providing similar analysis in the application assessment for relevant applications, to provide the group with a clear summary of the HRA CAG support. **ACTION:** NHS England Data Access Request Service Senior Approval Team (DARS SAT) to consider providing a HRA CAG analysis within the application assessment document when submitting applications to AGD with s251 support. **5.5.3** The independent advisers noted the inconsistent narrative in the internal application assessment form / application, noting that the HRA CAG support is for	DARS

year of birth **only**, whereas the application and supporting documents state the NHS England is flowing month **and** year of birth. The independent advisers noted that the application and supporting documentation should be updated, as appropriate, to align with the s251 support.

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

5.5.4 The independent advisers suggested that the identifiability of data relating to cohort B mapped to the identifiability fields outlined in the HRA CAG s251 support and mapped across to section 5 (Purpose / Methods / Outputs) of the DSA.

5.5.5 In addition, section 3(b) (Additional Data Access Requested) should be updated to be clear which cohort the '*personID bridge files'* extract is referring to.

5.5.6 The independent advisers noted that honorary contracts were being used for seconded staff and, as per usual process / advice, noted that the honorary contract should be counter-signed by the individual's substantive employer. The independent advisers suggested that NHS England ensure that written confirmation was received from the applicant that the document had been counter-signed by the employing body; and that the written confirmation was uploaded to NHS England's customer relationships management (CRM) system for future reference.

5.5.7 The independent advisers strongly suggested that the applicant carried out a Data Protection Impact Assessment (DPIA), before processing commences given the scale of processing being undertaken and significant quantum of data flowing, noting it is a key part of the applicant's accountability under the UK General Data Protection Regulation (UK GDPR). The ICO is a useful guide.

5.5.8 The independent advisers noted reference in section 5(a) (Objective for Processing) to "…*reduce variation in hospital data*…" and suggested this was further explained.

5.5.9 The independent advisers noted that cohort A identified by the University of Sheffield and Yorkshire Ambulance Service (YAS) included patients who had contacted the NHS 111 telephone triage service, and that cohort B defined by NHS England included patients receiving inpatient / outpatient NHS hospital care in England, and, noting the large amount of data, suggested that section 5(a) be updated with a justification for including this data.

5.5.10 Noting the useful processing and outputs expected from this application, the independent advisers queried if access could be extended to other researchers, and, if not, why not?

5.5.11 Noting that the applicant was in receipt of sensitive General Practice (GP) codes, and noting that conclusions could be drawn about GP practices or Primary Care Network (PCN) performance, suggested that a special condition be included in section 6 (special conditions) that **no** GP practice or PCN could be identified in any published outputs. The independent advisers noted that the study had **not** been

	designed to address GP / PCN performance and the applicant was not receiving all the necessary data to accurately access GP / PCN performance, for example, the applicant would need other contextual data to make these particular outputs robust. **5.5.12** The independent advisers noted that they had been provided with supporting document (SD) 2.2 '*TOR The CUREd Research Database refresh v1.0 data release committee 2022-04-28'* and suggested that the applicant update the committee's Terms of Reference (TOR) to include an assessment of public benefit and that the committee's remit would be to actively consider public benefit as part of their deliberations. **5.5.13** Separate to the application, the independent advisers suggested that NHS England ensure that the internal application assessment form or section 1 (Abstract) always include reference to linked or 'sister' applications by way of a NIC Number, since they are relevant to the groups review of applications. **ACTION:** NHS England Data Access Request Service Senior Approval Team (DARS SAT) to ensure the internal application assessment form / section 1 include reference to 'sister' or linked application reference numbers.	DARS
EXTERNAL DATA DISSEMINATION - SIRO APPROVED / SEEKING SIRO APPROVAL		
6.1	**Reference Number:** NIC-656761-R6H7W-v1.8 **Applicant:** University of Leeds **Application Title:** Yorkshire Specialist Register of Cancer in Children and Young People (ODR1516_163) **Presenter:** No Presenter **Previous Reviews:** The National Disease Registration Service (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. **Linked application:** NIC-11809-H1Y3W **Application:** The purpose of the application is for the University of Leeds to access the National Cancer Registration and Analysis Service (NCRAR) data for the Yorkshire Specialist Register of Cancer in Children and Young People (YSRCYP) research project. The SIRO approval was for a six-month extension to align this application with its sister application NIC-11809-H1Y3W, and a simple amendment for additional flags within the RTDS data product. **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: **6.1.1** Noting an action raised on the 22nd June with regard to the status of the NHS England DARS Standard for Honorary Contracts, independent advisers noted as per usual process, the honorary contract should be counter-signed by the individual's substantive employer. The independent advisers suggested that NHS England ensure that written confirmation was received from the applicant that the documentation had been counter-signed by the employing body; and that the written confirmation was uploaded to NHS England's customer relationship management (CRM) system for future reference. The NHS England SIRO representative thanked the group for their time.	
6.2	**Reference Number:** NIC-291981-Y7J2F-v7.4 **Applicant:** Imperial College London (ICL) **Application Title:** MR1108: CT colonography, colonoscopy, or barium enema for diagnosis of colorectal cancer in older symptomatic patients: SIGGAR1 (Special Interest Group in Gastrointestinal and Abdominal radiology). Plus SOCCER (Symptoms of Colorectal Cancer Evaluation Research). **Presenter:** No Presenter **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the Data Access & Advisory Group (DAAG) meetings on the 10th November 2015, 17th November 2015, 1st December 2015, and 9th February 2017. The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 31st January 2019, 20th August 2020, 4th February 2021, 9th September 2021, 16th June 2022, 13th October 2022, and 20th October 2022. **Application:** The purpose of the application is for the SOCCER study, which follows on from an earlier study on bowel cancer symptoms (the Special Interest Group Gastrointestinal and Abdominal Radiology (SIGGAR) study), with the aim of providing evidence that is needed to show whether flexible sigmoidoscopy (a technique which examines only the last [distal] part of the colon) is an effective and safe alternative to whole colon examinations for many people; which may change how doctors diagnose bowel cancer in their patients based on their symptoms. The SIRO approval was for archiving only. **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:	

	6.2.1 The independent advisers noted that the legal basis to disseminate had been changed within the documentation provided, because the recipient has now pseudonymised the data, and suggested this was incorrect. The NHS England SIRO representative noted that the legal basis to disseminate the data would not be amended as outlined in supporting documentation received and confirmed that the internal application assessment form and NHS England customer relationships management (CRM) system would be updated to reflect the original legal basis, which was correct. **6.2.2** The independent advisers noted that archive applications would usually come to AGD for advice as outlined in the NHS England DARS precedents. The NHS England SIRO Representative noted NHS England did not have a 'DARS Archive Precedent'. The NHS England SIRO representative thanked the group for their time.	
6.3	**Reference Number:** NIC-20951-D2K6S-v12.1 **Applicant:** Office for National Statistics (ONS) **Application Title:** Provision of data via PDS to ONS **Presenter:** No Presenter **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the Data Access & Advisory Group (DAAG) meetings on 22nd March 2016, and 12th July 2016. The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 15th October 2020, 19th November 2020 (as part of NIC-413717-C8Y6K), 22nd July 2021, 28th October 2021 (as part of NIC-413717-C8Y6K), 9th December 2021, 17th March 2022, 16th June 2022, and 27th April 2023. **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. The SIRO approval was for a simple amendment to add two variables, releasing the data in the next extraction on 31st July 2023. **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: **6.3.1** The independent advisers noted that two variables had been added to the data sharing agreement (DSA) which seemed to relate to a person's GP practice, and	

	which had been previously removed following consideration by the Independent Group Advising (NHS Digital) on the Release of Data (IGARD), and queried what the applicant was using the GP practice identifiers for. The NHS England SIRO Representative noted that the release of the two variables, within the dataset, was being used for population estimates (since it will help confirm detail on population movements) and was not being used for GP performance management which was the original concern raised by IGARD. The group noted the verbal update. The NHS England SIRO representative thanked the group for their time.	
6.4	**Reference Number:** NIC-148118-VCXW9-v5.5 **Applicant:** Institute for Cancer Research (ICR) **Application Title:** MR1211 - UK Genetic Prostate Cancer Study **Presenter:** No Presenter **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the IGARD meetings on the 6th October 2022, 10th November 2022, and 8th December 2022. **Application:** The purpose of the application, is for a study aiming 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: **1)** to screen other family members to see if they are also at a higher risk of developing prostate cancer; and **2)** to develop new prostate cancer treatments for the future. The SIRO approval was for a six-month extension to hold but not process, with a request by the SIRO for the application to be brought back to a future AGD meeting. **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 advised that they had no further comments to make on the documentation provided. The NHS England SIRO representative thanked the group for their time.	
6.5	**Reference Number:** NIC-201243-R7L2M-v2.5 **Applicant:** Department for Health & Social Care (DHSC) **Application Title:** NHS Health Checks: linking primary care dataset to hospital and mortality data **Presenter:** No Presenter **Previous Reviews:** The application and relevant supporting documents had previously been presented / discussed at the IGARD meeting on the 28th June 2018	

	The application and relevant supporting documents had previously been presented / discussed at the IGARD COVID-19 Response meetings on the 25th July 2020, and 30th July 2020 (as part of NIC-390154-Z4M0F with regard to any interplay / overlap and accessing GP data) **Application:** The purpose of the application is to produce an Analytical Strategy for the data extraction, described as follows: process, health data, outcomes and models. Stage 1 and 2 - process and health data - have been the primary focus of the initial data analysis. Stages 3 and 4 will evaluate longer term outcomes following an NHS Health Check and explore the development of models to evaluate risk prediction, economic impact and interventions related to the check. The SIRO approval was for three-month extension, with a request by the SIRO for the application to be brought back to a future AGD meeting. **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 advised that they had no further comments to make on the documentation provided. The NHS England SIRO representative thanked the group for their time.	
6.6	**Reference Number:** NIC-656749-G8K4G-v1.6 **Applicant:** University Hospitals Birmingham NHS Foundation Trust **Application Title:** Epidemiology of Cancer after solid Organ Transplantation - EPCOT study (ODR_2014_244) **Presenter:** No Presenter **Previous Reviews:** The National Disease Registration Service (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. **Linked application:** NIC-77142-Q4D1D **Application:** The purpose of the application is for an extension to retain and process the NDRS data already disseminated. The SIRO approval was for a three-month extension. **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 advised that they had no further comments to make on the documentation provided. The NHS England SIRO representative thanked the group for their time.	
6.7	**Reference Number:** NIC-656800-V6B5C-v1.5	

	Applicant: Cancer Research UK **Application Title:** Variation in access to treatments for lung cancer (ODR1718_079) **Presenter:** No Presenter **Previous Reviews:** The National Disease Registration Service (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. **Application:** The purpose of the application is for a service evaluation to establish **1)** factors that affect access to lung cancer treatment for non-small cell lunch cancer patients, **2)** whether there is any variation between hospital trusts in access to a range of treatment pathways, and **3)** the impact of patient, tumour and providers characteristics on access to treatments. The SIRO approval was for a twelve-month extension to allow the applicant to retain the data already disseminated, and for a journal submission. **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 advised that they had no further comments to make on the documentation provided. The NHS England SIRO representative thanked the group for their time.	
AGD Operations		
7	**Statutory Guidance** The independent advisers again noted the reference to reviewing materials in accordance with *"a clearly understood risk management framework"* 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. **ACTION:** NHS England SIRO Representative to provide further clarity on the risk management framework.	GC
8	**AGD Terms of Reference (ToR)** Garry Coleman noted that NHS England were still considering comments from stakeholders on the AGD ToR. **ACTION:** The NHS England SIRO Representative noted a previous action to clarify when a revised draft of the AGD ToR would be presented to AGD and when the	GC

	AGD ToR was scheduled to be considered by the NHS England Board / subcommittee of the Board.	
9	**Standard operating procedures** The ongoing forward plan of work for creating Standard Operating Procedures was discussed.	To note
10 **10.1**	**New Operational Actions & those carried forward from previous meetings of AGD:** **Zero Hours contracts for independent advisers** Vicki Williams noted that all ten independent advisers had now moved to NHS England zero hours contracts.	To note
11. Any Other Business		
11.1	**Legal Privilege** Andrew Martin provided a verbal update with regard to independent advisers being able to view legally privileged advice. Andrew noted that he would provide a further update in due course with regard to any amendments to documentation and once NHS England had reviewed the external legal advice received on this point.	
11.2	**Legal basis for dissemination** Andrew Martin noted that the legal privilege item (11.1 above) needed to be resolved before NHS England could consider sharing any relevant documentation on NHS England's legal basis for dissemination.	
Meeting Closure As there was no further business raised, the Chair thanked attendees for their time and closed the meeting.		